PERMEABLE BODIES: CHILDREN, CANCER, AND BIOMEDICINE IN ARGENTINA

by

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Abstract

The vast improvement in survival rates in childhood cancer, especially in childhood leukemia, has expanded expectations of survival. Surviving cancer is the result of invasive and life-disrupting treatments. To understand the long and taxing medical journeys of these children living with cancer this study traces children and families’ experiences at Hospital Infantil (public Children’s Hospital) in the City of Buenos Aires, Argentina. It examines how children and families as well as hematologists, communicable disease specialists, and palliativists struggle with the treatments and care for these children. This thesis asks: How does a “sick child” overcome a life-threatening illness such as a cancer and its painful treatments to become a “cancer survivor” living “life without illness” in the global south, particularly in a country like Argentina? This question leads to an anthropological reflection on the role of the body, especially children’s bodies, in cancer treatment, palliative care, and cure. It pays careful attention to issues of corporeality and subjectivity. The thesis examines how bodies work interactively while being the object of invasive and painful biomedical interventions. These interventions not only affect children but also their families and the professionals themselves. This ethnography investigates the potentials and perils of pediatric cancer treatment in its specific Argentinean context and the importance of carefully looking at the body to understand children, families, and professionals’ practices that aim for a life without cancer. By focusing on the production of “permeable bodies” this study argues that cancer treatment turns children’s bodies into permeable bodies, bodies painfully turned inside out, as a way of producing knowledge and an urgent therapeutic relation that stretches in multiple dimensions. Children become the embodied objects of cancer treatment.
Preface


The research design for this study was approved by UBC Behavioural Research Ethics Board (Certificate Number H09-02995) and by the Bioethics Board, the Research and Teaching Committee, and the Director of the Children’s Hospital in which I conducted fieldwork. It has also been approved by the head Psychologist in charge of the multi-families meeting and the Director of the NGO in which I conducted fieldwork.
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Chapter 1: “There is something strange in your child’s blood”: Setting the stage of the study

To assist children and adolescents with the highest complexity. To become a reference center within a vast pediatric network by coordinating activities and services with other hospitals in an integrative and participative framework. The hospital will be, as always, focused on the patient’s and the community’s needs with a profile on assistance, teaching, and research.

Mission of the Hospital Infantil (as stated on its website, my translation)

Valeria, a former cancer patient in her late twenties who had bone cancer as a child said on a cool July morning:

I remember when this woman [nurse] … who broke all my veins came [to introduce an IV for chemotherapy] and my mother told me ‘Bite me when it hurts.’ So I bit her, and I was biting, biting, biting because it hurt me. And when my mother moved her hand it was bleeding all over. She gave me her hand and told me “Bite me so I can feel what you feel.”

Valeria’s vivid story of pain, cancer, and the powerful emotions between a daughter and her mother reminds us of the intense, physical, and emotional impact of cancer treatment and the vast improvement in survival rates for childhood cancer in recent decades, especially for childhood leukemia. Expectations of survival have expanded despite the inherent invasiveness of treatment. Now, thanks to biomedical advancements, most children will endure treatment and survive cancer. Yet, we know little about the localized struggles and experiences of children living with cancer and going through intense and painful treatments. Also, we know little about the struggles of their families witnessing and participating in these painful clinical encounters. Furthermore, we have limited insight into the professional and institutional complexities of dealing with pediatric cancers.
This thesis asks: How does a “sick child” overcome a life-threatening illness such as a cancer de la sangre\(^1\) (“blood cancer”)? How does a child affect and is affected by a painful treatment to become a sobreviviente de cancer (“cancer survivor”) living una sobrevida sin enfermedad (“life without illness”) in the global south, particularly in a country like Argentina? This seemingly evident questions imply two contradictory processes. On the one hand, the professionals who deal with cancer treatment and care objectify children’s bodies by necessity in order to focus on wiping them of all malignant cells. They attempt to create a linear, teleological narrative from sickness to health. However, the children embody drastic and painful, personal and inter-personal, transformations in order to overcome illness. Thus, children’s bodies become the stage upon which these biomedical dramas are played out. This process entails a non-linear trajectory. The progression from a “sick” to a “healthy” child, from “patient” to “cancer survivor” is never unidirectional. When children are discovered to have algo raro en la sangre (“something strange in the blood”) they and their families are socialized into, and learn from, new relationships with doctors, nurses and other health professionals that will radically affect children’s corporeal existence and the lives of everyone around them. This relationship and the circuitous progression of treatment will go through countless convolutions, moving forward and backward between illness and treatment for an intense period of one to two years. In this context, children’s bodies become traversed by painful biomedical intensities, and these external forces constitute and permeate children’s bodies.

To understand these long and taxing medical journeys of treatment for enfermedad de la sangre (“sickness in the blood”), this study will trace children and families’ experiences at Hospital Infantil (“Children’s Hospital”) in Buenos Aires, Argentina. I will examine how

\(^1\) Throughout this dissertation, I have decided to draw on numerous words and phrases in Spanish when it seemed that an English word was not adequate to explain a particular local meaning.
children and families experience these biomedical journeys, as well as how palliativists, hematologists, communicable disease specialists, nurses, and allied professionals struggle with caring for, and curing, these children. I will center my analysis on the body to think about the “very ‘stuff’ of subjectivity” (Grosz 1994:ix). The emphasis on the body in this study points to the need to examine several key issues central to the lived experience of cancer. What is the role of the body, especially children’s bodies, in cancer treatment, palliative care, or cure? How do the participants in care interact and influence one another? What is their focus? What are the various social and political forces that shape the interaction?

Four main themes will emerge, woven through stories of children, professionals, and families experiencing cancer. The first theme is that it is essential to focus on the body as the intersection of multiple positions. In order to understand these subjective positions, we need to center our analysis on the body. The notion of “permeable body” I am proposing here refers to the phenomenological, social, and political (medicalized) corporealized experience of cancer treatment (Scheper-Hughes and Lock 1987). By following Grosz’ (1994) model of corporeal experience I propose the notion of “permeable body” to grasp children’s corporeal experience of cancer treatment literally, symbolically, and metaphorically. While aiming at eliminating malignant cells in children’s bodies, their bodies are quickly transformed into biotechnological hubs at the centre of relationships among children, professionals, and family members. By doing so throughout treatment, children are painfully embodying both cancer and treatment with long-lasting consequences. Thus, children’s bodies become both the source and the target of the application of these biotechnologies, knowledge and expertise. Hence, the notion of “permeable body” throughout the dissertation will help us understand the place of the body (mostly children’s but also parents’ and clinicians’ bodies) in cancer treatment.
Second, children’s therapeutic processes have to be analyzed by looking at the transformed social landscapes— the hospital’s rooms and the hospital generally, as well as the homes, neighborhoods, schools, and workplaces of parents and siblings that both sustain and surround children’s experiences in this pediatric hospital. Sometimes children and parents are isolated from their families. While focusing on the interactions among children, parents, and physicians within the clinical setting, it is important to avoid losing sight of life outside the hospital. Thus, we will be able to examine the mutual influences between the clinic and the larger social landscapes beyond the clinic. For this particular argument, I will rely more heavily on more than 20 multi-family meetings I observed at an NGO that supports families with children with cancer.

Third, these biomedical journeys must also be seen as multidirectional diachronic processes that include a series of medicallyorchestrated “thresholds.” Every child and family’s journey is a bit different. They will experience a wide variety of obstacles and complications. Those experiencing cancer treatment often embody a blurred liminal state as they fluctuate between chronic and acute care. Given these different treatments, children seem to move from one liminality to another, and, thus, it makes sense to talk about “thresholds.” Although children, professionals and family members experience these “thresholds” differently, by paying attention to these spatial, affective, and temporal dimensions we can better understand patients’, family members’, and clinicians’ experiences during care.

Fourth, as the introductory vignette shows, these medically mediated interactions among children, clinicians, and families are constituted by, and embedded in, issues of pain. Indeed, one of the main concerns in this thesis is, how can parents and clinicians inflict pain on a child with the uncertain promise of survival? I will argue that pain unites the corporeal and the subjective
experiences of children, parents, and clinical staff. Therefore, we need to consider the frictions created between parents and clinicians in regards to who controls children’s bodies, what can be done to them, and how much pain children’s bodies will endure throughout lengthy treatments.

These four arguments point to an ethnographically informed reflection not only on the potentiality and perils of pediatric cancer treatment, but also on the importance of carefully looking at the body to understand children, families, and professionals’ struggles for a life without cancer. By focusing on the production of “permeable bodies” this dissertation aims to understand the radical transformations that are triggered within children’s bodies through lengthy treatments, and among children, clinicians, and parents from the moment a child is diagnosed until she is considered free of illness.

“Permeable bodies” in the context of this study has a specific meaning. It points towards a corporealized social relation constituted by the exteriorization of bodily elements that would normally remain folded to the inside the body for therapeutic reasons. I argue that the intersection of cancer treatment and children turns children’s bodies into permeable bodies, bodies turned inside out, as a way of producing a knowledge and an urgent therapeutic relation that stretches in multiple dimensions. Indeed, the continuous intervention into children’s bodies makes the interior (blood, bone marrow, tissues, etc.) into new exteriorities. They become new corporeal surfaces in Grosz’s (1994) terms, radically affecting the subjectivity of children. By focusing on the corporeal experience and by talking of permeable bodies this thesis is pinpointing the social relations created from the moment a medical resident punctures a child’s arm with a needle sitting on the lap of his parent, to the fear of the resident learning to make this procedure avoiding to prick herself, to the instance when a fellow carefully pricks an adolescent in between two lumbar vertebrae to test if she has leukemia, to the communication of a diagnosis
to the parents by a staff hematologist, the development of trust by parents and children on the
efficacy of treatment, and the rearrangement of family around the therapeutic treatment of the
child’s cancer.

Within modern medicine there is a long history of cancer treatment on children’s bodies
that goes back (at least) to the 1950s and the discoveries by Sidney Farber and Yellapragada
Subbarow that led to the creation of methotrexate, one of the first effective anti-cancer drugs still
in use (Mukherjee 2010). As I will develop in the following chapters, these and more recent
forms of therapy involve drastic and invasive procedures. The process of making children’s
bodies permeable has complex personal and interpersonal impacts on children, family members,
and clinicians.

While the concept of permeable bodies may suggest that children are reduced to passive
bodies without agency or psyche in the everyday encounter among professionals, children, and
caregivers, this is not the case. Also, I am not proposing that professionals only interact with
children’s bodies; children and the people who treat them do care for them psychologically and
socially. Focusing on children’s bodies does not eliminate children’s agency and personal
identity. On the contrary, I would argue that these concrete medical processes have vast
constitutive influences in children’s corporalities and subjectivities. The notion of “permeable
body” points precisely to the core of these clinical interactions revealing frictions, pain, agency,
and resistance. We need to look at the corporeal experience of cancer in order to understand
children’s, parents’, and clinicians’ subjectivities. Thus, we need to examine this more deeply to
understand children as thinking agents acting together with other agents and objects. My point
here is that by looking at children’s bodies we can understand subjectivity. I agree with Grosz
(1994:vii) that: “All the effects of depth and interiority can be explained in terms of the
inscriptions and transformations of the subject’s corporeal surface.” Grosz’s remapping of the subject’s psyche or interior is an attempt to avoid reductionist and nondualist conceptualizations of the person. In her model, subjectivity is not produced as the interplay between surface/exterior and depth/interior but rather all the effects of depth are constituted by the corporeal subject’s surface. Everything that happens to children throughout cancer treatment (chemotherapy, biopsies, blood transfusions, bad news, temporal isolation, intense emotions, etc.) simultaneously affects their corporeal as well as subjective selves. Indeed, one of the findings of this study is that through lengthy cancer treatment children’s corporeal subjectivities are not only colonized by the actual physical interventions of biomedicine but also enhanced by multiple forms of biosociality that their care creates. Children living with cancer traverse long and intense processes of medicalized social interactions within the hospital that open them to new possibilities that create new layers of biosociality (Long, Hunter, and van der Geest 2008).

These new biosocial relationships are progressively created among families, caregivers, and other families, as treatment provides an opportunity for caregivers and children to interact and cultivate different forms of intimacy, friendship, and camaraderie (even for short periods). Children, through painful treatments, discover and embody new bodily dispositions and capacities. Their child’s care changes parents’ (usually mothers) social relationships as they leave behind their households and are secluded at the Hospital Infantil for several months, separated from other family members. Within the hospital, they become part of the network of news, rumors, gossip, and tips among children and caregivers. Both children and parents are aware of what is happening to other children; if they miss an appointment, if they are doing fine, or getting worse. In many instances, I observed parents and children who kept going to the hospital even though they had been discharged just to support others because they already
experienced these struggles. In this way, other children, caregivers, and professionals became part of the world of the patients and caregivers.

In the following chapters, we will look at how children are engulfed within the clinical gaze and how their bodies became the focus of various interventions aiming to diagnose, treat, and free children’s bodies from malignant cells growing in their bodies. I will also compare the experiences of children, families, and professionals in this hospital in Argentina with similar processes in North America and Europe to show the particularities of this site. In the remainder of this chapter, I will describe the ethnographic context, the research questions, and the two main sites where I conducted research. First, we need to consider the research questions of this study.

**Research question**

Originally, I intended to focus on children’s end-of-life experiences. Based on previous research in the hospital, the research questions I was hoping to answer were:

How does a healthy child become a terminally ill child? How do Argentine notions of childhood and medical interventions affect the social construction of the terminally ill child? And, how is the experience of these children medicalized?

However, when I began conducting fieldwork with the *Equipo de Cuidados Paliativos* (Palliative Care Team) I realized that we need to know more about the whole process, i.e. starting from the point that children get diagnosed and ending at the point that they either overcome the illness, or experience end of life. In particular, it became clear that it was important to grasp the complexities of the one to two years of treatment. Thus, I refocused my approach more heavily on the lengthy cancer treatments and less on the two different outcomes. For that
reason, I paid more attention to what happens during treatment, the rough path from the moments when a child gets diagnosed until professionals declare the end of treatment.

Consequently, in order to understand the complexities of the hematological treatment and its impact on children and families, I had to work with the two units dealing with cancer and the potential infectious diseases of these immuno-compromised patients. Thus, I contacted and received permission to conduct research at the Unidad de Hematología (Hematology Unit) and at the Unidad de Infectología (Communicable Diseases Unit). As part of my refocusing on the lengthy treatment, I also contacted the key NGO assisting children living with cancer and their families. The Fundación para Niños con Cancer (Children with Cancer Foundation) granted me permission to conduct fieldwork observing their weekly multi-family meetings. By working on these different sites, I became interested in children’s bodies as hubs of social, medical, familiar, and inter-personal processes. This led me to focus on permeability.

I wanted to understand how children’s bodies not only were physically, emotionally, and socially affected by these intense, painful, and invasive treatments but also how they were affecting others as well. I looked at children’s bodies as holey, fluctuating, constantly traversed by medically orchestrated affects. In this process, children’s bodies throughout cancer treatment became (re)assembled by means of an endless progression of in/out therapeutic exchanges aiming to wipe malignant cells from children’s bodies. In a sense, “permeability” has to do with the tangible flux of elements getting into/out of children’s bodies (drugs, blood, biopsies, needles, portacaths, etc.) but in a broader sense, it is also, what sustains the relationship between children-clinicians-parents: the promise of survival. In other words, children’s cancers and their treatments uniquely affect everyone. Becoming a cancer patient, a parent or caregiver, and a clinician aiming to cure and care children creates spaces of permeability, vulnerability, and trust.
Certainly, the advancement of cancer medicine has dramatically transformed pediatric experience of cancer and expanded expectations of survival. Many cancers now are less a life threatening condition and more a chronic life-long condition. Yet, in many ways, throughout the lengthy treatment the experience of cancer relates to both acute and chronic forms of care. Nonetheless, terminal care and the issues around failure of treatment remain as the backdrop of children’s, families’, and professionals’ experiences.

Every year in Argentina almost 500 new cases of pediatric leukemia are successfully treated if proper (aggressive) measures are taken. In 2008, the total mortality rate for all leukemias within the year of diagnosis was 15 % (ROHA 2008). The 3 year and 5 year survival rate for children with acute lymphoblastic leukemia (the more common type of pediatric leukemia) was 68 % and 63 % respectively; and the 3 year and 5 year survival rate for children with acute myeloid leukaemia was 40 % and 39 % (ROHA 2008:79). However, depending on the time of diagnosis, and the response to treatment, children will experience multiple complications and some of them may even die. These numbers show the intricate paths between cancer treatment efficacy and the experience of children enduring and surviving not only cancer but also its invasive treatment.

Given my desire to focus on the experience of childhood cancer and better understand the notion of “permeability” in this context, I reframed my research question to focus on the body of the child:

How is a child’s body (seen as a corporeal subjectivity) living with hematological cancer affected when invasive treatments are used to seek a “life without illness”?

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2 The incidence rates for children 15 and under in countries like Germany, Spain, Italy and US vary between 132 a 150 cases per million. According to the ROHA (2008) in Argentina every year approximately 1 270 children under 15 are diagnosed with cancer, an incidence rate of 124 per million.
This question is anthropologically significant in three ways. First, it points to the limits of our own body in the context of an intense and invasive medicalization of everyday life. Who has control over children’s bodies not only legally but also affectively? When looking at the way that others (mainly parents and clinicians) directly affect children living with cancer we understand their position of vulnerability despite their ability to act and affect others.

Second, it looks at the “stuff” that creates the subjective experience of cancer treatment not only in relation to children but also their parents and caregivers as well as their main sets of clinicians. The corporeal and subjective experience of cancer treatment implies an array of interventions and concessions around the boundaries of children’s bodies. By looking at these corporeal interventions we can understand children’s (and others’) subjectivities. Indeed, at the core of the inter-subjective relationships among children, parents, and several clinicians lies this constant compromise regarding the proper treatment of children’s bodies. There are conflicting ways in which children, parents, and clinicians describe and rationalize what children “are,” what they “have,” and what needs to be “done” to them.

Third, it directs our attention towards the drastic personal and interpersonal transformations that are dictated by the cancer treatment, and that I incorporate in the notion of “permeability.” The physically, emotionally, and socially charged therapeutic horizon that is associated with painful and invasive interventions into children’s bodies is an ongoing process that begins with diagnosis but continues even beyond the end of treatment. Throughout cancer treatment children are exposed to all sorts of intense experiences, ranging from pain to being secluded for weeks and months at a time. Indeed, what counts as “family” for children and their parents during these intense one to two years of treatment is also reconsidered. These drastic transformations affect children, parents, and their whole families.
The value of understanding children’s bodies as permeable is that we can focus on the frictions, pain, and resistance that are part of these invasive treatments. It adds a layer of complexity to our anthropological understanding of the body because in many ways what happens to children demonstrates that the body is less individual and more interconnected, dependable, and porous as it is traversed by biomedical forces. Parents, who give consent to clinicians to painfully intervene and breach children’s bodies for medical purposes, control those same bodies. Therefore, key tensions here are: To what extent do children understand these processes and have (or have not) the right to refuse these interventions? How often do clinicians let caregivers know about, and even be present during, invasive interventions? Caprotta et al. (2004) have shown that in the Argentine context the majority of clinicians let parents be present during minimally invasive procedures because parents can comfort children. Yet, they exclude parents during highly invasive procedures since it produces anxiety in clinicians and can be traumatic for parents. Throughout this study we will examine how this tension plays out in this particular clinical setting. For instance, we will see how parents support children through very invasive procedures such as lumbar punctures or bone marrow examinations. We will also pay attention to the struggles between parents, children, and clinicians around the decision to insert (or not) a semi-implantable catheter (portacath) inside children’s bodies. Indeed, the example of the portacath supports the claim that children’s bodies become permeable bodies. It also gives concreteness to the proposed concepts of corporeality/subjectivity and permeability in this study.

The therapeutic process must also be expanded beyond the clinical setting to understand how it is part of a broader social landscape of the child and family. Their journey can last for about two years including the main part of treatment in the hospital and for more years after children are declared free of illness in their home communities. Children enduring cancer
treatments often have to navigate critical, chronic, and painful care. The goal of this thesis is to explore the therapeutic process shared by the children, their parents and family members, and the clinical staff, as seen in the treatment of children’s bodies, and in the focus of their concern, care, and action.

This study follows one strategy. Chapter 4 on “thresholds” identifies the beginning and initial phases of treatment, leaving the end of treatment for the end of the dissertation. In this way I organize this study around the sequence of events prior to and following the diagnosis of the hematological illness.

**Ethnographic context: health care system, pediatric cancers, and medical travel**

Argentina, the third largest country in Latin America, has a population of more than 41 million people, with 92.7% of them living in urban areas (see Fig. 1). More than a third of Argentina’s population lives in the Greater Buenos Aires metropolitan area that surrounds the City of Buenos Aires. The Argentine health care system, particularly tertiary care, is highly concentrated in the urban areas. According to the United Nations Development Report Argentina is ranked among the “Very High Human Development” countries and is ranked 49 among 187 countries (UNDP 2014). The WHO overall health system performance score situates Argentina at 75 of 191 countries, as compared with Canada (30), and U.S. (37) (Tandon et al. n.d.).

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Since the beginning of 1990s, under global and local neoliberal policies, most of Argentina’s people saw their socio-economic situations deteriorate. During the 1990s, Argentina became increasingly impoverished and unequal, with wider economic gaps between the higher, middle, and lower class (Destremau & Salama 2002). The last economic crisis between 1998 and 2002 (also called “Argentine great depression”) brought more inequality and poverty. The peak was reached in October 2002 when 57% of the total population was living under the poverty line. Economic growth after 2003 and the development of redistribution policies targeting vulnerable populations helped to decrease poverty and inequality (Lustig et al. 2013). According to official statistics, poverty went from 54% in 2003 to 13% in 2009, and extreme-poverty from

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5 “Poverty headcount ratio at urban poverty line (% of urban population) | Data | Table”. Data.worldbank.org, Archived from the original on 30 October 2013. Accessed 20130422.
27% in 2003 to 3.5% in 2009. The last three governments in Argentina have prioritized *desarrollo económico con inclusión social* (“economic development with social inclusion”). Thus, social spending through various programs has vastly increased. For instance, the *Asignación Universal por Hijo* (“Universal Child Allowance”), which reaches approximately 3.7 million children and adolescents up to age 18, is a cash transfer that covers 9.3% of the population.

Within this general socio-economic and political context, Argentina has a long tradition of accessible public health care at the primary, secondary, and tertiary level. The health care system is organized into three different sub-systems. The three sub-systems are 1) public healthcare that is funded through taxes, 2) social health insurance (labor union-sponsored plans) that are funded through an obligatory scheme by employees to their union, and 3) private healthcare insurance which is paid for by an individual. Within the public health care sector there are several programs such as *Médicos de Cabecera* (“family doctors”) that provide clinical care for public hospital inpatients and outpatients. A charge is made to outpatients for medicines and services. However, if they cannot afford to pay, the care is free. In 2007, about 40% of the total Argentine population were not member of any private or social health insurance scheme (Cavagnero et al. 2006). This sub-system is under constant threat from lack of funding and

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8 The actual figure of the population without medical coverage (private or social health insurance) varies depending on the sources. The World Bank estimates that 70% of the total population rely on the public sector ([http://www.worldbank.org/en/country/argentina/overview#3](http://www.worldbank.org/en/country/argentina/overview#3); accessed 20150529).
understaffing. Care is also affected by constant labour strikes and disputes. The public sector was decentralized in the 1990s, with administration moving from the national level to provincial or municipal levels. At the same time, even though access to basic health services is universal in theory, with free access for uninsured people, “the implementation of (or increase in the number of) out-of-pocket payments for services [that] was introduced as a part of the [1990s] reform” have affected the levels of access to care to large sectors of the population (Cavagnero et al. 2006: 9). The main research site of this study is a pediatric hospital located in the public sector and with an enormous influence in the creation of pediatrics in Argentina. This is one of the main public pediatric institutions in Argentina in terms of its complexity and quality of care.

The second form of care is the Obras Sociales (Social Health Insurance, Labor union-sponsored plans), which are round 300 (200 are related to labor unions). These programs are administered by trade unions but are “flexible” and able to serve any client who is willing to join. Employers and employees each pay a fixed fee. This form of social security covers the cost of medical care and medicines in varying proportions. The patient pays the difference between the fixed fee and the actual cost of treatment. In the past, these union-run services have usually covered around 50-55% of the population. This percentage varies constantly according to a combination of factors such as the changes in unemployment (currently 7.5%), semi-employment, and under the table working conditions, and the growing inflation. Thus, in moments of economic crisis more people have to rely on the public sector as the only source of health provision. Within the Obras Sociales or social health insurance, there are three sub-

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10 data.worldbank.org/indicator/SL.UEM.TOTL.ZS; accessed 20150529.
systems: OSN (National Obras Sociales), OSP (Provincial Obras Sociales) and INSSJyP (special health insurance fund for the retired and their dependants). The third form of care is the private sector, which requires that patients meet the total cost of their medical care through private insurance. This sector includes around 5-15% of the population, or approximately 2 million people. More than 200 different national and international insurance companies provide coverage in this sector. These businesses are loosely regulated, which creates concerns about devious business practices.

As a middle-income country Argentina’s medical infrastructure is unusual. For instance, it has more than 153,000 hospital beds, 121,000 physicians, and 37,000 dentists (population ratios similar to or even higher than developed countries). Argentina’s investment in health of 8% GDP is comparable with European countries. Historically, people have had high access to health care, which has resulted in morbidity and mortality rates comparable to developed countries in the global North. For example, the increased access to medical care has drastically reduced infant mortality rate from 25 per 1,000 live births in 1990 to 12 per 1,000 live births in 2009.

The main research site of this dissertation is a public sector, tertiary level pediatric hospital that assists children from all over the country. As we will see later, many provinces send their patients who are complex to public hospitals like the Hospital Infantil. The main public

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11 Almost 4 million senior citizens (and their dependents) are covered by the INNSJP (also known as PAMI).
institutions dealing with pediatric cancers are located in the biggest cities of Argentina such as Buenos Aires, Mendoza, and Cordoba. Although the pushing provinces who send patients cover the costs of treatment and relocation for their patients, this situation often creates pressure at the hospitals receiving the referrals in these major urban areas that need to deal with patients and families from all over the country. Another strain to the public system is that one in three Argentines lives in the Gran Buenos Aires (“Greater Buenos Aires Area”) that includes the City of Buenos Aires and the adjacent 24 Municipalities of the Province of Buenos Aires. In the area that surrounds the City of Buenos Aires the majority are working poor, with lower levels of education, above the average levels of unemployment or working under the table, and lack social benefits. The Province of Buenos Aires is short of beds for hospitalization, and the quality of its public hospitals in outlying areas with some exceptions is generally poor. Thus, inhabitants of the province go to the City of Buenos Aires where the quality is better. This creates another layer of pressure on the public health care sub-system at the City of Buenos Aires. In addition, half of the children under the age of four in the Province of Buenos Aires do not have any medical coverage. One out of every two children that come to the hospital is from the Greater Buenos Aires Area where children are often living in difficult conditions, which places considerable strain on the hospital’s resources.

The Ministry of Health at the federal level supervises the three forms of the health care system and is in charge of regulations that ensure minimum standards of care. It is also responsible for evaluating and collecting statistics from the three sub-systems. Nevertheless, the national system of health services is inefficient and uneven. Each of the three forms of health coverage has their own system of insurance and health care provision. For example, the public sector has hospitals and clinics at the national, provincial, and municipal levels, offers primary,
secondary, and tertiary levels of care. Similarly, trade unions provide insurance and have their own hospitals and clinics. The private insurance system also has its own private clinics and hospitals. As we can see, there are overlaps but also gaps because many regions of the country have inadequate health care options.

Within the publicly funded system, both the municipal and national public pediatric hospitals in the City of Buenos Aires not only assist patients from the city but also attract patients from the densely populated surrounding Greater Buenos Aires Area and beyond. Included among the patients who arrive to the City of Buenos Aires for treatment are the hundreds of patients that every year generates 10,000 consultations for cancer at the Hospital Infantil in which this study took place (numbers from 2010).

Children’s cancers are complex and create demands on the Argentina’s public health care system that treats the majority of children living with cancer. In Argentina, the incidence of pediatric cancers is low, with a middle-to-high cancer incidence. Between 2000 and 2008 the incidence of pediatric cancers was about 124 for 1,000,000 per year in children under the age 15 (ROHA 2008), which is a slightly lower incidence rate than in Spain, Italy, Germany or U.S. The most common pediatric cancers in children under 15 in Argentina are leukemias (37%), Central Nervous System tumors (18%), and lymphomas (13%). Hematological conditions (leukemia and lymphomas) represent half of all the pediatric cancers (Moreno et al. 2013). Deaths within a month of diagnosis for all pediatric cancers show a decreasing trend. They were 5% in 2000 and 3% in 2008 (Moreno et al. 2013), although both mortality within a month and year of diagnosis

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16 Similarly than in Argentina, among Canadian children, leukemia is the most commonly occurring type of cancer (33%), followed by brain and nervous system cancers (20%) and lymphomas (11%). http://www.phac-aspc.gc.ca/cd-mc/cancer/fs-fi/cancer-child-enfant/index-eng.php; accessed 20140729.
is still relatively high in comparison to developed countries (ROHA 2008). Specifically, among patients with leukemias, in 2008, 15% of children died within one year of diagnosis, and this could be related to the characteristic aggressiveness of the tumor, the delay of diagnosis, and the problems of providing support to patients during the first phase of treatment, which generally requires high complexity care and a specialized professional team (ROHA 2008:21). Pediatric leukemias are the most predominant in terms of incidence (one out of three) among all pediatric cancers, and compose the largest cohort of this study.

Just to show the centrality of the public sector in relation to pediatric cancers, in Argentina, 80% of all children are treated in public hospitals such as the one in which I conducted fieldwork, and on average around 35% migrate to other institutions for some part of the treatment (ROHA 2008). As I will develop in more detail in Chapters 4 and 5, in the last decades, there has been a vast improvement in the treatment of pediatric cancers. Children have up to 80% (sometimes even more) of 5-year survival without illness in the developed countries, yet, in Argentina, overall 5-year survival without illness for pediatric cancers reaches 65%, although it greatly varies depending on the different regions.\(^{17}\) The other side of these percentages of survival without illness is that in spite of the outstanding progress in the treatment of pediatric cancers in the last decades still 20-30% or more of children living with cancer die of it or its complications. A number of different factors could explain the lower threshold of survival without illness in the Argentine context. We know that health inequalities are directly related with gradients of socioeconomic status (Black et al. 1980). Thus, social determinants of health have a major impact on how families with children living with cancer are able to mobilize myriad resources throughout the lengthy therapeutic process from diagnosis until survival

\(^{17}\) SIVER/INC–Ministry of Health. Based on death certificates DEIS-Argentina, 2014
without illness. First, children in Argentina are often diagnosed later than in comparison with the developed world and, thus, experience more advanced tumors, which lowers the chances of overcoming the disease. Second, depending on the difficulty of each pediatric cancer, children (and families) access to effective therapeutic protocols and proper referrals are unequally concentrated in certain parts of the country.\(^\text{18}\) Third, they also need social support like the one given by CCF, especially during the first part of treatment (Moreno et al. 2013, ROHA 2008). One reason some children fall into the cracks of the health care system is that pediatric cancer treatment is highly centralized and heavily dependent on public health care. In 2008, the *Registro Onco-Hematológico Argentino* (Argentine Onco-Hematological Registry) recorded from the total population of children under age 15 that 74% were registered at tertiary level public hospitals, 16% at private institutions, and 10% by other sources (pathology services, death certificates, etc.) This shows the centrality of the public sector to assist all pediatric patients notwithstanding the kind of health coverage their families have. Moreover, only three public pediatric institutions treated more than 50% of all new pediatric cancers in Argentina (ROHA 2008) (including the institution where I conducted research). The particularity of the Argentine health care system is that public pediatric institutions play a fundamental role not only in assisting three out four pediatric patients but also in providing the expertise for the other two sectors. In fact, the great majority of the staff physicians (hematologists, communicable diseases specialists, and palliativists) and physicians doing the residency in Pediatrics (especially during third and fourth years) at the *Hospital Infantil* that I worked with during fieldwork work at both the private sector and the social health insurance as well. As I already mentioned the three

\(^{18}\) Just to give a quick idea of the concentration of health services and resources in Argentina, the City of Buenos Aires and the Province of Buenos Aires together have half the total numbers of doctors and of beds available in the whole country (ROHA 2008).
sectors of the health care system run their own hospitals and clinics. Yet, children in the private sector are treated in that sector, and children from the public and social insurance sectors (especially provincial and municipals social plans) often end up treated at the public institutions. Moreover, given the Argentine’s socio-demographic patterns, many of the uninsured children that rely on the public sector live in the Greater Buenos Aires Area and are sent for care in the public pediatric hospitals in the City of Buenos Aires.

Argentina has a continuum of children with hematological conditions. On one side, there are those children who receive effective, up-to-date treatment in a few key central institutions who have a slightly lower five-year survival rate without illness than in the developed world. On the other side, many children only receive partial treatments or are never diagnosed and receive no treatment (Scopinaro and Casak 2002). Social and economic inequalities within the country prevent certain children and families for accessing good, reliable, and free hematological treatment. As I will show in Chapter 9, families will frequently need to travel and relocate to pursue good, reliable, and free treatment, which raises more layers of social, cultural, economic, and ethical issues (Vindrola-Padros 2012, 2015).

Given the specificity of the required treatments and the concentrated nature of the medical system in Argentina, a large percentage of families go through taxing experiences of medical travel and medical relocation in order to seek and obtain treatment for their children. Thus, medical relocation, moving from one’s home to another location for treatment, is a common experience for patients and families. In Argentina, there are “core” and “peripheral” provinces in terms of their capacity to assist children with pediatric cancers. For instance, of the twenty-four provinces only three report less than 10% of medical travel for children with pediatric cancers. That is, only three provinces that do not push their children to other provinces
to receive treatment for their onco-hematological diseases. These provinces are the City of Buenos Aires (0%), Cordoba (4%) and Mendoza (7%). Thus, these provinces not only treat children from their own jurisdictions but also pull patients from the rest of the country (ROHA 2008). On the other end of the spectrum, two provinces (Santa Cruz and Tierra del Fuego both in the Patagonia region) send 100% of their children with pediatric cancers to other provinces for treatments (ROHA 2008). However, the majority of the provinces fall in between treating some of their children and sending others to one or more of the provinces that pull patients. Some provinces provide children with the first part of treatment and then send them to core provinces for the continuation of treatment. Although it should be noted that (from the Provincial State’s governmental logic) this kind of arrangement makes sense since the numbers of children with pediatric cancers are low and it is expensive to treat them. Thus, it is more cost-effective to send them to the more complex centers and help those families during their stay than to invest in having their own medical institutions in their provinces. Yet, given the high concentration of population in the center of the country, if we exclude the city of Buenos Aires and the Greater Buenos Aires metropolitan area only 30% of all medical relocalization related to pediatric cancers had to migrate to another province for some part of the treatment (ROHA 2008). In fact, according to Moreno et al. (2013), between 2000-08, 57% of children living with cancer were taken care of in institutions situated in their province of residence, in the City of Buenos Aires 37%, and 6% in hospitals located in provinces other than that of residence. This shows two things: that population in Argentina is highly concentrated in few areas with high density, and that medical relocation in many provinces is very prevalent although the number of cases in those “peripheral” provinces is relatively low. Of course, if we look this from the family’s perspective the story can be seen very differently. Most of the relocated families I talked with at
the Hospital Infantil would have preferred to be treated in their own provinces and not to be sent far away from their homes and social networks although they were thankful to the possibility of being treated in such a renowned clinical site (I will discuss this in more detail in Chapter 9).

Given the central role of hospitals within the biomedical system, and the great variability in local settings, one would assume many ethnographies have focused on hospital settings worldwide. Nevertheless, according to van der Geest and Finkler (2004:1995) within the rich history of medical anthropology research “less attention has been given to the hospital as the premier site of biomedicine cross-culturally.” Particularly, few ethnographic studies have focused on pediatric hospitals and children living with and beyond cancer. Bluebond-Langner (1978) was one of the first ethnographies that worked with children living and dying with cancer. Her main finding was that children from as early as three-year old knew they were dying but they had to engage in particular forms of communication with both their parents and clinical staff. Bluebond-Langner et al. (2007) have studied communicational and decision-making process (the reasoning and emotions) parents, physicians and often children engage in relation to children’s care, especially when cancer treatment is not working. They propose the need for an integrative care simultaneously focused on cancer, symptoms, and supportive care. Rindstedt (2013) conducted a video ethnography following five patients in their everyday clinical encounters to understand children’s coping strategies (imaginical coping). Children, parents, and staff were all involved in implicit and explicit ways of developing children’s coping with cancer. In these ethnographies, we can see the particular assemblage of specific actors (children, parents, and clinicians) and both the implicit and explicit ways they mutually affect one another.
If we look worldwide, even fewer ethnographies have concentrated on pediatric hospitals
outside global north. This is remarkable given the importance society pays to vulnerable
children as future-citizens needing help, and the vast influence pediatric hospitals produce at the
social, familiar, and inter-personal levels in terms of practices, behaviors, and infusing new
pedagogies and technologies of the self (Smith 2012).

In fact, when considering how societies take care of children, Sobo (2015) finds two
different kinds of models: a pediatric model and a pedagogic model of childcare. A pediatric
model focuses on “infant’s survival, physical growth, and health,” whereas a pedagogic model
focuses on “behavioral development and preparation for educational interaction” (Sobo
2015:48). These models are related not only to child-rearing notions but also to larger ideas of
social relationships too. In societies in which people are living in direr conditions a pediatric
model focused on child’s survival would be emphasized whereas in “more developed” societies
like U.S. a pedagogic model focused on development and education would be encouraged
(Lareau 2011). In the context of this study, in Argentina it seems that we are dealing with a
pediatric model aiming to assist children and families to overcome pediatric cancers in a broader
social context of inequality and social struggle. In this thesis, I will look at children living with
cancer in Argentina as traversing these two models of childcare. Their survival is dependent on
access to health and reliable cancer treatments at key pediatric institutions such as the Hospital
Infantil.

Livingsgton (2012) is a great ethnography of a cancer ward in the global south, though it
focuses on adult patients.
**The Hospital Infantil**

As one of the main tertiary care referral pediatric institutions within the Argentine health care system the *Hospital Infantil* covers a whole range of services, specialties and sub-specialties within pediatric medicine (from age zero to age eighteen). The mission of the hospital, as stated in its website, is:

To assist children and adolescents with the highest complexity. To become a reference center within a vast pediatric network by coordinating activities and services with other hospitals in an integrative and participative framework. The hospital will be, as always, focused on the patient and the community needs with a profile on assistance, teaching and research.  

The pediatric hospital in which this study is based is one of the most complex pediatric hospitals in the whole country with vast influences within and outside Argentina. This, however, does not mean it only covers complex conditions. Many patients with ‘simple’ conditions also receive primary care. Furthermore, healthy children are seen in “Healthy Child Clinic.” Where medical residents doing the basic residency rotation treat them. The *Hospital Infantil* has had an enormous influence not only in the development of pediatrics in Argentina but also in terms of expanding effective treatments for children living with cancer.

Throughout the dissertation, I will describe and analyze the complexities of the hospital, which was my main research site. I will also place the clinical site in relation to the greater landscape of care for children and families, including the *Fundación para Niños con Cancer*. This is one of the main NGOs helping children living with cancer. The *Fundación para Niños con Cancer* was the second institutional site for my fieldwork where I observed multi-family meetings. I will describe the *Fundación para Niños con Cancer* and these meetings in more detail in Chapter 9.

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20 I am not citing this Internet reference to protect the anonymity of the institution.
Overview of the dissertation

In Chapter 2, I will provide the theoretical framework of this study and place this dissertation within general discussions in anthropology and other disciplines about children’s and others’ bodies. More specifically, this chapter focuses on the centrality of children’s bodies living with cancer that are constituted in relationships among children, professionals, and families. In Chapter 3, I will discuss the methodological basis of this study. I will reflect on the different tools that I used for grasping the three sets of actors’ points of view at the Hospital Infantil and CCF. In Chapter 4, I will examine the different temporal, affective, and spatial junctures that children, professionals, and families traverse throughout treatment. Here, I discuss “threshold,” the process of entering into different aspects of treatment. These therapeutic thresholds are guided by the logics of treatment and are under the guidance of different key health professionals resulting in different relationships and experiences of children, professionals, and families. In Chapter 5, I will focus on the different phases of hematological treatment (induction, consolidation, maintenance) and how they intersect with treatments of hematological and communicable diseases when children need to be hospitalized. In Chapter 6, I will look at how cancer treatment transforms both the children’s bodies and the social relationships focused on the care of their bodies. I refer to this as “modulation.” In contrast to the hematological emphasis on chemically manipulating children’s bone marrow in a narrow sense, I argue that we can use the notion of “modulation” to look at how children’s whole lives (and those of caregivers) are transformed. In Chapter 7, I will pay special attention to children’s corporeality and subjectivity and how children’s bodies are placed at the center of cancer treatments. I employ several examples to show how different actors, including children, make sense of childhood and
children, what they “are” and what should be “done” to them. In this way, I claim that we are dealing with particular kinds of children’s bodies. In Chapter 8, I will examine the inter-personal nature of children’s pain and how these experiences of pain and suffering are both an affect that shuts meaning and a by-product of illness and treatment. In Chapter 9, I will investigate the impacts of hematological treatments on family dynamics. It focuses on “therapeutic relatedness” as family ties are rearranged during the therapeutic trajectory of the sick child. In Chapter 10, I will conclude by synthesizing many of the issues discussed in this dissertation by reflecting on “(im)permeability,” and how children’s (im)permeability (and others) is related to everyone’s dignity of life. In Chapter 11, I will bring to a close this dissertation by consolidating the main arguments of this dissertation. I reflect on how within children-professionals-families relationships children’s bodies became the focal points of bio-technologies and bio-knowledge applied in order to free children from illness but nevertheless experienced by children, professionals and families in different, frictional and contradictory ways.
Chapter 2: Theoretical framework

“Bodies are not inert; they function interactively and productively. They generate what is new, surprising, unpredictable.”
Elizabeth Grosz (1994:xi)

Over the last forty years, anthropologists and sociologists have renewed their interest in the human body by looking at embodiment (Csordas 1994), the medicalized body (Frank 1990), medical knowledge-making of the body (Good 1994), and the phenomenological, social, and political dimensions of the body (Schepere-Hughes and Lock 1987), among other issues. We live and suffer in this world as interconnected bodies. In the rich anthropological theorization of the body, embodiment, and subjectivity there is an increasing recognition of the interpersonal nature of social suffering and its capacity to remake the world (Kleinman, Lock, Das 1997; Das et al. 2001). This anthropological rethinking of/from the body is part of a long conversation that can be traced back (at least) to Marcel Mauss (1973). Mauss considered that all bodily expressions are learned, and, thus, he focused on physiological, psychological, and sociological aspects of the body. Mauss pointed out that “techniques of the body”, meaning actions such as walking or standing that occur before they are unconsciously assimilated or embodied, are highly developed body actions and sets of behaviors that embody aspects of a given culture. For Mauss, the body is constantly adapting through “a series of assembled actions, and assembled for the individual not by himself (sic) alone but by all his education, by the whole society to which he belongs, in the place he occupies in it” (1973:76). Mauss’ arguments about body’s reorganization by external forces, its constant adaptation, and the place it occupies in society are still theoretically relevant today when considering the role of children’s (and others’) bodies in cancer treatment. For instance, what are the “assembled actions” and the place of the body when looking at biomedical practices aimed at wiping malignant cells from children’s bodies? Which are the
embodied “techniques of the body” applied to, and learned by, children during the lengthy cancer treatment?

Within the recent discussions about the body three key dimensions stand out as pertinent to this study about the role of children’s (and others’) bodies during cancer treatment: 1) sociality, 2) medical normalization, and 3) power relationships. Those that focus on the first dimension are concerned with the body’s re-creation of sociality through practice (Bourdieu 1977, 1989; Butler 1993; Latour 2005). The cultural logic of biomedical practice produces particular forms of sociality, and in some cases biosociality when participants of the biomedical encounter (re)create social relationships based on biological conditions (see Rabinow 1996). Those that focus on the second dimension show how bodies become objects of medical normalization through a professional capture of countless aspects of everyday life (Conrad 2007; Cooper and Waldby 2014; Foucault 1994, 1979; Lock 1993). Those that focus on the third dimension pay attention not only to bodies as the targets of unequal power relationships but also to the capacities of bodies as sites of contestation to those same power relationships (Aretxaga 1997; Boddy 1989, 2007; Sharp 2000). From different perspectives, these authors helped me to consider how crucial is to understand power, sociality, and medicalization in the corporeal and subjective lives of children experiencing cancer treatment, their parents, and different health professionals. In fact, it is key to situate biomedical practices in relation to children’s bodies in particular contexts to understand the multidimensionality of the body in a broader sense. Current anthropological approaches to the body illustrate that we must not take the body for granted nor bracket it. Instead, we should attempt to understand bodily practices within wider interpersonal, social, and political contexts.
A fundamental issue within recent debates over the body that is worth rethinking is the legacy of Cartesian dualism (body/mind, nature/culture, thoughts/feelings), especially in the anthropological reconsideration of the body in relation to health and illness. In an influential article, Scheper-Hughes and Lock (1987) proposed the notion of “mindful body” to reconsider Western assumptions around the body and a highly individualized self. By looking at the three bodies (phenomenological, social, and political), Scheper-Hughes and Lock offered a roadmap to overcome the epistemological and political entrapment between mind and body, and to think about the role of the body in our modern corporeal existence even when, and in spite of, being colonized and biologicized by biomedical practices.

From a cultural phenomenological angle, Csordas (1994) proposed the notion of embodiment as the methodological template to remap our understanding of the body going through ritual healings. For Csordas (1994), religious practices such as glossolalia non-dualistically condense aspects of the body in relation to both perception (the body as object) and the cultural and social logic of practice (the body as subject). In another article, Csordas (2008) goes beyond individualized notions of the body to draw a direct connection between intersubjectivity (a concrete rather than abstract relationship between two material mental entities) and intercorporeality (the primary experience of being always-already embodied in the interactions with other human and nonhuman bodies). For Csordas (2008:117), intercorporeality is a “mode of collective presence in the world.” In this study I consider the terms intercorporeality and intersubjectivity from a slightly different angle, and look at particular constitutive interactions such as transgressions of corporeal boundaries (Williams and Bendelow 2000) in order to grasp the space “in between” children’s painful bodies and others. I argue that both cancer and pain not only unite the corporeal and subjective aspects of the body, but also
situate and ligate individuals within broader social and cultural contexts, collectivizing children’s and others’ experiences. In this sense, I agree with Bendelow and Williams (1995) that we need to pay more attention to the emotional and cultural aspects of pain to transcend reductionist, dualistic, medico-psychological, and individualistic approaches to pain and suffering.

In order to think about intercorporeality and intersubjectivity we need to place these considerations within the expanding anthropological studies of subjectivity and the body. Yet, I am more interested in the relational modes of collective presence in the world, and how structural forces like biomedicine, in particular the construction of pediatric cancer patients, create inter-personal and inter-subjective collective experiences. Biehl, Good, and Kleinman (2007) suggest that subjectivity is both an empirical reality and an analytical category. Subjectivity is a dynamic and transforming process. In this sense subjectivity is always social, is always inter-subjectivity, and it is something we need to discover in our ethnographic explorations. Similarly, the resurgence of our interest in the body, on its corporeality and materiality, echoes Turner’s (1995:145) emphasis on the intrinsically social nature of the human body in “all its material, phenomenal, biological, psychological, social and cultural dimensions.”

Certainly, there is an intimate connection between corporeality and subjectivity but the question is how much weight we give to these interconnected dimensions of the human body. Luhrmann (2006) put more emphasis on the emotional and psychological aspects in order to understand subjectivity. Using a Bourdieuan understanding of subjectivity, Ortner (2005) frames subjectivity within cultural practice and agency, and viewing power as central. Nonetheless, understanding subjectivity through a psychological model of emotion or through the cultural logic of practice we often lose sight of the inter-subjective and intercorporeal dimensions of the body. That is, the constitutive and relational aspects of bodies needs to be considered in order to
understand the corporeality and subjectivity of children, and others, as they become cancer patients. Therefore, we need to examine in more depth the connection between (inter)corporeal bodies and (inter)subjectivities. The experiences of children living with cancer and undergoing invasive treatment forces us to think about the body in non-dualistic terms, not only because they have a limited agency during the process and others are making transcendental decisions on their behalf; but also because the inextricably connection between emotional and rational, psychological and social aspects of the body. During children’s treatment, their bodies become the focal point of social interactions between children and their parents, between children and their clinicians, and even among parents, clinicians, medical residents, and nurses.

In order to understand the intercorporeality and intersubjectivity of children and others, I adopt Elizabeth Grosz’s (1994) philosophical and political analysis of corporeality to frame my investigation, especially her claim that bodies and minds are not different substances or two types of attributes of the same substance, but something in between these two options. Grosz’s project is a feminist reconfiguration of the body, for thinking about the materiality of the body, and attempting to overcome mind/body dualism. Grosz argues that there is urgent need to refocus on bodies in accounts of subjectivity. Subjectivity, for Grosz, should not be conceived in terms of depth or latency, but as a changing surface against the colonization of the body by biology and medicine: “Bodies are not inert; they function interactively and productively. They generate what is new, surprising, unpredictable” (1994:xi). For Grosz, bodies are not only actively participating in the world; there is also an irreducible dependence between the psychical interiority and corporeal exteriority of bodies with neither of the two predominating over the other. Grosz argues that constant movements by the subject can be seen as a Möbius strip with its psychical interior and corporeal exterior endlessly folding in out. Grosz (1994:xii) claims, “The
Möbius strip has the advantage of showing the inflection of mind into body and body into mind, the ways in which, through a kind of twisting or inversion, one side becomes another.” Indeed, these movements are the cores of what produces bodies. This constant inflection does not mean a new dualistic division between “body” and “mind” but the mutual dependency between corporeality and subjectivity.

The human body is, as Grosz (1994) says, always-already sexed, racialized, portrayed, and taught using stereotypical notions of gender and sexual division. Similarly, Emily Martin (1991) demonstrated this attribution of gendered behaviour to gametes in her analysis of biology textbooks. In my study, I also found certain assumptions about children’s bodies that become embedded in the medical practice. In Chapter 7, we will see how children (especially small children) are conceived as having the capacity to endure more, and be more permeable and malleable to, cancer treatment. If we consider Grosz’s approach when looking at children’s bodies, we can begin to rethink the role of the body’s involvement in biomedicine, clinical investigations and interventions, and especially in relation to the constant transgressions of corporeal limits. This enables us to focus on both the corporeal experiences and the subjective aspects of care, such as the psyche and spiritual care, which medical professionals generally disregard as beyond medical practice.

I decided to use Grosz’s Möbius strip model for two main reasons. First, it encompasses any differentiation between the corporeal (often seen as the exteriority of the body) and the subjective (often seen as the interiority or psychological aspects of the body). When looking at children’s bodies throughout cancer treatment, especially the painful interventions and the drastic transformations, we can see the inextricable relationship between corporeality and subjectivity. Second, it allows us to carefully look at these inflections between “interiorities” being
exteriorized and “exteriorities” being interiorized for medical purposes; which, according to Grosz, are the cores of what makes bodies. By looking at these social and medical processes I will be able to see the kinds of connections, disruptions, frictions, and negotiations that are established between children, parents, and key professional teams throughout the lengthy and taxing treatment.

One of the limitations of using Grosz’s analysis of “interiorities” and “exteriorities” in a medical anthropological study is that one risks falling again into a dualistic approach, as both concepts are new versions of “mind” and “body,” that are also disconnected from the social realm. Yet, the point here is to remind the reader of Grosz’s argument in regards to refocusing on the body in order to think of subjectivity as a changing surface engulfed under the different medical gazes. But perhaps the main limitation of using Grosz, which Grosz herself states in her conceptualization of the body, is the inability to account for the transformation and becoming of the bodies. Particularly important are the cumulative transformations that materialize when children’s bodies are systematically broken into. Biehl and Locke (2010) propose an anthropology of becoming to consider the preeminence of desire over power and to understand the irreducible and incomplete vitality of the actual lives of the participants we are working with. What actually happens when children’s bodies are becoming cancer patients? Rouse (2004) talks about the racially and religiously mediated relationship between children’s terminally ill bodies and (inter)subjectivity and how often parents and professionals compete in relation to how they signify and metaphoricize children’s bodies. Williams and Bendelow (2000) talk about “recalcitrant bodies” when looking at children living with cancer as active agents throughout treatment, in spite of the constant breaching of corporeal boundaries. Williams and Bendelow argue that children’s malignant bodies become simultaneously a resource and a constriction, a
precisely, it is in this biological and cultural co-construction of children’s bodies and in the corporeal transgression for medical reasons that we need to look at the material, cultural, physical, social, and emotional aspects of the body becoming a “Leukemia patient.” For this reason, it is important to think about children’s bodies along four axes: 1) physical body-biology, 2) social body, 3) medicalized body, and 4) permeable body.

The first axis is the physical body-biology, and it focuses on how biomedicine has a tendency to individualize and biologicize what happens between people (Scheper-Hughes and Lock 1987; Taussig 1980). Instead, many scholars have argued that biomedicine should do the opposite: de-individualize suffering and politicize pain (Greenhalgh 2001; Lock 1993; Throop 2010). The individualization of cancer and pain is increasingly problematic in this so-called “genomics era” (Guttmacher and Collins 2003) when the conventional view of nature/fixed vs. culture/malleable has been undermined (Fox Keller 2010). Now nature/biology can be split, reshaped, transmuted, replicated, reset, relocated, and commodified in unimaginable ways (Kaufman and Morgan 2005; Lock and Nguyen 2010; Martin 1994; Scheper-Hughes and Wacquant 2002; Rheinberger 2000; Sharp 2000). Scheper-Hughes and Lock (1987) have criticized the modern notion of individual subject and have shown how sickness is not a secluded event. For Scheper-Hughes and Lock (1987:38) sickness is a sign in a communication process where “nature, society and culture speak simultaneously.” Consequently, Scheper-Hughes and Lock argue, that the individual, biologicized body “should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle” (1987:31).

21 I will discuss later this dual process of constriction and enhancement.
In regards to the second axis, the social body, many scholars have already argued that the body is a primary mediator of social *relationships*, a hub of all sorts of connections (Deleuze and Guattari 1987; Frank 1990; Ingold 2011; Latour 2005; Turner 1994). Seen in this way, medicalized bodies during treatment become the boundary objects (Star 2010) among the various clinicians and family members or the material anchors (Hutchins 2005) for a more political form of distributed cognition (Hutchins 2006). Given their short biographies, and compared to adult’s bodies, children’s bodies can be seen as an even more intense boundary object because there is less consensus among the different actors and because they are not highly structured. The body is also something we *do* in myriad (often unpredictable) ways, and is what we *become* (Biehl and Locke 2010), especially in the clinical encounter (Mol 2002). It is simultaneously subjective and objective, meaning and matter, personal and social, and can be the “‘material infrastructure’ of the production of selves, belonging, and identities” (von Walputte 2004:256). Yet, for a long time the body as the “‘material infrastructure’” of social relations remained unproblematised in anthropology. Lock (1993:133) argued in the 1990s that researchers “‘bracketed’ it as a black box and set it aside.” In the last decades, however, the anthropology and sociology of the body have shown that the body is not simply given, it is something to discover (Frank 1990; Lock 1993; Martin 1994; Scheper-Hughes and Lock 1987). Indeed, if we focus on children’s bodies living with cancer and what has been medically done to them we need to remember what Bluebond-Langner (1978) was saying in 1970s: children are social actors in their own rights. As actors, they are aware from very early in life, what happens to them, even when they become sedated or terminal patients. Therefore, when considering children going through cancer treatment, we need to uncover the intrinsic relatedness of children’s bodies. Furthermore, we also need to understand the body as a focus for the social activity of others, e.g. various professional
and lay actors who surround children and participate in their relational construction during a foundational period of their childhood (see Silverman 2011). The actors surrounding children play a key role in the assembly of the experience of becoming a particular ill child receiving hematological treatments. Thus, we need to understand how children are suddenly introduced into a set of powerful forces in which their bodies will become new nodes within webs of multiple biomedical interventions (Waldby 2000).

This dissertation explores these forces and the ways children’s bodies not only become simultaneously subjected to social and medical regulation and intervention but also how they react to it. Children’s bodies are sites for enhancing possibilities and socialities. By focusing on this apparent inherent duality between constraints and enhancements, this thesis examines children’s intense experiences of procedures that produce pain, and cancer itself, as central nodes in the medicalization of social relations. I emphasize the simultaneous nature of these interactions in two ways: as constrictors and expanders of children’s lived experiences. It is a process that unfolds among children, professionals, and family, which is apprehended differently by each of these three sets of actors.

Cancer, like the pain that frequently accompanies it, is never an individual experience although it is embodied and lived in uniquely different ways. Children, professionals, or caregivers do not experience pediatric cancers or its after-effects in vacuum, detached from others (McGrath 2001; Woodgate 2006). As Livingston (2012:6) argues, “Understanding cancer as something that happens between people is critical to grasping its gravity.” To grasp how cancer happens “between people” we need to look at the interactions between children, clinicians, and parents interacting simultaneously at very different levels. Thus, I will locate this study within an intellectual tradition that aims to understand the social, medical, and intra-family
consequences of *having* a pediatric cancer and *becoming* a cancer patient (Bluebond-Langner 1978; Bluebond-Langner et al. 2007; Dixon-Woods et al. 2002; Jain 2013). By doing so, I will also look at the ways in which expert, practical knowledge is locally situated and negotiated in relation to lay, practical knowledge around cancer, what Kleinman (1988) describes as “explanatory models.”

In regards to the third axis, medicalization and normalization, when looking at the broad medical and social field of cancer the last sixty years have shown a global explosion of cancer research. With an increase in research on pediatric cancers, and the rapid rise in the effectiveness of cancer treatment for children, comes multiple layers of etiology(ies) that improve treatment options (Mukherjee 2010), and the complex social and interpersonal consequences and the meanings attached to treatment (Bell 2013; Jain 2013). When considering the vast clinical improvements in the last decades I also see a growing concern, both in the global north and south, not only over children’s quality of life during and after cancer treatment (Eiser 2004) but also over children’s agency, capacities, sexuality, and who makes decision for children (Bluebond-Langer et al. 2010, Woodgate 2006). This is consistent with Sobo’s (2015) notion of the move from children’s survival to quality of life.

This general concern over children’s wellbeing during cancer treatment plays out differently depending on each particular medical, historical, and social context. As we will see later in this chapter, and throughout the dissertation, the particular milieu of this study shows the uniqueness of the Argentine’s long history of public health services and the context in which quality of life is assessed. When we look at the national figures of years of survival without illness, we are also looking at the large social context that preclude, or promote, increasing rates of success with cancer treatment. The vast improvement in survival rates in childhood leukemia
(more than 80% 5-year survival in countries like Canada, around 65% in Argentina\textsuperscript{22}; see Moreno et al. 2013) gives us a picture of these everyday struggles for survival. Considering the need to understand and improve children’s corporeal experiences with cancer it is surprising that relatively few ethnographic studies look at the ways in which children, cancer, and biomedicine are assembled in particular local contexts, especially outside North America and Europe (Vindrola Padros 2011).

Understanding children’s experience of cancer poses ethical, social, and practical concerns. Most communication with clinicians and treatment decisions are made by parents on behalf of the child. Socially, while children maintain a limited role as agents, they are in most interactions “patients,” recipients of care decided upon by their parents and doctors. In terms of anthropological research practice, it was difficult to me to ethically involve children in research while they undergo critical and medical medical procedures. Yet, as I will explain in the following chapter, I had to both observe and talk with children, parents, and professionals to also grasp the uneasy uncertainty and the fluidity of the encounters between those who are “producers” and “receivers” of the medicalization and normalization of children’s lives throughout cancer treatment. Indeed, central concerns of this thesis are: How do parents make care decisions, including authorizing invasive treatments that inflict pain on their child when in other circumstances their role is to protect their child? What are their understandings of the care provided and its impact on their child’s body? How do children literally put their body into cancer treatment; and how are they affected by it, understand it, and in turn affect parents and professionals? How do professionals manage their need for urgent, invasive, treatments without

\textsuperscript{22} Depending on the medical jurisdictions and access to reliable and good quality health care.
losing sight each child’s corporeal and subjective experience of treatment and how they are affecting parents as well?

The individual and familial life-altering experience of becoming a paciente (“patient”) (which implies passivity, a recipient of care) brings to the forefront the rationalization and realization of this unpleasant paradox. There is the need to inflict pain today for the real possibility of providing cure, or reducing the progression of the disease. However, if the painful treatment is delayed or not intense enough to counter-act the progression of the disease the treatment may fail. During the course of the treatment and the medicalization of their lives, children’s bodies are constantly changing and developing mentally, emotionally, and physically. Thus, children, their families and medical residents and doctors must try to make sense of their constantly fluctuating worlds.

When looking at the inherent invasiveness of hematological treatments from different perspectives, children and family members raised questions about the appropriateness of interventions. Another paradox is present when looking at childhood cancers. On the one hand, children and family members are very often thankful to the professionals for the medical interventions that help their children overcome potentially life-threatening illnesses. On the other hand, there is often an unease among children, clinicians and parents over where to draw the line between urgently needed therapeutic interventions and children’s (and caregivers’) capacities to (re)act and make sense of these intrusions (Bluebond-Langner et al. 2010). Perhaps, one reason for the success of biomedicine, and especially cancer medicine, is that it is continually pushing the envelope both technologically and experientially (Keating and Cambrosio 2012). As Kaufman (2015) argues in regards to older patients, treatments that were once seen as extraordinary are now considered obligatory, and even mandatory (see also Muller and Koenig
Yet, pushing limits has costs. How do children, and their families, (re)act to the constant medical interventions, and life disruption, that children and parents say changes their lives so “life is never the same” (Woodgate 2006)? And, conversely, how do health professionals react to their endless need to intervene, and the invasiveness of their urgently needed medical interventions? Furthermore, how we can look at the frictions that occur between the structural context of care (availability of up-to-date cancer care) and the lived experiences of children, professionals, and families pursuing treatment? That is, how is the corporeality and subjectivity of everyone involved in this process being affected by pushing the limits of children’s bodies?

At a very basic level this study is about understanding the impact of the invasive medical interventions (and the medical and social imperative to intervene) on children’s lives, and participants’ assessments of the value of the interventions. Frank (1990:135) has posed a critical question in regards to the power of biomedicine to determine our everyday lives experiences, he asks, “How are our bodies ‘medicalized’ in the sense of our experience of them being conditioned by parameters which institutionalized medicine has set in place?” Everyone is indeed conditioned by these parameters (included professionals). Yet, the lives of children living with cancer and other disabled people are often constrained by biomedical forces. In fact, for Frank (1990:143), “The problem for the disabled is to redefine the parameters of experience according to their own embodiment.” This is also the problem for children experiencing “sickness of the blood.” I will also argue that by socializing children as targets of medical interventions, children’s lives are enhanced as well. However, a question we need to ask is: How
can children redefine the boundaries of their experiences from their own bodies, and how can
caregivers and professionals be attuned to children’s intensively medicalized lived experiences?

The fourth axis look at the body relates to the notion proposed in this dissertation, that is, the “permeable body.” Permeability in its literal form refers to children’s corporeal experience of medical procedures and treatments. It relates to the individual, unique, lived, phenomenologically experienced body. Permeability in its symbolic dimension, is the notion that children’s bodies are “stuff to think of”, comparable to Scheper-Hughes and Lock’s social body. Permeability, a metaphor for the notion that children’s bodies are more penetrable and can endure more than other bodies, relates to the political body. If we consider biomedicalization and normalization as a form of surveillance and control of, and over, children’s bodies undergoing cancer treatment, then we have to pay attention to how the different bodies (of children, parents, professionals) become part of a political body (biomedicine). We need to understand how a political institution (pediatric hospital) that aims to erase malignant cells from children’s bodies then control these biologically driven clinical encounters. Yet, in these encounters, in these intense medical processes in which children’s bodies are constantly broken into, we can also see the frictions, resistance, and attempt to signify the permeability of children’s bodies. In the next section I will further develop what I mean by “permeable bodies.”

Within these four axes there are two basic dimensions that require special attention to understand how children, clinicians, and parents are simultaneously (re)acting towards one another. The first is the developmental dimension and the second is the interpersonal dimension. The former is central given the fact that children are “still developing,” and at the same time they are “processing” what happens to them. Considering the notion of development is vital not only because the focus of the study is on children, but also because there is a significant
anthropological/sociological constructionist critique of developmentalism as a prevailing global discourse on children and childhood. Allison and Prout (1990) have shown how childhood is neither some universal phenomena nor a singular one. As any given variable of social analysis it cannot be isolated from other variables such as class, gender, and ethnicity. In fact, one major critique to developmentalism is that children’s relationships and “cultures” need to be studied in their own right and not presumed. By looking at children and how they act and react to cancer treatment, and the connections they create with parents, family members, and various professionals, I will grasp how they are able to process intense experiences associated with lengthy cancer treatments.

The interpersonal dimension is also important because we need to look at the kinds of relationships children are able to produce, the abilities they develop through treatment, and the ways they can affect others, while being intensely intervened. This whole dissertation is an ethnographic analysis of the interpersonal, mutual affectations among children, parents, and several professionals. I will develop in more detail my proposed concept of “therapeutic relatedness” in Chapter 9 when I consider the kinds of socialization that are produced in the everyday lives of children and caregivers. In this dissertation I attempt to look at children’s bodies and their social worlds from multiple perspectives in the context of a particular pediatric hospital embedded in macro-social structures, including the hospital, the health care system, and the State agencies that play roles in their experience of cancer care. As Latour (2005: 2) reminds us, to grasp “the exact content of what is ‘assembled’ under the umbrella of a society” we have to try to look at these perspectives simultaneously.
**Permeable bodies**

I have borrowed Grosz’s (1994) model of a Möbius strip in order to think of children’s corporeal existence for two main reasons. First, her focus on particular permeable corporeal experiences (in her case of women, in my case of children) directs our thinking towards the material, raw aspects of everyday life. Her focus is to rethink sexual difference and sexed bodies. But in the process she gives us a way to understand how medicalized bodies are socially and medically constructed. Grosz proposes that our subjectivity is entirely corporeal-material, something that deeply resonates with the clinical encounters of children living with cancer. Second, Grosz emphasizes on women’s corporeal flows and the need to control and differentiate them from men’s. This can also be used in regards to children’s corporeal flows, especially children living with cancer. Grosz points to the fluidity and indeterminacy of female body parts and how that has been coded as passive dependence in relation to male fluids. Women’s bodies are often seen as bodies that leak, that bleed, and that are passive to hormonal and reproductive forces. In the same vein, we can also think about children’s bodies in those terms to grasp the cultural scripts that place children corporeal existence, especially the fluidity of their body parts, as passive receptacle of others’ (doctors, parents) interventions. In the context of painful cancer care, children are made “permeable,” that is, colonized, opened up as interior components are brought to the exterior, and through this permeability, come to be in the world differently.

The notion of *permeable bodies* that I develop from Grosz (1994) helps understand the ways in which being a “patient” implies a constant, daily, and lengthy series of in/out manipulations and corporeal inscriptions that affect the materiality of children’s subjectivities. These constitutive transformations, especially the medical examinations that produce a sort of
“disembodiment,” resituate patients from social subjects into medical objects (Young 1997), and, therefore, drastically affect children’s corporeal subjectivity. For example, when hematologists intervene into children’s bodies to perform a lumbar puncture, we can see how children’s subjectivity/interiority become extruded and forced out (Nancy 2006). If we consider bodies to be open, interactive, and dynamic systems, how does the relationship of “interiority” and “exteriority” become reshaped throughout the long and taxing therapeutic journey and the colonization of the body by biology and medicine (Grosz 1994)? Following Grosz (1994:210), how can we understand subjectivity as a surface “whose inscriptions and rotations in three-dimensional space produce all the effects of depth”? Another way of putting this is to call for a way to understand how particular biomedical materializing practices are organized, what Taylor (2005) described as “surfacing the body interior.”

Throughout this dissertation, permeability will be understood as polysemic. First, the actual physical and literal body-permeation and the centrality of children’s bodies are nodes within wider medical webs. Second, the symbolic permeability to which children, families and professionals are exposed while negotiating meanings in relation to illness and treatment. Third, the metaphoric permeability that is often used to think about children’s bodies as if they were more permeable than adults in the context of extremely strenuous cancer treatments. As explained in the previous section, I borrowed from Grosz (1994) the Möbius strip model to build my notion of permeability and how cancer treatment transform children’s corporeal subjectivity into permeable bodies. I decided to use this theoretical approach instead of others like subjectivity, embodiment, or social suffering given its potential to look at the material, raw transformations that happen simultaneously at the (inter)corporeal (inter)subjective levels during the lengthy treatment process.
Therapeutic process

Chemotherapy treatments create a series of massive changes in children and families’ lives that are both drastic and gradual transitions, which I call “thresholds.” These therapeutic thresholds are guided by the logics of treatment and are under the supervision of key health professionals. However, children, professionals, and families experience them in different ways. Cancer patients can often experience “sustained liminality” (Little et al. 1998) with variations during each course of treatment. Each of these courses of treatment within this more prolonged liminality constitutes a “threshold”.

But “threshold” is a polysemic word. Professionals and laypeople use it in different ways, not always referring to the word but to the notion of it. For instance, adolescents talk about the threshold of “*estar hecho mierda*” (to feel like shit) days after a big chemo and how slowly they came back to “normal” (feeling less like shit). Caregivers when talking about their children’s disease, particularly at the beginning of their medical journeys (maybe still in denial), were often thinking about thresholds of the disease itself. Hematologists also refer to it when talking about “toxicity thresholds” of chemotherapy, or “platelet transfusion threshold” when need blood transfusion. Palliativists refer to it when attempting to understand children’s “pain threshold.” Communicable disease specialists talk about it when looking at the “threshold of fever” or other symptoms that would indicate the beginning of an infection.

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23 Thresholds are ambiguous situations in which something (from an organism to an ecological system) is at the same time beginning and ending. My emphasis on thresholds in this thesis is to show how these different therapeutic thresholds show how, first, the overall trajectory is seen both by parents and clinicians as linear, though it is incrementally circuitous, and, second, there is an uneven process from “sick” to “healthy”.

47
For this dissertation I use the notion of threshold in a particular way. Thresholds imply some sort of reference between a point A and a point B. When looking at blood samples there is always reference ranges to measure the normal range of, for example, Lymphocytes. There are, indeed, thresholds that would mark the initiation of Leukemia (or, even pre-Leukemia). For instance, 5% or less of (lympho)blasts (immature cells) within the bone marrow is considered “normal” (plus other factors such as normal blood cells and no presence of tumor cells from blood or signs and symptoms of the disease) and above it is considered “abnormal.” In fact, if we think on the three phases of chemotherapy: induction, consolidation, and maintenance they would all deal with thresholds in the ambiguous presence/absence of “bad cells” at the bone marrow.

In these many uses the notion of threshold implies ranges of transitions. Not always these transitions worsen the whole organisms but nevertheless would entail reorganization and adaptation to new scenarios. At the social level often during a period of liminality societies are keen to ritually mark these transitions and potentially encourage crossing through it (Turner 1995). In a similar line, I consider these therapeutic thresholds as medically orchestrated, frequently highly ritualized transitions that children, professionals, and families not always in synch have to go through. Indeed, one could argue that the hospital in itself is a liminal space. Long et al. (2008:73) state:

Hospitals are ultimately liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed, etc. For many people, hospitals are places in which their previous identities as a healthy person, as a mobile person, as an immobile person, are stripped bare. New identities, such as a cancer survivor, a more mobile person with a new hip, a rehabilitated person with one less limb are forged.

Csordas and Kleinman (1996) argue that when thinking broadly about the therapeutic process we need to de-naturalize some of the cultural assumptions about what the healing
process entails. The first assumption they point it out is the difference between diagnosis and treatment, or between identifying a problem and trying to solve it. The second assumption is between medical (scientific, empirical) and non-medical (non-scientific, non-empirical) aspects of the healing process. A third assumption is derived from the previous one: the dichotomy between technological and non-technological healing acts, and how there is a technological imperative within biomedicine that often takes precedence over other healing practices, and, thus, affect the therapeutic process.

Another distinction Csordas and Kleinman mention is between professional (Western, biomedical) and non-professional (non-Western) therapeutic processes. Kleinman (1980) has shown the complex relations within a health care system between professional, folk and popular forms of healing. For Kleinman, professional care is one part of the healing process that begins at the popular forms of care. Csordas and Kleinman (1996:14) remind us “physicians themselves are likely to be unaware of the wide range of alternative treatments sought by their patients.”

During my research I observed similar tensions between parents’ adherence to treatment and professionals’ partial awareness of the “other things” parents were doing besides the core biomedical treatment.

Lastly, Csordas and Kleinman show the presence of biomedical cultural assumptions in regards to the distinction between therapeutic procedures (actions performed) from therapeutic outcomes (results achieved). The myriad procedures that children living with cancer are exposed to on a daily basis do not always produce the kinds of therapeutic outcomes that professionals originally envisioned (which somehow needs to be communicated to children and families). There are often frictions and contradictory views between professionals and laypeople in what is
done to children’s bodies and what is expected to obtain by performing those procedures, and the ultimate therapeutic outcomes of a “life without illness” (Bluebond-Langner 1978).

Certainly, to a certain extent there is a linear path when looking at the diagnosis-prognosis-treatment process. Usually, particular events happen before others and professionals use statistically relevant information to foresee their linearity. Indeed, Mol (2002) shows how epidemiological general data influence the ways clinicians see their particular patients. Yet, when considering these broad cultural assumptions about the biomedical therapeutic process, particularly how they play out on this research site, one thing stands out: the therapeutic process is not always an unvarying, mechanical, linear process. In particular, when looking at children living with cancer, and the montaña rusa (“rollercoaster”) of ups and downs they often go through, it becomes evident that in between “getting sick” and “overcoming cancer” or “dying of cancer” there are innumerable subtle processes that can be grasped by looking at spatial, affective, and temporal thresholds. In this way, I use threshold not only to think about these multiple (culturally localized) presuppositions of what treatment “is” for the different actors, but also to understand the temporal processes embedded in these long medical journeys.24

In her classic ethnography In the shadow of illness Myra Bluebond-Langner (1996) shows the progressive irruption of cystic fibrosis in family life. She demonstrates how when the illness first presents itself in to the child’s body and into the family’s life, the parents, the ill child, and healthy siblings try to control the intrusion of the disease into their lives. As the condition progresses and as hospitalizations increase, the members of the family internalize the trajectory of this incurable, chronic, and ultimately terminal disease. As Bluebond-Langner (1978) argues in her groundbreaking study of children with cancer, everyone knows the

24 For the cultural assumptions of what the therapeutic process entails in Argentina see Menendez (1990).
seriousness of the child’s condition, including three-year old children, but the progression of the condition is less clear for cancer than it is with cystic fibrosis. This is why I use the notion of “threshold” to talk about this zigzagging therapeutic process.

Children

The children that I worked with were generally attuned to the imperceptible changes in their surrounding environments. How people act and react gives them clues to how they may be progressing with their treatment. They are responsive to how their parents are feeling about them, and their expectations for treatments. Age is not necessarily the main indicator of how much children know about their conditions (Bluebond-Langner et al. 1991; Bluebond-Langner et al. 2005). Bluebond-Langner et al. (2010) found that the length of an illness constitutes the main source of awareness and knowledge. They claimed, “Children’s experiences with their illnesses play a major role in their understanding, especially children who have been living with the illness for some time” (Bluebond-Langner et al. 2010:334). This fragmented but cumulative gathering of information and filtering out of bits of facts lead children to producing their own–fragmented and incomplete by nature–knowledge. As Bluebond-Langner et al. (2010:333) argue,

Experiences of relapses and recoveries and all that comes with living with a serious illness from tests to overheard discussions to the ministrations of family, friends, and clinicians are critical to children’s acquisition of information and to their integration of that information into their views of themselves.

Not surprisingly, children would then, like others, “demonstrate different understandings and present different views to different individuals on different occasions” (Bluebond-Langner et al. 2010:333). In this regard, children are not only permeable to outside influences from parents, close relatives, and clinicians, they also adjust their responses according to the audience and viewers.
Conclusion

In this dissertation, the key components of my theoretical framework are a combination of concepts and models taken from different disciplinary lineages. First, I build my argument on “permeability” using Grosz’s Möbius strip model, which suggests a constant twisting of “exteriorities” folded in and “interiorities” folded out. As a critical feminist theorist she wants to re-think the dualistic ways of conceiving human sexed body. I found this model useful to ethnographically reflect on the role of the body, especially children’s bodies, in cancer treatment, palliative care, and cure. During the different phases of cancer treatment children’s bodies need to be under urgent and constant medical surveillance and, thus, become “extroverted” (turn inside out). How does this constant folding in/out affect children and those around them? Particularly important here is the folding process in which, for instance, surgically inserted ports become the new inside of the outside. Second, I pay careful attention to issues of corporeality and subjectivity largely thought about within the anthropological literature. I argue that it is essential to look at the corporeal, raw, painful experiences of children, parents, and professionals to understand the inter-corporeal and intersubjective aspects of their experiences. Csordas (2008:117) considers intercorporeality as a “mode of collective presence in the world.” In this dissertation I use both terms intercorporeality and intersubjectivity to focus on specific interactions in which the corporeal and subjective boundaries of children are broken into (Williams and Bendelow 2000). I also argue that in order to understand children’s, parents’, and professionals’ experiences throughout cancer treatment we must look at the space “in between” children’s painful bodies and others. In this way we will be able to grasp how the liminality of both cancer and pain not only bond the corporeal and subjective aspects of the body (Jackson 2005) but also locate and connect individuals within broader social and cultural contexts.
In the following chapter I will reflect on the methods used and the methodological and ethical challenges I faced.
Chapter 3: Methodological issues

“What do you write in that book?”
Second-year medical resident at the CDU

This dissertation is based on ten months of field research at the Hospital Infantil and the Fundación para Niños con Cancer (CCF) in the City of Buenos Aires between December 2009 and August 2010, with an additional one-month follow up in July 2011. It also builds on previous research in 2007 (four months) for my MA thesis (Wainer 2008).

Multiple levels of meanings and affects must be considered when looking with a qualitative approach at clinical institutions. I was only able to learn and appreciate glimpses of these experiences, and understand some of the key spaces within the pediatric hospital. I was able to comprehend some of the basic aspects of the different medical cultures of palliative care, hematology, and communicable diseases that were fundamental to children and families’ everyday experiences. I had only a partial entrance into the lives of children, families, and several professional teams. Yet, slowly, as I came to know the staff, the patients, and their families, I recognized the activities that shaped the experiences of the children, families, and key health professionals I worked with on a daily basis. I wanted to grasp not only how they are mutually affecting one another but also how they affect differently children and families throughout the lengthy therapeutic process. I wanted to understand the complexity of multiple simultaneous perspectives—patients, families, and several professionals—and how each one in itself, and in combination with the others, contributed to the complex ontology and epistemology of the hospital (Long et al. 2008).

As Hardman (1973) clearly stated back in the 1970s, there is a difference between studying children and studying their own social construction (researching about children or with children). In the last decades a considerable body of work has been developed in relation to
conducting more horizontal, participatory research with children (Christensen and James 2008; Johnson, Pfister, and Vindrola-Padros 2012; Mitchel 2006; Pires 2007). I agree with this approach in the anthropology of children, and sought to incorporate it into my ethnographic account with some caveats. Specifically, this study did not incorporate children’s perspectives in the design, collection or analysis of the data. Given the complexity of keeping the simultaneous focus on the three perspectives (children, family members, and professionals) I opted for a more “traditional” research in which I was the only person designing, collecting, and analyzing the data. Yet, during my research I methodically paid attention to how children themselves understood their bodies and the kinds of experiences that emerged from their interactions with family members and professionals. This study suggests the need to study children both in their interrelationships with their large social milieu and in the micro-spaces of clinical interaction. Thus, in the process of researching about and with children we cannot re-encapsulate their worlds, and not relate them with other key actors.

Here I will describe the techniques and methods I used while conducting fieldwork. During my eleven-month fieldwork at the Hospital Infantil I followed and observed children (and families) with all kinds of medical conditions but I paid more attention to children with hematological cancers. I concentrated my analysis on these children, their families, and several key professionals given the intense forms of biomedical interventions that are produced in the interactions among children-families-professionals when dealing with hematological cancers.

I conducted research at three key units: Hematology (three months), Communicable Diseases (three months), and Palliative Care (three months). In each of these medical spaces I observed the interactions between staff, medical residents, nurses and children and caregivers. At the Hospital Infantil, among other instances, I observed medical check-ups, procedures like bone
marrow examinations and lumbar punctures, family meetings, daily revision of cases (staff and medical residents), inter-unit meetings, walking rounds, grand rounds at night, night rounds at the Communicable Diseases Unit, nurses’ rounds at the Communicable Diseases Unit, professionals-parents formal and informal talks (with and without children present), and bibliography discussions. As a methodological precaution I only formally interviewed adult subjects (caregivers, professionals, and former cancer patients), and only engaged in informal talks with children and adolescents.

In view of the specificity of the ethnographic relationships I was trying to observe and the kinds of participants I was aiming to work with, most of the data I collected was purposely based on participant-observations, non-participant observation, and informal talks with all the participants. Besides the NGO in which I observed multi-family meetings, the main portion of my study was conducted within a tertiary public pediatric hospital and the setting in itself crated the conditions for my engagement with the participants. I was aware of the expanding creative battery of alternative qualitative and ethnographic methods to elicit children’s point of views but I decided instead to use a minimal methodology. In some cases, children were hospitalized for months at the Communicable Diseases Unit and I would talk with them and their parents and siblings inside their rooms, in the corridors, or when meeting them outside the unit. It takes time to build rapport with children and since I was constrained by the space and time of the clinic I often would interact briefly or intermittently with children when hospitalized in the Communicable Diseases Unit or as in-patient of the Hematology Unit. For this reason, but especially for the difficult personal, familiar, and medical situations in which children with cancer are often placed, I opted to talk with children, follow them, and observe their interactions with family members and professionals as my main methods. I performed two basic forms of
observations. One in which I was participating in the phenomena observed, for example, in the multi-family meetings at the CCF or at the patient reviews at the Communicable Diseases Unit. On the other hand, I refer to non-participant observations to those instances in which I was not talking with participants or directly participating, for example, when shadowing medical residents throughout the hospital.

During nine months I also participated in twenty-two weekly multi-family meetings at the CCF. The CFF is one of the main NGOs in regards to social support for families with children with cancer in Argentina. These meetings are conducted by a psychologist and are open to any family member of a child with cancer who is being assisted at this foundation. The meetings consist of a one to two-hour conversation among multiple family members. I observed meetings ranging from three to twelve family members. The basic idea of the multi-family meeting is to have as many caregivers as possible talking about whatever issues are relevant to them. Usually Telma, the psychologist, began the meeting introducing her, and then if there were other members of the foundation as well, I would also introduce myself, and then each caregiver would do so. After these introductions, the agenda was open and caregivers would bring their own topics for discussion. Children are outside playing supervised by volunteers so their parents and other family members can focus on the meetings. I performed participant-observation at these multi-familial meetings. My participation was at the beginning of each meeting when I introduce myself to the family members. In my introduction, I often said in Spanish, “Hello, my name is Rafael and I am anthropologist doing research to understand the kinds of relationships that are built among children with cancer, their parents, and several key doctors.” Very rarely, I would intervene in the meetings to comment something. Usually I took mental notes and some brief notes on my notebook. After the meetings, I often approached parents and family members
and informally talked with them about their own experiences, which was an invaluable source of data.

CCF is an essential resource for families. Many families who were finishing their treatment did not need to go to the Hospital Infantil frequently, but they continued to go to the CCF every week for support. There is a close association between the hospital and CCF geographical as well as social – CCF is located adjacent to the Hospital Infantil on a side street. It was interesting to hear parents and caregivers talking about their own concerns with treatment in general and with their relationships with their children in particular outside the clinical encounter. It helped me to grasp the family’s perspectives in relation to treatment and care, especially the social context of care.

In my previous study with the palliative care team, I was intrigued by how the experience of being legally a minor under the care of an adult within the biomedical culture would be different when looking at pediatric patients experiencing life-limiting conditions. In other words, how different is the therapeutic process for a child, and his/her social worlds, when experiencing cancer? The findings of my previous research (Wainer 2008) led me to look more closely at the biomedical interventions. In particular, at how children’s bodies became sick bodies that were urgently transformed into targets of medical interventions.

Thus, for this current study I had to widen my perspective and look at key places that are crucial in the configuration of biomedical sociabilities (Rabinow 1992). I needed to expand my view and look beyond the palliative care team. I wanted to understand not only the end of children’s lives but more importantly the long therapeutic processes that are crucial in the lived experiences of children with hematological conditions, their families, and professionals involved with them.
In addition to my Ethics approval by UBC BREB, I had to ask permissions to several gatekeepers at the Hospital Infantil: a) the head of each team (Palliative Care, Hematology, and Communicable Diseases), b) the head of all the clinical units at the hospital, c) the Director of the Hospital, d) the Research Ethics Board Committee, and e) the Teaching and Research Committee. At the CCF, I received permission from the psychologist in charge of the multi-familial meetings, and from the director of the foundation. My aim when I designed my fieldwork was to look at the long therapeutic processes and how children *ponen el cuerpo* (“put their bodies”) to these medical interventions that intend to produce new bodies free of illness. Thus, I decided I needed a broader approach, one that would help me to study how particular teams *simultaneously* interact and affect, while being affected by, children and families.

In this study, I attempt to focus my lens upon the “lived experience” of children, families, and professionals in the hospital setting. Only gradually, I was able to get access to these “lived experiences” and recognize key actors who play central roles during the daily interactions, and often long hospitalizations, with children and families. What Malinowski called as “the imponderabilia of everyday life,” these “lived experiences,” needs to be transformed into a question that attempt to grasp how children, parents, and professionals experience cancer care, “How does it feel” to endure cancer treatment? The grasping of the lived experiences of these three actors emerged slowly. I was able to map out key spaces that became fundamental to children living with cancer and their families. I also became a socio-cultural broker between children and families and different kinds of professional teams learning their idioms of distress (Nichter 1981). I was able to understand each perspective within this story. But I was not a patient, nor a father, nor a medical professional. I was a medical anthropologist working with children, parents, and professionals trying to understand their lived experiences from their own
perspectives. Yet, this was often not clear for all the participants I worked with. At the beginning of each phase of research (palliative care, hematology, communicable diseases) during my fieldwork I had to explain many times what I was doing, which I took as the incomplete and fragmented nature of conducting fieldwork at the clinical site.

**Children**

Studying children’s bodies is both a practical and creative process. Children’s concerns are important as well as their siblings’, parents’, and health professionals’ since all of them are, on different degrees, immersed on the lived experiences of people attempting to radically cure children’s (sick) bodies (Bluebond-Langner et al. 2010; Mattingly 2010; Mol, Moser and Pols 2010). While children are often painfully aware of their treatment, their experiences of treatment and long-term care occupy a marginal space in the everyday concerns of the professionals providing treatment. They focus on the medical objects, predominantly the biological markers of treatments and the adherence to protocols.

Consequently, I made the methodological decision to focus on children’s bodies, not on discourses or narratives’ over children, or children’s self-expression through drawings or other artistic means (to mention some valid, and proven, methodological tools) to place children in the middle of these contradictory and powerful forces. Needless to say, I have had informal and formal talks with children, parents, siblings, family members, and several professionals to grasp their worldviews and their own explanations in relation to their lived experiences of cancer treatments.

Thus, it makes sense to focus my analysis on children’s bodies as the locus of the intense forms of medicalization and biomedical interventions. By focusing on children’s bodies I will
also be able to see many dimensions of care and relatedness, especially the gender of care through the intimate relationship between children and mothers. Carsten (2002:19) argues that the general omission of mothers as the main caregiver has to do with the exclusion of the domestic world of women and children from kinship and gender studies, and because “motherhood” has been largely understood in anthropology as an obvious and unmediated relation with the “natural world.” In this way, in Chapter 9, I will look at how not only this domestic world of women and children are intensely medicalized but also the broader social worlds are transformed by what I refer as “therapeutic relatedness.” The specific forms of motherhood and the intense bonding between mothers and sick children in general and with children living with cancer in particular has been often ignored in the anthropology literature of kinship and gender (Carsten 2002).

Throughout this dissertation, I talk about “children” not to indicate that they are a homogenous group and age differences among them are not important. Children’s ages at the Hospital Infantil range between birth and 18 years of age. By talking about “children”, I am not aiming to erase the clear intellectual, emotional, physical differences among newborn babies, infants, children, and adolescents. When the situation dictates I will provide more specific information about the patients I discuss. However, generally speaking, I will refer to this group as “children” not only to remind the reader of the target group for these medical, invasive, interventions and of the legal status of minors under the legal guardian of adults deciding for their best interest but also to highlight their capacity as children to affect/be affected by others.25

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25 The recently passed Código Civil y Comercial de la Nación (National Civil and Commercial Code) states that a child under 16 is considered as an adult for decisions over his/her body, and that an adolescent between 13 and 16 is capable of deciding for herself in regards to non-invasive treatments that do not put in danger her health or provoke a risk for her physical integrity and life.
Ethical considerations and methodological limitations

The main focus of this dissertation is children’s lived experience of cancer care. In order to successfully illuminate and understand the lived, perceived, felt features of child’s experiences I faced countless methodological difficulties. My decision on focusing on informal conversations and observations brought strengths and weaknesses to this study. My unmediated relationship with children, family members, and professionals helped me construct the trust needed to talk about the everyday experiences of children with cancer care. Children already know about cancer and actively affect others in their encounters with cancer care. I agree with Bendelow, Williams and Oakley (1996:18) when they say, “it is possible to carry out research on children about their beliefs and attitudes regarding cancer, without running the risk of being unable to collect usable data, or of upsetting the sensitivities of the research population.” Using “draw and write” techniques Bendelow, Williams and Oakley (1996) consider children as active agents and producers of their own health-related knowledge, believes, and behaviors because they are powerfully affected by the material and social worlds in which they are living. One of the limitations of my study is that by not using alternative methods such as drawings, video or photo-voice to elucidate children’s own experiences of cancer care one could miss the opportunity to build on what children already know. I decided not to use interviews with the children and alternative non-verbal methods (Mitchell 2006) because these seemed too invasive in the clinical setting and the non-verbal tools would pose problems in maintaining the necessary sterility of the clinic. By providing other means beyond talking about their own experiences and observing what happens to them one could get access to other aspects of children’s experiences. Evidently, there are several qualitative techniques developed to interact with sick and often
terminally ill children and families in ways that are respectful and attentive to each particular children and family needs. I considered the pros and cons of using alternative methodologies. Still, for this study, I opted for a minimal methodology that allowed me to talk with and observe what happened to, and in between, children, parents, and professionals.

A central challenge I faced was the double requirement to engage in a meaningful communication regarding what I wanted to do while also discussing what others wanted me to do. Thus my role was not only to inform people I worked with about my research but also to get them involved in this research. I tried to be clear from the first encounter that my intention was to protect the identity of the people through the gathering of anonymous information and the use of pseudonyms and to produce something that could be of use for all the people involved in the care of children with cancer. Another important, and often present, obstacle was the task of dealing with another timing beyond my own; particularly bureaucratic timing and different personal timing. These are two types of time handling. One is how the institution experiences me, and the other is how people experience me. It took me a long time to be granted permission to conduct fieldwork in the different units, and to receive the formal approval of the direction, and both the ethics and teaching committees at the hospital. But though unexpected this timing was something I foresaw (I had experienced it on my previous study). Something I did not expect, however, was the personal timing of each particular health professional, family member or child in relation to their decision to let me work with them or not. Sometimes children for instance would wait to see how I related with their parents to begin to talk to me. This process of being accepted took some time and it was central to my entry to the field and my approval from the different people with whom I worked with. These two divergent rhythms played out very differently as one could expect. The institution manages a very codified and formal time, there
are several doors and filters one has to go through to be accepted. Whereas children, family members, and professionals manage their own personal time and space and as an ethnographer I was aware of it, and I had to adjust to it.

**Ethnographic insights**

Working in the context of the hospital means that as an ethnographer I had to be very conscious about the proper ways to approach the people I worked with and the right time and place where to approach them. For instance, I only observed a family when a child was experiencing the last days of life when a father, mother, or relative gave me a clear indication that I could be present when I followed different health professionals. I did not want to force my presence in those situations. Under these circumstances, I did observe some children in their final agony phases.

At the beginning of my research I was associated with the Palliative Care Team from my previous MA project. I thought I would have some difficulties while working with other teams such as those in Hematology and Communicable Diseases Units. Fortunately, I did not have any barriers and everyone was receptive to my research. After the first moments of doubts and uncertainties about my role those that participated on this research opened their hearts and minds to answer my often silly questions and let me conduct my observations. In general children, families, and professionals from the three key units were interested in my research.

Another methodological decision I took was not to formally interview children. Early on, when compiling my application to the UBC Research Ethics Board, I considered that I was not going to formally interview children given not only the multiple technical and ethical complexities of conducting interviews inside a clinical setting. I opted to focus more on participant-observations and informal chats with families and children, and conducted formal
interviews with professionals, caregivers, and cancer survivors. I did obtain assent from participants for participant-observations and informal talks, and consent for formal interviews.

One methodological concern I had during the writing process of this dissertation was assessing how my own participant-observations both constructed and shaped what I have found. I was also concerned with the way that different people I worked with considered my research and myself as ethnographer. Was I viewed as staff, visitor, volunteer, patient, parent, something in-between or something altogether different (van der Geest and Finkler 2004)? I suspect that people’s perception of me changed during my fieldwork according to a broader understanding of my work. In many instances, I felt I was suspiciously observed by health professionals as a sort of spy. Most likely, this was the case because instead of my previous fieldwork I decided to take notes in front of doctors, less often in front children and families. On countless occasions health professionals, especially medical residents, asked me “What do you write in that book”? Or, told me, “I would love to read what you write there.” Ironically, after they came to know me and my work parents and staff would often help me by saying, “Hey, Rafa, write this thing down. This is important. You should write what X told me.” People would explain to me something that happened that they thought was important for me to write down. It seems professionals were asking me a question Taussig (2011:75) asks himself during fieldwork “To whom are you writing”? In other instances, health professionals thought I was not capable of observing certain medically intense events. For instance, on one occasion when I was observing a male nurse and a fellow at the Hematology Unit performing a bone marrow examination and lumbar puncture the nurse asked me, “You are not going to faint, aren’t you?” They then told me that a father had fainted the day before. The father told the nurse he had no problem observing the procedure and all of the sudden he said “I don’t feel good” and he went to the stretcher and fainted.
The next chapter begins my examination of children as the loci of multiple forms of biomedical interventions and my understanding of the clinical thresholds, children’s experiences, production of permeable bodies, and medicalized, therapeutic social relationships.
Chapter 4: The beginning of a long medical journey: Passing through therapeutic thresholds

“You have something *raro* (“strange”) in your blood. Within your body, there are a lot of tubes that transport blood, which carries oxygen to all your organs and tissues. Well, your blood is behaving strangely; it seems you have a disease in your blood. Here we will first confirm this and, if it is true, with your help and the help of your family, we will start right away to help you overcome this.”

Doctor at a provincial hospital (told this to a mother and his eight-year old boy before being diagnosed with acute lymphoblastic leukemia)

Everything that happens to children and families within the hospital in this chapter will be seen as part of several therapeutic “thresholds.” Though children’s journeys to the hospital may have started in any number of villages, towns, or cities, they all arrive at the same hospital and pass through its doors. The hospital occupies two full blocks and has more than 20 buildings and more than 60 departments, services, and units. It is one of the main public pediatric hospitals in the country. The building itself still retains the features that it had when it was created more than a hundred years ago. There are more than twenty different wings with parks in between and some old trees in a city with almost no trees and green spaces. It takes time for families and even doctors to get to know the place. Many wings are intricate labyrinths and often when I was following residents, they would take a short cut that I was not aware of.

Surrounded by walls there are two main entrances to the *Hospital Infantil*, each from two different streets. The main one has on top the name of the hospital and there are some stairs that always full of people getting in and out. The other entrance on the opposite side is gate where staff enters to park their cars at the parking lot but people also use it to enter the hospital. Paradoxically (or not) there is no ramp on the main entrance so people have to lift baby’s cars or wheel chairs if they want to get inside the hospital, or they may go and ask to the security guards to let them enter through the ambulance’s door, which is always closed to control the movement
of people within the hospital. In the mornings during the weekdays it is a village full of life and hectic movements. From very early in the morning, before sunrise, families come to the hospital, form long queues for appointments, or wait on the waiting room of the Emergency Unit. Health personnel also start very early in the morning. Cleaning personnel, cooks, administrative, technicians, nurses, medical residents, staff doctors, psychologists, psychiatrists also arrive for their usual activities. During weekends and after 4:00 pm the hospital staff is reduced and only some technicians, nurses, medical residents and staff doctors remain at key units (e.g. the emergency unit and the pediatric acute care unit).

The Hospital Infantil attracts professionals from all over the country (and even other countries), including many M.D.s pursuing their Residencia en Pediatría (Residency in Pediatrics). From all the M.D.s conducting their residency at the Hospital that I met, more than 1/3 where not from the City of Buenos Aires, and came to this hospital given its renowned reputation. There are two types of medical residencies: the Residencia Municipal en Pediatría (Clinical Pediatrics, 4 years), Psicología Infanto-Juvenil (Pediatric Psychopathology, 3 years), Bioquímica (Biochemist, 3 years), Farmacia (Pharmacy, 3 years), and Anatomía Patológica Pediátrica (Pediatric Anatomical Pathology, 3 years). The other type of residency is the Municipal Fellowship, which lasts three years, and have fellowships in more than 15 sub-disciplines including Oncology and Hematology. In order to qualify for a Fellowship, first doctors need six years of medical school and four years of clinical pediatrics.

In many ways it can be argued that medical residents and nurses are the staff who sustain the everyday functioning of this hospital in Argentina (I will further describe this in Chapter 5).26

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26 The role of medical residents doing the 4-year residency in Pediatrics is a bit different than in other places. In some countries nurses are playing a more central role whereas in Argentina medical residents rotating within different units at the Hospital Infantil play a more central
Without their work and without the work of technicians, administrative, and the auxiliary personnel (biochemists, biologists, biotechnologists, pharmacists, mycologists, etc.) this hospital could not operate. However, it is worth mentioning that during the weekdays a wide range of specialists work at this hospital across the many departments, services, units, and teams. Thus, in many ways this is a complex site in terms of the space and the biotechnologies available and people and specializations.

Once inside the hospital families and patients need to understand the place and how to move within it. There is a clear rhythm of hectic activities and work from very early in the morning until 1:00 or 2:00 pm when everything starts to slow down. Usually staff professionals (doctors, psychologists, some technicians) work from 6:00 am until 2:00 pm, and sometimes they leave at that time to work somewhere else at either the private or social health insurance sectors (private offices, private clinics, other hospitals, etc.). Thus, usually after 2:00 pm only resident doctors, patients, family members, and few staff doctors, technicians, and administrative stay at the hospital. Often by 4:00 pm the hospital seems empty, but still there is a lot of work in all the units and other clinical sites.

The Hospital Infantil is also a place where other hospitals bring their patients to perform specific studies. The City of Buenos Aires network of city hospitals share their resources so, for instance, CAT scans are performed at this hospital. It is common to see adult patients waiting in radiology for their turn. Certain studies like CAT scans can be done at any time because the machine is working 24/7. Thus, sometimes children have a CAT scan at infrequent times like 4:00 am because it is used during the day by patients from other hospitals.

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role in relation to the everyday activities of the units and the level of contact with children and families.
The emergency room works 24/7 and is always full of people, but it is more crowded in the morning. It is next to the main entrance and is the only way a child can enter any unit for hospitalized. Even children treated as outpatients need to go through the emergency room. It is the same emergency room for all the types of patients that are treated within the hospital. If children need to be hospitalized, they send them to the units that have treated them before according to the specific child’s condition or depending the availability of beds at any given time. Sometimes there are no beds, like in the peak of flu season during the winter, and they may stay at the emergency room for days or have to be transferred to another hospital (though this is very rare). Often parents and family members of children with oncological and hematological conditions complained a lot about the lack of a specific place for their children. These are particular kinds of patients since they almost always have their immune system compromised. Therefore, being close to other children with other kinds of diseases is a serious risk. This is something that parents would like to avoid.\textsuperscript{27}

At the Hospital Infantil oncologists and hematologists work at the Unidad de Onco-Hematología ("Onco-Hematology Unit"). Both "Oncology" and "Hematology" have their own Heads and in theory they are part of the same unit, for instance, fellows are trained as "pediatric hematologists / oncologists."\textsuperscript{28} Yet, in practice, Hematology and Oncology work as two different units, with Hematology treating patients with leukemias and lymphomas, and Oncology dealing with solid tumors. For instance, they relate differently with the Equipo de Cuidados Paliativos

\textsuperscript{27} At the time of my fieldwork there was a Facebook account that was collecting signatures to open a new ward only for children with onco-hematologic conditions.

\textsuperscript{28} This often is not the case and in other places of the world Oncology and Hematology are two separated units. As we see there is a tension between an international language of training guided by organizations like the American Society of Pediatric Hematology/Oncology or the European Hematology Association, and local uses and particular training programs for medical residents. At the Hospital Infantil fellows were trained in both Pediatric Oncology and Hematology but each sub-unit works differently.
My research focused on the Hematology Unit (HU). I did not conduct any fieldwork with the Oncology Unit. In addition to treating blood cancers, the HU also treats other bleeding disorders such as hemophilia, and hemoglobinopathies. They are also one of the main specialists when dealing with blood transfusion, blood banks, as well as bone marrow and stem cells transplantations. At the time of my fieldwork children who needed bone marrow transplants had to go to another institution to perform the transplant. However, in 2015 three isolated rooms from CDU were separated and transformed into a new bright Transplant Unit.29

Hematology provides care for the different kinds of Leukemia, non-Hodgkin lymphoma, Hodgkin lymphoma, myelodysplastic syndromes, myeloma, and myeloproliferative neoplasms which are cancers that affect the bone marrow, the blood cells, the lymph nodes, and other parts of the lymphatic system. In a sense these hematological diseases are all related since they may all result from acquired mutations to the DNA of a single lymph or blood-precursor stem cell.

Hematological malignancies may derive from either one of the two main blood cell lineages: myeloid and lymphoid cell lines (see Figure 2 below). The myeloid cell line typically generates granulocytes, erythrocytes, thrombocytes, macrophages, and mast cells; whereas the lymphoid cell line generates B, T, NK and plasma cells. Lymphomas, lymphoblastic/lymphocytic leukemias, and myeloma are from the lymphoid line, while acute and chronic myelogenous leukemia, myelodysplastic syndromes and myeloproliferative diseases are myeloid in origin (Arceci et al. 2006). Here, below, to understand how Leukemias originate, is

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29 It began in 2015 and so far they had only performed autotransplant (not from donors). The CCF economically supported its creation.
the image of the hematopoiesis process from the hematopoietic stem cell to the multiple components of the blood.

![Hematopoiesis process](image)

**Figure 2: Hematopoiesis process by Mikael Häggström, CC.**

Leukemias are divided into two major types: Acute (which progresses quickly with many immature white cells), and Chronic (which progresses slowly and has more mature white cells). Both leukemia and lymphomas (Hodgkin’s disease and non-Hodgkin’s lymphomas) are cancers of lymphocytes. The distinction is that leukemia originates in the bone marrow whereas lymphomas begin in lymph nodes and then attack the bone marrow or other organs. White blood cells (*leukocytes*) develop from immature or naive cells referred as *lymphoblasts*, or in cancer jargon as *blasts*. Leukemia occurs when there is a malignancy of these blast cells. In a normal human body, blasts represent 5% or less of healthy bone marrow. Yet, in leukemia, these blasts not only stay immature but also reproduce continuously without properly maturing. If untreated, it can increase to between 30 - 100% of the bone marrow. By doing so these immature cells preclude the production of the different component of blood (red cells, platelets, and mature white cells). Then, malignant blasts overflow the bone marrow into the bloodstream and lymphatic system. They can also invade the central nervous system (brain and spinal cord). Some
blasts are called lymphoblasts (which normally become mature cells called lymphocytes) and others are called myeloblasts (which mature to myeloid cells). Acute leukemias are subdivided into two classifications according to whether the malignant blasts are lymphocytes or myeloid: Acute lymphoblastic or lymphocytic leukemia (ALL) (the most common type of Leukemia) and Acute myeloid leukemia (AML).

Hematologists, and other professionals within the hospital, constantly face medical and ethical issues when attempting to cure children living with hematological conditions. Scopinaro and Casak (2002) show that in Argentina some children receive treatments with an almost similar rate of success as in Europe and North America but there are a vast number of children who are not treated (or are under-treated) and often die undiagnosed from their malignant diseases. Scopinaro and Casak (2002:115) argue,

To be a pediatric oncologist in a country like Argentina is difficult, not only because of economic and professional problems, and lack of infrastructure, but also because the kinds of [medical, ethical, structural, social] questions we are posing in this article have no answer and create a great deal of bitterness.

One of the sources of bitterness for pediatric oncologists and hematologists is the pediatric population who lack access to care and cannot be properly treated in the Argentine health care system.³⁰

In the case of children and families, the initial reactions to treatment are not only related to children’s morphological, immunological, genetic responses to treatment, as hematologists may tend to focus. Children react to intense and severe treatment and hospitalization far away

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³⁰ Argentina is one of the few Latin American countries that keep systematic records of the incidence of childhood cancer, with a high level of coverage achieved through the ROHA (Moreno and Schwartzman 2010). Its data constitute a close representation of childhood cancer morbidity among Argentinean children and adolescents. Still between 6 and 10 % of children’s death medically categorized as cancer-related were not recorded by the ROHA, and, thus, were not assisted by any of these tertiary institutions of the health care system.
from their parents, siblings and other family members. They also respond to treatment in more idiosyncratic ways that cannot be easily reduced to objective parameters. While hematologists’ main concerns are how children’s biology reacts to treatment, children and families are overwhelmingly concerned with how much their emotional and social lives have drastically changed following diagnosis and treatment.

The Unidad de Onco-Hematología (Onco-Hematology Unit), in 2010, when I conducted fieldwork, performed 800 consultations and 300 hospitalizations per month for children with solid and liquid cancers and different kinds of anemia. Yet, this unit does not have its own beds to hospitalize children. Thus, when children have to be hospitalized the first option was the CDU, because it has single isolation rooms available. Given the intensity of the treatments these children go through in cycles their immune systems are frequently compromised. Chemotherapy attacks all células ("cells") ("good" and "bad") and especially those cells that divide faster. This, in turn, significantly decreased production of blood cells, produced mucositis (inflammation of the lining of the digestive tract) and hair loss, among other effects. The HU has a Hospital de Día (‘Day Hospital’) where they provide children with chemotherapy, blood transfusions, immune-globulin, etc., without the ability to provide inpatient care in the HU. Therefore, they rely on other units, such as the CDU. (In Chapter 5 I will explain in more detail the everyday dynamics of the HU.) This may bring tensions between the HU and the other professionals and units who are in charge of the everyday care of children living with hematological cancers. One significant issue here is that hematologists cannot control the whole treatment process and other clinicians are involved, complicating the relation among children, families, and different groups of professionals.
Hematologists play a key role in finding the right diagnosis. However, Communicable Diseases specialists and palliativists are central to the experience of these children and families after the initial diagnostic moment. The Hospital Infantil is an intricate place where different disciplines and sub-disciplines interact with children and families during the long diagnostic and therapeutic processes. After feeling bad for days, weeks, or months a child may be diagnosed at the Hospital Infantil with a particular condition. Diagnoses such as ALL (acute lymphoblastic leukemia) type L2 may be constructed after some days while he or she was hospitalized and many different tests were run in order to confirm it (and discard other conditions). This means diagnosis, prognosis, and treatment are entangled in many different ways and children, and family members, will learn this with and from their bodies. There are diagnostic tools and procedures (which sometimes can also work as therapeutic) for the ‘main condition’ like in this case, leukemia, but there are other moments during the treatment process in which they also need to diagnose a specific fungus or bacteria that is developing and growing inside or at the surface of the child’s body. This means that children interact with multiple teams, groups, units, and are exposed to manifold diagnostic tools such as MRIs, X-Rays, CAT scans, Biopsies, Ultrasounds, Dopplers, etc.\(^1\) Therefore, diagnostic tools are continuously present in the experience of children, families, and health professionals. Especially, in a tertiary care teaching hospital like this in which all kinds of specialists and biomedical technologies are available and “ready to be used.”

Children and families’ experience are related to some specific units and groups of professionals rather than others. It is accurate to say that for the families there are a group of core professionals with whom they interact with the most and establish long-term relationships and

\(^1\)Usually these techniques are meant to produce images, take a small sample from the body to test it, or visualize the speed and direction of a particular sample volume.
satellite professionals. Particularly, children with leukemia have as their core professionals the hematology unit and the communicable diseases unit (where they are usually hospitalized). They may be hospitalized in other clinical units temporarily if isolation rooms are not available in CDU, but the HU and CDU remain their “homes” (preferably with isolated rooms) during their many hospitalizations. Children and parents develop deeper relationships with medical residents and staff clinicians at both HU and CDU. When children have to be hospitalized in other units they often ask to be transferred back to CDU as soon as an open bed is available. When children whose treatment seems not to be working (any condition not only leukemia) or who are experiencing multiple treatment’s side-effects will have the palliative care team as one of their core professionals at certain moments during the treatment.

“Social issues”

It is a central feature of western biomedical knowledge production to consider the extra-organic and extra-sensorial as less relevant in the etiological explanation of health problems (Scheper-Hughes and Lock 1987). The majority of families assisted at the Hospital Infantil come from lower or middle-lower classes with a variety of material difficulties. These families are forced to re-prioritize their usually scarce resources, which creates both financial and ethical dilemmas. Many of the structural issues at the clinical site are beyond families and health professionals’ capacities to change. Yet, physicians and policy makers deem some of these structural issues causas sociales (“social issues”) and they are aware of its importance in the everyday analysis and equations of treatment feasibility. As a medical anthropologist I could refer to this as social determinants of health. But, in this clinical context, the particular notion of “social issue” refers to the social world of children with hematological conditions at least in two ways. On the one
hand, it shows the epistemological boundaries in which the biomedical knowledge-practice is set (i.e. “organic” causes vs. “social” causes). These boundaries are often influencing different illness trajectories not only for children but also for their network of concerned others. That is, health professionals produce knowledge on the “organic causes.” Others deal with the “social issues” (politicians, epidemiologists, NGOs, patients and families support groups, etc.). On the other hand, “social issue” also refers to the incapacities of biomedical practitioners to do what should be done due to institutional, social, and/or circumstantial constrains. In this sense, this category collapses many different obstacles to care and treatment. Yet, if we consider the social world of children with hematological conditions, these “social issues” are experienced directly in the everyday lives and hardships faced by children and their families. In many ways, these issues are part of the political contexts of care. To be fair, health professionals are also influencing these “others” who deal with these “social issues” by countless ways (pressing governments, going on strikes, looking for private support for their public institutions, etc.) but they feel that is not their job, they are committed to public free medical institutions and ask others to support their commitment.

In the Argentinean case, this more general biomedical concern was articulated in particular ways. Doctors, social workers, psychologists (among others) were deeply aware of the contextual structural inequality faced by families. Directly or indirectly, they sensed what each child, main caregiver, and overall family actually needed. They were able to step beyond the “biomedical tool kit.” In some cases, this was demonstrated by allowing a child stay in a hospital room for an extra day to avoid having to leave and return early the next morning for another chemotherapy session.
In my study, I observed and talked with children, parents, and other main caregivers from a wide range of socioeconomic groups and geographical regions. They ranged from lower class families living in working class neighbourhoods in the Greater Buenos Aires Area to those from distant parts of the country, where they experienced different forms of “structural violence” (Farmer 2004) and every day was a struggle. According to parents, these different forms of struggle were ever-present and were part of the ways they dealt with their own children living with cancer. In other words, having a child living with cancer was one crisis among other crises they had to deal with on a daily basis. Due to the hospital’s expertise in treating childhood cancers, children from middle and upper-middle class families (with either private or social insurance health care coverage) also came for care in the hospital and were included in my study. These children were few in numbers but still represent the wide range of children treated in the hospital. These families had more resources and in comparison with the working class families could navigate the everyday life of treatments and hospitalizations with some ease. But still they also had to confront the life and family disruption of pediatric cancers and its treatments.

Perhaps part of the “ethics of keep on fighting” that I will describe in more detail in Chapter 9 is that the majority of the families (if not all) assisted at the Hospital Infantil have been fighting all their lives. Indeed, fighting is what they do. Instead of opposing one another, structure violence and their children’s illnesses are part of a continuum of struggle only now expanded by the presence of a pediatric cancer. Their children’s illnesses are not disconnected from their everyday lives. Thus, their children’s cancer is a painful, but not isolated, collective experience that is often framed within other forms of struggle families have to face.

Throughout the rest of the chapter, I will highlight some of the life-altering transitions children and family have to face and the different interactions they will begin to experience with
key professionals within the hospital. In fact, there are competing ways in which all these actors understand these transformations, and how different subjects understand and embody children’s “strangeness in the blood.” At an analytical level, this chapter focuses on the transformations and adjustments of children and families’ daily lives, the irruption of a serious disease in the family social landscape, and the growing influence of several health professionals in the shifting of children’s and families’ everyday lives. These transformations are experienced in the particular contexts of a pediatric hospital and the families’ houses (and other key spaces like the CCF). They have as the backdrop professional narratives that shed light not only on the biological processes occurring within children’s bodies but also on the social processes that sustain and give meanings to these medical journeys. Indeed, there are laypeople and professional contending views between the roles of the strange and the abnormal in the explanation of children’s conditions (Canguilhem 1991). A series of changes and adjustments will mark the detour from a prior social life without illness to a new life with illness, and utterly shift into becoming a “Leukemia patient.” Thus, how does this whole process happen? How do these different trajectories of children, families, medical residents, staff doctors, and other health professionals come together at this particular site with this specific infrastructure and resources? I will describe this process through the series of events that characterize the entrance into the “kingdom of the sick” (Edwards 2013) and the space of cure, care, chronicity, pain, and suffering.

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32 Canguilhem has pointed to the fact that “normal” and “abnormal” are highly ambiguous categories in medicine. “Normal” often represents both the habitual and ideal state of organs. Especially when looking at the pathological Canguilhem reminds us about the difference between normality (statistical) and normativity (the capacity of each organism to create norms that regulate the relation with the environment).
“Everything started with him getting very tired”

I will give one example to illuminate how the transitional change from “healthy” to “sick,” that is, the discovery of a hematological condition, often starts for children and families. Here is the case of a five-year boy from the northeast province of Corrientes (900 km from the City of Buenos Aires and on the border with Brazil). They did not come to the hospital where I conducted fieldwork but I got in contact with them while conducting fieldwork at the CCF. I interviewed his mother Cecilia at one of the inexpensive hotels she was staying with her son Pablo with the financial help of the provincial government. I asked the mother how everything started for them and she replied:

Cecilia: Everything started with him getting very tired. So then we went to the town’s “salita” (local public clinic) and they took some X-Rays and nothing appeared there. Then, he kept feeling tired so we decided to go to Corrientes (Capital city) to the Pediatric Hospital 150 km from my town. And, then, there they conducted more analysis and it appeared he has Leukemia. They told us that we had to stay there and began with the first part of the treatment. After we finished that part, they came and told us we had to travel to Buenos Aires. I told them very clearly that we do not have any money and that they should arrange everything for us. So the people from the Pediatric Hospital in Corrientes got in contact with the Pediatric Hospital Salud [close to the Autonomous City of Buenos Aires] and they arranged the bus tickets to come here.

R: Did you come by bus and not by ambulance?
Cecilia: Yes, by bus. We should have come by ambulance because my son had nausea from the chemotherapy, but we ended up at the Pediatric Hospital Salud and we stayed there for months…

As I will discuss in Chapter 9, internal medical travel for cancer treatment in Argentina is very common given the scarce and uneven distribution of medical resources throughout the country (Vindrola Padros 2011). Very frequently, children and families from the “interior” (this is a native category) of the country are sent for their main part of treatment to one of the three public pediatric hospitals in the city of Buenos Aires. Often the majority of the provinces have

33 All names are pseudonyms.
some sort of arrangement with the city of Buenos Aires so they can send their cases to these pediatric institutions. Indeed, poor provinces with relatively few cases find it more efficient to invest in sending children and families to the City of Buenos Aires, paying them for a cheap hotel, some subsidies, and social programs than having to assist them in their own public institutions. Few provinces assist the totality of their children from their own jurisdictions throughout the lengthy exhausting treatments (ROHA 2008).

Undoubtedly, each child and family is different and the situation in which they are living is too. When I interviewed Cecilia she and her son Pablo had lived in this cheap hotel for the last five months, but the first previous five months they spent it at the Pediatric Hospital Sarmiento at the Province of Buenos Aires. They were there for most of the chemotherapy because the son could not recover to the point of discharge so they had to be hospitalized for five consecutive months. Only once Pablo had recovered were they discharged and kept on going during the day but coming back to the hotel in the afternoon. In addition, it was only after six months they left their house that the father could come from Corrientes and the other five children were left under the care of two aunts and some neighbors. They did not have money and they were living with the help of their province and some informal jobs the father was doing at the hotel where they were living. Lower or middle class families who experience medical travels and displacements of family members shared common issues (Vindrola-Padros 2011). Cecilia told me that it was hard for her to be far from the rest of her family. However, she understood that it was “an extraordinary situation that required an extraordinary commitment.” This is one of many examples of the struggles the majority of the families face when attempting to help their children and to cure them. Particularly, the structural obstacles families face when they have to move from their own places to the City of Buenos Aires and concentrate at the same time on the
recovery of their children while having all sorts of emotional, financial, and familiar burdens. Families need to find housing, jobs, look for subsidies and schooling in the new relocated place while also helping, and economically and emotionally supporting the family members left behind in their own places (Vindrola Prados and Whiteford 2012). As we see, this major transition has ripple effects.

Depending on their circumstances, families go to different places to try to find out what is going on with their children, and eventually they will find a place where they could start treatment. The situation varies according to the province and the social, financial, and emotional resources each family is able to manage and mobilize. For instance, poor families, with no private or union-run health coverage, from the city of Buenos Aires and the surrounding area needed assistance at one of these public institutions at the city of Buenos Aires. A lower class families from the greater Buenos Aires metropolitan area often went first to a small public clinic nearby and then to either the big pediatric hospitals in the province of Buenos Aires or to a public pediatric hospital in the city of Buenos Aires.³⁴ Often families from the densely populated greater Buenos Aires metropolitan area decided to go straight to the city of Buenos Aires (with its concentration of health care resources), even though they could (in theory) treat their children in hospitals closer to their homes. Yet, these families knew that it can be easier to go directly to the city of Buenos Aires than to wait to see what happens in a nearby hospital and keep delaying the identification of the problem. This is also part of the calculation of how to navigate these

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³⁴ Surrounding the city of Buenos Aires, the Greater Buenos Aires metropolitan area consists of 24 municipalities over 3,820 km² and has three main public pediatric hospitals, one in the north, one in the south, and one in the west of the city of Buenos Aires. These hospitals cover a vast area and often families prefer to take their children to the city of Buenos Aires to be assisted.
thresholds. For instance, Maria, the mother of 11-year old Brenda, explained in one of the multi-
familial meetings at the CCF that, after seeing her daughter weak for several weeks:

…We took her to the small medical clinic in our neighborhood in Ezeiza [35k from the
city of Buenos Aires] and they told us to wait a little bit longer to run some studies, so I
told my husband “We have to take her to Buenos Aires with us, right now.” We had lived
in Buenos Aires before and my other children had been treated in Buenos Aires before.
So we took the train, and then the bus and we went to Buenos Aires and we had to decide
if we were to go to the [one of the three pediatric hospitals in the city of Buenos Aires].
We went to the Children’s Hospital [one of the three pediatric public hospitals] and I
can’t complain because they were fast to diagnose her and to start the treatment. In fact,
they told us we did the right thing because we brought her very early, as soon as the
disease was starting…

As we see with both Cecilia’s and Maria’s examples parents begin to question themselves
if their children long weakness and tiredness were normal or if there was something wrong with
it. This is a threshold parents and other family members must cross before even reaching a
medical institution. Once they are able to do that, they will be able to ask professionals to
identify the problem.

**Becoming a sick child: *Hay algo raro en tu sangre* (“Something is strange in
your blood”)**

On many occasions, parents narrated to me how they began to think that something wrong was
happening to their children and how long it took them not only to know their children’s diagnosis
but also to partially or fully understand it. Parents told me how the process of identifying the
problem radically impacted them and their family daily lives.

For children later diagnosed with leukemia things started with feeling tired, running a
high temperature, or vomiting. Parents and/or other main caregivers had to take them to a close
hospital or clinic where doctors would perform some tests on them (very often this did not
happen the first time and caregivers had to revisit these institutions on more than one occasion).
Depending on the place of residence, they might have also taken their children straight to the Hospital Infantil (even though it is a tertiary level health care provider). These first encounters with the different institutions would then color the different illness and therapeutic trajectories children and families would experience. These trajectories contribute to the different frames used by the child, parents, and family members for a sickness episode and form their “explanatory models” (Kleinman 1980). These models are (similarly to the North American context) the clinical narratives (Good 1994) that are usually focused on (quick and urgent) diagnosis and (gradual, step-by-step) prognosis (del Vecchio Good et al. 1990).

Normally, after some blood tests were done to confirm the condition, someone from the local hospital, or, if they went straight to the Hospital Infantil, from the Hematology Unit, would come and explain to the parents *hay algo raro en tu sangre* (“something is strange in your blood”), something parents frequently told me. On one occasion, Marisa a mother of an eight-year old boy living with acute lymphoblastic leukemia described to me how it all started for her family in her province before being transferred to the Hospital Infantil. She told me that when her child had been lacking energy for days she went with him to the local provincial hospital to perform some tests. She clearly remembered how then one of the doctors came and explained to her while bending down to talk to her child sitting in a chair:

> You have something *raro* (“strange”) in your blood. Within your body, there are a lot of tubes that transport blood, which carries oxygen to all your organs and tissues. Well, your blood is behaving strangely; it seems you have a disease in your blood. Here we will first confirm this and, if it is true, with your help and the help of your family, we will start right away to help you overcome this.

> Then, looking to the mother and the child the doctor told the mother “Something is wrong in your child’s blood. But don’t worry we will help you. Now there are many things we can do to help your child.” The mother remembered her mixed feelings of confirming her suspicious that
something was indeed wrong and thinking she would have to find ways support her daughter in her medical journey.

In other instances, as another mother narrated to me, professionals would only talk with parents without their children present and explain to them that algo anormal está pasando en la sangre de tu hijo (“something abnormal is happening in your child’s blood”) and that they need to start treating them right away, sin más demora (“without any further delay”). In one way or another, this idea that there is something “strange in the blood” as described and explained by hematologists will follow and haunt children, families, and key professionals all along their efforts to eradicate the malignant cells from children’s bodies. Even after the treatment has ended, parents told me every control would make this phantom emerge and only the pass of time and the routinely confirmation of inexistence of illness would gradually fade it away. A mother told me, siempre queda el miedo en algún lugar de tu cabeza que reaparezca (“you always have that fear somewhere in your mind that it could reappear”).

Therefore, it is crucial to start from the beginning, starting with the raro y anormal en la sangre (“strangeness and abnormality in the blood”) that becomes strangeness in the whole body, and strangeness in their whole lives, which is radically transformed by the diagnosis and its treatment. From the early stages of seeking a diagnosis, parents enter the erratic passage down the therapeutic process.

The appearance of symptoms associated with the diagnosis of the different forms of hematological conditions has recurring patterns. Initially children lack energy and appetite, have repeated infections, pain, fever, and/or having long-lasting hematomas. During this time it is evident that the child is experiencing something unknown and uncommon and parents and other family members start to look for answers. Children can live with these ambiguous signs for
weeks or even months until a medical check-up shows abnormal blood test results that push the child over the threshold from “healthy” to “sick”. Abnormal test results introduce additional layers of complexity into the professional and lay management of uncertainty (Alonso 2008). Often the moment of discovery of the “disease” is silent and invisible. It takes some work and pedagogical persuasion from health professionals to convince laypeople such as children, parents and other family members (who are also in denial and struggling to accept the diagnosis) that children are sick, *muy enfermos* (“really sick”), that they have crossed a threshold and are now “patients” who need to be treated immediately. Until well into the early stages of treatment, children, parents, and family members may experience a mixture of denial, miscommunication, and misunderstanding about the child’s condition among themselves and with health professionals. Some parents told me that the lack of direct visible evidence made it difficult for them to think that their children had a disease. This contracted with parents of children with solid tumors where the cancers were visible on X-ray and following surgery. I often heard parents telling the psychologist at the CCF that they were doing everything doctors asked them to do. For them their children were not sick since nothing showed them that they were.

Each particular family I observed was different. However, families followed the paths proposed by the doctors adhered strictly to the treatment. Nevertheless, I often saw a discrepancy between the families;’ and the doctors’ perception of the children’s conditions. For example, in the early stages the children, according to hematologists were *already* sick, while to some parents and to children themselves they were neither healthy nor sick. Hematologists when lacking the final diagnosis would often tell parents that it was *una patología en estudio* (“a pathology under study”). Thus, they embodied an ambiguous social, lay, and medical category that would be further revisited through the different stages of treatment.
Often there was ambiguity about where each actor stood in relation to the threshold. Thus, how do a healthy child and his/her family suddenly discover that they have “bad cells” and become a child with sickness in the blood? This is not a self-evident question with a clear answer. There are competing ways in which all these actors understand these series of transformations and adaptations. Therefore, how do children, family members, and key health professionals contradictorily and frictionally experience and traverse these series of transitions? I argue in this chapter that in order to understand these transformations from healthy to sick child we need to look at the series of thresholds that are disjointedly traversed by children, professionals, and family members.

**Finding the exact diagnosis takes time**

Once families reach a clinic they begin to understand what is wrong with their children. Still the diagnosis of any cancer takes time. Generally, it is made in a secondary care medical institution or at *Hospital Infantil* itself if it is also providing primary care. Thus, if a child is diagnosed in a provincial pediatric, that lacks the capacity and skills to treat the child, the Ministry of Health in a particular province will send the child and his or her family to the *Hospital Infantil*, for confirmation of the regional hospital’s diagnosis and treatment.

Hematologists consider the time taken to diagnose the particular condition as crucial. Often hematologists told me how a *temprano* (“early”) or *tarde* (“late”) diagnosis could directly impact the types of prognosis and potential outcomes of the proposed treatment. In the previous quote María said they were fast (and doctors emphasized that too) and went straight to one of the three pediatric hospitals in the city of Buenos Aires where they confirmed the diagnosis and started treatment right away.
But things can go differently and often diagnoses take time. I will bring the case of Chris, a 14-year old boy from a far-away province. This is not a case of a hematological condition, but a case of a solid tumor and it shows that even when something more “visible” is occurring often health professionals still cannot or are not able to “see” it.  

Chris’ mother narrated to me how they found out he had an osteosarcoma (bone tumor):

It is a long story. One day, while we still were in Jujuy (Northern Province that borders Bolivia), Chris got up from bed with a red spot in one of his legs and he told me it hurts a lot. We took him to the Children’s Hospital there to the ER and they looked at him and told him that it was nothing. They asked him if he had played soccer or if he had received a hit or fallen and he replied he didn’t, he had played soccer because he likes it a lot but he didn’t remember any hit he had received. They told us it was nothing and we shouldn’t worry about it. After some time, it kept bothering Chris, he had more pain, and the red spot became a hematoma. So we took him again to the ER and again they told us it was nothing; that we shouldn’t worry about it. Only after I repeatedly insisted to take him to get an X-Ray did they do one. Then one doctor read the X-Ray and didn’t find anything, but I told you if he would have had a garage girlly calendar in front of him he would had been more enthusiastic about it than looking at his X-Ray; he looked at it very carelessly. After some more time, I don’t remember for how long, but at that time Chris had to walk with help, he made himself something like a crutch and his leg had changed it color, it had a black color that zone. We went again to the ER at the Children’s Hospital in Jujuy and I told the doctors that we were not going to leave that place until they hospitalize him and figure out what he had. When we were there a doctor passed by and asked us what was going on. I told her and showed the X-Ray we had from our previous visit some weeks ago. She looked at the X-Ray many times, then she called another doctor to take a look at it, and they left the room. After a long time, she came back and told me “Listen Madam, what we see here is not good at all. We have to do more tests but your son will stay hospitalized here.”

So then they started to give him medicines to ease his pain and he felt a little bit less pain. Then, they came and did more tests and so they confirmed he had a bone tumor. Doctors told me there were two options either to send him to Salta (nearby province) or the [one of the three pediatric hospitals in the city of Buenos Aires], we didn’t doubt it and decided to come here to Buenos Aires. The province paid us for the plane and we came by plane on October 2009. When we came we went direct to the National Pediatric Hospital and there they saw Chris and they told us that it was going to be difficult the treatment. They warned us that since the disease was very advanced there were higher chances they would need to amputate that leg. They tried with chemo but then they had no chance than to amputate his leg. This is what it is, we did a big effort and sometimes it

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35 Cancers are divided in two categories: non-malignant and malignant, and within the later between solid and liquid tumors. Sometimes parents and children (and some professionals) consider liquid tumors as “invisible,” or at least as less visible than solid tumors.
seemed it was going well, but then we moved one step backward. You have to have a lot of patience, because with the chemo his defences go down, and so we had to wait until they could give him another session of chemo.

This is something that happens very often. Families frequently do not have the knowledge or experience to understand what is going on in their children’s bodies, and they often face professionals in particular institutions where they cannot properly figure out what is happening to their children either. Although the child may actually be experiencing a disease, the professional recognition of it had not yet arrived. In this case children, professionals, and family members were in a liminal stage in regards to identifying the problem. Going back to Cecilia and Chris, Cecilia told me that when they came alone, leaving the other five siblings in charge of the father in the far away province of Jujuy, at the beginning…

…Chris didn’t talk, he didn’t want to do anything, and he didn’t eat nor drink anything. He was like this for many days. I was next to him all the time, I didn’t move from beside his bed at all. Until a psychologist came and told Chris “I want to listen to you, I want to know what’s happening to you, if you need to know something, if you need to know what we are going to do with you. Every time you will talk to me I will give you an ice cream.” Chris didn’t say anything that time, not even a single word. The psychologist asked me to go out of the room that day, to go for a walk for a while. I did what she said, I went for a walk to the park, I walked for two hours through the corridors and park, I got lost, I cried a lot, I found some relief from everything I was feeling. When I came to the room Chris was another person, he told me he wanted to eat, he started talking and it was a change we both did. Then he started to become better. After that they told us they had to amputate his leg and now they are trying to find prosthesis for his leg. This is what it is. We have to keep on fighting.

Slowly Chris and Cecilia began to be socialized in the social and cultural dynamics of the hospital. Imagine having to go through all these changes and trying to make sense of them. As we see here different thresholds were crossed (diagnosis, [delaying] treatment, medical travel to another city, entering to the flow of procedures) that intensively affected Chris’ personhood (the loss of his leg was one big impact among many) via particular kinds of biomedical interventions.
In this case permeability as an experience from the body helps to understand how the mother understood the whole process (“this is what it is”) and what Chris had to experience through these extreme events such as a leg’s amputation and the further expansion of treatment and moving to another far away city in order to find a cure.

Once the diagnosis of the main condition was made, the family and health professionals started to know what they are dealing with, though often they do not entenderse (“on the same page”) as professionals might tend to think. Children may or may not “know,” they may not be told but they could grasp things anyway. Depending on the age and other factors they will know with/from their bodies that something strange is happening to them. This includes entering the new world of the Hospital Infantil, the dispersion of the family members, and the different reactions parents, siblings, friends, doctors have when interacting with sick children (Bluebond-Langner 1978, Bluebond-Langner et al. 2010). Only slowly parents, family members, and children were able to assimilate their new situations of being medicalized for a cancer treatment, often hospitalized, and frequently far in a strange place. Parents very often told me, as Chris’ mother put it, that they had to “keep on fighting” in order to push for treatments and cure. I will come back to the importance (differently perceived by professionals, parents, and children) of finding the right diagnosis in Chapter 5 and to the family’s ethics of “keep on fighting” on Chapter 9.

Here I want to emphasize on the transitional changes that occur within the family and in relation to key health professional teams. When the diagnosis of the main conditions is made (at the local hospital or at the Hospital Infantil) a drastic life-altering transition happens and families have to re-adjust to the new situation of having a child with enfermedad de la sangre (“sickness in the blood”). Another threshold has been crossed. They are going to be spending weeks,
months, and years at the Hospital Infantil in its complex spaces and interacting with different teams of professionals. Thus, it is important to move now to an analysis of key thresholds children go through from the moment they began to be assisted at the Hospital Infantil in order to understand how the impact of treatment on children and families’ lives transform the family as a whole.

**Entering the Hospital Infantil**

For children and families, reaching the Hospital Infantil for the first time usually involves a few options: getting in with an ambulance from a nearby Municipality, parents bring the child on their own (often by public transportation), or different provinces send children and usually one parent either on an ambulance or by bus (less frequently by plane though this happens to families from far away provinces). It should be noted that although the Hospital Infantil is a tertiary level hospital this does not mean that parents cannot take their children directly to the hospital without referral from another institution. On an everyday basis the Hospital Infantil works as a primary, secondary, and tertiary level institution. Also, no children will be left untreated on the basis of their residence, level of income, or even nationality (this makes the Argentine’s health care system a rare and complex case). In fact, as I will show on Chapter 9, some families from Paraguay and Bolivia come straight to the City of Buenos Aires, and especially to the Hospital Infantil to treat their children with pediatric cancers (Vindrola Padros and Witheford 2012). Simply put, every child that comes to the hospital is treated and none are rejected.³⁶ Families often leave everything behind and decide to start from scratch in order to provide the best

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³⁶ I saw children from far away countries such as Dominican Republic coming to be treated at the Hospital Infantil. I remember a 9-year old boy with a bone cancer in his right leg, which since it was diagnosed late it ultimately had to be amputated. He came to live with his mother (she was working as a sex worker) to have the chance, almost impossible in Dominican Republic, to access an efficient, free and reliable treatment.
possible treatment (frequently free) for their children, something that is unavailable in their own provinces or countries. For instance, a father from a northern east province told me he had to ask for a one-year leave from his work as a school teacher to relocate with her wife and his two children to treat her daughter from a rare anemia. Normally, some member of the family (very often the mothers) would come with their children and would try to use some social and kin networks for support such as housing, informal jobs, help with caring the child, etc., if available. The mere act of reaching the Hospital Infantil can have enormous consequences for families. Many parents told me how lucky they felt because they were able to mobilize resources and “find” the Hospital Infantil. As Moreno et al. (2013) remind, us not all children in Argentina are able to access treatment expeditiously, and some are not even able to cross this threshold.

When children and families do enter the Hospital Infantil (even if referred from another hospital) for the first time they would do it through the Guardia Externa (“Emergency Room”) located next to the main entrance. The kinds of experiences families face when entering for the first time to the hospital depends on the day of the week, the time of the day, and the particular staff who are working on that shift. Monday mornings looked like this (taken from my notes):

Today instead of entering to the hospital from the back door I do it through the main entrance. As always, this Monday morning is as busy as it can be. There is a constant hectic movement of people coming and going, leaving the hospital and entering it. Sometimes people have to navigate their way through by jumping bodies seating in the stairways or lying in the corridors. When you are able to enter the hospital there is a long space filled with long benches always full of people at this early time of the day (8.30am). On the left there are four hospital staff inside glassy boxes assisting people that are waiting on a long queue line that, at this time, goes for about 30 meters. These people are waiting to have an appointment marked for a specialist. On the right side of this big space there is the Emergency Room. This place works both as the Guardia Externa in which families can go 24/7 on the 365 days per year to be assisted, or, where patients come transferred from other medical institutions and this is the first filter to enter the hospital. On one corner, next to the stairs to the first floor, there is a big TV on showing the morning news (weather report: today: cloudy). Above the main entrance to the Emergency Room there is a small digital box that announces the numbers for people to go and enter one of the boxes with clinicians. There are two small clinic boxes with a
table and two doctors in each one; the doctors are assisting patients without pause. They are the first filters of the Emergency Room (and the rest of the hospital). If they decide that children need to be assisted at the hospital they will let them go to another clinical boxes inside and, if needed, will call specialists from the rest of the hospital to assess these children and decide how to proceed. In the middle of this big hall, across the waiting room from the main entrance, there is Social Work. People go there if they need some assistance with IDs, health coverage, and different bureaucratic procedures and institutions. Today is a busy day and I would guess there are between 50 and 70 people waiting to be seen in the Emergency Room sitting on the benches, standing, walking with children in their arms, breastfeeding babies, some babies are crying; this is not a quiet morning at all. The waiting area for the Emergency Room have no toys in it or things to entertain children, it is a big area with long benches in the crossroads of multiple paths to different wings of the hospital. Some small children are bored and want to go for a walk and parents refrain them for doing it; a mother say, “We will be done shortly” (but she does not seem very convinced). Some older people (parents? Grandparents?) are watching the TV. The majority of children and adults seem used to waiting and specially to sit and wait at the waiting room of the Emergency Room.

The Emergency Room is also the space in which people wait, and waiting becomes a central part of their lives. When a child comes to the Emergency Room they are checked-up by the staff doctors that are working that day at the Emergency Room. The Emergency Room’s physicians determine if the child needs some tests or be seen by other specialists. If they order blood tests and the results identify something abnormal the physician will call the hematologists to look at them. One of the staff clinicians or hematologists, or very often one of the fellows at the Hematology Unit will come and perform a check-up of the child at the Emergency Room. With the information provided by the check-up and the blood tests, and depending on the seriousness of the child’s condition, hematologists will decide a course of action. They may decide that the child needs to be hospitalized or simply treated as an outpatient who can go back home and return on another day. Often the hematologist sends the child and her/his family to the HU for more tests to confirm the child’s condition. Thus, even when a child comes with a diagnosis from another institution the hematologists often re-test them or at least try to develop their own picture. This may include performing a Lumbar Puncture and/or Bone Marrow
Examination on *Día uno* (“Day One”) of treatment, or, *debut* (“debut”) in the onco-hematological jargon. Many times hematologists told me that the first 33 days of treatment are crucial for them. According to the hematologists this first month of treatment (besides other clinical and biological factors) marks the types of risk and prognosis each child would likely to possess. On the other hand, parents told me that the first months are always difficult, especially if they are from faraway places and do not even know the city or have any kind of network or support available. Cecilia, the mother from Corrientes Province I quoted previously told me that:

> At the beginning everything was very difficult. We came straight to the hospital and we stayed there from September 2010 only Martin and myself in a room. When I had to do some errands or paperwork within the hospital at the beginning I would get lost but then by asking people I began to know more the place. Then, I began to know other mothers who told me tips or how to do things. We both were very lost at the beginning. And Martin wanted to go back home; he would every day tell me, “Mommy I want to go home.” It was hard at the beginning, but then we started to know more, and we saw how Martin was getting better and he was doing well through his treatment and chemo.

**Becoming a “Leukemia patient”**

The moment when doctors tell parents their child’s diagnosis it is traumatic and terrifying. Given all the cultural associations and popular beliefs linked to the densely loaded word “cancer” both in the global north and in a country like Argentina (Jain 2013; Luxardo and Alonso 2009; Sontag 1978) it is not a surprise parents told me they often try to avoid this word. It is not an easy task for health professionals either. Both parents and professionals preferred that that moment had never occurred. Many times I heard hematologists say to parents that they had to check and double-check and be sure about the diagnosis before telling it to parents. Certainly they attempted to translate to the laypeople their meticulous search for diagnosis and their sense of urgency.
On one occasion I observed Malena, one of the clinicians that works at the Hematology Unit, use a phrase “queremos estar completamente seguros de la enfermedad que tiene tu hija, queremos llamarla por su nombre y apellido” (“we want to be completely sure about the disease your child has, we want to name it with its first name and surname”). While Malena was talking with the parents of María who had been hospitalized two days before for something strange in her skin, Malena told them,

“We are seeing that there are células malas (“bad cells”) that are not working OK, because of this she has that thing in her skin, but we are trying to fine-tune what is the exact diagnosis in order to start treatment. In order to do that we need three or four days more. Maybe a week more. Because we have a great responsibility and we can't confirm nor discard anything until we have the precise diagnosis. We want to be completely sure about the disease your child has, we want to call it with its name and surname whatever María has. We don’t want to over-treat her because that can also bring undesired consequences.”

As soon as the clinician finished to say that, Pablo, María’s father said, “So what my daughter has is… a skin cancer”? [The clinician agreed with her head. Instantly, the father stood up from his chair and said that his blood pressure went down and he left the room (a medical resident that was with us followed him). The clinician continued the conversation with the mother (the professional was the one talking, the mother was listening and shaking her head) Then, after twenty minutes the father came back and said, “I had to leave and lay down in a bench, I even put my legs up... this is una enfermedad de mierda (“a shitty disease”) ... two members of my family already died from cancer.”

I use this vignette to show how the moment in which the diagnosis is pronounced, or, in this case, when professionals say they are doing their best to find the exact diagnosis (still at that time officially unpronounced) both were affected differently and had diverse meanings for the people involved. What the father heard was that her daughter had a cancer de piel (“skin cancer”) although for Malena they had not yet found the precise diagnosis. Nonetheless, she did mention células malas (“bad cells”). Malena and María’s parents were somehow standing in a bridge waiting to reach the exact diagnosis, however Pablo had already cross the diagnostic threshold and he knew María had cancer.
Once I was participating at one of the multi-familial meetings at the CCF, when the staff psychologist asked all the parents at the meeting about how the doctors told them their children’s main diagnosis and what their reactions were and some of them explained:

Sara (mother): When they told me about it I wanted to kill myself, I was close to killing myself when they told me that my son had cancer, that he had an ALL [acute lymphoblastic leukemia].

(Telma (Psychologist): And how did you overcome it?

Sara: Because I thought that in fact if I was going to do it my son would have stayed alone, I didn’t take my life because of my son, I wanted to be here and help him. I didn’t have any help at all, and I didn’t see any way out, but then they told me that it’s a curable Leukemia…

Telma: This happens very often, when doctors give the diagnosis it is very hard, because it seems that everything ends…

Ana (mother): It is like the world fell on you; in a second everything changes…

Maria (mother): Yes, in an instant your whole life changes…

Telma: And what we see is that very often the strength comes from the children; that one has to be strong to take care and accompany them…

Ana: Yes, because when they give you the diagnosis it seems that everything ends, and that it will never finish, it is like your peor pesadilla (“worst nightmare”).

These are life-changing moments (“your whole life changes”) when doctors, in this case hematologists, tell parents that, although they may not see it or do not want to see it, in fact their children are sick and they need to quickly start a very aggressive treatment. Evidently, there are two explanatory models at work here (Kleinman 1976). There is the hematological explanation that sees children as muy enfermos (“very sick”), and the laypeople explanation that does not see children as no parecen enfermos (“don’t look really sick”). This clash of views (not-so-sick Vs. very sick) will often be carried on re-emerging at different times in the relationship between professionals and parents. Thus, parents seek ways to overcome this shocking news, this peor pesadilla (“worst nightmare”).

In many ways professionals and parents are traversing different thresholds. Professionals are attempting to identify the problem at the molecular level, and parents are still trying to
understand what is going on to their children’s whole lives. In fact, soon after parents heard this news they started asking questions to themselves, to doctors, and to life, sometimes very philosophical questions. In the same meeting two mothers asked:

Marina: One always ask oneself why me, why her? But then one keeps going. I asked doctors from the very beginning that they talk with me with the truth, that they would tell things as they are to me and to my 11-year old daughter. When they gave me the diagnosis I looked the doctor straight to her eyes and asked, “This thing can be cured”? And she told me “Yes, it can be cured”. So from that moment until now I always kept on going and fighting.

Ana: And then, for instance, when hair started falling off and she cried a lot, or the first time you entered the hospital and you don’t understand anything, you laid down your head and asked to yourself “Where am I”? But then you start getting used to it, and you familiarize with the place and the people, there are doctors you like more or less but I have to say that all the doctors were good to me and my daughter…

Marina: I also asked the doctors from the first moment to tell my daughter the truth and to me too. I asked them to tell her what things they were going to give her or to do to her, and if she could not understand something and I could not explain it to her, because there are many things that I can’t explain to her, I always asked a doctor to come and sit with my daughter for five minutes and explained to her with her own plain words what was going on and what they were going to do to her, and that gave her confidence to herself, to her doctors, and to me.

It is clear that these performative moments when professionals tell, perform, and pronounce the diagnosis are critical in the sense that they alter the normal course of life in a radical way. These are moments not only in which everything changes and families are shaken up by these unexpected news, but also moments in which families develop the basic connections with key professionals who will be crucial in the months (and years) to come. Families and children will have to go through all these zigzagging changes, overcoming innumerable obstacles. There is the shocking first moment in which families, especially parents know, or at least hear what is their daughter or son “having” according to the specialists. And although they may have imagined that something was wrong, no one would have imagined that their children have “Leukemia” or a “serious disease in the blood” as often hematologists refer to.

Consequently, as Marina clearly stated, in those occasions you need to hear that something can
be done, and that the just-recently-pronounced diagnosis has a good prognosis, or, at least, that they will try as hard as possible to cure your child (even with a terrible prognosis) so parents can seguir peleándola (“keep on going and fighting”). From now on parents may need to build trust with professionals and between them (which will be re-visited many times during the long treatment).

Still, in many instances parents and other family members do not foresee anything wrong and they suddenly receive this much-unexpected news. All of a sudden they have traversed a threshold that they did not even know existed. For this reason, how professionals communicate bad news is of fundamental importance. Indeed, this central aspect of their professional labor is often unproblematicized or underestimated. And the ability to communicate bad information in an honest and sensible way is something that is rarely taught at medical schools in Argentina.\(^{37}\) Thus, medical residents must develop communication skills to face children and families.\(^{38}\) Parents told me that what is important for them during those critical minutes to find professionals who are honest and show at least some empathy when telling them that they would do their best to cure their children. Although this was not always the case, that was something parents were looking for in their relationships with the different health care professionals they relate to on a daily basis. During my research at the HU, there was a constant discussion about diagnosing each child’s condition. These were very rich discussions about diagnosis in hematological jargon that would only seldom be disclosed and reframed for parents according to what hematologist thought they would understand. In the majority of the cases the professionals at that Unit could

\(^{37}\) There are almost no curricula about this issue in Argentina at the undergrad level.

\(^{38}\) Indeed, as we will see in the next chapters, hematologists and other professionals that assist children living with cancer will often interact more with those children that treatment is not working so well. Thus, it becomes even more important the ways professionals learn to talk about bad news.
come up with the diagnosis but in a few instances they had to ask other professionals outside the hospital, for instance, at the National Academy of Medicine to confirm some unusual diagnosis or do more tests in order to be sure about a specific diagnosis.

Finding the precise diagnosis takes time and resources. It implies many different skills, techniques, and technologies. It also requires the presence of resources and the people who have the necessary political-economic ties inside and outside of the Hospital Infantil. Just to give a small example, one day when I was conducting fieldwork at the Hematology Unit the Cooperadora discovered that it did not have enough money for the vital cytometry, a technique during diagnosis to assess the morphology of individual cells that helps to pinpoint specific subtypes of hematological conditions. In response, the Senior Attending Physician of Hematology exerted his influence and found a private foundation that would assist cancer patients to secure funding for one year to do five cytometries per month for free.

**Getting into the flow of procedures**

Once children and their families are admitted to the Hospital Infantil, a whole world of bio-techno-medical-entanglements is revealed. Families use their various resources to guarantee that their child receives the care they need. As many parents told me, they hacen lo que sea necesario (“do whatever it takes”) to find a treatment that would restore their children’s health. Thus, getting into the flow of procedures is something they wish for and aspire to. Yet, once inside the biomedical institutional system with its bureaucracies, rhythms, and bodily interventions, they find something they were often not prepared for. This complex and constantly changing entanglement has many key places that would become sites of difficult treatments and intense

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39 The Children’s Hospital is a non-for profit entity so all the money is handled through a staff that coordinates both the donations and the spending of certain part of the hospital’s budget.
experiences. For children with hematological conditions the waiting room, the clinical boxes, the procedures rooms, and the Hospital de Día (“Day Hospital”) at the Hematology Unit became the different sites where illness and treatments were lived through their bodies. These were places that families and children needed to learn to navigate quickly.

Once families are enveloped within the Hospital Infantil they needed to figure out how to deal with multiple bureaucratic entities and bureaucratic schedules within and outside the hospital. They will need to learn how to fill paper work, and how to follow and embody the flow of procedures at the different units within the Hospital Infantil. Often residents would ask parents to do small errands (not only for their own children but for others). They will constantly go from one place to another to ask for a particular test result or a particular drug and bring them to the medical residents in charge of their children when hospitalized. They will need to get in contact with the Ministry of Health of their own provinces and the Provincial House in the City of Buenos Aires (a sort of “consulate” each province has in the Capital of the country). If they need subsidies and subventions for social support from the National Ministry of Social Action (if they were not having others before), for instance, for the Asignación Universal por Hijo (“Universal Child Allowance”) that covers approximately 3.7M children per month and which is tied to medical controls and the effective schooling of the child.40

Families also need to go to the National Drugs Bank (NDB) every month if they cannot afford the drugs or lack any medical coverage. The drugs given by the NDB are free. If, for instance, a child, due to her condition needs a bone marrow transplant they will need a histocompatibility test to determine if a close relative could be compatible for a bone marrow transplant. These tests are performed at another county hospital in the city of Buenos Aires.

Thus, many patients need to travel there by bus or other means. Often families from far-away provinces do not know the city and got lost easily.

The list of paper work with different bureaucracies goes on. Families often need a disability certificate for getting access to resources such as free transport, and they also need different kinds of proof from the hospital to show to employers to obtain permissions to visit children if they work legally. If they are working under the table (still a high percentage when I was conducting fieldwork) it would depend on the relationship they have with their employer if they are allowed to visit children. As we have seen families needed to navigate this fluctuating web of bureaucratic institutions, routines, rhythms, and multiple governmental and non-governmental spaces within and outside of the Hospital Infantil in order to become effective caregivers for their children.

**Starting treatment and many hospitalizations…**

Once when I was walking from the Hematology Unit to the Communicable Diseases Unit with Malena from the Hematology Unit and a medical resident from the hospital who was rotating at the unit on our way to see children under their care, the medical resident asked the staff, “What would have happened before if a child with Leukemia was not treated?” The staff clinician looked at her and replied:

They would probably die in weeks. Before the 1950s children would die in weeks. Today 75% of all types of Leukemia have many years of survival without illness and that other 25% is where all the research is focused, but depending the case the development of the disease would be different. In 1950s, they started to treat with Vincristine and at that moment they started to prolong children’s lives. Then, they stopped using mono-drug chemotherapy that had a limited success and started to use multi-drugs therapy and new protocols and that was when they started to greatly improve treatment.
From *morir en semanas* (“die in weeks”) in the past to the current situation in which an oncological or hematological disease can be effectively treated, often with a long-lasting remission, many things have (quiet dramatically) changed. As I mentioned in Chapter 1, the statistics percentages of “survival without illness”—professionals cannot assure they “cure” someone but can be as certain as possible the disease has been wiped out from the body—vary throughout the global north and global south, and even across each country. Currently there is the highest percentage of remission and therapeutic success for pediatric oncological and hematological conditions. This is what cancer researchers, clinicians, oncologists, hematologists, health activists, and family support organizations have been working for in order to provide better treatment options and better outcomes to children and families. On the other hand, children and families have been the receptors and producers of all these changes, in many instances in a blurry world were children-as-patients are not very different from children-as-research subjects (Jain 2013; Mukherjee 2010).

Families have a different perspective. After the diagnosis is made families have to quickly start learning about a myriad of things they did not know before. They learn about the specific type of Leukemia, with its subtypes, morphology, genetic background, and the protocol that hematologists will follow for treatment. The technical terms may not fully be understood by laypeople nor explained by hematologists. They also learn about the kinds of drugs that hematologists prescribe and how they will obtain them. With the treatments the ‘alarms’ and particular forms of care will need to be understood in order to ensure that treatment is effective.

Parents and children will have difficulties moving from “pre-diagnosis” to “diagnosis” and later to “prognosis.” Therefore, children and families will not absorb all this knowledge and go through these new experiences in a straightforward, linear manner. It takes time to
comprehend and adjust to new situations, even to accept that their children are sick, something health professionals tend to quickly overlook.

**Phases of chemotherapy treatment**

Let’s focus now on the different phases of chemotherapy treatment since their rhythms organize the lives of children, families, and clinicians in many different ways. I will briefly describe them. I will analyze them in more detail in the next chapter. During the first “induction” phase, which often lasts about a month, the multiple drugs given in quick progression and in high doses will try to push the leukemia into prolonged remission. The aim of the induction is to eliminate the malign cells (blasts) from the blood, and to reduce the number of blasts at the bone marrow to a normal level. This a radical experience when hematologists drive children to an almost-near total devastation—a body with zero white blood cells—in order to get children on full remission. “For few critical days”, as Mukherjee (2010:127) highlights, a patient going through the induction phase “would inhabit one of the most vulnerable states that modern medicine can produce: a body with no immune system, defenseless against the environment around it.” During this first period children may stay hospitalized for quite some time.

If leukemia does actually go into remission, then, the second phase, “consolidation and intensification,” will deepen the remission over several months, ideally two or three but depending on the case, and the potential multiple hospitalizations and delays, it can take longer. This will require more chemotherapy but at smaller doses, given over stretched periods. At this point children may go back home if they live close by, to a close-relative house, or to a hotel if
they are from faraway places, and return to the hospital every week for more chemotherapy.\textsuperscript{41}

Depending on the kind of leukemia (Lymphomas, lymphoblastic/lymphocytic leukemias, myeloma, acute and chronic myelogenous leukemia, myelodysplastic syndromes, myeloproliferative diseases) and the type of ‘risk’ (low, standard, high) hematologists may also need to inject chemotherapy into the brain, which is protected by the blood-brain barrier (also called as the ‘sanctuary’), by intrathecally injecting chemotherapy drugs directly into the cerebrospinal fluid. This is usually performed at the same time hematologists carry out a lumbar puncture to test for the presence of malignant cells at the cerebrospinal fluid. (First, some spinal fluid is extracted and then, using the same needle, drugs are injected into the cerebrospinal fluid.)

Then, after some months, sometimes a year, children finish the treatment and move to third phase, “maintenance/prophylaxis”, in which a low dose of chemotherapy is administered for a long period of time to protect the body from relapsing. These are the three different stages of the chemotherapy treatment. But let’s take a closer look into each chemotherapy phase.

**Induction**

The first day, also called *debut* (“debut”), of induction is, as one mother described it, *intenso* (“intense”). Often, in the same day, children and parents receive the news about the confirmed diagnosis, and, on top of that, children will start treatment right away. In this first month of treatment children undergo at least four lumbar punctures at day 1, day 8, day 15 and day 33, and at least two bone marrow examinations at day 1 and day 33. At one point during the first phase the usual ‘alarms’ given by professionals of things to do or avoid, food to eat or elude, etc., are

\textsuperscript{41} Depending on each particular case this may vary, in fact, it is not uncommon for children and their main caregivers to be hospitalized for many months after the start of the induction phase and way into the consolidation/intensification phase.
prescribed. At the end of the first month (day 33) children are evaluated to detect minimum residual disease. According to the results they are re-categorized for the following phase.

Almost invariably children on “debut” are hospitalized. A large number of children at this first stage will actually be hospitalized for a combination of multiple reasons (infections, lack of infrastructure at home, lack of resources to travel back and forth, families are from faraway places, etc.). And this creates another layer of complexity since children are hospitalized outside the hematology unit. Therefore, this first month of treatment is very important not only since its impacts and consequences will carry on during all the treatment but also given the new biomedical world in which children and families are immersed (and the tensions between different specialties and units at the backdrop of families experiences). Sometimes families knew something was wrong and they may feel relieved by knowing the exact condition, with “its name and surname” as one hematologist put it. But very often no one expected anything, and as a mother told me, that first day, “It was like a pesadilla (nightmare)... I wish no one would have to go through what I felt that day.”

When children are not hospitalized they are assisted at the “Day Hospital” for their treatment. They have to sit plugged for hours to the IV-poles pouring drugs into them. Children found themselves somehow confined for hours in this place. Their time is regulated and controlled by the hematological treatment and its different temporalities. They play with their parents and caregivers, eat, sleep, and try to let time passes quickly. Yet, there is an adaptation to someone else’s lived time and their particular places. Thus, their time is also being regulated.

Every day children are exposed to multiple diagnostic and therapeutic techniques, which are often considered as harmless for the adults but that “could cause great anxiety and pain [to children], being in many instances the worst thing of having a cancer” (Álvarez-López et al.)
2006:406, my translation). Sometimes, important tests have to be re-done. For instance, I remember Miriam, a two-year old girl with acute lymphoblastic leukemia who had to go through a painful lumbar puncture two days in a row since the first day the fellow performing the procedure could not perform it properly. One of the first-year fellows at the Hematology Unit tried to perform a lumbar puncture but she pricked her five times without success. During the early morning meeting hematologists wondered if they could perform it again or not. Julia [second-year fellow] had to see Miriam’s back to check the area where she was pricked was not edematous (and so they could prick her again the following day). I went to see Miriam to the procedure room and Julia could perform a lumbar puncture to Miriam after sedating her, she did it with only one prick. Neither the mother nor Miriam was happy about needing a new lumbar puncture the following day (Miriam was uncomfortable and crying for a bit). After both mother and daughter left Julia explained to me, “Yesterday, Susana [the first-year fellow] could at the end of many attempts extract some fluid but it was not transparent as it should be, it had a bit of blood because of the traumatism inflicted on the area and so we could not use it as a sample.”

She was holding in her left hand the little tube while she told me, “It is a pity, this sample they took yesterday is useless for us,” and she threw it to the garbage container next to the procedure table. I asked myself at that time how much stuff (painfully taken out of children’s bodies) has to be thrown away and be done again, and how do children and family felt about it. How children and caregivers make sense of the professionals’ need to prick children again and again, especially for lumbar punctures or bone marrow examinations? In this case, if the fellow had performed the lumbar puncture successfully Miriam could have avoided a second painful procedure on the following day. This is just one example, but the accumulation of “random” acts, like being unlucky and having a less experienced fellow learning to perform the test, is what
creates the particular therapeutic process of each child and how it will potentially affect in the long run the corporeal experience of cancer treatment.

**Intensification/Consolidation**

Once the child has recovered from the induction phase, hematologists begin with the second phase. This is a longer phase in comparison with the previous short but intense phase. It is supposed to take two or three months but it can take more than that depending on myriad (un)expected complications. At this stage, children, families, and hematologists are all trying to keep track of everyday slight changes. Hematologists are also trying to finish the specific protocol with its specific number of cycles and blocks of chemotherapy. Yet, very often children are getting sicker with infections and more hospitalizations, and, thus, certain blocks or cycles have to be kept on hold for some time (until children get better and can carry on with the next cycle).

A typical cycle of chemotherapy implies blocks of different chemotherapy drugs and some time in between to let children’s bodies recover. This second phase of treatment implies lower doses of chemotherapy but over a longer and stretched period of time (with rest in between). And as children told me plenty of times, they often need to “get used” to particular rhythms: chemotherapy cycle, feeling “terrible,” being “absent from the world,” then they would slowly recover, and go back to certain “normal life” and then rhythmically face another cycle for as long as the treatment lasts.

Once the induction phase ends, during the consolidation phase children and families are able to recover some of their lives and, to certain extent, de-medicalize or at least de-hospitalize their everyday lives a little bit more. At this stage, children may experience more time outside
the hospital at home or in the cheap hotels if they are from far-away provinces. Yet, unless children are clearly sick, every time they go to the hospital for a follow up the potential for staying hospitalized will re-emerge. Thus, after a while children and families understand this dynamic, although they are not comfortable with the idea that every time they go to the hospital they may (or may not) go back home. Indeed, every time parents would go to the hospital for a follow-up they had to somehow prepare their children in advance of the possibility they will stay hospitalized even though their may appeared to be all right and apparently not needing to stay hospitalized.

At this second phase children and caregivers are not new to the hematological treatment. Thus, they often try to negotiate more with their doctors in order to influence their therapeutic paths. But, still, they may go through constant ups and downs, and they may end up enclose at the hospital more than what children and caregivers would want to. In the long illness and therapeutic processes, home and hospital become blurred spaces. Undeniably, children and families’ existence is tied to what is going on at the Hospital Infantil. One mother with a child in the consolidation phase of chemotherapy told me:

I always say to other parents that every time you go to the hospital [for a check-up] you better take a bag with you with food and clothes, because you never know when you are coming home again, and you never know how long you will stay at the hospital.

This is how the close future looks like for children and families at the beginning of treatment. Once children and their families start treatments, a series of therapeutic steps and life-altering transitions occur. They cross a series of thresholds. The speed of these changes can greatly vary from one child to another and one family to another. There were countless hospitalizations at the beginning of treatment. Children stay in the hospital for months depending how they reacted to the first part of treatment. The notion of “threshold” implies spatial, affective
and temporal changes. Families move to the City of Buenos Aires and relocate for their child’s care. For many it is a cultural and social shock not only to start the treatment but also the need to relocate and, therefore, fragment families.

**Maintenance/Prophylaxis**

After the major portion of treatment is done children still need to be protected for years through a maintenance/prophylaxis phase. In this third phase that can last between one to three years, families and children go less often to the hospital, they may recover some of the “previous life” (although drastically changed) before the irruption of the disease. They may spend more time at home, or living in the hotels paid for by the provincial government if they come from outside the City of Buenos Aires, or they may go home at the faraway provinces for some small breaks and travel back to test for the continuous absence of tumor cells in the body. Maintenance therapy includes a combination of drugs given orally such as 6-mercaptopurine, methotrexate, steroids, and vincristine; and intrathecally to protect the central nervous system and prevent from relapsing. Some drugs are given daily, others weekly, and others monthly. Depending on the kind of hematological condition and its risk the dosage and combination of drugs vary. This is the longest phase. It can take up to two, three years. After the end of this phase children are officially labeled “free of illness” and they would come for regular controls for five to ten years more.

**Therapeutic conclusions**

Usually the relationship between family members, children, and clinicians is not a smooth one. Professionals want children and families to “adhere” to and “comply” with treatment, and different clinicians want different kinds of compliance. But in order to comply with treatments,
caregivers and children need to believe in them, even when everything is against them. I once observed a meeting between Juana from Bariloche (in the Patagonia), the mother of ten-year old Sebastian, who had a brain tumor and was in a terminal phase and Elizabeth from the Palliative Care Team,

Juana: I don’t know you but I need to believe that he is going to be cured, if not I cannot go on…
Elizabeth: No one knows what you are going through, you always have to have hope that he is going to get better, that is something no one can take from you, but this is getting difficult…
Juana (Crying): I don’t get it, I can’t understand why this is happening to my child, there are so many killers and bad people out there and nothing happens to them…

This is a dramatic example of the end of treatment, in this case of failure of treatment, in which a mother was still hoping to believe in treatment. With cancer in general, pediatric cancers in particular, and especially with hematological cancers in children, there is often no clear-cut linearity, especially in regards to sudden deterioration. While conducting research with the HU one of the children’s dying process that affected the team the most was Laura’s death. She was a thirteen-year-old girl with acute lymphoblastic leukemia in consolidation phase. Until her last week of life, she seemed to be medically stable but when she was not able to come to the last control everything got complicated fairly quickly. She ended up going into septic shock and ultimately dying at the Pediatric Intensive Care Unit. After she came that day there was a delay to start treatment because hematologists could not find a bed for her in any of the clinical units. It took them three hours to start antibiotics treatment and by then it was too late. Yet, Laura’s death epitomizes the zigzagging nature of pediatric cancer treatments. Her death shows the ways the unexpected and the prognostic uncertainties (Alonso 2009) are also part of the therapeutic thresholds children, professionals, and families have to go through while aiming to cure children.
In this chapter, I attempted to use the concept of threshold to show not only the temporal-spatial nature of the transitional changes embedded in children’s therapeutic process but also its liminal aspects (Turner 1995). When children finish one cycle of chemotherapy and begin to recover from it they may feel less hecho mierda (“shitty”) but, needless to say, they are still inhabiting an ambiguous liminal stage between being sick (present) and becoming a cancer survivor (potential future). A critical juncture in life that is hard to understand if we are only looking at it statistically as when professionals consider particular prognosis for particular conditions (Jain 2013). While conducting this study and analyzing the data it became apparent that children, professionals, and family members often disjointedly and asynchronously navigate these liminal and transitional stages—the different thresholds that come to constitute their experience of illness. When children start their hematological treatments, hematologists will lead these therapeutic paths but children’s long medical journeys will inevitably be challenged by constant negotiations, articulations and adaptations to countless medical interventions. The great majority of children were able to overcome their illnesses and live a “life without illness” although with different degrees of complications. This chapter described seven different types of thresholds that children, their families, and their health care practitioners experienced while embarking in a hematological treatment.

These thresholds that I have shown are important to familiarize the reader with the drastic changes children and families face. In the following two chapters I will focus on the clinical setting, how the actual hematological treatment works, and its impact on children’s bodies.
Chapter 5: Clinical setting: The context of hematological treatment

Father: But he has a catheter to have less infection, doesn’t he?
Nurse: Yes, but because he has a little bug in the catheter we are trying to kill it.
Danny (6 y/o, ALL): I will grab a rifle and I will kill that bug! I will go and will kill all these bugs with the help of my father and I will help all the people.

“We have a sobreviviente (survivor), and we have to respect him as such. We did everything right with him, we gave chemo and everything 100%, but I don’t think no one could say we should go for a third [bone marrow] transplant if he starts to get worse, because it would kill him…”
Flora, hematologist.

“In the first contact (with parents) we give an alert, we tell them, “Well, now you are doing everything with the hematology team, but it is likely that we will see you again, because they will leave your children with no defenses. So if they have fever it is an urgency.” We explain that and we give some information to prevent infections.”
Norma, former head of Communicable Diseases Unit.

To grasp the kinds of experiences children living with hematological cancers and their families undergo, it is important to understand the key players in these clinical dramas. The Hematology Unit is central but not the only player. In this chapter, we will look at how the clinical setting works by focusing on the diachronic process and the different transitions children experience through the different stages of their treatments. Within the clinical setting, we will also examine how both hematological and communicable diseases treatments overlap and what the consequences entail for children and families.

As I already showed in Chapter 1, Argentina has three health care systems. In the public sector, pediatric hematological services are concentrated in few tertiary institutions (Moreno et al. 2013). The professionals that work at these key hematological units are trained in the genetics and biology of hematological conditions in ways unimaginable ten or twenty years ago. How is this hematological knowledge translated into everyday practice? I will pay particular attention to how the different phases of the hematological treatment are organized and how it often overlaps...
with communicable diseases treatments given children’s propensity to get infected multiple times during treatments.

There are many moments during children’s hematological treatments that are important in children-professionals-family relationships. In this chapter, I will focus on four key moments to highlight the kinds of interactions that are created among children, professionals, and caregivers and to show the complexity of these therapeutic processes aimed at pushing these children to the land of “free of illness.” I will focus on the objectification of children’s bodies, infections, the pedagogical teaching to parents on how to look at their own children’s bodies, and the moments when a child relapse.

The clinical setting

Within the Hospital Infantil the key clinical settings I will focus on in this chapter are the Hematology Unit (hereafter HU) and Communicable Diseases Unit (hereafter CDU). Within the organizational chart at the Hospital Infantil both units belong to the Medicine Department. When children get diagnosed with a hematological cancer the HU will be in charge of their cancer treatment. But they will not be the only specialists who will indeed treat children and families. Other units and teams will assist them throughout the lengthy treatment, just to mention a few of them: social service, psychopathology, palliative care, and more importantly communicable diseases. These are some of the different actors that will play important roles in the everyday lives of children living with hematological cancers and their families.

Within this broad clinical setting, the HU and the CDU become central places in relation to children’s cancer treatments. Within each unit there is a diversity of actors that play different roles. For instance, at the HU there are at least four different kinds of actors that play an
important role within the everyday dynamics of the unit: there are staff hematologists, staff clinicians (specialized in Hematological conditions), fellows, and nurses. Whereas at the CDU those that play key roles are staff communicable diseases specialists, (basic) residents and nurses. In the next sections I will consider the Hematology Unit.

**The Hematology Unit**

The main work of the HU is to diagnose, treat and manage hematological conditions, their chemotherapy treatments, complications, and provide psychological and social support to children and families. This unit is one of the main units throughout the country in terms of number of patients they assist, the level of complexity they manage, number of journal articles they publish, and influence wield within and outside Argentina. Physicians in the unit are divided between non-malignant (I did not work with them) and malignant pathologies. For the standards of the *Hospital Infantil* this is a big unit.

The staff of the HU was composed by the head (male, in his mid-fifties), staff hematologists and staff clinicians (all female, and between mid-thirties to mid-fifties). Another male staff was the acting sub-director of the *Hospital Infantil* and was not assisting children. Additionally, there were trainees including fellows (all female between mid-twenties and mid-thirties), fourth-year (R4) basic residents from the hospital or from other hospitals, nurses, lab technicians, and administrative secretaries. The *Residencia Post-Básica en Pediatría Oncológico-Hematológica* (“Fellowship in Pediatrics Onco-Hematology”) is a sub-specialization after finishing four years of medical residency in Pediatrics. The municipal fellowship lasts 3 years and usually fellows spend 1.5 year with oncology (solid tumors) and 1.5 year with hematology (non-malignant and Leukemia). The fourth-year (R4) residents from the hospital or from other
hospitals rotate three months in each unit (some rotations at the Hospital Infantil are mandatory and other elective). They rotate for 1.5 month with oncology and 1.5 month with hematology. The number of staff and residents performing the clinical work assisting children with hematological conditions (excluding secretaries, technicians, nurses, and others) when I was conducting fieldwork was between eight and ten and nurses at the Hospital de Día ("Day Hospital") were between three and five (the head of Nurses was male in his mid-thirties).

The Onco-Hematology Unit functions in a separate ward in the middle of the hospital on a three-floor building. It has on the main floor one wing with clinical boxes for check-ups and follow-ups (often at the end there are some tables where the teachers from the hospital’s special education school come and work with children), and another wing with the Hospital de Día ("Day Hospital") in which outpatient children receive their doses of chemotherapy and/or blood transfusions, and if required they would often stay in observation for some time after the daily treatment. Between these two wings there is the waiting room with benches and chairs, a foosball, and a big TV always on (usually full of children and caregivers between 7:00 am and 1:00 pm). There is also a front desk where caregivers come daily early in the morning from Monday until Friday to check-in with one of the members of the team (who already has the pile of medical histories of all the patients that will be seen that day). There is also a small cubicle next to it where a nurse extracts blood samples to check how children are doing before starting treatment that day. On the second floor, there is one big conference room, another two meeting rooms, one for oncology, another for hematology, the head of oncology’s office, the head of

\[\text{\footnotesize 42 The different professionals had different contractual relationships while working at the unit. Some were staff clinicians, others staff pediatrician oncologists or hematologists, some post-basic residents on pediatric oncology or hematology, some fellows, and others were working with no remuneration hoping that one day a job post would be offered (they were working on other jobs outside the hospital as their main income).} \]
hematology’s office, a changing room with lockers, and the secretary’s office where families can come and contact the secretaries of the unit for bureaucratic matters. On the same second floor there is the “Procedures Room” that is used for the procedures such as bone marrow aspirations and lumbar punctures (later I will describe one procedure). It has three rooms, one bathroom, and a small waiting room area with a TV. On the third floor of the ward there are the different labs where technicians, staff and fellows from the Hematology Unit analyze blood, cerebrospinal fluids, and bone marrow samples.

Given the differentiation at the interior of each particular hematological condition diverse techniques have been developed to look at the molecular biology, the genetic level, the forms of the cells, and the way they interact. (As I will show later within one particular condition different sub-types can have totally dissimilar prognosis and percentages of survival without illness.) The majority of the diagnostic techniques (needed to diagnose and treat children) are performed within the unit or at the Hospital Infantil’s Central Pathological Lab. While I was conducting fieldwork only rarely did they need to go somewhere else to look for a particular test to diagnose children under their assistance for the main diagnosis related to the original blood cancer or for secondary diagnosis related to the management of the cancer treatment.

*Residentes post-basicos en la Unidad de Hematología (“Fellows at the HU”)*

In order to become a Pediatric Hematologist, students need first to do take six years of medical school and a seventh year of an annual internal rotation in which students rotate through hospitals focusing on larger areas of Medicine. After this, students receive the degree on General Medicine and need to matriculate at the National Ministry of Health to practice as M.D. But as an inexpert physician the best way to follow the career is to apply for a residency. After four
years of basic residency in Pediatrics residents become Pediatricians. After three years of fellowship in onco-hematology pediatrics a pediatrician becomes a Pediatric Onco/Hematologists. In Argentina once students graduate medical school they become M.D and can practice medicine but the general path is to follow a basic residency, and even to become a sub-specialist with a fellowship. In Europe residencies are different and, for instance, French residents are still considered as students and become M.D. only at the end of their residency and after submitting a thesis (Seguin et al. 2007).  

In the City of Buenos Aires, the Fellowship in Onco/Hematology can be taken in the three tertiary pediatric institutions that are under the Ministry of Health of the City of Buenos Aires (one of these three institutions is under the jurisdiction of both the City of Buenos Aires and the Federal Government). The residency recognizes pediatrics onco/hematology as one specialty and it provides a theoretical-practical training in both areas of this specialty (Programa Residencia Post-Básica en Onco/Hematologia Ciudad de Buenos Aires, 2011). Similarly to Canada where residents are trained in both pediatric oncology and hematology, in Argentina, fellows develop an expertise in the full spectrum of oncology and hematology clinics and research.

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43 In US and Canada students need to take four years of undergraduate studies plus four years in medical school to take the examination that would grant the M.D. but they would also need to do a residency. In Canada, Royal College certification in Pediatric Hematology/Oncology requires a certification in Pediatrics or Internal Medicine; a completion of a three-year Royal College accredited program in Pediatric Hematology/Oncology; a demonstrated progress in a scholarly project relevant to Pediatric Hematology/Oncology; and a successful completion of the certification examination in Pediatric Hematology/Oncology (www.royalcollege.ca).  

44 Trainees/residents are capacitated in: General knowledge of Hematology and Oncology; Clinical knowledge on Pediatrics Oncology and Hematology; General techniques on Hematology and Pediatric Hematology; Bone Marrow Transplant (autonomous and allogenic); Basic notions on Oncological and Hematological Research; and Medical Ethics (Programa Residencia Post-Basica en Onco/Hematologia Ciudad de Buenos Aires, 2011, p. 3).
Since the HU can only assist outpatients when they need to hospitalize their patients they have to do it in other clinical units, particularly those with isolated, individual rooms such as one of the two Communicable Diseases Units. Every day members of the HU assist both outpatients and hospitalized patients. Members of the Hematology team divide their work and usually one or two staff with one or two of the fellows go to check patients to the different units while other staff and fellows stay at the HU following patients at the clinical boxes and checking them at the “Day Hospital.” When I was conducting fieldwork 1st and 2nd year fellow performed procedures (lumbar punctures and bone marrow examinations) from Monday until Thursday and only on Friday the head of fellows (more trained) performed them. Fellows were learning how to perform these critical procedures and often when observing them I was able to see the intricacies of such learning (imagine inserting a thin needle between two lumbar vertebrae looking for the specific spot to extract cerebrospinal fluid to picture how delicate is this procedure).

Fellows are critical to the everyday activities of the HU. They assist patients inside the HU, go to other units to talk with other specialists and to check their patients, they perform bone marrow aspirations and lumbar punctures, and then analyze the results in the lab. In sum, in many ways they are the backbone of the unit while staff hematologists and clinicians are also assisting patients, revising cases, managing the overall activities of the unit.

“Observando” Leucemias (“Seeing” Leukemia)

How do health professionals frame hematological malignancies? There are different types of cancer that affect blood, bone marrow, and lymph nodes and since the three are interconnected a disease affecting one of them will likely affect the others as well, although this is not always the case. The proliferation of abnormal components of the blood could be triggered by many
different causes. One historical way of “seeing” the presence or absence of different forms of hematological conditions is by microscopically looking at the blood to see its morphology and its behavior. Not so long ago hematological conditions were defined by looking at whether it was mainly located in the blood (leukemia) or in the lymph nodes (lymphoma, a biopsy would confirm this). In the last decades another way to find etiological explanations is to look “deeper” at the genetic level to find out what kind of genetic information (often a mutation) is codifying the abnormal production of the different components of the blood. More recently a great emphasis has been placed on categorizing the different hematological conditions by cell lineage in hematopoiesis; that is, how the different cellular components of the blood are formed.45 The members of the HU when looking at a particular child consider all these different forms of “seeing” the hematological conditions.

As I will develop in more detail later in order to figure out the different abnormalities associated with specific components of the blood, hematologists routinely perform invasive procedures such as bone marrow examinations and lumbar punctures for cytopathological studies (a specialized form of pathology that study diseases at the cellular level), as well as clinical check-ups. Thus, these different kinds of evidence from the molecular to the molar are combined to have a broad picture of what is going on within each child’s body. Some types of hematological diseases can now also be categorized by cytogenetics (acute myelogenous leukemia, chronic myelogenous leukemia) and immunophenotyping (lymphoma, myeloma, chronic lymphocytic leukemia). Hematologists are constantly moving between the microscopic

45 In a normal process the multiple cells that compose blood are divided and specialized according to the different tasks they are designed to perform. When one or more than one of these components start to behave abnormally is when the different types of leukemia and other hematological conditions occur. For instance, one kind of abnormality that appears more often in the hematological malignancies than in solid tumors is chromosomal translocations (rearrangement of sections between nonhomologous chromosomes).
and molecular levels where they can “see” how the blood malignancies “behave,” how they are expanding or shrinking depending on the treatment’s grades of success to the macroscopic level of an actual flesh-and-blood child. This constant movement entails different skills. As Muriel from the Hematology Unit told me “after all they are still children,” and thus they need to interact with children’s whole bodies (and their caregivers) in their broader emotional and social contexts. Children that are overflowed with drugs and made permeable by the flow of multiple procedures. Yet, even before beginning a hematological treatment children and families need to actually enter into the HU for the first time and wait at the waiting room.

**The Hematology Unit’s waiting room**

From children and families’ perspectives probably the key place in which they first began to be socialized into the world of hematological cancers is the Hematology Unit’s waiting room. This is the place, where, as Juan, the father of five-years old Luis told me,

> Te la pasas mirando tus propios zapatos. No queres comparar tu niño con otros. Vos podes ver que algunos parecen estar mejor o peor que el tuyo. Por eso no queres mirar a nadie. (“You keep staring at one’s shoes. You don’t want to compare your child with the others, you can see some children that look worse or better than yours, and so you don’t want to look at anyone.”)

In the sense giving by Juan, the waiting room is not only a place of intense forms of socialization into becoming a *paciente con leucemia* (“Leukemia patient”) and a caregiver of that child, but also a place in which children and parents can imagine their potential, uncertain futures. That is perhaps why Juan did not want to look at other children, instead he wanted to stay in the present. But even the present is also full of uncertainties. In this way the waiting room also becomes a key place where children and families experience a “zone of uncertainty” (Auyero 2011).
This waiting room is like others experienced by working class people. Auyero (2011) describes the world of working class people waiting in welfare agencies in Argentina and how uncertain it can often be experiencing someone else’s time. I found similarities in how children and families have to adapt to professionals’ time-constrains and time-management: waiting to be seen by a professional who would decide what would happen next. Like Emergency Room’s waiting room the Hematology Unit’s waiting room is also a hectic place. From early morning until noon or 1:00 pm there is a lot of movement of people. The waiting room has approximately ten long benches facing the main entrance, multiple chairs close to the walls, a big TV always on above the door entrance, and a foosball between the main door and the benches often used by young children (not only by sick children but also by healthy siblings waiting for the brother or sister to be assisted). Families come very early to announce themselves to the secretary and let the oncologists and hematologists know they are there so they can look for their medical history and instruct nurses to prepare the medication children may need. They often wait at the waiting room for hours until a staff hematologists or clinician or a fellow check their children. In the meantime, they may eat something, sleep, go for a walk, talk to other children or parents, or do some paperwork. But while at the waiting room, as Juan said above, families see and are seen, caregivers talk about their children’s conditions and treatment, they exchange information about alternative medicines or biomedical treatments, they share phone numbers, they text messages to their far away family members. Children may play or sleep or be left alone to not interact with other children and prevent contagion (often children use masks when they have an infection or cold, especially during winter time). This is a place for long-term socialization on the everydayness of the flow of procedures, especially the Hematology Unit daily activities, its jargon, bureaucratic rhythms, and therapeutic sequences. This is, as Auyero (2011) clearly puts
it, the place of waiting, where people embody someone else’s time, where patients and their families need to be *patient* (and compliant).

**Dynamics of Hematology Unit**

The HU assists outpatients that are followed-up clinically at the “Day Hospital” for their chemotherapy treatment and/or blood transfusions. When patients need to be hospitalized given their medical complications they have to be hospitalized in other clinical units, particularly those with isolated, individual rooms. The two Communicable Diseases Units (I worked on only one of them) are the first place to look for beds for hospitalizations. Thus, members of the Hematology team divide their daily workload between activities done inside the unit and following-up patients in other units. Some staff and fellows, follow-up patients dispersed throughout the different clinical units while others work at the unit checking-up outpatients at the clinical boxes, performing the essential bone marrow examinations and lumbar punctures, or checking-up children at the “Day Hospital.” The “Day Hospital” is a common area within the unit with approximately 15 comfortable single sofas with IV-poles on their sides, some computers, two always-on TVs, games, and toys. Following directives from the Hematology team (usually the head of fellows is in charge of these patients) the Head of Nurses run the “Day Hospital” and is usually assisted by two or three more nurses. The main work of nurses is to introduce the IV and manage chemotherapy drugs and blood (platelet) transfusions. At the “Day Hospital” children are sitting in comfortable reclining wide single mushy sofas with one or two caregivers sitting next to them. Depending on the kinds of IV fluids that are being poured into children’s bodies, children can stay plug to the IV pole from one or two hours to the whole day. The “Day Hospital” also becomes a key place of socialization. Children (and caregivers) see and are being
seen. (Sometimes children cover their faces with a towel to fall asleep, but also I suppose as 
Juan told me about the waiting room, to not see/be seen to/by other children.) They are affecting 
others and are affected by others. Parents of different children also talk one another about their 
children’s treatment and other aspects of their medicalized lives. In the following excerpt from 
my notes we can see how children are constantly affecting one another even though they have 
been through these experiences plenty of times:

I see Melanie, a 4-year old girl, she was with her parents, she was quiet watching a 
cartoon on the big TV, but all of a sudden I turned my head and looked at what Melanie 
was observing and I saw how Marcelo, the head of the nurses, was trying to introduce an 
IV into Muriel, a twelve-year old girl sitting on the other side of the room. Clearly 
Melanie began to feel uncomfortable and nervous. Melanie’s mother was giving her 
caresses and the father was talking to the mother. I could see how Melanie was gradually 
feeling worse. Muriel was crying and refusing to have an IV introduced in her left arm, 
she was yelling, “Don’t prick me!” with all her strength. After maybe three minutes 
Melanie started to cry too. Although she already had an IV plug into her right arm and 
medication pouring into her body for the last two hours…

Children’s corporeal experience of chemotherapy (and its effects) not only becomes part 
of different constructions of bio-sociality (after all they are there because they share certain 
hematological (sub)conditions) but also of “the inescapably physical experience of a human 
undergoing an invasive procedure” (Jain 2013:17). At the “Day Hospital” children are traversed 
by constant flows of affects, such as witnessing other’s pain and suffering (or, being reminded of 
their own pain and suffering by witnessing others). These are some of the kinds of bio-sociality 
(Rabinow 1996) and medical socializations that are made in-between children’s objectified 
odies and children’s corporeal subjectivities re-created daily at the “Day Hospital.” For 
instance, some parents and family members who have passed the main part of their children’s 
treatment and do not need to go so often to the hospital told me they still go every day to talk 
with other families and “see how things are going” or merely to “support one another” and “give 
back what others gave me when I was starting with my child’s treatment.”
Ana, the mother of a six-year-old boy with acute lymphoblastic leukemia who, at the time I chatted with her, had to go every two weeks to the hospital for regular check-ups told me: “Even though we are supposed to go every fifteen days we do the same things all the time [they go everyday to the hospital], we call among us [parents], we get together with other parents to see how things are going, we text each other all the time…” We often see this tension between bio-sociality and different forms of relatedness. The notion of bio-sociality is particularly important to grasp these kinds of interactions because everyone is being affected by children’s chemotherapy and wants to interact in biosocial terms. But not every child is equally affected by chemotherapy: children whose leukemia cells have certain gene mutations (chromosomal translocations, deletions, inversions) or markers on the leukemia cells (like CD34 protein) may indeed have a better or worse outlook. Therefore, this creates sameness and difference within children living with hematological conditions.

**Hematology Unit’s division of labor: The clinician’s day**

While patients and family members wait, doctors, nurses and technicians perform their work, see patients, and offer treatment. As I have showed the HU divides its workday between the “Day Hospital,” the “Procedures Room,” following-up patients at the clinic cubicles, analyzing some tests at the lab, and seeing their patients hospitalized in other units. Early morning around 8 am the team meets at the meeting room on the second floor to revise medical histories and talk about the patients they will assist that day, then at mid-morning they revise the information they collected with the blood tests and some of the follow-ups they did. At this mid-morning meeting they decide what to do with the outpatients (if they can go back home or need to find–sometimes they need to fight for–beds to hospitalize them). Usually by 1 pm they finish seeing outpatients
at the clinical boxes. Typically, around 2 pm they adjust all the information they have about all
the outpatients and hospitalized patients they saw that day and instruct fellows (who will keep
working until later in the afternoon) what to do in case there is an emergency with the most
critical hospitalized children (even with the outpatients they often talk about what to do if they
cannot come the following week, how to keep track of them). These are the things they do on a
daily basis from Monday till Friday.

The diagnostic process plays a vital role in the configuration of children’s (and their
families) therapeutic trajectories within the Hospital Infantil. When the treatment starts, from the
first day, a succession of analyses, procedures, and expertise knowledge is abruptly brought to
the front of children and families’ experiences and usually a specific chemotherapy protocol is
randomized chosen. The first day a child is assisted by the HU is considered as the “debut” or
Day 1. Usually, on this first day, post-basic medical residents at the unit perform a lumbar
puncture and a series of other test as well as a thorough clinical check up and clinical history.
These procedures are crucial, for instance, if the lumbar puncture at the “debut” comes “bad”
(that is, if it shows malignant cells at the cerebrospinal fluid) it would automatically means that

46 Among the many types of tests and/or procedures children may undergo are:
- Clinical exam: full examination of child’s body to look for signs of any disease (masses, lumps,
infections, etc.), and a full and as complete as possible clinic history is taken.
- Full blood count: a blood sample is drawn from the child to measure:
  - Total number of red blood cells, white blood cells, and platelets.
  - Total number of hemoglobin (oxygen transport protein) in red blood cells
  - The fraction of whole blood volume that consists of red blood cells.
  - Total number of white blood cells may also differentiate: neutrophil granulocytes, lymphocytes,
    monocytes, eosinophil granulocytes, basophil granulocytes.
- Chest x-ray.
- Biopsy(ies): lymphatic glands, bone marrow aspiration and examination (usually extracted
  from the hip bone), among others.
- Cytogenetic analysis: looking for chromosomal translocations, genetic mutations, etc.
- Immunophenotyping: analysis of the proteins expressed by the cells that target the specific
  structural and functional differences of particular forms of hematological conditions.
- Lumbar puncture: extraction of cerebrospinal fluid through a needle inserted in the spine.
this child’s risk is re-categorized from standard to intermediate or high depending other variables. Consequently, with the change in “risk” there would not be a change in the chemotherapy protocol since it continues to be the same but it would change the doses and combination of drugs. And depending on the kind of hematological condition it would often also add the need to radiotherapy as well.

The first 33 days since the start of treatment on Day 1 are fundamental for hematologists in the way it would frame the diagnosis, its suggested treatment, and potential prognosis. During the first month of treatment, besides the less invasive but nevertheless yet painful blood extractions and other minor procedures, each child will be exposed to at least four lumbar punctures (day 1, day 8, day 15, and day 33) and two or three bone marrow examinations. During the following months of treatment each child may go through at least half a dozen bone marrow examinations and a dozen lumbar punctures. As María, a staff hematologist told me, once the child goes through these first thirty-three days then “We can have a wider picture of the particular type of hematological illness and the child’s reaction to treatment, especially if the bone marrow had a complete remission or not.” Generally speaking the specific prognosis

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47 A chemotherapy protocol is an ongoing, collectively constructed, internationally tested, standardized treatment option according to each specific condition. Each protocol has advantages and disadvantages. Hematologists at the Hospital Infantil are constantly updating their knowledge in relation to the new development of pediatric onco-hematological treatments at the national and international levels. Indeed, they are a key actor at GATLA (Argentine Group for the Treatment of Acute Leukemia), an organization dedicated to the research and advancement of new pediatric chemotherapy protocols. I often heard hematologists complaining that they received children transferred from other provinces with outdated chemotherapy protocols.

48 Each bone marrow examination or lumbar puncture would potentially produce a strong impact on each child and their social worlds.
associated with a particular hematological condition and the potential treatment options are constrained by multiple factors that need to be considered during this first month.49

Thus, on the one hand, this first month is vital for hematologists because it sets up the potential therapeutic trajectory for each child, and, on the other hand, it profoundly alters children’s corporealities and subjectivities in myriad ways. As we will see after hematologists, children, and families often have different perspectives in relation to this first month of treatment.

The key role of the laboratory in relation to the daily clinical check-up

Every early morning when children come to the HU they first need to announce himself or herself to the secretary and then see a technician who would take a blood sample. After the blood sample has been taken children and caregivers would wait on the big waiting room for some time. Then, after 9 am, staff clinicians and/or fellows from the HU would perform a clinical check-up. With the information from blood samples and check-ups, hematologists, clinicians, and fellows usually have two meetings at mid-morning and at noon to decide how to proceed with each specific case. The clinical check-up is crucial for the hematologists because they can compare what the blood test “says” and what they are able to “see” and to talk with children and their caregivers.

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49 Among others: 1. Child’s age at the time of diagnosis; 2. Total number of white blood cells, red blood cells, and/or platelets in the blood at the time of diagnosis; 3. If the hematological condition is primary of secondary to another cancer; 4. The morphologic, genetic and immunological subtype; 5. Cytogenetics: chromosomal translocations; 6. If the child has Down syndrome; 7. Child’s response to the first month of treatment; 8. If the hematological condition is just diagnosed or if it has relapsed; 9. The time that passed between the end of treatment and the relapse of the disease; 10. Child’s gender (females tend to do better than males); and 11. If the disease has spread to the central nervous system (CNS) or not.
There is this constant relationship between looking at children clinically in the follow-ups or when they are hospitalized in different wards and “microscopically” at the laboratory. Hematologists are revising and fine-tuning their tests results vis-à-vis their clinical assessments all the time. There is a fluid connection between diagnostic tools and therapeutic interventions and hematologists rely on this to spot not only the expansion or shrinking of the particular hematological condition each child experience, but also potential signs of infections and other sorts of complications that may arise in the very near future. For hematologists this fine-tuning is constant, non-stop, and so they are often upset when others (i.e. communicable diseases specialists) do not “throw everything they have” to contain the emergence of unexpected conditions such as bacterial infection (the most common unwanted effects of chemotherapy treatments).

The majority of the tests needed to diagnose hematological conditions were done within the Hospital Infantil either at the Hematology Unit’s Labs or at the Central Laboratory within the hospital. Seldom certain key analyses were done in other hospitals within the City of Buenos Aires network of Public Hospitals. Some times these tests took a while and I frequently saw how the Hematology Team had to either push and lobby it (for instance, the Head of Hematology had to talk directly with director of the other hospital) or persuade the hospital to start doing these tests at the own hospital lab. One example is the test for dosage of FK for tacrolimus (immunosuppressive drug), which is done to determine whether the concentration has reached a therapeutic level and is below the toxic threshold (it can affect liver, heart and kidney among other organs). At one point instead of waiting for others to do the test the Hematology Unit successfully lobbied to the Hospital Infantil to do it in their own lab (some of these tests are very expensive).
Labs provide two types of tests: routine, daily blood count samples and extraordinary tests such as those oriented to identify the subtype of leukemia a particular child has for instance, if it is an acute lymphoblastic leukemia (B-cell, T-cell, precursor B-cell) or by identifying specific antigens that are expressed in the surface of the cell (for instance, CD3, CD5 and CD7 in T-cell; CD10 in precursor B-cell). This particularization of each subtype of leukemia is crucial for the hematologists since it gives a more precise diagnosis and, therefore, a more targeted treatment. And these precise diagnostic procedures are constantly evolving. In fact, hematologists told me that even in 2005 it was a totally different world in relation to their capacity to diagnose (and treat) particular sub-types of hematological conditions. In this way, the laboratory plays a fundamental role for hematologists because it gives another essential layer of information beyond what they can “see” in their clinical check-up. Particularly, during the intensification / consolidation phase (when children tend to be less hospitalized) the laboratory results give them a “deeper” perspective beyond what they can see clinically during the check-up (and it can help hematologists to “foresee” potential therapeutic pitfalls). Therefore, every day when a child and the family come to the hospital for chemotherapy hematologists, after the follow-up and the lab tests, have to decide if children can go back home or not. After each chemotherapy session hematologists need to know either if the child needs blood or platelet transfusion, or if they may need to stay hospitalized given their unstable clinical status, or if they are safe to go back home until the next session. As I already noted, hematologists have to be very careful to try to foresee any potential unwanted effect of treatment (infection or other complications). They know that during a specific block of chemotherapy cycle children’s

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50 The precise diagnosis, its potential prognosis, and the percentage of “survival without illness” can widely vary between different subtypes of leukemia, even within the “same” kind of leukemia.
immune system will be seriously compromised and they try to advice children, families, and other professionals on those wards in which children are hospitalized (who might be less aware of the chemotherapy side effects) that in the following X days, as one hematologist once said, “Everyone should be over-precautious with Federico because things could get complicated quickly, I mean really quick.” Therefore, in many ways, the laboratory not only helps hematologists to understand how the treatment is working with each child but also to anticipate some of the potential future(s).

In addition, the laboratory plays an important role on the constant fragmentation and re-composition of children’s bodies since blood has the capacity to “reveal the truth” (Carsten 2013). In what follows I show a description of two post-basic medical residents looking at a bone marrow smear at the microscope (just taken the same day through a bone marrow aspiration). In this case, hematologists were counting lymphoblasts or ‘blasts’ (enlarged immature cells) in hematological everyday language. By looking at these samples (extracted under painful and stressful circumstances) hematologists are able to see microscopically (some of the) ‘stories’ told by children’s bodies, particularly their bone marrows. Therefore, clinical check-ups and laboratory tests are two sides of the same clinical gaze (Foucault 1976) that tries to objectively see the (in)visible. It is very interesting to see how these two fellows were learning to look at María’s body microscopically. This specific site of assembly informs hematologists on what is going on at María’s body “internally,” at the molecular level, and both the act of extracting samples from children’s bodies and reading them have to be carefully learned:

One day I was with two medical fellows at the Hematology Unit Lab observing María’s bone marrow sample through the microscope. María is an eight-year old girl with chronic myelogenous leukemia (a kind of leukemia that only rarely appears in children). She lives in the Province of Buenos Aires and was taken care by her mother (the rest of the family was in their home town). Gloria and Julia were looking at the same sample using a double-lens microscope so both could see it at once:
Gabriela: What is this moving thing? Move! Come on move! … That’s a super-myeloid!
Julia: This is a little erythroid cluster.
Gabriela: Yes.
Julia: There are lympho[blast]s, there are two, it’s ugly the one here to the left, there are two erythroids over there…
Gabriela: I don’t see a damn thing…
Rafael [Seating next to them but not looking through the microscope]: Can you clearly differentiate them?
Julia: There are cells that are shared in each field, but yes…
Gabriela: Wow, very nice, I love it…
Rafael: In this case genetics plays a key role in María’s condition?
Julia: Yes, because we know that she has a 9/22 chromosomal translocation. Since 2000 we have been treating children with targeted therapies such as imatinib [TK inhibitor targeted drug] with very good results.
Gabriela: We count 10 blasts, 27 lymphos, 61 erythroids, and the rest myeloid.

Julia and Gabriela had a microscopic picture of how affected (or not) was Maria’s bone marrow, and, I would add, as a consequence, her whole life.

**Chemotherapy protocols**

In the everyday hematological discourse used by hematologists at the HU, when hematologists attempt to explain what they do, they often use gardening-like imageries of hematological diseases seen as weeds that have to be eradicated from the beautiful flower garden (bone marrow). Thus, no traces of even the smallest weed seeds (malignant cells) should be left, and, then, the garden should be kept clean and free of weeds as longer as possible. Hematologists at the Hospital Infantil often used these images when explaining the illness to children and families. Muriel from the Hematology Team once told me,

> Every medical specialty has its own way of communicating ideas to patients and families. I often use the image of the body as a field that has weeds and we need to spray it with special chemicals that can cut them and prevent them to grow again. When you saw me yesterday talking with Mariana we did not have the diagnosis and I did not know how to explain to her that and I saw a jug with flowers and the idea of the field popped to my
mind. Many times you are not so conscious of the images you use and how you explain the situation.\textsuperscript{51}

The HU follow chemotherapy protocols developed by the GATLA (Argentine Group for the Treatment of Acute Leukemia). The different protocols hematologists use were often not fully discussed with families since they are a technical description of lists of drugs, its combination, the doses, the phase in which are given (intensification, consolidation or maintenance), the number of cycles and for how many weeks or months should be given. In fact, not even hematologists themselves know them by heart and had to check them.\textsuperscript{52}

What doctors transmit to parents, children, and other family members in relation to the particular type of protocol they use with their children is very important. I was present in some instances in which caregivers were asking hematologists about the kinds of cancer treatment their children received. I also asked hematologists what kinds of information concerning each chemotherapy protocol they have discussed with caregivers. They often told me this information is very technical and some parents more than others were willing to ask about it. Similarly to what delVecchio Good et al. (1990) saw in the U.S. context about oncologists’ management of hope usually when I was present hematologists at this clinical setting would tell parents they will slowly explain the different therapeutic stages, and they would ask parents to focus on “one step at a time.” This shows there is a slow digestive process not only of medical information for caregivers but also of how to handle uncertainties (Alonso 2013). In many ways it is important that cancer professionals be aware of how to communicate about children’s prognosis (Bluebond-Langner et al. 2010), but this communicative process is often conceptualized from the

\textsuperscript{51} See, for instance, Jankovic et al. (1994) for an example of this hematological discourse.
\textsuperscript{52} They have some binders with all the different protocols they are currently following and those they have been following throughout the years at their office. Hematologists go and check whenever they have doubts about the different phases, cycles, or blocks each protocol entitles and specific doses of particular drugs.
point of view that everyone wants to know; which is not always the case. In fact, as one mother
told me, parents in some instances choose not to know, because,

You do not want to know, because sometimes one rolls down the curtain and, no matter
how much they talk to you, you don’t want to listen and you don’t remember anything, as
if everything passes beside or through you.

Still, in general, after a while, throughout the months of treatment and the many
explanations by the hematologists and other professionals, and exchange of information with
other parents, caregivers (and even small children) have some knowledge of the different phases
and the different drugs that are being poured into their children’s bodies during the different
phases and cycles of the chemotherapy treatment. As Lisandro, the head of HU, told me “a
patient absolutely knows what he has, he is the one taking all the drugs everyday.”

Children depending on their age will quickly learn to recognize the different
chemotherapy drugs just by looking at the color, name, or the amount of liquid at the IV bag
hung on the IV pole. Mariana, one of the hematologists told me that before some of the
randomized treatments were called as “experimental protocol” but parents “they talk to each
other all the time, they exchange information, they send texts [phone messages] all the time, and
if we call something as ‘experimental’ this could have implied we were experimenting on their
children and it wasn’t like that.” In fact, Mariana added, “we have to be very careful with the
terminology we use [with the parents], so when we realized that we started to call it as ‘protocol
1b’.”

Some clarification should be made about parents’ notion (and often fear) that
hematologists may be experimenting with their children (or, that they do not quite know how
treatment may work for their particular child). One thing that hematologists (and, with
differences, children and parents as well) are acutely aware is the need to avoid over- or under-
treatment of children. Both can have long-term consequences. Though, this is a very complex issue since where, when, and how to measure the exact ‘right’ treatment becomes a crucial problem. And, how parents may understand what the ‘right’ treatment is when what they often see are unwanted side effects? When discussing about the beginning of the multi-drugs treatment in 1960s Mukherjee (2010:143) says, “But chemotherapy was poison even at the correct dose” and then he adds a footnote that says,

Since most of the early anticancer drugs were cytotoxic–cell-killing–the threshold between a therapeutic (cancer-killing) dose and a toxic dose was extremely narrow. Many of the drugs had to be very carefully dosed to avoid unwarranted but inextricably linked toxicity.

Although a lot has indeed changed in the world of cancer clinical research still this question is very much present when looking at what hematologists do and how children and family members perceive and try to understand what is going on within children’s bodies and what is done to children’s bodies. In fact, we could also look at what families search and do in relation to “non- or less-toxic therapies” (less invasive) often associated with complementary medical approaches. But this would lead us to a completely different direction. Biomedicine in general and hematology in particular has a predominantly biological approach and thus malignant cells growth has to be stopped as soon as possible and this would also impact the healthy cells too. (Although, there is a constant research within biomedicine to try to find more targeted treatment that would only affect malignant cells.) But everything that is out of the “scientific method” is seen with certain disdain. However, it seemed to me during my research that health professionals are increasingly aware that parents and families look for any therapy that may help their children within and outside the biomedical realm. Thus, in many instances, I heard hematologists, communicable diseases professionals, and palliativists telling children and family members that if those things they were doing outside their treatment did not interfere with
their biomedical treatments they were fine with it. Although there are also constant tensions between different professionals about the interaction of particular medications and how they may be affecting children’s overall treatment. One recurrent example is the management of minerals such magnesium or potassium, which are drastically affected by chemotherapy. Very often, children have to take enormous amount of these minerals per day, they are often poorly absorbed by children’s damaged bodies. I heard cases of families giving alternative medicine to children to boost these minerals in the blood.

For all these reasons, children and family members often complain that in fact what are making them worse is the treatment and not the disease (they feel more the treatment than the objective signs of the disease), and this is an important issue that should not be avoided or rejected as mere “lay knowledge” or “false ideas.” Besides the communication difficulties that different health professionals may face with children and family members when people think that the medicine (the particular chemotherapy treatment) is worse than the illness we have to pay close attention at what is being said, who is saying it, and why they are saying it. Indeed, there are myriad changes in the relationship between children, families, and hematologists throughout their long treatments (this is not a linear relationship). And those changes are influenced by the different phases of treatment hematologists propose to, ask to adhere, and, are ultimately negotiated between children and family members who are deciding for their children’s best interests. But let’s focus on vital role of the CDU since when children living with hematological cancers have to be hospitalized this unit will become critical.
The Communicable Diseases Unit

The main work of the CDU is to diagnose, treat, and manage communicable diseases, particularly infections, its antibiotics treatment and its complications, and the psychological and social support to children and their families. The CDU is located in separate ward on a second and third floor of a long building. On the second floor there are sixteen individual and isolated rooms for patients, at the end of the corridor there is the residents’ office, at the middle of the corridor there is the nurses’ station where they prepare all the medication for children, and there is also the staff’s office. On the third floor there are more offices, one for the head of the unit and a conference room.

When hematologists need to look for clinical units to hospitalize their patients in isolated rooms the CDU is usually the first place to look for beds. As I showed with HU in relation to the centrality of both the waiting room and the “Day Hospital”, when looking at the CDU the key place of socialization for children and families is the individual, isolated room. Children and caregivers spend days, weeks, and even months in those rooms. In fact, when hospitalized for long time children often customize their rooms with drawings, pictures, toys, etc. When I was conducting fieldwork at the Palliative Care Team I followed two artists who were working with the team and was able to observe the positive effects painting and drawing had on children (and even caregivers). One difference with other medical institutions is that the Hospital Infantil is often more friendly and permissive. In other public pediatric hospitals often children are not allowed to hang their drawings or paints, or make their rooms feel a bit like home. Indeed, in some hospitals the room has to stay completely empty. Norma, a former head of the Communicable Diseases Unit, when comparing the Hospital Infantil with the national pediatric

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53 Personal communication with Maria Laura Requena who did fieldwork in the Palliative Care Unit at a Province of Buenos Aires Pediatric Hospital, July 2013.
hospital (there is always some rivalry between the two) explains this particular commitment in this way:

We have the first pediatric residency of this country, the one with highest scientific level. This is the hospital that publishes more, and there is a big commitment (…) a special commitment, something we don’t see if we compare with other pediatric hospitals, I am not underestimating other institutions, they have their [kinds of] commitment but ours is a very pragmatic [commitment] whereas the Hospital Z. it’s a bit more scientific, more organicist, but the feeling of love, members of the Hospital Z. say that, maybe these walls are filled with affection….

Norma was referring to this particular kind of commitment, one that according to her goes back to the very beginning of the Hospital Infantil (the first pediatric institution in the country) or to the major revolutionary changes proposed by renown pediatricians like Dr. Escardo (at the same CDU in which I conducted fieldwork) who in the 1950s in order to combat “hospitalism” created the reform that allowed to hospitalize children with their mothers in the same room (before they were only allowed to see your children two hours per day).

The CDU plays a vital role in these relationships between children-professionals-families; they provide a helping hand to the Hematology Team by hospitalizing their patients and by aiming to eradicate infections from children’s bodies. Children living with cancer are often living in an endless immunocompromised state and so they can become potential hosts of countless infectious diseases (even, less likely though, transmitted through blood transfusions). Yet, since hematologists are in charge of the hematological treatment, they are aware of the different phases of the chemotherapy treatment and how each child’s organism would probably react through highs and lows of the immune system (often more lows than highs). Indeed, hematologists manage a different set of “urgencies” than communicable diseases professionals (generally those in charge of children with infections), children or parents. Hematologists at the Hospital Infantil would probably agree with Mukherjee (2010:139) when he says, “For a child
with leukemia, even a week’s delay meant the difference between life and death.” Mariana, a hematologist told me that often the rest of the hospital does not understand why they push children sometimes a bit more and decide to continue with another cycle of chemotherapy even when children seem to be less prepared for it:

   It is hard to take that decision but sometimes it is the only option [the child has] to live, and often the rest of the hospital look at us from their side as if we are mad, that we largamos (release) chemotherapy… chemotherapy bombs to children that are not in a condition [to handle it] but we saw children that salen (overcome) fine and go to school, and then come with their own children…

   This urgent need to largar (“release”) chemotherapy treatments is often poorly understood by other specialists outside the HU. But the fact is that many children are hospitalized from the beginning of treatment for many reasons (“debut”, induction, re-induction, relapse, etc.) but there is a delicate balance for hematologists between holding treatment to recover children and keep going with chemotherapy to achieve finish treatments and achieve full remission.

   On the other hand, communicable diseases professionals are more focused on controlling infections and thus they manage a different therapeutic temporality and set of “urgencies” (and often these divergent time handling provokes clashes between these two types of professionals). In a way these alarms make children and families over-cautious and hyper-alert with children bodies and the urgent need to avoid infections at all costs.

   Usually during this first month children are hospitalized at one of the two Communicable Diseases Units. At this point they may not develop any infection but they will likely soon, so very often staff from the CDU would alert caregivers to be ready to come as soon as they see something is wrong with their children. Norma, a former head of the Communicable Diseases Unit, once narrated how they begin this relationship with children and caregivers:
In the first contact we give an alert, we tell them, “Well, now you are doing everything with the hematology team, but it is likely that we will see you again, because they will leave your children with no defenses. So if they have fever it is an urgency.” We explain that and we give some information to prevent infections. Then, they start coming, again and again, and so we begin a less formal relationship. I remember that more than one mother would call me by my name. We would have a close, affectionate relationship. We would be nearby, we would not distance them, but get closer with them.

Children’s intimate relationships with medical residents at the CDU

Many health professionals interact with children living with hematological cancer. One of the professionals that often create intense forms of interaction with children, especially during long hospitalizations, are the medical residents at the CDU. According to the division of labour and the dynamics of the CDU when children are hospitalized in one of the sixteen individual, isolated rooms second-year residents will be in charge (with the support of fourth-year residents, head of residents and staff) of two or three children and so they would constantly be nearby them. Within the structure of the hospital medical residents are the dynamos that sustain the immense everyday load of work at the Hospital Infantil. Second-year, fourth-year and head of residents (fifth-year) at the CDU were the ones that knew the children and their families more intimately, especially those children and families that had to stay hospitalized for a long stretch of time. In many ways these medical residents, especially the second-year residents who were in charge of children and had to take the weekly (often bi-weekly) night rounds, had a first-hand, direct knowledge of the specificities, needs, and personalities of each child (and his or her caregiver). During the night the medical staffs in charge of the whole hospital are those who work at the Emergency Room. They often do two “grand rounds” (at the beginning and end of the night-shift) and check with the medical residents in charge of each unit how are patients doing, especially those that are in

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54 I can only talk about those residents I worked with at the Communicable Diseases Unit (I also indirectly observed others in other units but no systematically).
critical situation. Besides this brief contact with staff second-year residents during the night are alone in charge of very complex patients.\textsuperscript{55} Indeed, I was able to observe clear effects of these intense relationships when children were hospitalized for longer periods (weeks, months) of time. In the everydayness of their encounters they knit their medicalized relationships.

For children and parents, medical residents at the CDU showed a special kind of commitment. They are in charge of children with hematological conditions and responsible for their everyday treatment (tests, medications, procedures, etc.) to prevent and cure children’s infections. This makes them important members along with Hematology fellows of the teams that care for each of the children. What makes the Argentine case special is that medical residents (second-year, fourth-year and head of residents) are at the center of these daily hectic activities in children’s care. Each second-year resident is in charge of two or three patients, then fourth-year residents assist the second-year residents and the head of residents is in charge of all the residents of the unit. They are responsible for everything from blood extraction to filling medical records, from presenting patients to the whole unit at the beginning of day to taking children to do some tests or images at another unit within the \textit{Hospital Infantil}, from talking with children and parents about what will happen next to dealing with hematologists and other specialists, from asking a referral to palliative care when they see children with pain to managing a sudden sepsis crisis before quickly rushing them to PICU.

\textsuperscript{55} Medical residents in Argentina work in very difficult conditions. They are often drained by the long work hours, and especially second-year residents, the many night shifts they do per week. On a recent survey of 300 medical residents at the City of Buenos Aires public hospitals 67\% of residents had worked non-stop between 35 and 40 hours and up to 64 hours per week, 79\% said that they do not have a free day after their night shift, 90\% of residents went to work when ill, 80\% of residents experienced violence at work, and 98\% of residents believe that the “Residents’ Law” that regulate their work is not respected (\url{http://nueva-ciudad.com.ar/preocupa-la-salud-de-los-medicos-residentes-de-la-ciudad/}); assessed 28082015.
Medical residents are constantly moving and their workdays are endless. Medical residents, especially second-year residents, need to learn quickly about infections and how to treat them with a broad spectrum of antibiotics, how to foresee infections and spot almost imperceptible clues, how to look for *focos profundos de infección* (“deeper focus of infections”) and what to do when they need to quickly *expandir* (“expand”, give lots of fluids) children’s bodies in the event of septic shock. As we see these two notions are very much related with idioms of permeability.

As, Ricardo, one the head residents put it, this unit is a very difficult place to rotate within the *Hospital Infantil* not only because of the kinds of patients (and families) they would interact with but also because they are constantly being physically and emotionally loaded with “stuff.” He said:

This unit is very particular. You will see residents crying or laughing hysterically [at the residents’ room]. The residents’ room is a place where residents come and unload their stuff, they need to handle a lot of social issues that are beyond them, and so they feel impotent and anguished. It is not an easy rotation in this unit because of the emotional load; only few want to do an elective rotation here [after their mandatory second-year rotation]. To me this unit and PICU are the most difficult places in the *Hospital Infantil*.

Ricardo’s feeling that the CDU is one of the most difficult places in the *Hospital Infantil* echoes other medical residents. Not only do they have to assist children living with oncologocial and hematological cancers, they also assist children with other potentially life-threatening conditions as well. Also they cannot avoid these difficult situations and have the time to unload this emotional “stuff.” Indeed, some of the most difficult children they assisted while I was conducting fieldwork were children with both solid tumors and hematological cancers. At this unit second-year residents experienced children getting sicker, due to their hematological conditions and its treatments. They watched as children *se incendian* (“burn”) and *se hacen pelota* (“break down”) very quickly as Julio a second-year resident once told me. An example of
children that in the communicable diseases jargon “burn” is Mariana’s case. Mariana is a twelve-year old girl living with acute lymphoblastic leukemia who had been hospitalized for a persistent infection at the CDU during her consolidation phase. One night at 8:00 pm she had a reaction to a fungicide and developed a pick of fever (38º) for two hours and then had temperature until 1:00 am. She received seven liters of fluids, then lost four liters and gained three kilograms. She was urinating fine and had no edema. She had vaginal bleeding and so she had platelets transfusion (she had only 19 000). When staff and residents were discussing about Mariana, Amanda, one of the staff said,

Amanda: With Mariana everything is complicated because all the time new things keep popping up, if we knew the catheter was the direct cause of her sepsis we would have taken it right away, but she always has other infectious foci, like her perianal, and also she has fever, so it is not easy to decide to take the catheter away. Also because then we need to insert another one…

Claudia (2-year resident): The thing is that this girl quema (burns).

Amanda: She is quemando (burning) all the time. Karina, Mariana, they are two bombas (bombs), and besides you cannot run in front of them, you always come from behind, because everything is complicated, they have 20 days of neutropenia [low number of neutrophils].

Residents, especially second-year residents, are often the first frontline of the CDU.

When children with highly compromised immune systems end up experiencing all sorts of crisis up to the point of full body failures they would be the first to manage these crises (expanding children with lots of fluids and transferring them as soon as possible to the PICU). I once observed how a second-year resident, with the help of two other residents, had to give four fluid expansions in her bed at the CDU to Anabelle a nine-year old girl from the northern west part of Argentina diagnosed with acute myeloid leukemia (M2–with maturation–). They had to wait to transfer her to the PICU (it took the PICU some time to prepare a bed for her). Anabelle had received platelet transfusions the days before but she had started the night before with temperature (38.6), shivering, and hypertension. So they did one fluid expansion and began antibiotics. She was fine but by 8:00 am she had fever again and hypertension and began
deteriorating very rapidly. By 10:00 am the resident in charge of Anabelle had already done four expansions and, after she was stabilized, took some more blood tests for the PICU. When I was at the residents’ office, Marina, another second-year resident entered and said,

How did this girl *enchotó* (break up) so much! She is so edematized. Her eyes are all swollen, she was crying. The PICU is still preparing a bed for her. She was an outpatient, she already had four cycles of chemo and now she is going to PICU…

I had known Anabelle and her mother from the first time they came to the hospital five months before this crisis. When she was hospitalized for the “debut” and during the induction she had twenty days of constipation (she had started her treatment back in her own province with morphine for her pain and that could have caused her constipation) and also was under several antibiotics for a typhlitis (inflammation of cecum [part of large intestine]). At that time, I was conducting research with the Palliative team and they were referred to her because of her pain and constipation. Anabelle’s case shows the entanglements of different specializations dealing with her leukemia (hematologists, pallitivists, communicable diseases specialists), the side effects of her treatment, and the several hospitalizations during the different phases of chemotherapy. Yet, it also highlights the centrality and intimate relationship children hospitalized within the CDU create with the medical residents in charge of them.

It is not a minor issue that medical residents are learning to become a pediatrician, they are in a constant state of becoming. For instance, when rotating for three months at the CDU as a second-year resident, besides their previous knowledge, they have to quickly learn about communicable diseases and its management. In many ways they are in-between the CDU and HU staff (and in-between hematological and communicable diseases treatments). Mariana, a fellow from the HU, told me in an interview how CDU and HU usually work fine when children are doing OK but with children with complications tensions between the units arise,
…they see [patients] from a communicable diseases approach, they see bacteria, etc., but they don’t see [them] in relation to our treatment. So we talk more about our treatment. And the thing is that Fiona, Muriel, Susana they have a lot of experience, they saw a lot of children getting infected. Children that get hospitalized are the few, but you see them after the hospitalization, and you see their medical evolution, but 2nd, 3rd, 4th year residents they don’t have this experience. And they are the ones that take the majority of the decisions, of course with [the approval of] staff doctors, but a lot of time they [residents] take the decisions. Of course, it depends if they are alone, or with the staff doctors, or night round… In many ways residents are very vulnerable when dealing with critical patients.

Thus, medical residents in general, but particularly second-year residents who only one year earlier were at medical schools, have to navigate these extremely taxing clinical environments and have to learn to manage critical patients while experiencing very vulnerable situations. During my fieldwork within the first week of the three-month rotation three children living with cancer (two solid and one liquid) had to be transferred to the Pediatric Intensive Care Unit because of medical complications. Susana, a second-year resident, told me “On my previous year as first-year resident at this hospital I saw three cases of septic shock, and here [at the CDU] I saw four cases in three days!” Sometimes they would even experience for the first time the physical-emotional-intellectual demanding experience of a child living the end-of-life.

Silvia, another second-year resident told me,

Here children se hacen mierda (“get screwed”) very quickly because they are in bad shape, they enter walking but then they have no defense and everything they catch los hace mierda (“fucks them up”); a common flu for a regular kid is a pneumonia for these children.

Precisely because very often they are in “bad shape” children and families learn that children’s bodies are constantly under surveillance. Given children’s whole organism unstable balance almost every bodily aspect of their lives is measured to track the progress/retreat of the

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56 This is not representative of a specific kind of risk but it shows the borderline zone in which both children’s bodies and those directly assisting them (second-year residents) are often placed: the thin threshold between “getting screwed” or not “getting screwed.”
disease(s) (for instance, fluid balance). Indeed, not only their bodies but also their byproducts are carefully watched. In many occasions I heard how residents where constantly checking about keeping their children’s urine for tests, Catalina a medical resident once opened the door of one room while running to do things and said to one mother “Hello, mother, please, remember to keep your son’s pee; don’t throw it, we need to have a bit more to do a test” and she closed the door and kept rushing to the nurse’s office. This is common stuff for families. Children’s whole bodies and its byproduct are carefully watched under several clinical gazes (hematology, communicable diseases, palliative care). And this not only creates a certain “intimacy” but also a more fluid relationship among children, parents, and medical residents.

In addition, because of the real risks of children suddenly hacerse mierda (“getting screwed”) medical residents need to be constantly alert around these children. Children with compromised immune systems live in a very delicate state. Every day when the head of residents and fourth-year residents are finishing their day of work at around 6:00 pm they would go over all the cases. They asked the second-year residents, who usually stay longer, especially the one doing the night rounds, what to do in case a child develops fever or other symptoms. Typically, they would have patients’ evaluation at the end of the day like this one:

Manuela (10 y/o with AML):
Doing Chemo (Ara-C and Mitoxantrone)
Good aspect, good breathing
Yesterday: Sepsis (Meropenem and Vancomycin [antibiotics])
Cultures: Negative
244 000 platelet
See when she’ll do a lumbar puncture
If she develops low fever, do nothing, if she has sepsis do a culture of everything (semi-implanted port needs to be locked again)

Medical residents at the CDU have to be hyper-alert as they constantly move between looking at the surface of children’s bodies and looking for focos infecciosos profundos (“deeper
focus of infections”). In this case communicable diseases physicians manage a different set of alarms than hematologists (I will come back to this later).

During long hospitalizations more intense bonding relationships were built between residents, children, and families. Tamara, a head of residents, once told me that as a second-year resident at the CDU:

Just half way trough my rotation one of my patient died, I had swapped her with Norman (another resident) because it was like my sister that girl. When I saw that I was losing perspective with her… One day I had to prick her to extract blood and I could not do it, I almost cried in front of her, so I said to myself, “OK. This is my limit.” I kept accompanying her and her parents but as a doctor I could not take it. I was not emotionally prepared for that…

Tamara shows how permeable she became to this particular child (she was “like her sister”), how her own corporeality/subjectivity was imbued by the connection with this child, and how she realized she had lost her ‘objectivity’ with her (also note how she called the child “my patient”). Yet, given the intense, intimate relationships medical residents build with children and families they often become the main reference within the hospital for many families throughout treatment (even when residents have long finished their rotation at the CDU). After some time, they become like their “main pediatrician,” the one to ask about medical issues. Tamara said,

You already know them, and you know which veins they still have accessible for pricking. And they know you; they know who can extract blood better or not, who plays with them, to whom they can ask certain things… Each child has its own personality. For instance, there was a girl who liked that Norman (another second-year resident) talked to her, but she did not want him to prick her at all. And this is because there is a relationship, they know you and you know them.

Indeed, I was able to observe that when “their” residents were gone (at the end of their three months rotation, usually moving to another unit within the hospital) some children suddenly got worse. Of course, it is hard to correlate this. Yet, it is a radical change for someone that has been hospitalized for weeks or months to start a new relationship all over again with a
new resident that does not know him or her, does not know what he or she needs or dislikes. For instance, at the final day of one of the rotations at the CDU, when everyone was having some food and chatting at the Residents’ Office when, all of sudden one girl that was hospitalized for two months for an infection (her main diagnosis was an acute lymphoblastic leukemia) got a major septic crisis and was transferred to the Pediatric Intensive Care Unit. By coincidence (or not) some of the residents that treated her during that time were going to start rotating the next day at the PICU. This was not a single case I was able to observe. Of course, we cannot generalize this but in some ways it shows some of the experiences children go through and how children’s bodies are both absorbing and affecting particular social relationships at this clinical setting. In many ways the relationship children living with hematological conditions build with their key medical residents at the CDU show the kinds of connections and the intensity of their mutual permeability. But these connections are built on general ideas of what is the children’s basic nature.

**Four key moments during chemotherapy treatment**

**Becoming an object of medical practice**

A child with a hematological condition who presents for a medical appointment at the Oncology-Hematology Unit arrives with her family early in the morning, usually at 7:30 am (often families come even earlier), to be ready for blood tests. To be on time, families have to get up very early and the majority of them will use all types of public transportation. They arrive at the unit and give their child’s name to the receptionist, and then sit in a large waiting room (or, if it is busy stay standing, or sit in the stairs) with chairs facing the entrance and a big television that is always on. The receptionist informs the medical professionals of the Unit how many children
who had appointments for that day actually came. After 8:00 am, a technician or nurse calls each in turn, so she can take some blood. Families often wait for hours until a doctor calls them by their child’s name and surname, and asks them to enter a cubicle for an examination. At the time when I was conducting fieldwork the hematologists used to see between twenty and thirty children per day, sometimes more, at their own unit; but they also saw children with hematological conditions hospitalized in other units. If the blood test and the examination indicate that there is nothing to worry about, the clinicians and hematologists, after they discuss the case, will either advise the family to come back for another check-up, or to go to the ‘Day Hospital’ for chemotherapy if that was planned for that day. This will depend on the exact moment of each child’s treatment during the major hematological phases. If the child appears to be deteriorating, they may seek permission to do a blood transfusion or to hospitalize the child for some time. Without any further guidance, children and their families have to work out how to move and dwell within this pre-arranged and ‘othering’ medical territory (Johnson et al. 2004).

From the first time that children and their families come to the hospital, they begin the gradual and cumulative process of familiarization with an alien and often-hostile environment. This ‘other space’ becomes internalized over the weeks and months and the many hospitalizations children may experience. Children and families need to understand quickly the logic by which this ‘foreign land’ is organized.

How children’s bodies become an object of medical intervention and permeation is a process of biomedical objectification. In Presence in the Flesh (1997), Katherine Young argues that it is crucial to understand the process by which a body becomes a medical object, premised on health professionals’ need to get access to a corporeality that is seen as Other. The instances in which health professionals attempt to get access to Other Bodies are crucial. Young focuses on
the various structures and frontiers, such as waiting rooms, beds, surgery rooms, offices, desks, tables and chairs, through which the body is instructed and located as a medical object. Space and time in medical practice help turn the self into an object, or person into patient. Young describes the transformation that occurs when a subject enters into a waiting room, when she gives her name to a receptionist (a ‘guardian’ of the realm of medicine [1997:13]). Each movement in which the subject is located is followed by certain spatial normalizing attributes, such as particular locations, arrangement of space, control of flows of people, and so on. I observed the same spatial composition occur at the Hospital Infantil. Professionals learn to make others’ bodies legible, that is, how to objectify other’s bodies. Good (1994) has shown how often physicians learn to see cancer patients not as full persons embedded in families and communities but instead they see them at the levels of organs, cells, and molecules.

Let me give an example, taken from my field notes, of this inter-relationship between the body’s (im)permeability and the transformation of subjectivity through the objectification of bodies. This particular case follows Ulysses, a six-year old boy who comes with his mother, Martha, to the Hematology Unit for a lumbar puncture (done to obtain cerebrospinal fluid by introducing a needle usually between the fourth and fifth lumbar vertebrae) to be performed by one of the medical post-residents at the unit. This is a method used to confirm that there are no traces of the diseases at the level of cerebrospinal fluid.\textsuperscript{57} The Procedure Rooms are located on the second floor of the Oncology-Hematology Unit above the consultations rooms, the large waiting room, and the Day Hospital in which children receive chemotherapy and blood

\textsuperscript{57} In this particular case, it was done as both diagnostic and therapeutic. When done as a diagnostic tool the aim is to take a sample of the cerebrospinal fluid to confirm the absence (or not) of malignant cells, which could not be done any other way. In some cases, after the aspiration, hematologists inject chemotherapy into the cerebrospinal fluid. See following note below.
transfusions. There are in total three rooms and a bathroom. Two rooms are used as waiting rooms before and after the procedures, their TVs are always on, and one has beds with a 45° backwards inclination for chemotherapy drugs administration.\textsuperscript{58} The Procedure Room is almost empty: it has a big stretcher, a chair next to it, oxygen masks connected to the oxygen-centralized system, a table, a glass storage unit with some medicine, gauze, catheters and syringes, and other implements. There is also a bar with a sink, a collection of syringes, needles, tubes, and procedure kits (packs with gloves, gown, gauze, and a piece of cloth with an opening to be used during the procedure).

The fellow Denise is waiting for Gerardo the nurse. Gerardo is late and she is getting a little bit upset. To get ready, Denise cleans her hands with soap. She then covers her hair with a net cloth, puts on a white disposable gown, and disposable gloves. Since Gerardo is late, Denise asks me to help her with the prep. She asks me to look for specific needles, open the plastic wrap without touching the interior, and she then takes it and puts it on the tray with the procedure kit she has already opened with care (from the inside out). Denise takes the tray and puts it down on the table next to the stretcher and her chair. She prepares the chemotherapy drugs she will inject after she performs the lumbar puncture. Finally, Gerardo comes; he says that he was trying to introduce the IV to the next patient. Denise goes out and calls for Ulysses and Martha. Ulysses is the first child to have a procedure today and he arrived early in the morning. By this time, mid-morning, he is becoming anxious and very hungry. He is still fasting, which is needed for the lumbar puncture (LP) and bone marrow aspiration (BMA), and he is losing his patience. Ulysses’

\textsuperscript{58} The 45° inclination lets the chemotherapy sink into the head when it is introduced through the cerebrospinal fluid to “protect the nervous system,” as one medical resident explained to me. In some cases, when hematologists need chemotherapy to reach the brain, they inject it through the cerebrospinal fluid since it cannot be done through IV therapy given the blood-brain barrier.
mother says to Denise and Gerardo, “you better hurry up, if not he will behave crazily.” Ulysses says, “I want to go mom, I want to go mom, and I want to eat.” His mother was holding his right hand tightly and caressing his hair. Ulysses enters the procedure room in a wheel chair with a pump and IV pole attached to it.

Gerardo then prepares the medication (sedatives and chemo) with Denise, telling jokes as he always does. When Ulysses enters the room Gerardo talks to the child and says he will give him medication to “make him sleep.” Ulysses is staring at his mother, who is holding him in her arms. Gerardo raises Ulysses to the stretcher and situates him with his back towards Denise, holding him with a lot of strength (sometimes doctors and parents complain that he uses too much strength). He grabs him from behind and curves Ulysses’ back, pushes his head towards his chest, and crosses his legs in meditation position. He grabs his arms and holds them tight. In this way, Ulysses’ back is concave, so that the vertebrae spread apart and there is enough space to introduce the long needle.

Denise then informs Ulysses that she is going to disinfect his back with something cold, and she is not going to prick him, although she adds, “when I will prick you, you will know.” Then, she takes two pieces of gauze with povidone-iodine topical antiseptics and disinfects Ulysses’ lower back. Gerard brings two syringes with Ketamine [anesthetic] and Midazolam [sedative] and injects them through the IV Ulysses has connected in his left arm. After some seconds, Ulysses starts laughing, and then falls asleep. Denise looks at Ulysses’ back and presses both sides above the iliac crests to check that the back is straight. Then, with her thumbnail, she marks the place where she will insert the needle. When she is marking with the thumbnail, Ulysses complains with a groan and Denise and Gerardo both repeat that they have not pricked him yet. Then, Denise introduces the big needle and Ulysses’ back starts to bleed. Denise takes
the needle out and throws it into the disposable container. She cleans Ulysses’ back with more povidone-iodine topical antiseptic; her gloves are spotted with blood in the process. Denise says she will try again. Ulysses complains and whines. He says he is having pain, and his mother says, “everything will be alright, we need to do this now, quickly, and then we can go back to the room and have breakfast.”

Denise checks again if the spine is correctly positioned, she marks the spot between the vertebrae, and introduces another needle (they always have more than one, just in case). This time, a transparent liquid (cerebrospinal fluid) first spurts and then runs slowly from Ulysses’ back. Denise quickly grabs a tube and fills it with liquid. She waits until it reaches the amount of liquid needed, approximately the width of two fingers. Little drops of blood continue to drip from the first unsuccessful try. Denise waits a bit more to fill the tube, drop by drop. Then she covers the tube, puts it on the table, grabs another syringe filled with Methotrexate [chemotherapy drug] and Dexamethasone [anti-inflammatory and immunosuppressant] and injects it to the spinal column. She takes the needle out and applies pressure to the area with clean gauze. Gerardo grabs a wide tape and covers the gauze very tightly, then adds two more layers of tape and asks Ulysses’ mother to keep putting pressure on the gauze to avoid bruising the place where the needles were introduced. Denise says to the mother that everything is done, and they can go to the room next door to rest until Ulysses is recovered. Then they can go back to his room at the unit in which he is hospitalized. Ulysses and his mother slowly leave the room.

The experience of children with hematological conditions is an endless process of formation of particular subjectivities from and through the body (a specific form of the medicalized body). Ulysses’ semi-conscious, hungry, in pain body is traversed via a syringe, its cerebrospinal fluid taken; his body-subjectivity is reshaped both at the interior and surface levels.
At the same time, instances like the one just described are a momentary interruption of the child’s capacity to decide how to use his body. Ulysses wants to leave the room and eat, but his mother and the doctors explain he has to stay and complete the procedure. Every day, there are similar instances where children, family members and health professionals find themselves in complex, stressful and very conflicting situations, when professionals try to permeate a child’s body in order to obtain fluids that will provide new and valuable information for fine-tuning their treatment (e.g. how the bone marrow or the cerebrospinal fluid “behave”). In these encounters, children and their family members let professionals permeate those bodies (although not without resistance, as Ulysses demonstrated), with the expectation of a move towards a cure, and, ultimately, towards a “life free of illness”, in spite of the fact that often there is a enormous discrepancy between the physician’s perception of the child’s pain and the parents’ or child’s perception of that same pain (Hilden et al. 2001:209).

The body of the child becomes the object of medical diagnosis and treatment through the use of particular procedures. As occurred for Ulysses, the child’s body becomes permeable by the action of the resident (Denise) and the aid of needles, catheters, and other tools. Children’s bodies are breached on a daily basis for the extraction of all sorts of samples, and sedatives and chemo and other drugs are introduced to the body. While these instances are not often as extreme as a lumbar puncture, in which a needle is inserted into the spine, or a bone marrow examination, in which an even larger large needle is introduced into the back of the hipbone, these daily micro-cases of (im)permeability are, cumulatively, of a similar hurting intensity.
Infections

Medical objects such as Portacaths, IVs, and syringes as well as viruses, bacteria, and fungi are central characters in these clinical dramas. From an Actor-Network-Theory approach these “non-human agents” have certain capacity to influence and affect (and be affected by) humans (Latour 1987, 2005). One the one hand, our relationships with medical objects show the increasingly difficult task of disentangling the hybrid connections between society and technology, the interactions between biomedical technologies and people mutually constitute one another (Prout 1996). On the other hand, we are not “purely” human: Not only our DNA has traces of ancient viruses but also we can be seen now as a super-organism, a host of trillions and trillions of “guests” that most often are helping instead of disrupting our health. The non-human agents of cancer treatment seem to be inseparable from how children’s bodies become permeable. For instance, Portacaths become critical sites through which children articulate their desires, fears, defiance, and agency, as well as permanent sources of memory, endurance, and survival. In a continuum degree of capacity to affect/be affected, the relationships between children’s (and others’) bodies and these medical objects and non-human agents transmute bodies and subjectivity. Indeed, we also use metaphors to signify the subjectivity of others than oneself. In Rouse’s (2004) terms, very often parents develop an “embodiment-by-proxy” in which they re-signify their children’s subjectivity or how their children’s subjectivity is affected by certain objects or interactions with medical professionals.

In many ways it is not only the hematological treatment what can promise a new life without illness, but also the capacity of main caregivers and family members (among others) to protect children from getting infected. Even things beyond the control of families or professionals like seasonal changes (i.e. flu season) would also affect this process. Therefore, so
many different variables would delay or speed up the hematological treatment process, many variables often out of human control, and others within (certain) human control like avoiding getting in contact with super-resistant intra-hospital bugs (although this implies institutional changes to decrease the presence of these kinds of bugs). When infections do occur the CDU emerges as a key player within these medical dramas. Children would be hospitalized for long periods of time when infected and so both the hematological and communicable diseases treatments would often overlap. And with this overlap there would be a natural and unavoidable tension between these two teams.

During the different chemotherapy phases, but especially on both the induction and consolidation phases, children will be exposed to all sorts of complications; they will be permeable to infections, they will embody long periods in which their bodies will be almost defenseless. Bacterial, viral and/or fungal infections will be part of their daily concerns. But living beings (any) are constantly adapting and constantly changing according to their relationships with their (changing) environments. Indeed, we are constantly adapting by creating new norms in the relation between organisms-and-environments (Canguilhem 1991). It is becoming more and more clear that we need to think differently the relationships between hosts and pathogens. It seems there is a need for a new paradigm that will replace the “war” metaphor (Martin 1994). Host-pathogens relationships are central for both health and illness relationships, but for these children often defenseless to their environment, these relationships become essential, dangerous and potentially lethal.

Norma, the former head of the CDU, now second in charge of all the clinical area of the hospital, gave me a unique and long meditated vision of this interaction between humans and nonhumans actors. This is especially important in the case of children with hematological
conditions given their propensity to become infected and hospitalized for weeks or months at a

time. Norma said:

Before they [pathogens] were kinder, but, on the one hand, we started to attack them with
antibiotics and they developed resistance, so forget it, the antibiotics don’t work. On the
other hand, they became more aggressive, so, yes, did you figure out how this thing
works? So now I am going to release cytokines and will create a big mess. Now they are
more violent. And those that were quiet they re-emerged. The ones that used to kill
reappeared, and they are constantly changing.

She is an eloquent speaker, and thus she gave me a detailed interpretation of how
interconnected are these processes of bacterial, fungi, viral infections:

I have a phrase when I teach, “If humans were as solidary as pathogens things would go
much better.” And now I will tell you a cartoon story. You have a catarrh of the upper
respiratory part and viruses cause it, those we can’t cure with these antibiotics. Thus,
viruses enter and except some that can have some treatment for the majority we have to
wait. Viruses first will hurt all the cells at the nose; they act into the blood’s defense.
They make the cells that have to eat them to walk slowly. Then, they stay there for a
while and then they say to the bacteria “Look, bacteria, things are pretty nice here, it is
warm, there is no wind, we cleaned those spikes, and so what do you say, you want to
come?” Then, behind viruses come bacteria. And bacteria stay there and they start to
reproduce and to be happy, they have some little place for love and reproduction and so
bacteria start to go down. Whether they go down through the tube of the respiratory
system and they do pneumonia, or they just jump into the blood stream, but they are so
solidary that also one bacterium says, “Look, there is this antibiotic, and I have something
that can help you to resist it.” Thus, this bacterium that is from another family gives the
virus a code to help to resist the antibiotic. In addition to all this when they are all there
inside, and they say, “OK, they have attacked us. What should we do? Should we stay
here in this corner?” Many stay in one corner and they can stay for years, which are the
case of the gram-negative bacteria. And, so then they say, “Guys, fungi, would you like to
come? They gave us so many antibiotics that now if you want you can come and stay.”
Take a look at how solidary they are that before, many years before, they never shared the
same time and now they are overlapping.

In this case, when looking at the hematological treatment and the long and multifaceted
effects of those treatments on the level of the inter-relationships and inter-connections among
bodies, we can see how, indeed, pathogens become central actors in the lives of children and
those that attempt to cure their diseases. And this thus confirms what children and parents told
me plenty of times, that for them to (avoid to) get infected (that is, their intimate relationships with pathogens) becomes a central topic in their lives, something like an obsession.

On an early Monday morning at the medical residents’ office at the CDU patients’ there were thirteen people in a tiny room all compressed in our chairs. All the R2s (second year residents), R4s (fourth year residents), the head of residents, the three staff and the head of the unit were updating about the patients assisted at the unit (especially what happened during the weekend). Alex (R2) was talking about Guillermo (a 7-year-old boy with acute myeloid leukemia),

Alex: He is a-febrile since the last 10 days, he has a retro culture Gram-positive that we couldn’t typify at the beginning but now we know it is a Rhodococcus [an infection that appears in immune-compromised patients], the hematological always come negative. He is with Lock-Therapy because of the catheter’s infection [they are cleaning the catheter to try to save it].
Laura (staff doctor 1): It took time to know it was a Rhodococcus…
Rafael (in a quiet voice to Ana, staff doctor 2): They are like important actors these bacteria and germs in what you do…
Ana (in a quiet voice): Yes, they are important actors, and we study them all the time, it’s because Rhodococcus is such a character, “Rhodo” [like a nickname] it’s a character…

In the everyday clinical dramas both hematologists and communicable diseases specialists but also children and parents interact with these critical “non-human agents.” They “interact” with them all the time, and they try to extinguish them by isolating them and breaking their “solidary” relationships. Yet, children have also their own ways to understand these other “non-human agents” and how they interact with them. One of the nurses who specialized in managing catheters, particularly those that are implanted under the skin visited Danny, a nine-year old child with acute lymphoblastic leukemia, and his father. The father was asking about the infection in the implantable catheter.

Father: But he has a catheter in order to have less infection, doesn’t he?
Nurse: Yes, but because he has a little bug in the catheter we are trying to kill it.
Danny: I will grab a rifle and I will kill that bug! I will go and will kill all these bugs with the help of my father and I will help all the people.

Danny was naturally furious with this bug: he wanted to kill it! It is of fundamental importance to have in mind these kinds of relationships between children-families-professionals-pathogens because it is a constant source of worries for children, families, communicable diseases specialists, and for hematologists as well. If, indeed, children get constantly infected, if their semi-implanted catheters get infected (and need to be surgically removed), if they need to receive several kinds of antibiotics and to be hospitalized for weeks and put their hematological treatment on hold, all these factors may halt the progression of the treatment and delay the recovery of the child. Therefore, these detours become as central as the main hematological trajectories. In fact, an example of the frictions associated with pricking children’s bodies is when and why to introduce a portacath. The different therapeutic trajectories suggested by health professionals and negotiated with caregivers (and children) are understood from different points of view. At certain moment during the hematological treatment (usually after the induction phase) hematologists may suggest to parents the need for introducing a portacath (under the surface of the skin usually in the upper chest area). The benefits of it implantation are many according to the hematologists, from avoidance of everyday painful pricking for blood samples or IV insertions, to a rapid and relatively non-risky access to the bloodstream in case of emergency, though hematologists also remind caregivers that it has some risks (i.e. infections, thrombosis, pneumothorax or arterial injury). As we read in the above vignette from the parents’ perspective it brings a series of issues to the foreground. Parents need to decide if they want to avoid unnecessarily hurting their children by pricking in their arms, especially at the beginning of treatment. Every day, they risk of an infected portacath with its ripple effects and, often, acute
consequences. Both implantation and removal has to be performed via a surgical procedure. At one point during treatment discussions about the pros and cons of portacaths become very common for children and parents.

Avoiding infections become an obsession not only for children and families but also for the several professionals that assist children with hematological conditions. Each time a child begins a phase of treatment, or a new cycle of chemotherapy within a particular phase, hematologists, with the help of communicable diseases specialists if the child is experiencing an infection, have to evaluate how to continue with the treatment. Often, hematologists have to postpone it if they see the child is not ready for the new cycle of chemotherapy. Therefore, there is a constant tweaking and re-assessment for each child’s condition. Thus, the threshold in which chemotherapy can (or cannot be given) has to be carefully managed in order to move on with the treatment but without risking further medical complications.

**Instructing parents how to look at their children’s bodies**

Cancer changes parents’ relationship to their child’s body. Hematologists emphasize to parents that they need to be proactive in seeking/perceiving the smallest clue of infections in children and taking their children right away to the hospital. Chemotherapy drugs work by destroying those cells that replicate faster such as tumor cells. But they also attack other cells that divide fast such as cells at the bone marrow, mouth, digestive system, or those that produce hair. Chemotherapy drugs will most likely affect these cells. Thus, children will personally experience loss of hair, mucositis, lack of appetite, gastritis, and nausea, among other unwanted effects. In

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59 Sadly, in spite of the institutional efforts to prevent portacath infections during my fieldwork there was a high percentage of portacath that got infected and either they could control the infection without removing them or had to surgically remove them.
general, children have a higher chance of getting infected (given the low levels of white blood cells), of hemorrhages (given their low levels of platelets), and general tiredness (given the low levels of red blood cells). The very basic set of guidance offered by hematologists (and communicable diseases specialists) was to wash hands very regularly, to avoid fresh and raw fruits and vegetables, to avoid crowded places and people that are sick, or if they could not avoid them to use a mask and ask those in contact with children to wash their hands thoroughly and regularly. The logic behind these sets of ‘alarms’ is to protect children from getting infected and thus delaying their progress on treatment.

Thus, children’s lives are constantly medicalized even beyond the hospital settings, and one way this is done is by teaching pedagogy of close bodily awareness, ‘alarms’, and a set of guidance. At the same time there are multiple beliefs and practices involved in ‘getting better’ that hematologists try to infused into children’s and family’s lives. After being flooded with chemotherapy, the digestive system and its mucosa are often hypersensitive thus hematologists recommend parents to avoid certain foods, to cook them, not to eat from street’s vendors, etc. These different kinds of ‘alarms’ are related to food, to places to avoid, and some are specific clues parents need to pay attention and be aware of. Both children and parents become over-cautious of every little change on children’s bodies. Hematologists teach them, they transmit a specific pedagogy in which several forms of bodily surveillance are constantly looked upon. Parents are trained to look at slightest changes. Oral or anal mucositis, or fever, or pain, or other symptoms can be showing a sign of (early) infection.

There is never a “full adherence” to professional treatment, and there should not be since biomedicine implies constant negotiation (Montgomery 2006). These are the sets of guidance hematologists give to parents and children. Yet, each child and family is different, and the ways
they will react would be tailored to their needs. In one of the multi-familial meetings I observed at CCF some mothers were talking about this specific time and the different strategies parents develop with their children. One of the key strategies developed by parents was to focus on having a “positive attitude.” As we can see from the following quote families negotiate what things they feel they can ask their children to do and what things they do not:

Juana (mother of two children): I think an important factor, maybe the most important factor, has to do with the mood and how it affects the illness and how much does medication or chemo work. My older son [who died of cancer five years ago, she now has a small child with leukemia] was strong and active but the last time he was depressed, and if you are depressed everything goes wrong, and chemo doesn’t work.

Paula (mother of 8-year old girl with acute lymphoblastic leukemia since she was 3, she now only goes for follow-ups, she also has three more children): Because of that I don’t do everything doctors say, I don’t want my daughter to get depressed. So if they say she shouldn’t go to parties, shouldn’t do this or that, I let her go, with a mask, if not she would feel worst. If she goes to a bouncy castle [pelotero in Spanish] I tell her to enter when there are only two or three kids, and if someone has a cold I ask her to stay away from this kid.

Gloria (mother of a 8-year old girl with acute lymphoblastic leukemia in the maintenance phase and four more children): I instead send her to school with a mask and she tells everyone she has leukemia, since she was little I told her she has leukemia, which is an infectious in the blood. She herself takes masks to school to give to other children and sometimes she gathers all the kids of her class in a circle and she tells them about her illness, her trips to the hospital, that she is pricked all the time, and the medicine she receives.

Two families with children with leukemia took a different approach; one of the children was very open about being sick at school, whereas the other child did not want to be treated differently. We can also see how parents re-interpret what they heard or were told at the clinic (and they adapt their knowledge to different audiences). For instance, Gloria called her daughter Alex’s leukemia a infección en la sangre (“infection of her blood”) (probably something less stigmatized than “leukemia”). Alex was on the maintenance phase, she had already passed the previous two phases, and she was giving testimony of her own difficult trajectory during her long

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60 When I was conducting fieldwork oncologists and hematologists frequently talked with parents and children about developing a “positive attitude.” See the classic del Vecchio Good et al. (1990) for an anthropological analysis of this.
treatment. She was not hiding her condition and the immense hardships she went through. Whereas, in Paula’s daughter’s case she did not want to tell anyone about her condition to avoid being treated differently at school and among her friends.

**Patients in *recaída* or relapsed patients**

The possibility of relapsing, that is, that the same or another hematological condition (re)appears is a real prospect in some (if not all) cases. Thus, when a patient *recae* (“relapses”), when the same or a new cancer (re)appears not always but often one last therapeutic option beside starting a new chemotherapy treatment (with a relapse protocol) is to perform a bone marrow transplant. The severity of the relapse is marked by a combination of multiple factors such as the place where it relapsed (intra or extra bone marrow), the age of the patient, how many months or years after the end of treatment, if the relapse happens within treatment, among others.61

I will describe in some detail the consequences of relapsing to understand its impact on family’s life. As I noted before, a big percentage of children would not relapse but the medical dramas around each relapse are important to understand its severity and the ways it is handled by the hematology team. One day when I was conducting fieldwork within the hematology unit I asked one of the fellows about relapsed patients and she told me, “It is always worse to relapse earlier than later; the closest to the end of treatment the worst, but even worst is if the relapse happens within treatment… that’s too bad.”

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61 In some cases, though, before even children going into relapse a bone marrow transplant is advised as part of the treatment. Given the particular genetic or morphologic features of certain hematological conditions not matter how good the treatment would be the chances of survival are higher if a child goes for a bone marrow transplant as part of the treatment and not as a back up plan in case treatment does not work.
Miguel, a 10-year old boy finished his treatment for acute lymphoblastic leukemia in 2006 and four years later, he had a late relapse, though he avoided a common risk for boys, testicular or bone marrow cancer. In fact, at the moment of diagnosing his relapse he had a “enfermedad mínima residual” (“minimum residual illness”) so he was categorized as “standard risk” and started a “re-induction phase + radiotherapy.” At that time, he did not have a histocompatible donor in case they needed a transplant. I remember how hematologists were saying in one of the daily team meetings, “we are going to have our fingers crossed for Miguel,” meaning that they were hoping treatment could work without the need for a transplant. In fact, Fiona one of the hematologists told me that in the event of a second relapse the only thing they could do was, “to go for bone marrow transplant… and pray.”

Some particular sub-types of leukemia that have a relative poor prognosis may have a quick suggestion for bone marrow transplant and still would embody a high risk even after the transplant is performed. For instance, I remember one day talking with the hematologists and they told me that none of the children with acute lymphoblastic leukemia with Philadelphia chromosome (a chromosomal translocation 9-22, approximately 5% of pediatric ALL,) they treated at the hospital that had a bone marrow transplant were alive. But the total number of children with this sub-type of ALL was very low.62

When children are considered a ‘high risk,’ or when they relapse from the first condition within treatment, or after treatment, a bone marrow transplant is usually the ‘last therapeutic option’ hematologists are able to offer. This was not always the case though and often the

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62 This poor prognosis for this particular sub-type of hematological condition is similar worldwide, even at the top pediatric institutions at the global north. Philadelphia translocation is a chromosomal abnormality often highly associated with Chronic Myelogenous Leukemia but still present in some cases of pediatric ALL. Usually a transplant is indicated after remission.
hematologist team began a re-induction phase adjusted to the child’s post-relapsed condition so they often did not plan for a transplant, they were confident that chemotherapy treatment was going to work this second time. When hematologists offer the transplant it is because they consider that this procedure in which they replace damaged or destroyed bone marrow with healthy bone marrow stem cells will finally offer a chance to free the child from disease. A bone marrow transplant is a hazardous procedure with potential myriad hurdles (the most complicated are infections and graft-versus-host complications). Beyond a failed bone marrow transplant, if there is a bad engraftment, typically there is a “land of no return” (as one hematologist put it). Though they will keep treating children hoping they will eventually be free of illness. Rarely a second bone marrow transplant can be performed but usually there is only “palliative treatment” (though “palliative treatment” means different things for hematologists and palliativists). When I was conducting fieldwork at the Hospital Infantil there were few children with more than one transplant still alive. For instance, one day I was with the hematologists and they started to talk about Ricardo, a ten-year-old boy that had a chronic myelogenous leukemia since the age of two. They were discussing what to do with him that day that he was coming to control. It was a hectic (as usual) cold morning of August 2010. Flora one of the hematologists quickly read his clinical history:

Flora: Ricardo P. 10-year old. Chronic myeloid leukemia since 05-2002 (eight years ago), post-second allogenic transplant with the same donor, an oldest sister. First allogenic transplant was performed on a chronic phase. We gave him chemo to consolidate complete remission. Second transplant to sustain his complete remission. He had an altered hepatogram so he is now with mycophenolic acid, T4, and acyclovir. He had a good engraftment because the genetic pattern of both the transplanted and the donor matched. Should we give him Imatinib [targeted therapy]? We suspended it in January 2010, one year after the last post-transplant.

María: We have a difficult situation here, so I wouldn’t recommend starting with the diagnostic battery, because although we have to watch him very closely, I doubt if we should do more tests... We know he has a full engraftment.
Flora: We have a sobreviviente (survivor), and we have to respect him as such. We did everything right with him, we gave chemo and everything 100%, but I don’t think no one could say we should go for a third transplant if he starts to get worse, because it would kill him…

Notice the reference to Ricardo as a sobreviviente (“survivor”). Hematologists are fully aware of the extreme hardships children have to go through when transplanted. By becoming a “second-transplanted survivor” he had gained respect from the team that treated him (which meant to be over-cautious with the ‘diagnostic battery’). Ricardo also had radiotherapy. Often when children are labeled as having intermediate or high risk, and depending on the sub-type of leukemia, hematologists also advise (which implies a prescription) to give cranial radiation (CR) to the “sanctuary” as either a preventive (when there is no trace of malignant cells) or therapeutic measure (this is not prescribed or given to all children). When radiation therapy is given to the central nervous system (CNS) as a preventive treatment it kills cancer cells that may be in the brain and spinal cord, even though often no cancer has been detected there.

As we have seen, depending on each condition, a bone marrow transplant is often considered the last therapeutic chance and, if performed, and if children have a good engraftment and a good post-transplant process, it can help children to overcome the illness and reach a new life without illness. Transplants also create tensions within the family structure since often the healthy bone marrow has to be “mined” from within the family. Moreover, given that both donor and recipient are children, most often siblings, a whole series of questions are brought to the front: How much children (both donor and recipient) understand about the transplant? How do parents manage not only the decision-making process, but also the overall family dynamic, especially the relation between the two siblings? Donors might experience some difficulties since they will also need to go through a strictly controlled biomedical process in order to extract a

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63 For a good example of these kinds of intra-familiar tensions but in relation to elder members of the family pressing their grandchildren to donate them kidneys see Kaufman et al. (2006).
portion of their bone marrow. Quite logically, siblings are afraid of the procedure (I could not ask siblings about it). I cannot imagine the kinds of discussion and debates that happened with the family and how relieved they were after everything had worked out well. After all, healthy siblings had indeed saved their sick siblings’ lives. But this shows yet another layer of effects in relation to how collectively the whole family is affected by the hematological treatment.

In many cases the news of relapse (as often is the case with the original diagnosis) comes quite suddenly and is shocking to patients and caregivers. Here, I will describe the moments in which a mother and her daughter received the news that the child was relapsing. They both had just come from a province in the northeast part of Argentina for a regular control after treatment was finished six months ago. Before this meeting, during that day, the hematologists had just detected that Celina, a nine-year old who had an acute lymphoblastic leukemia as the primary cancer, was in fact relapsing. In what follows I insert an excerpt from my notes when the hematologist tells Carolina, Celina’s mother, the news. I want to show how unexpected and drastic is the moment the news of relapsing is introduced:

I followed Margot, staff clinician from the Hematology Unit, she was going to talk with Celina’s mother; I’ve heard in the mid-morning patients’ discussion that Celina is relapsing. The hematologists have just found out today. We go to the second floor of the unit to the “Procedure Rooms.” I was following Mariana, a fellow at the Unit, Jenny (another R4), and Margot. Margot told us we couldn’t be so many people to talk with the mother. She said we can take turns so I can go with her this time and another time they will go and I will wait outside. In the waiting area I see Marcos (a patient I’ve been seeing before) lying in a bed looking at the wall and his mother next to him. Celina and Carolina were also there. Margot then told Celina’s mother that they (for the other two in our group) could take Celina to another room to watch some TV while they talk for five minutes and they did so. Mariana grabbed Celina by her hands and they walked to the TV room and Margot asked the mother to enter another tiny room with a bed, two sinks and a toilet (it was a deposit room, but she did not have any other quiet and private room available at that time).
The hematologists needed to talk about Celina’s relapse with her mother alone. This was a critical moment, she was going to tell her that all the efforts they made were right, but sometimes cancers come back:

Margot grabbed a chair and asked the mother to seat. Celina’s mother sat. I entered last with them and Margot asked me to close the door. Margot started talking; she was standing looking from above to the seated mother.

Margot: I am sorry but I have to tell you the disease went back, Celina is relapsing. The mother was waving her head as in disbelief and often she was asking something but the major portion of time Margot was the one talking.

Margot: It is not the same situation, but it can serves as an example. When bacteria attack a person we use antibiotics to cure that person. Usually that works but when bacteria become resistant to antibiotics we have to give her something even more aggressive.

Carolina: I understand. (Long silence) But we did everything we were asked to do with her...

Margot: Yes, you are absolutely right. You did everything right, you don’t have to think otherwise. You did exactly what your doctors asked you to do. But we now know she has the disease again in her body so we have to start again with treatment. We have hope on the treatment. This is not something we came up with; this is something that is being done internationally and statistically speaking this treatment has eighty percent of cure. Unfortunately, Celina is on the other twenty percent but we have to start again and we trust on our treatment. We know it is good. And we will start again but not from zero since she has relapsed within six months after the end of treatment. So, I am afraid we will have to give her something even stronger and more aggressive. The first month will be the same as when she started with treatment but then there will be blocks of chemotherapy stronger than before. Therefore, from now on we have to support Celina and you and your husband have to support one another and among all of you and with our support we will find a way through it.

Mother: God will want to cure her.

As we can see in this long excerpt the moment the hematologist pronounced her being relapsing is an emotional, cognitive disruption for Carolina. She had to absorb this drastic change in their lives. Not only they would have to go back again to start treatment with an even harsher therapy but also she needed to make sense of the unsuccessful treatment. Carolina needed to understand that everything they did (all their efforts) was right and also had to develop trust again in the hematologists and their treatments.
In another case a healthy brother was going to donate his bone marrow to his sick sibling. Cesar needed a bone marrow transplant, and Tristan, his five-year old brother, was histocompatible (matching) so he became the donor. Silvia, his mother, said,

At the beginning he had thirty percent of life (sic) and if they were given the strongest drugs he had fifty percent of life (sic) but then they did not have any other chance than the transplant. He had many problems after the transplant but Tristan saved Cesar’s life. Doctors told Tristan he was very brave for donating the bone marrow. Tristan, at the beginning was afraid, but the day that they were going to take the bone marrow he behaved very well. And, then, after two weeks, after radiotherapy and a strong chemo, they did the transplant to Cesar. Right now he is doing OK. Doctors asked Tristan what he was going to ask to Cesar after the transplant and Tristan said that he only wanted Cesar to come to his birthday that was going to be in a month. Cesar was hospitalized for a month and the same day of Tristan’s birthday he was discharged and he went to Tristan’s birthday. His aunts had organized a surprise party for Tristan. And he was super-happy with his party and, especially, having Cesar there.

Children like Cesar, Celina and Ricardo that have survived long chemotherapy treatments, transplants, and even radiotherapy, experience drastic changes in their lives. Parents, siblings, and other family members and close friends have been radically affected by these changes as well. These children will all embody these long therapeutic journeys with its harsh consequences as long as they live. With the improvement in treatments cancer children survivorship is a relatively new sub-field within onc-hematology and medicine in general. Children that survive cancer experience all sorts of treatment-induced effects when reaching adulthood. They will experience musculoskeletal, cardiopulmonary, genitourinary, fertility, endocrine, and/or neurological issues (among others), they will also age more rapidly (especially if they received radiotherapy), and they will embody a higher chance of getting a secondary cancer caused by the treatment that tried to cure the first cancer for some of the long-term consequences for childhood cancer survivorship (Marina 1997). In 2010, I interviewed a 28-year old cancer survivor that had a bone cancer when she was nine-year old and still 19 years after she was visiting her oncologist every year. She told me her pediatric oncologist was now for her “a
mix between a psychologist and a friend.” Hence, she would go to visit her whenever some
doubts would reappear because “an acquaintance has died of cancer or things like that.” And she
did that until, in 2010, the oncologist asked her “please do not come any more.” This small
example means that in all this time, in all these years after the end of treatment, even living free
of illness still children and adolescents are often haunted by their pediatric cancers.

But sometimes treatment cannot work. We know that approximately twenty to thirty
percent of the overall kinds of pediatric leukemia are refractory to treatment (thus, treatment may
not end up working) though it varies according to particular hematological conditions (and sub-
types) and the overall available resources (global north, global south, and within each country).
When treatment can not work or when can only partially work leukemia will relapse. If it
relapses after treatment it would depend on how close or far from the end of treatment the
severity of the relapse would be. Thus, the higher the chance for an even more aggressive
treatment since the first one was not effective enough. Alternatively, in some children allogeneic
(from a genetically non-identical donor) bone marrow transplant would be considered (usually as
the last therapeutic option) for high-risk or relapsed patients. Bone marrow transplants are very
difficult to go through because close relatives are not necessarily histocompatible (matching or
having mostly the same alleles of a set of genes) adding the problem of a potentially lengthy
process to find donors beyond the family from national and/or international banks. They are also
difficult because of the time management and small window in which a transplant will be
technically feasible. Still, even if the transplant is successfully performed children will need to be
under a close control to check the engraftment (good match) has occurred and to monitor
organ(s) function(s). In addition, they will need drugs for life (transplanted people become
chronic patients).
But even if children recover relatively quickly and achieve complete remission, for at least one or two years their immune system will be seriously compromised, intermittently depressed, and generally jeopardized due to the combination of overproduction of cancer cells like in the case of acute lymphoblastic leukemia (the most common type of leukemia in children) and halt in the normal development of cells caused by the medical treatment. That is, their immune system would often be in a situation in which they could hardly fight microbial, viral and/or fungal infections. Therefore, as medical residents, hematologists, communicable diseases specialists and nurses constantly reminded children and parents when I was doing fieldwork, for these children in those situations, “even a tiny little scratch in the skin means an emergency.”

Patients’ roles

Generally speaking, the majority of children overcome hematological conditions, although each child will experience cancer survival in different ways in a continuum from minor to severe chronic issues. From Parsons (1975) we know that as a patient, one of the main roles is to “get better”, that is the nature of the “sick role.” During this lengthy hematological therapeutic process in which children are exposed to all sorts of knowledge, procedures, and drugs, and interact with different kinds of professional teams each of the main characters in these clinical dramas from children to parents and to the different professionals perceive in different ways what are the patients’ roles and how to get better.

Children experience months and even years of their lives in a strange place, trying to understand not only what is going on to their own bodies that now “seems to be broken and need

64 Though, some kinds of leukemia, like Chronic Meylogenous Leukemia, have been successfully treated with a more targeted treatment (i.e. Imatinib) that tends to have less cytotoxicity. This is a growing field within oncology, targeted treatment that only aims to cancer cells without destroying normal cells. See Talpaz et al. (2006).
“to be fixed” as a ten-year old boy told me but also how their illness and its treatment is affecting the whole family system. Children (and caregivers) also try to understand what is expected from them while going through hardly imaginable hardships. Mariana from the HU told me:

You need to be aware that you are placed in such an important place for the parents because you are dealing with their illnesses, and this keeps you [as professional] working. Because this pathology is terrible, what children are going through is something horrible, but the connection you have with the family is what helps you to keep on going.

As I will discuss in more detail in the following two chapters, children’s bodies and their social relationships were increasingly medicalized over the course of their treatments. The roles of both patients and professionals developed hand in hand, as children painfully learned from their own bodies, while staff followed their patients’ lead (Day et al. 2014). Physicians from hematologists to communicable diseases specialists were aware of patients’ struggles as they underwent invasive treatment(s). Children (and their caregivers) did their best to “adhere” and “comply” with the different treatments. However, differences between hematological and communicative disease teams and different therapeutic approaches and decisions created ambiguity and ambivalence among patients, parents, and even medical residents who needed to be fully committed to difficult course of treatment. This issue will be addressed more fully in my consideration of “modulation” in the next chapter.

Conclusions

Keating and Cambrosio (2002) argue that the work of the cooperative groups and the Acute Leukemia Task Force in the U.S. during 1950s-1960s formed the basis of a wider approach within hematology that influenced the rest of the world, in which clinical research, clinical trials, chemotherapy development, and new ways of screening were all entangled. In writing about oncology Ilana Löwy (1996) clearly shows that within cancer research and cancer medicine the
relationship between “the laboratory” and “the clinics” are complex. Clinicians and researchers are constantly moving back and forth between the two realms, yet both are part of an overall “culture of clinical experimentation in oncology” (1996:81).

In this chapter, I have described the participants in the clinical encounters of children suffering from cancer and the particular culture of clinical experimentation as performed in this clinical site. I have described the roles of the patients, the overlap work of various specialists, and the diagnostic and treatment processes. In order to understand the kinds of experiences children and their families have to undergo I needed to show the dynamics of the HU and the different therapeutic phases children experience while attempting to wipe the malignant cells from their bodies. In this chapter we have seen how the clinical setting works. I showed how both the hematological and communicable diseases treatments work often under frictions. In the next chapter we will focus more on these changes to see the kinds of impacts these treatments create on children and their families.

Diagnosing, treating, and prognosticating each child’s condition are interconnected activities professionals conduct on a daily basis, and children and families also learn to grab pieces of information from here and there to fit into their own explanations – which Kleinman (1976) calls “explanatory models”. Professionals constantly break and re-assemble children’s bodies by taking them in different levels—from the molecular to the interpersonal levels. This epistemological movement often situates the emotional and social aspects of the children-families-clinicians’ relationships as the backdrop of the more biological and physical causes. In this way, both the laboratory and the regular check-ups are central aspects of these therapeutic processes. They both keep track of the constant changes children are going through from the molecular/‘deeper’ to the interpersonal/‘outer’ levels. Yet, hematologists can only deal with one
portion of the myriad adjustments children and families need to embark on so many different levels. Thus, another key actor in these clinical dramas is the CDU and their treatments to contain and eradicate infections. In the following chapter we will see how children experience these treatments from their bodies.
Chapter 6: Modulation: Children’s experiences from their bodies of chemotherapy

“Marianela survived the ara-C!”
Hematologist staff

Children and families are exposed to myriad experiences when pursuing hematological treatments. Their hematological team tells them that in order to free children from their illness they will have to wipe out the células malas (“bad cells”) at the bone marrow. They often add that the aim of the chemotherapy treatment through the three phases (induction, consolidation, maintenance) is to modular (“modulate”) the bone marrow to get rid of the bad cells and let the good one grow. But what is meant by “modulation” in relation to the hematological treatment, how it impacts on children’s lives, and how it reconfigures the re-setting of children’s bodies? In this chapter, I will focus on the experience of being treated for an hematological condition. How does the treatment impact not only children’s bodies but also their caregivers, family members as siblings, friends, and others? By focusing on children’s bodies I will be able to look at these impacts and its social and medical ripple effects.

As I showed in the previous chapters, a high percentage of children actually reach the land of “survival free of illness.” However, the lived experiences of these children and families are often lost from sight. Their bodies and the impact of treatment on their selves and personhood are usually overlooked. Indeed, there is a gap between hematological explanations of how treatment works and their affects on children and families’ corporeal and collective lived experiences of painful therapeutic treatments. This breach rests on a broader biomedical landscape shaped by biotechnologies of diagnosis and therapies for hematological diseases. It is the setting for the continuous exchange between “human agents” (children, family members,
professionals, ethnographers, hospital administrators, state agencies) and “nonhuman agents” (cancers, virus, bacteria, fungi) in particular clinical contexts. 65

This chapter deals with that lacunae between hematological explanations and the impact of treatments on children’s bodies. I will focus on the social impact and collective implications of hematological treatments and the specific actions hematologists perform on children’s bodies. In particular, I will focus on the impacts of the reajuste (“re-setting”) of the bone marrow and the attempt to wipe all malignant cells from it. In order to understand the clinical encounters and the kinds of experiences they create we have to look at different types of mechanisms, actors, and agents working (and being worked) at the same time. These are different collectives with differential agencies placed together in particular space-time. All these types of mechanisms, actors, and agents are simultaneously and differently affecting/being affected when hematologists are trying to reset the bone marrow, the fábrica de sangre (“blood factory”) or campo (“field”), as the metaphors they often use when explaining to children and families the disease and how they will attempt to cure it. 66

From the very beginning, from the first time children enter to the hospital, children’s bodies and selves will face an endless series of changes with innumerable unexpected consequences. A cancer treatment is a collective effort that brings together different biotechnologies, actors, and sets of knowledge and expertise. There is a “thrown-togetherness” of “social” and “natural” trajectories (Massey 2005), there is a fluidity of elements that collide on

65 Just to give a small example about the mixing and recombination of these different actors and agents, Escherichia coli, or, E. Coli, a gram-positive bacterium that can potentially kill any person with a compromised immune system (like children under long hematological treatments) is also the source of Asparaginase, a chemotherapy drug for killing tumor cells. 66 Of course, this is a metaphor that each child or family would understand differently. One should not assume or take for granted that these key biomedical metaphors work in the same way; for looking at how medical metaphors work see for instance Sontag (1978), Johnson and Lakoff (1997), and Martin (1991).
this clinical place. It is crucial, then, to think about the short and long term effects of this
“modulation” not only on children’s bone marrows but also on their selves as a whole,
particularly on their corporeality-subjectivity. While under the “hematological gaze” children
continued to grow and experience life in during these modulation processes. They also
reassembled their social lives. Throughout their long treatments children alternatively went
through phases of separation, when hospitalized, often in isolated rooms, and re-inclusion into
their social worlds at home. Besides their parents, their main caregiver(s) who were taking care
of them throughout the many hospitalizations, other family members, friends, and schoolmates
also visited, cared for, and supported the children. Thus, during these periods of seclusion/re-
inclusion, especially during the times of isolation, children were exposed to new actors at the
Hospital Infantil that all of a sudden would become central to their lived experiences. In all these
months and years, children will find themselves (and their families) being part of particular
hematological treatments aiming to wipe all the malignant cells from by modulating their bone
marrows (and lives). Hence this is precisely the central question of this chapter: How do children
and families experience this ‘modulation’ and how it impacts on children and families’ lives? In
this chapter I will mainly focus on the impact of hematological treatments on children (and
families). I will argue that ‘modulation’ provides a fitting metaphor not only for a particular kind
of treatment, but also for emotionally taxing clinical encounters that transform children and
family’s lives. By looking at these encounters through which clinical treatments are organized,
explained, and de-codified but also, and more importantly, corporealized I want to focus on both
the side-effects of treatment and on the re-appropriations of children and caregivers of their
modulated lives.
As I already showed in the previous chapter, children, families, hematologists, and communicable diseases specialists are differently but mutually affected by interaction with one another. Hematologists try to wipe the malignant cells from children’s bone marrow while attempting to keep control of the toxicity of the chemotherapy and the potential for infection. In many ways during this long medical journey it is neither simply the hematological protocols nor the communicable diseases prevention routines that promise life without illness, but also the skill and ability to handle countless unpredictable outcome of treatments. The children’s and the families’ experiences and their capacity to navigate illness are also shaped by the ability to access simple things like having a place to sleep, a fridge to store drugs, or the ability to suddenly travel to the Hospital Infantil when an emergency arises to prevent a delay in treatment. Ultimately, in this clinical context, everything that happens to children is part of the social worlds of children with cancer.

Wiping células malas (“bad cells”)

When hematologists explain to parents and children what they do, they often tell parents they need to wipe the malignant cells from the body by intervening where the blood is produced in the bone marrow. Usually hematologists’ explanations focus on the “bad blood cells” that are outgrowing the normal cells. Hematologists explain this by comparing cancer to weed that needs to be wiped out from the field. This is constantly emphasized to children and parents. Yet, they say this often without considering how it affects the totality of children’s perception of their own bodies. In this chapter, I will focus on this notion of modulation to understand the impact on children’s bodies from hematological treatments that attempt to attack malignant cells. The treatments are carefully managed with potent drugs that are designed to re-set the bone marrow
as the producer of the different blood compounds. Hematologists often tell parents that they have to adjust the drugs to each particular child’s body. This is the idea of modulation, that each child’s bone marrow and immune system has to be carefully monitored according to the specific type (or sub-type) of condition and each particular child’s body.

One day I followed Susana, an attending staff physician, and two fellows from the Hematology Team to see a new patient. Eleven-month Greta was from the province La Pampa (600 km from the City of Buenos Aires). She arrived with her mother Claudia, and her father Roberto and she had just been hospitalized at the CDU. This was the “debut”, or day 1 for Greta. We went to their room and Susana introduced her and told Claudia

Hello Madam we are from the Hematology Team and we will be accompanying you throughout Greta’s treatment. Today we will need to perform some tests to confirm her exact diagnosis and start the treatment right away.

Then, Claudia asked, “What is this treatment and what we could expect from it?” Susana replied “You don’t have to worry about the treatment right now, we are going to tell you about it later, we are going to go through phases of treatment to try to cure Greta.” Claudia asked questions while Roberto kept silent standing next to Greta’s bed. Susana told them they had to perform an important test that day to “take a look at the state of Greta’s bone marrow” and the parents agreed. Susana explained to them that day was

... The start of a long journey in which many different professionals from the hospital will accompany you, and, don’t worry, we will slowly explain the different phases of treatment. We would be close to you all the time to try to answer any questions or doubts you may have. But you need to know that in the next four weeks or so your daughter is going to receive chemotherapy adjusted to her own particular disease and body.

After that day during the induction phase she, like other children, was given a quick succession of chemotherapy drugs such as Methotrexate (MTX), Cyclophosphamide, 6-Mercaptopurine (6-MP), Cytarabine (Ara-C), Vincristine, L-Asparaginase, Prednisone mixed
with anti-inflammatory and immunosuppressant drugs such as Dexamethasone. Family members and children will slowly get used to these names and different kinds of liquids hanging at the IV-poles and radically affecting each child’s body and emotions.

Certainly, not a single child or parent expected to go through the physically and emotionally taxing treatment that started with that first “debut day.” All children during this “debut” are hospitalized. Also throughout some part of the induction phase they will need to be hospitalized for multiple reasons (infections, lack of infrastructure at home, lack of resources to travel back and forth, families are from faraway places, etc.). And this creates another layer of complexity since children are hospitalized outside the HU. Thus, many times I heard hematologists complaining about the clinical management of their patients from other specialists. And, vice versa, I also heard how communicable diseases specialists and residents complained about hematologists giving too much chemotherapy to their patients.

Lisandro, the head of the HU, came to the staff room one day while staff and fellows discussed Melisa’s condition (pre-B ALL) and the way she was treated at the CDU. Melisa was on the induction phase and had been hospitalized for two weeks receiving different antibiotics plus non-steroidal anti-inflammatory drugs while having low white blood cell count. During the meeting they discussed how they needed to educate other units in the different kinds of hematological conditions and treatments. Lisandro said:

They [staff at the CDU] have to understand that not all the leukemias are the same, that not all the chemotherapies are the same, that not all the neutropenias [low number of neutrophils] are the same…

And, Sonia, one of the staff clinicians added:

We have to go to all the units that have our patients every day, we cannot skip one day without going because then we will find unpleasant surprises…
Children and families are immersed in this field of tensions between different units that see and prioritize medical problems differently. As we have seen, the first month of treatment is very important not only since its impacts and consequences will persist throughout the treatment, but also due to the tensions created between units in which children and families are submerged. Since children were hospitalized in other units, inevitably there are tensions between the different specialties with different therapeutic orientations and models. That is why the hematology team felt they needed to have a close watch on their own patients. A kind of “hematological pedagogy” was needed, to educate others about the differences between hematological treatments and what to expect from it.

In many cases children started treatment and were hospitalized for some time in the same unit and so both the Hematology Team and the staff and residents of that specific unit will manage the child’s case. Often one resident was in charge of the same child all the time. In other cases children were hospitalized in different units throughout the first months of treatment. If the child needs to be hospitalized because he or she develops some symptoms during treatment there would be a discussion between the Hematology Team and the staff and residents of the unit in how to proceed. Usually hematological treatment can continue but it will depend on the particular co-occurrence of other medical conditions. For instance, if it is a mild or severe infection in some cases the hematological treatment will have to be put on hold until the child recovers from the infection.

**Treatment and invasiveness**

Hematological cancers are not located in particular organs or systems like solid cancers, but malignant cells are spread throughout the body through the bloodstream. Consequently, there are no surgical options as there are with solid tumors. Usually treatment for the different kinds of
Hematological conditions is a combination of different treatments such as steroids, chemotherapy, and in some cases bone marrow or stem cells transplants. Radiation therapy is rarely used. Particular conditions, and sub-conditions, are targeted with specific treatment protocols that lay out the combination of drugs, dosages, duration and periods between treatments. These protocols are constantly tested and tweaked. They regularly morphed into slightly different protocols according to new data and new studies that determined appropriate levels of toxicity and survival rates.

Hematologists at the Hospital Infantil keep meticulous track of each individual child’s treatment in the medical records including the particular type (and sub-type) of diagnosis, how the treatment is evolving, the recategorization of the risk associated with its condition, and if the disease is changing in relationship to the expected trajectory of the treatment. That is why it is crucial to know the exact diagnosis to apply the kind of treatment developed for that condition. Indeed, how well (or bad) and promptly (or not) the particular kind of leukemia responds to treatment also shapes the long-term prognosis. Statistically speaking better and quicker responses to treatment have been correlated with superior long-term therapeutic outcomes (Jain et al. 2013). Some leukemias (acute lymphoblastic leukemia) do well with certain combination of anti-cancer drugs while others (acute myelogenous leukemia) from the beginning hematologists know that it will have a statistically low percentage of survival without illness (and a probable suggestion for a quick bone marrow transplant).

Therefore, hematologists look at the impact of treatment through particular windows that aim to “see” how the bone marrow behaves. A blood sample, a lumbar puncture, or a clinical check-up are all windows into the disease. But hematologists are also vigilant to the appearance of potential unwanted outcomes of chemotherapy from the evident hair loss to sores of the
gastrointestinal duct, nausea, vomiting, diarrhea, infections, bleeding, fatigue, numbness or weakness in hands or feet (to mention some).

During long term treatment children may experience low white cell and/or platelet counts, frequently resulting in countless blood transfusion. While most of these side effects disappear when active treatment is over, long-term side effects of chemotherapy treatment may persist, effecting the functioning of many organs such as brain, liver, kidney, lungs, heart, testicles, and ovaries.

Other than suffering a relapse, probably the worst possible long-term side effect of chemotherapy is the appearance of a secondary tumor at a later time, often as a side-effect of the original chemotherapy itself. Hematologists are painfully aware that anti-cancer treatments leave a narrow margin to maneuver between curing and injuring bodies (Mukherjee 2010). I often heard hematologists say things like “Marianela survived the Ara-C!” [Cytarabine, chemotherapy drug] as if hematologists themselves were incredulous of that possibility.

As I already noted, a typical cycle of chemotherapy implies regimes of different chemotherapy drugs and some time in between them to let children’s bodies recover after the massive chemical disruptions. Not surprisingly, their impact can be remembered clearly even after a long time. When I interviewed Valeria, a woman in her late twenties who had a bone tumor when she was nine-year old, she vividly remembered the painful and devastating experiences that are typical of chemotherapy cycle. In her words,

…Sometimes I was not vomiting, but for three days I was gone, like absent from the world. That is, they would give me medication, I would stay [at a private clinic] while they poured it onto my body for some hours, don’t remember how many, three, five, don’t remember. You know? It was like an IV pole with a red liquid, that was the medication they would give me. And then when they were done with the medication I would go home and I would spend three days in bed. Then, after the third day I would feel better, I could go back to life, I would go to school and do my things. And, then, after
two weeks they would start again with more medication… and the moment when they would give me the medication was… terrible.

Clearly, living in a medicalized body under hematological treatment is not easy. Even after a long time, Valeria still remember the days in bed “absent from the world,” and the “terrible” moment when she would get her medication. When children living with hematological conditions were under constant surveillance, when their bodies are under the hematological gaze, children and caregivers learned to embody these invasive interventions in different ways.

These hematological treatments are long and required periods of hospitalized due to the toxicity of the chemotherapy and its side effects, as well as the risks of infection. Significantly, these long therapeutic journeys, coincided with these children’s formative years during childhood and teenage years. Their physical, emotional, mental and social maturation were strongly marked by the radical transformation caused by cancer, its treatment(s), and their unwanted side-effects, and the social isolation of hospitalization.

Invasiveness is perhaps the most difficult aspect of hematological treatments for children and families. Invasiveness also poses an interesting theoretical question in medicine. In Argentina as well as North America one of the first things that medical students are taught in epidemiology is that the skin is the first line in the prevention of disease. But one wonders how do parents and children understand the concept of the frontier of the body and invasiveness? Breaching the skin becomes the source of different kinds of worries for children and caregivers on the one side, and for professionals on the other side. When I observed the multi-family meetings at the CCF Telma, the psychologist coordinating these meetings, would often mention the need to begin thinking about semi-implantable catheter or portacath (a central venous line with a small reservoir that is implanted under the skin). She often told parents “You need to think
about it because, for instance, it helps children to free their arms and so they can play and move around better.”

During chemotherapy treatment it is quite common for children with frequent intravenous procedures to have a catheter surgically inserted under the skin so treatments can be done through the portacath, which is then the only actual breach of the skin. Since this port is usually attached on a semi-permanent basis, does this become part of the body? Are the injections into the portacath still invasive? Children and parents were constantly negotiating and adapting to these intrusions into the boundaries of children’s bodies. This especially raised questions at the beginning of treatment when portacaths are not used, or not properly understood.

Alex, a fourteen-year old survivor that when I met him lived more than two years free of illness from his acute lymphoblastic leukemia told me he kept the portacath he used for two years as a souvenir at home. Alex said,

The catheter was so important for me that I wanted to keep it. It is like a souvenir of what I’ve been through. I am going to show it to my own children.

Alex then told me that he knows a lot about portacaths, in fact, as we will see below, following the advice of Telma from the CCF he knew the exact name and model of the portacath he used for two years (he wrote it on his note book). He told me he had a couple of instances in which he had to run to the closest Emergency Room in the south of the Greater Buenos Aires Area (he could not risk to go to the Hospital Infantil) and his mother told the doctors the exact type of catheter to help them start with the treatment right away.

I was one day working with hematologists at the Hematology Unit when I observed a discussion between Julia (mother), Silvia (a fifteen-year old girl with acute lymphoblastic leukemia type B on consolidation phase), and two members of the HU. Silvia had her two arms visible damaged by the many punctures she had had during the last months of treatment,
sometimes children’s arms are so damaged that nurses and residents need to find other veins, for instance, in legs to prick them. During the morning discussion of patients, a clinician at the HU said “the girl does not have good access” (no veins) and so they suggested she could benefit by having a portacath. They also discussed that she was “sad and prone to crying a lot, and she has diarrhoea.” They asked for a bowel biopsy. One of the clinicians left the room to see Silvia and I followed her. When we arrived to one of the small cubicles at the main floor the medical resident was discussing with the mother the pros and cons of a portacath. Julia refused the idea for fear of infections whereas the resident suggested the need for one. When the resident checked Silvia (before we arrived to the cubicle) she found that Silvia had a severe rash in the area surrounding her anus. According to the clinician it required extreme and close attention. This small example shows the multiplicities of processes that are often co-occurring when thinking about children’s pain. Hematologists suggested the need for a portacath to avoid more painful pricks to Silvia with her already damaged arms but they were also worried about the rash that could potentially and quickly morph into a mucositis. These kinds of therapeutic trade-offs are part of the everyday practice of professionals and the lives of children and families.

In many ways hematologists were extremely aware of the invasiveness of the chemotherapy and other hematological treatments. For instance, Mariana from the HU calls the Procedure Room *ese cuarto es casi como un cuarto de torturas* (“that room is almost like a torture room”). They repeatedly tell children and parents they wish they had other ways to diagnosis and treat children that would create little or no pain. When children have problems with broken or difficulty to fine veins, hematologists usually advise parents to opt for a semi-permanent portacath surgically implanted under the skin in the chest. Implantable ports are suggested for convenience and because it implies fewer punctures.
Many families follow the advice. Both parents and children told me that they felt invaded by these daily procedures. At the CCF in every multi-family meeting I observed at one point during the hour and half meetings parents brought up the issue of invasiveness. Telma responded by giving tips on how to deal with these issues. Telma frequently gave parents new with treatment a book written by the foundation about pricks, punctures, and invasiveness, which helped them to navigate the acute pain produced by medical procedures.

Other parents preferred not to have their child receive a portacath for fear of infection, because implantable ports need to be removed by surgery. Yet, this is not an easy decision especially when dealing with older children who have a say in their treatment. I once observed a resident rotating at the HU talk with Alejandra, a fourteen-year old girl and her mother, Laura, about the possibility of implanting a semi-permanent catheter to avoid constant pricking. Alejandra was in favor of it whereas Laura was against it because she saw how many children’s semi-implanted ports became infected. The residents told them they had three days to think about it because the surgeons who implant portacaths had an opening in three days in their operating schedules. Alejandra wanted to avoid more pricking whereas Laura was worried about potential severe infections. Both dealt with this invasiveness in different ways.

Some children have these ports implanted for months, and even years (although very rare). Some had to be removed quickly after implanted because it got infected. After each procedure, a small amount of heparin [anti-coagulant] fluid is flushed into the catheter so it does not get clot. Usually the port will need to be flushed approximately every four weeks if it is not being used regularly. Specialized nurses at the Hospital Infantil manage these semi-implantable ports for fear of infection. Parents fear infection to the point that they asked that no other staff or residents touch the catheters. Certainly, it becomes an outside of the inside that helps permeate
more smoothly children’s bodies. As I showed with Alex, this semi-implanted port in fact
becomes part of children’s bodies. When hematologists and other professionals explain to
children how these ports are used they say that just before any treatment or blood test, the skin
will be carefully cleaned. The nurse will then introduce a special thin long needle through the
skin and into the port. Hematologists often say that this should not be painful, but that children
may feel a pushing sensation through the skin. Yet, for what children and parents told me, it
seems pricking into semi-implanted ports are invasive not so much because of the pain of going
through the skin but more so for the symbolism and the cumulative pain children have been
experiencing before.

In one of the multi-family meetings at the CCF, Telma, the psychologist guiding the
meetings, after parents talked about the invasiveness of the cancer treatments said,

It’s a topic you’ll need to learn to handle. They will be constantly pricked to extract
blood, to give them medication, for myriad procedures. This is something doctors decide,
but you as parents what you can do is to get informed, here you have all our books, and
help your children to anticipate to these procedures. For example, if they will prick your
child you can ask first the doctor or nurse to explain to your child what they are going to
do, you can say (and she winks) “Now the doctor will explain why they need to prick
you” and then you can prepare your child telling him you will count together from ten, or
five, or three to zero. The idea is to give them some sort of control over the situation
instead of something they do not have any control whatsoever. Also, you need to explain
that for instance when they would extract blood or prick it is better to leave the arm that
will be pricked loose, that if they want they can put the other arm tight but if they put the
arm that will be pricked tight the muscles will contract and after the prick it will hurt and
bother more.

Parents listened carefully to Telma. She further explained about the semi-implanted ports,

Catheters are important for many reasons. You’ll see that whenever they could they will
try to use a port for your children; there are different kinds of ports, some more
temporary than others. You need to know the exact port your child is having, take note of
its name and model in your notebook, because if there is an emergency and you have to
go to another institution it will be very useful to know quickly what kind of port they
have so you can give that information to the doctors quickly. In general ports save a lot of
pricks because the implantable ones are inserted under the skin and are connected into a
vein so instead of pricking your children’s arms they use a long needle that goes inside
the port. Then they can either take blood or flush medication into it. The port and its surrounding area have to be extremely clean all the time because we don’t want to have infections and then they will have to remove it. (...) As I said I think it is important to explain with your own words to your children or to ask doctors or nurses to explain them why they are pricking them, they need to know before it happens so it does not hit them by surprise and they don’t know what it is happening.

In countless occasions I observed children resisting to be pricked. They would yell, shout, contort, cry, ask for help, and move their arms and legs and whole bodies to avoid to be pricked. Sometimes children would start crying just by looking at the fellow of hematology who performed the previous lumbar puncture. One day a nurse came to the residents’ office at the CDU and complained to residents, “I tried put an IV to Karina [ten-year old, ALL] but she resisted, she is so strong. Can someone help me with that?” Children learned that these pricks are routine, they are part of the rhythms of their daily lives, and thus children and parents have to find ways to live with them. As Telma said to parents at that meeting, children needed to be prepared for these pricks, and to learn and be informed about them. The doctors and nurses helped them to be more prepared as well. Indeed, Telma at that same meeting touched upon the notion that being prepared for the pricks could help children to identify their emotions and able to navigate its suffering. She said:

Children’s imaginations are very creative and they can even be wild. But if you prepare them and explain to them what’s going to happen, that will calm them, you, and even the staff. The idea is that they could feel, given their possibilities, they are controlling the situation. Furthermore, it helps them to cope with what they are feeling, and that’s a part of what you give to your children, which is to help them to grow while living and facing what they have to face. Even more, if you can’t help them to feel they have some control of their situation, at least you can help them to recognize their emotions and that they are suffering.

Telma told to these parents something they already knew and saw every day that indeed their children “grow while living and facing what they have to face.” But it was a reminder for caregivers that as parents they also help their children in countless ways and that both children
and caregivers are never passive to the medicalization processes they have to endure, rather they both actively engage with “what they have to face.” Slowly children and caregivers realize that they need to learn to “feel” how they can “control the situation.” Children put their body to treatment and thus they are growing while being treated.

**Lived responses to treatment outcomes**

How do children and their main caregivers literally give their bodies to chemotherapy treatments? How do they embody these complex relationships between what is going on within children’s bodies vis-à-vis their endless bodily change during the different phases of treatment, and the hematological pedagogy of “keep a close eye” to children’s bodies?

Children and their families are inserted in these particular hematological-entanglements, complicated situations where not only biomedical knowledge and practices but also biotechnologies, drugs, genetic mutations, bacteria and so on are all interconnected. The chemotherapies attempt to wipe all the malignant cells from children’s bodies, to shrink blasts present in the bone marrow to a normal level of fewer than 5%. Children and parents suddenly become part of complex networks and systems that attempt to reset children’s bodies, which are under constant close surveillance. I observed many examples of how children who were directed by professionals to closely watch their own bodies. One material aspect of these modulations was related to things to do or avoid: hematologists gave children a long list of *don’ts: do not* eat in the streets, go to shopping malls in the winter, drink grapefruit juice (it creates interactions with some chemotherapy drugs), etc. They were also told things to avoid, most importantly contact with people with infections or other sickness. Therefore, children and caregivers were forced to adjust to different rhythms of illness and treatment while learning to manage the
treatment and its emergencies. They needed to be separated from a dangerous environment prone to invade and makes even sicker children’s bodies.

In a sense children’s bodies while under treatment were always more-than-a-body. Clinicians were constantly looking for pieces of matter that could be removed from the body into samples, biopsies, fluids to be measured, etc., that would eventually provide new information for each child’s treatment. Needless to say, each medical intervention, whether a blood sample extraction and the news it created in return had a direct effect on the patient and his or her surrounding world. Children’s bodies are entangled in endless dynamic webs of syringes, intravenous lines, pumps, monitors, people, emotions, and knowledge. Therefore, what is behind and in-between the interactions between children, families, and hematologists is as important as other clinical measures, especially when considering how these modulation processes sustain these interactions and affect the long term therapeutic outcomes. The outcomes of these massive re/dis-placement that is occurring within and beyond each child’s bones marrow (and, of course, their whole bodies) have an impact at the level of social interactions, experiences, and connections children, families and hematologists constantly create.

Generally speaking, there are three kinds of therapeutic outcomes possible for children living with hematological conditions (in a gradient of endlessly changing concrete situations):

1. **Remission (complete remission)**: No evidence of disease after treatment. This means that fewer than 5% of (lympho)blast cells are present in the bone marrow, the blood cell counts are within the normal range, and there are no symptoms or indicators of the disease. There are different kinds of tests to measure this; flow cytometry and PCR (polymerase chain reaction) can confirm at the molecular level there is no presence of disease.
2. **Minimal residual disease**: No evidence of disease after treatment at the microscopic level with standard tests but at the molecular level there is still a threshold of disease in the bone marrow.
3. **Active disease**: Either there is evidence leukemia is still present during treatment or that it has relapsed. In order to be considered a relapse there must be more than 5% blast cell in the bone marrow.
During my research I was able to observe children (and caregivers) in these three categories. Of course, everything is dynamic and indeed hematologists need to manage a wide length of time if we think that from the beginning of treatment until the end of the last control it may take ten years. Yet, even when the most active part of treatment is done hematologists are also aware that some children can fall into the cracks if they do not follow the routine controls. Still, the great majority of children at this clinical site achieves complete remission and is properly followed and controlled by the HU for years. The children that I observed more often during my fieldwork, and that actually interact more with the different professionals are the children under active treatment, within the three phases, but also children that are experiencing more complications during treatment such as infections, or children that have relapsed and have to start with new post-relapse treatment.

Phenomenological impact of illness / sickness experience on family

There are many ways in which the hematology team can access child and family’s everyday lives, and one key way is through the setting of *alarmas* (“alarms”), which are changes that clinicians expect caregivers to identify and react in certain ways, for instance, the appearance of fever. The induction phase ends when the first phase of chemotherapy is concluded. In the second, consolidation phase, children and families are able to recover some of their lives and, to certain extent, de-medicalize or at least de-hospitalize their everyday lives a little bit more. At that moment children are able to leave the hospital and spend more time at home. At this stage, children experienced more time outside the hospital at home or in hotels if they are from far-away provinces.
One day I observed the follow up clinic with Claudia, an R4 (4th-year Resident) who was doing a rotation in the Hematology Unit. We were at one of the clinical cubicles, when Claudia called in Nora, a 6-year old girl, with her parents. Nora had an acute lymphoblastic leukemia. Claudia, Nora, and her parents and I were left in the clinic by ourselves because the Fellow in Hematology had gone with another patient to do some images. They came with the results of the blood test taken early that morning with a note that said “Nora will need red blood cells and platelets transfusion” (one of the hematologists must have written that after checking the result). Claudia proceeded with the clinical examination. She asked Nora different questions while she checked if the ganglions in Nora’s neck and at the back of her ears were swollen, she checked her mouth and ears for infections, and checked other parts of Nora’s body. Suddenly she informed Nora and her parents that she had to stay at the Hospital de Día (‘Day Hospital’) for a transfusion. As soon as she said that, Nora started to cry, and told her mother,

… You always do the same to me, you tell me we are coming quickly and then we have to stay all day at the hospital. I already overcame difficult moments, and now I have to go through another difficult moment again.

The mother tried to comfort her and she told Claudia that may be they could do the transfusion via an IV instead via a catheter (it would be faster since they had to “unlock” the catheter). Claudia told them she was going to check with the Hematology Team and left the room. As soon as the mother suggested the use of an IV, Nora opened her arms and her mother started looking for veins. This small vignette shows the kinds of lived experiences children and families embody while going through the intensification/consolidation phase. They were not new to the hematological treatment at all. Indeed, they tried to negotiate with their doctors in order to influence their therapeutic paths. But, still, children may go through constant ups and downs, and they may end up enclose at the hospital more than what children would want to.
When talking with parents I often told them how much I marveled at their constant care for children. Analia, a mother of fourteen-year old Pablo with acute lymphoblastic leukemia from a far-away province once told me,

Yes, yes, yes. From the very beginning we are doing everything that we could to make Pablo feel better. And it is hard, very hard not only for Pablo, my husband, and myself but also for our six other kids. Because I’ve been far away from them for almost a year and Victor from February but thank God things are getting better, and now next week they would possibly give us the final discharge. We could have gone to our home already a week ago, but we decided to stay to be sure that everything was right. If all the tests are fine, on August 5 [2011], they will give the discharge from the maintenance [phase] and he will just need to come for routinely controls. We will be able to go for two weeks to our province and then come back. But this would be great because Pablo will be able to see his siblings and go back to his town. Now we are better organized, but at the beginning everything was so difficult, so painfully difficult.

As Analia says, from the beginning she did everything she could to make Pablo feel better. She told me that coming from a faraway province and leaving her big family behind was very difficult. But when I interviewed her both parents were taking care of Pablo, having gone through the first two therapeutic phases, while the other siblings were left in charge of an aunt. By this time they were attempting to recover some of their lives. According to Analia, Pablo was eager to go back home and have some time with his siblings. Throughout the lengthy treatment children and caregivers inhabit this liminal state, this blurry threshold, between sickness (becoming a leukemia patient) and healing (becoming a cancer survivor and healthy child). Parents and children experienced a sense of relief at the end of treatment, though some fears may stay latent. As Brenda, the mother of Luisa told me,

Luisa is doing fine. They are giving her maintenance chemotherapy via mouth but I kept wondering from the beginning why they [hematologists] say that leukemia can be cured if you cannot cure it? To me, you cannot cure it; at best you can adormercer (send it to sleep). But how can doctors say that leukemia or any cancer can be cured?

Brenda had already taken care of Luisa throughout the almost two years of treatment. Still, she wondered about a fundamental issue in the world of cancer: does treatment “cure”
leukemia or “send it to sleep”? As a mother and caregiver Brenda embodied this fundamental fear. Children’s long treatment processes normally take more than one year (frequently more than two years). However, when children formally finish their treatments, usually that is not the end of their medical journeys. Then, children will have to be followed-up for five to ten years. Therefore, their lives will still be under different kinds of medical gaze (although in low intensity mode) even when formally considered a “cancer survivor” living a “life free of illness.” And every time children would come for a regular check-up to confirm they are still “free of illness” that event will bring loaded images and emotions. In another case Carla, the mother of six-year old Cecilia with acute lymphoblastic leukemia (ALL) in “complete remission,” one morning recounted that the hematologists told her,

…the ALL was not going to be cured; they said they will put it to sleep. Fortunately, Cecilia is fine now. Since the beginning of this year we went from having a check up every month to one every three months. Cecilia is free of illness but … ((she stops and starts crying))… I can’t talk any more…

As Carla shows us we need to focus on what sorts of long-term effects do these encounters produce in children and those involved in treating and caring them. Both Brenda and Carla were talking about the impact of treatment to the caregivers and family, and the contradictory ways they both understood cancer and what can be medically done with it (cure it or put it to sleep?). They also show the fundamental fear caregivers feel even after treatment is completed: will it come back?

**Conclusions: Children’s whole lives are modulated**

As we have seen in this chapter, children’s corporealities and subjectivities are dramatically changed while going through the hematological treatment. Their usual patterns of maturation are disrupted by the double irruption of the illness and the professional attempts to cure it. Children’s
experiences are intermingled with their families and several key professionals’ experiences: they are part of a collective embodiment process in which the hematological treatments become a fundamental entity. The hematological treatment in particular and the clinics in general play a central role on framing the different kinds of experiences children and their families endure throughout the one to two years usually treatment takes.

Chemotherapy’s rhythms as well as its unpredictable and unwanted side effects are part of children, families, and hematologists’ everyday experiences; they organize and play a central role on these collective modulations of children’s lives. These events change the relationships within the family, as other healthy siblings are often set aside and parents concentrate on curing the sick child (Blueblond-Langner 1996), or when the mother has to leave home and move to the City of Buenos Aires for months or even years leaving the father (if there is a father) and children under the care of old siblings, fathers, aunts and other forms of kin arrangements.

During the many multi-family meetings I attended at the CCF, parents talked about key themes related to this modulation processes. Parents described in different ways how their children’s illnesses had affected their relation with their children and with themselves. A regular refrain was, “I have to keep fighting for my son.” They also frequently commented on how their sick children changed their relationships with them and with their siblings. They also mentioned how each parent had to change their relationships with other siblings, and how the medical travel to the Hospital Infantil affected the family dynamic and created a big financial and economic burden. Often families had to either split or relocate in order to pursue treatment, and that was not an easy decision. Indeed, it is clear that the long treatment process affects the family as a whole, with families trying to find meaning in those drastic changes.
Some parents talked about how they tell their children that overcoming the illness becomes a sort of legacy for the future. One mother said she always reminded her son, “You will tell your own children and family about everything you went through.” Parents also mentioned how peer-support from other parents in similar situations become essential, indeed, how only those that are experiencing these kinds of situations are able to understand it (other family members often do not get it and can be even detrimental). In many cases husbands and wives struggled to keep their marriages intact. Consequently, many couples split and divorce, usually leaving the mothers in charge of the sick child and responsible to continue his/her treatment.

In general, after overcoming the child’s illness families felt they need to give back to those parents that are starting the journey and support them with good advices and encouragement. As one mother told me, these types of medical journeys are “hard, complicated, and you can get lost and discouraged very easily.” In the next chapter we will continue deconstructing these journeys and focus on children and how we can think about their experiences from their own bodies.
Chapter 7: “He can do everything”: Children’s permeable bodies at the center of cancer treatment

“Prick me here; please don’t prick me in this other arm. I know my body.”
Leonardo, 5-year old, treated for an undiagnosable anemia.

“The most difficult thing is that he talks to me like an older child. He tells me ‘You don’t understand that I don’t like this!’”
Mother of a 4-year old boy living with acute lymphoblastic leukemia.

“Alejandrito [little Alejandro] is a super smart kid. He can do everything.”
Emilia, mother of 10-year old Alejandro living with acute lymphoblastic leukemia.

What can a child like Alejandro, a ten-year old boy with an acute lymphoblastic leukemia (in remission) actually do during a lengthy hematological treatment? In the midst of blood tests, monitors, portacaths, chemotherapy, and other treatments, children may possess, expand, and discover different kinds of capacities and abilities built through months and years of medical interventions, hospitalizations, and medically mediated interactions. In this chapter, I examine not only constraints but also capacities built through these social and medical relationships. I ask: How can we think of children’s individual, but not isolated bodies? How do their bodies mediate their experiences to develop capacities acquired through treatment in this clinical context? What specific knowledge and actions are central to the experiences of children, family members and key professionals in this setting, in particular to children’s capacities to (re)act? I will consider two key areas in regards to children’s experiences of intense medicalization: children’s corporealities/subjectivities and their personal development during treatment.
Making sense of children’s bodies

As Hirschfeld (2002:614) argues, “People everywhere and at all times have some beliefs about what children are and what should be ‘done’ with them.” And this is precisely the question I am asking in this chapter: What are the underlined beliefs about what children “are,” and not only what should be (medically) “done” with them but also what medicalized children’s bodies can do (under these circumstances)? In other words, after looking at what professionals do in Chapter 5, and how the treatments impact on children and families in Chapter 6, in this chapter I am interested in locating children’s bodies at the center of my analysis. One way of making sense of how children in this particular medical and social context are understood is to look at the medicalized and hospitalized children’s individual bodies and what they are capable of doing, particularly in relation to face-to-face relationships they build with others.

As Montgomery (2009:3) puts it, “there is no universal child and the concept of the child is one that must be defined internally and in its own context.” Thus, “childhood” does not constitute a universal phenomenon or a singular one; and it is not less culturally produced as “adulthood,” or “parenthood.” Nor it can be isolated from other variables such as class, gender, ethnicity, and able-bodiedness. In fact, I would argue that illness/disability/chronicity in tension with able-bodiedness is a crucial aspect to consider when looking at different kinds of childhoods throughout the world and within a particular society. Toren (1993) argues that we not only need to constantly re-think the relation between childhood and adulthood but also to investigate children as both products and producers of specific biological, cultural, and historical conditions. For Toren, children’s cognition develops in a continuum within particular micro-historical and phenomenological conditions through an embodied engagement in the world. In this chapter on children’s experiences, I will focus on the impact of hematological treatments on their bodies
and what they are able to do in spite of and even because of treatment. By so doing, I will reflect on how children’s bodies, as a corporeality/subjectivity continuum were conceptualized, what children “are” in relationship to, and what needs to be “done” to them.

**What can a (medicalized) child’s body do?**

The multi-family meetings at the CCF I attended once a week was going to be cancelled. Telma, the psychologist in charge, was very busy upstairs and some parents were still around with their children playing and running all over the place. Other parents left the place realizing that it was too late to start the meeting anyway. Emilia, the mother of Alejandro, a ten-year old boy with an acute lymphoblastic leukemia in remission, came to me and asked me again what I was doing. She asked me, “You are not a father, are you?” I had already participated twice on different meetings with Emilia and I was seen in the building between meetings. Yet, my presence was not clear enough for her. I rephrased the explanation I usually gave at the beginning of every meeting during introduction. I told Emilia that I was conducting research to understand what kinds of relationships are built between children with cancer, their parents and families, and the several professionals that assist them. Emilia looked at me, and said,

> Yes, it is very important to understand this relationship and how it affects children. For instance, I have to tell you, [she looked at my small field notes book] write this down, Alejandro [little Alejandro] is a super smart kid. **He can do everything.** He failed [school] last year because of all the treatment and everything but now he is happy because he is in the same class with his younger brother, they are together all the time [I could hear them yelling while playing games at the computer in the other room]. But, I tell you, this damn disease made him smarter. Anything that is broken at home, radio, remote control, tools, he fixes them. He is a very intelligent kid.

That day, while biking home from the hospital after fieldwork, I contemplated the complicated paths of children with all sorts of chronic and potential life-limiting conditions such as leukemia. Against commonsensical notions that children with cancer might passively suffer
all the time, I also reflected upon Emilia’s narrative of cancer making children not only smarter, but also a cancer-enduring super-child, like little Alejandro who “can do everything.”

Emilia’s words resonated with me on multiple levels (personally and professionally). At the time of our encounter I already had a small daughter and was amazed by everything she could do (and every now and then I would meditate on our luck of not having to go through the kinds of experiences these children and families had to go through). I also continued to think about how the literature has considered and analyzed children with cancer capacities to act and influence others, to be in “the same boat” (Kelly, Pearce and Mulhall 2004), especially on the centrality of children’s bodies, who make decisions, and what happens around them through cancer treatment (Bluebond-Langner 1978, Bluebond-Langner et al. 1990).

Those involved in treating and caring for children, and me, as the ethnographer, can never be so certain of what a child’s body can actually do under these extreme circumstances. Like in the case of Alejandrino, in the midst of all sorts of unimaginable material and symbolic hardships (often with life-long effects), children may possess, expand, and discover different kinds of capacities and abilities built through months and years of medical interventions, hospitalizations, and medically mediated interactions. Therefore, I need to focus on both constrains and capacities built through these social and medical relationships. Thus, how do children themselves, parents, and several key professionals see and act upon these bodily changes? Furthermore, how can we think about children’s individual but never isolated bodies and their experiences from their bodies in this clinical context? What specific knowledge/actions were central to the experiences of children, family members and key health care professionals in this setting, in particular to children’s capacities to act and affect others?
Family members, professionals, and children themselves expressed on multiple occasions many different, and often contradictory, notions about what children’s individual bodies can (or cannot) do. For instance, just to mention simple examples taken from my field notes, parents would often say things like, “I have to do something with my daughter because she gets so bored at school all the time, she does not seem to care anymore” (mother of 13-year old girl with chronic myeloid leukemia on maintenance phase). Or, “I think the medicines have changed his character, he used to be shy and calm, and now he is more open and he talks and contradicts me all the time, he is now very rebellious” (mother of a 14-year old boy with osteosarcoma during the intensification phase).

These descriptions seem evident, yet they show the singularities of these changes not only at the level of children’s corporealities and subjectivities, but also at the inter-personal realms in which children were socialized and grew. At the time of these utterances both children had already had more than a year of treatment. Yet, children were acting in “unexpected ways” (at least for their main caregivers). For these parents something needed to be done. They were witnessing these changes and were trying to act upon this awareness. In fact, it is not surprising that a teenage girl that went through a highly demanding treatment may find her school boring. Or, it is also likely that a boy who was shy, during treatment became less shy and more prone to revolt and argue (at least with his mother, the one that is usually unconditional) after all the changes he experienced in his life. According to his oncologists, this could also have been the case of being on corticoids at high doses (see, for instance, Harris et al. 1986), but the mother disagreed with that. Certainly, something of the changes children experience has to do with their hyper-medicalized bodies and their growth. But how many of these changes had to do with the impacts of treatment and how many had to do with children’s re-appropriations and re-
contextualization of what was going on in their lives? In other words, if medicalization is an independent and complex variable, which are the multiple dependent variables that manifest in children’s lives as myriad effects of treatment?

Children too revealed conflicting perspectives in regards to their own long experiences of medicalization and hospitalization. The children had shifting reactions in regards to the long hospitalization. While I observed several children’s tiredness manifested in periods of incessant questions about when they would “return home”, at other times those same children made themselves comfortable in their room. For example, they hung drawings they had made in their rooms. Children’s ability to manage medicalization and living in the hospital depended on their age, gender, and family’s social class and also site of residence (to mention a few). Throughout my fieldwork I observed on multiple occasions how from early age children attempted to give meaning to their experiences and affect others. For instance, children would see how their parents and caregivers reacted to particular news or how other children (with “similar conditions”) were getting better or worse and used this knowledge to act in certain ways.

Children also acted as if they did not care about anything. One day I observed Yesica, a ten-year old girl with her mother Adriana at the Procedure Room at the HU. The nurse and fellow had prepared for a lumbar puncture and Adriana asked Yesica what she was going to eat for lunch, “Are you going to eat pasta”? “No”, “Are you going to eat potato”? “No”, and they kept going for sometime and Yesica was saying “no” to everything. It seemed evident to me at that time that Yesica was reacting to the procedure more than to what Adriana was asking her. Yet, both were trying to normalize an intense and invasive situation by chitchatting about lunch. This shows the centrality of children’s bodies and how from the beginning of treatment and hospitalizations there is often a “basic physiology” that children and parents are mostly concerned with: the
“simple” bodily processes. Parents are concerned in maintaining children’s physical well being, they are worried about children eating or losing their hair, basic things that happen to their bodies. However, it also shows how entangled these basic needs are with the rhythms of treatment and its interventions.

Doctors and nurses also showed multiple notions and practices in relation to what children’s bodies could do, and, how they should be treated professionally. As we saw in previous chapters, children’s sick bodies were forcefully changed and intervened with in order to free them from illness. Professionals are constantly juggling with the internal tension within medical practice between objectifying patient’s body and finding the subjective person in the ached body they are treating (Young 1997). As Josefina, a second-year medical resident at the CDU told me,

Many times you treat children as if they were little machines, that, OK, they are sick, and we need to fix them. Until you realize, after a mini-reflection, and you say “this is a child that should be playing soccer, and that is hospitalized, pricked everywhere, and that says ‘OK, if you have to prick me, prick me.’”

To different degrees everyone is invested in thinking and acting upon certain institutionalized notions and practices in regards to what children’s bodies can (or, cannot) do. These are heterogeneous notions/practices also informed by each particular medical specialization. However, what can a (medicalized) child’s body actually do? Certainly, I am not referring to an abstract body. I am thinking about that particular five-year old child Leonardo that had to be pricked four times in his left arm one rainy afternoon because the nurse could not find a vein for the IV for the blood transfusion, and how he cried, and how his mother was grabbing his right hand. Leonardo then said to the head nurse, “Prick me here, please and don’t prick me in this other arm. I know my body.” When I ask what can a child’s body do I am considering him
and so many other children I observed during my fieldwork. I am always thinking about particular bodies. To answer what they can do I need to re-contextualize their fields of actions.

I observed bodies becoming holey and leaky entities constantly traversed by inside-out and outside-in opposing forces. Corporeality/subjectivity is developed from specific coordinates. Following Grosz (1994) I have focused on children’s corporeality/subjectivity as a continuum, not in terms of interiorities but rather as a shifting surface constantly being claimed by biomedicine.

In the next sections I will focus on illustrative examples of how children attempted to make sense of their experiences under multiple opposing forces. Each case shows a different theme in relation to permeability, social influences, and what children can do. First, I will consider Flor’s case, a rare example of an older patient who was also a mother. This case shows the impact that treatment had on her, how being a mother affected her clinicians (both at HU and CDU), and her relationship with her own mother who was caring for her at the hospital. Then, I will look at Gloria’s case, an example of how the particularly violent social world in which Gloria and her family were inserted drastically affected Gloria’s body and her experience of pain. Finally, I will consider Rubén’s case to think of how he embodied his end-of-life and how this affected his family and the palliative care team.

Flor: A Patient and Mother

The first time I saw Flor was in the Communicable Diseases Unit on my first day of fieldwork there. I started my day by introducing myself to the rest of the staff at the unit (at that time I had so far met the Head of the Unit and the Head of Clinics at the Hospital). Then, I met the medical residents who were rotating at the Unit (second- and fourth-year residents, and the head
resident), and to some of the parents and children that were hospitalized that day. Flor, a sixteen-year old girl, was at one of the isolation rooms accompanied by her mother Sofia. They both had come from a rural indigenous community from one of the North Eastern provinces beside Paraguay less than a month ago. Flor was first diagnosed with acute lymphoblastic leukemia and started treatment in the capital city of her province (more than 200 km from her town). One month after the initial treatment, both were sent on an ambulance on a 24h, non-stop, drive to the City of Buenos Aires. The doctors at her province told Flor and Sofia that she was going to go to the City of Buenos Aires “just for one week.” On that first day at Hospital Infantil, the staff doctor knocked the door and we entered. Flor had just taken a shower and she was standing next to her room drying her hair. The staff doctor asked her if she could cover the site of the IV well to not get wet while taking the shower and Flor said “Yes, no problem.” She introduced me as “an anthropologist.” Flor seemed to be in good mood and was laughing every time the staff doctor would call her reina (“queen”) [doctors at this unit often refer to little girls as mi reina (“my queen”) or mi princesita (“my little princess”)]. Flor was at day 31 of her hematological treatment for a “high risk pre-B ALL” and according to the staff doctor she was en perfecto estado clínico (“clinically perfect”), she did not have lesions in the mucosa, constipation, or other side effects. She was going to have a bone marrow aspiration and lumbar puncture in two days (day 33 of treatment) and she was taking asparginase for her treatment. She was initially hospitalized at this unit for an infection on her left forearm with fever (she was under multi-antibiotics treatment). Both Flor and Sofia said fever came just after her cancer medication. She also had diabetes as a consequence of her treatment with high doses of corticoids. Sofia then told me that when Flor was originally diagnosed she was “vomiting blood for three straight days. We didn't know what was going on.”
After some days I began to notice that when the residents talked about them they referred that both, but especially Sofia were “difficult to deal with.” When I encountered them and talked with them Flor would tell me that she did not understand many things, for instance, why they needed to check and prick her fingers every day to check her “sugar in her blood.” The medical resident in charge of her would come every day to check the glucose test on her in the early morning and in the afternoon and she seemed to be fine and only rarely she needed correction with medicine. The resident after sometime tried to teach her how to do it herself. The resident in charge one day asked the other residents “Do you notice that she writes in random places when she has to record her medication or her diabetes”? They were not sure whether Flor was literate.

During the two months I saw Flor and Sofia as they went through a myriad of hardships. Flor never left the hospital during all that time. Sofia was lost in the big city of Buenos Aires - she was even lost within the hospital at the beginning. One day I volunteered to accompany Sofia on the subway and guide her to the delegation of her Provincial Government in the City of Buenos Aires to do some paperwork for Flor’s subsidy. She had never taken a subway and it was a big shock for her. She almost fell on the escalator and had to grab my arm when we put our first foot on it. On our way back to the hospital, she wanted to walk so we did that. Both Flor and Sofia seemed to be lost and took them awhile to become familiar to the hospital setting.

The first time I heard from the medical residents that Flor had a one-year old daughter I was surprised. Apparently, the paternal grandmother looked after the daughter in another province. Flor had already split with the father and she was very worried she would never see her

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67 The staff and residents at the Communicable Diseases Unit thank me for that but I was glad I could have time to talk with Sofia about her life as an indigenous woman in her rural place and how it had been affected by Flor’s disease.
daughter again.\textsuperscript{68} This was a “rare case” for two reasons: none of the professionals (from Hematology, Communicable Diseases, or other units who treated her) remembered a case of a patient/mother with pediatric cancer before. Moreover, in this case the mother had been forcibly separated from her daughter by the abrupt start of the treatment, which was a constant source of worry for her, her mother, and key health care professionals treating her. She was going through an intense form of medicalization while being separated from her own daughter.

As a patient Flor had had a tough experience while treated in her province. Even a routine check-up in the dentist that hematologists request before a new cycle of chemotherapy was stressful for Flor. She told me that in her province she went to a dentist that removed one of her molars and she suffered a lot of pain, she did not eat for four days straight. Now going to the dentist caused her fear and a vivid memory of that pain. Indeed, I accompanied Flor and Sofia and saw how she was contorting her body on the dentist chair just for a check-up.

Medical residents and staff at the Communicable Diseases Unit were worried about Flor at the beginning of her consolidation phase (she was finishing the third chemotherapy cycle). Because she was under control they wanted to discharge her and send her to a cheap hotel in the City of Buenos Aires subsidized by their Provincial Government. Yet, they worried she was not going to appropriately self-manage her diabetes or come to the Hospital Infantil when needed. They said that this was caused by \textit{una causa social} (“a social issue”). The head of residents said, “Here she is under control, and sometimes you delay some hours to give her medication or her glucose, but imagine if she is in the hotel and she gets worse because her mother let her out. If one day passes [without medication] she could die.”

\textsuperscript{68} Indeed, there is ethnographic evidence of “stolen children” in this ethnic group taken by grandparents from parents so her worries were logical. Also her former partner was already engaged with another woman and he had sold all her furniture and things after she left her place.
Flor’s individual body was seen somehow differently from other teenager patients and she attracted considerable sympathy from both Hematologists and Communicable Diseases specialists. I wondered at that time if there was a third layer to the patient/mother story: she was also indigenous. She was exoticized and seen as “different.” I was able to observe meetings between Hematologists and staff doctors at the Communicable Diseases Unit in which they discussed with Flor not only the need for her to go back to her place to see her daughter, but also the required logistics for that to happen. Hematologists were pushing more for her to travel whereas Communicable Diseases specialists were more doubtful since they were the ones that treated her on a daily basis.

She had ups and downs in her relationships with Hematologists. On one occasion the fellows from Hematology came and “hung her chemo” [set the chemotherapy medicine in an IV pole] as one of the Hematology residents quickly informed the medical residents at the Communicable Diseases Unit without giving her pre-medication (fluid expansion and/or anti-emetic) nor explaining to her about the chemotherapy she was to receive. Consequently, Flor was infuriated with the hematologists. However, after knowing more about Flor and her separation from her daughter, the hematologists created a ventana segura (“safe window”) that enabled her to take a one-week trip to her home to see her daughter. They talked a lot about this during their daily review of cases. Also, the head of the Communicable Diseases Unit herself went to the bus station and took Flor and Sofia to find a bus ticket.

Eventually, Flor was transferred to other units, where she had less face-to-face interactions and quality time with residents and staff. People there knew less about her, and in

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69 The whole institutional work done by Hematology, Communicable Diseases, and Social Work to create the conditions for this trip was an indication of how much this patient/mother/indigenous woman affected them.
some cases even distrusted her. One nurse in another unit claimed that one night she saw Flor taking food from the parents’ fridge that did not belong to her. In another instance staff thought because she was indigenous she could not properly speak Spanish. Residents on another unit, while trying to prick her without explaining the procedure were surprised when Flor resisted and demanded, qué carajo estás haciendo? (“What the hell are you doing”?). When I heard about rumors of stealing I wondered how Flor and Sofia would feel in a place, different from their everyday lives in their rural indigenous village, in which food is not shared and perceived as individually owned.

The mostly white-middle class medical residents and staff are usually aware of social class or ethnic differences but often do not have the sensibilities or training to deal with them. Moreover, concentration on their medical competencies and the biomedical model in which they operated compelled them to focus on the individual, biological realm leaving aside social dimensions of care.

At one point tensions between Sofia and the doctors and residents on the other units were so high that doctors asked Social Work to find a therapeutic companion for Flor since they felt Sofia was not helping with Flor’s treatment. Although rare, I observed few cases in which caregivers were separated from children because doctors and social work thought they were harmful to their children. After that she had two part-time therapeutic companions for a while.

For some time, hematologists and others tried to find out where Flor’s daughter was. After tracing Flor’s daughter through the provincial Police, and calling by phone to the biological grandmother, after many attempts, social workers and hematologists were able to
locate the daughter. Then, both social work and hematology planned for a safe gap during her treatment in which she could take the trip. Flor had to explain to the doctors that she could not go for less than one week, preferably ten days, because only the trip on bus was one day to the capital city and then another day to her village. One of the hematologists warned Flor in that meeting “If you abandon treatment you will die. You know that, don’t you”? And Flor responded, “Yes, I won’t abandon my treatment because I want to get better.”

I moved to another part of the hospital to continue with my fieldwork and did not see Flor for a while. Then, one of the residents told me how Flor found her daughter. She and other resident that knew Flor were very moved by the story of this re-encounter. She said,

Flor went to this rural village to look for her daughter. It was already night and she went to the house of the lady that was taking care of her daughter. Flor came with her lantern and her dog (it was taken care by one of Flor’s sister). At the beginning her daughter did not recognize Flor, she was bald and she hadn’t seen her for six months. But Flor’s dog went to her daughter and ‘showed’ her that she was her mother, her dog pushed her daughter to Flor. The lady did not say anything and she gave her to Flor and Flor took her to her place.

After ten days of travelling to her home, Flor returned to the hospital with her daughter and her former partner. Sofia went back to her town and did not return back to the city of Buenos Aires because she was missing her three other children. Flor, her daughter and the former partner lived in a cheap hotel paid by the provincial government. After three months I received an email from one of the residents that took care of Flor at the CDU:

Bad news…Flor had a cerebral haemorrhage last Saturday caused by her thrombocytopenia and she is in coma at the PICU, she almost has brain death… this is a shock! She was perfect up until a week ago, and her ex-husband and her daughter are here…

Then, one day after, she sent another email in which she explained:

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70 I also asked Dr. Tola who work with indigenous people in this area and she contacted some of her key informants that told her that both the father and grandmother were “white.” Dr. Tola was worried they would never return the baby as it happened many times during her fieldwork (personal communication July 2011).
Hello Rafa! She was in U10. Apparently she had a peak of hypertension and she began with headache and when they did a CAT she was already in coma… The brain CAT is a disaster. They said it is just blood… There is always a risk of this when you have such a low platelet level… That’s why whenever they start with headache or some other neurologic symptom you have to turn the alarm…

Two days after Flor went to PICU she died. After that I lost track of her daughter and her former partner. Sofia returned to her province and never came back to Buenos Aires. Flor’s doctors did not know what happened with her daughter and former partner.

Gloria: How the different social worlds influence children’s individual bodies?
I met Gloria, a thirteen-year old girl originally diagnosed with osteosarcoma, when the Palliative Care Team (PCT) was treating her. The Oncology Team was her main care providers but she had been treated by the PCT for more than a year. At the time I met her she already had her left leg amputated below her knee. She also had lost her right eye as well. She had had severe, intractable pain for many months until the palliativists could only decrease her pain to a “manageable” level (Gloria referred to her pain was 4/10). The first day I saw her she was in a wheel chair, using a mask on a cold winter morning, with her mother behind her seating in a bench outside the Oncology Unit. She was on high doses of methadone (they used morphine first but could only partially control her acute pain). Marcos, from the PCT, described to me how hard was to reach a point in which Gloria could feel comfortable without so much pain. That first day Marcos, Gloria and her mother talked about her Magnesium levels, a source of worries for them and for their oncologists. I could see that day there were some tension between PCT and Oncology. Oncology said that her magnesium was never under control because of the pain medication she was receiving from the PCT. In response, Marcos from the PCT told them, “I understand the oncologists’ worries, but there is no bibliography to back that up.”
That day the PCT was asked by both the clinical units and the oncologists to see Gloria in order to explore the possibility to decreasing the doses of methadone. One of the oncologists asked them to descomplejar los remedios paliativos (“decomplexify her [palliative] medication”). One of the doctors from the PCT was telling me on our way to see Gloria, “It took us a lot of time to reach this point in which Gloria has no pain. She had a lot of pain, she lost one eye, and they had to insert prosthesis on her leg after two surgeries.”

After a while, and after tweaking her medications, her pain came under (certain) control. However, one day her cousin and best friend were kidnapped in her working class neighborhood in the Greater Buenos Aires Area and her pain became incontrollable. Gloria and her mother Susana described the event in one of the visits I observed with the PCT. Gloria told us that she was very close to her 14-year old cousin Florencia, because they were only a year apart in age. Florencia was quiet and frequently stayed at home and did school homework and talked with Gloria when she needed rest after a chemotherapy cycle. They lived in a working class neighborhood and according to Susana, “There is a lot of drugs in our neighborhood, and the police and drug dealers are all the same. They work together and there are a lot of girls that disappear and are enslaved to work as prostitutes.” Gloria described to us what it was like to live in a place where young girls were kidnapped and I could not stop thinking about how this social world affected her. Gloria told us:

My cousin Florencia was kidnapped last Friday in my neighbourhood. [She disappeared for three days]. Florencia is a very shy and quiet person, and she is always at home watching TV with me, she helped me a lot while going through all the chemo. She left home that Friday with a friend. She never goes alone because she takes care of her other siblings, but this time a friend from school came to look for her and told her they were going to a birthday party of another friend and that they would be back at 9:00 pm. She didn’t come back at that time and so when time was starting to pass everyone began to worry. After two or three hours her parents went to the local police station to denounce her disappearing and they told them to stay calm, that they were going to look for her.
Gloria’s uncle and other family members are also part of the provincial police forces, and thus they started to use all their contacts. They walked the neighbourhood and moved every stone until they found Gloria three days after her disappearance. Gloria continued,

They’ve found out that the person that kidnapped her was a transa [local drug dealer] of the neighbourhood that lives just behind the local police station. And, of course, the local police station was doing business with this transa. So some of my uncles, and other members of my family who work at the different police forces went and talked with a puntero [local politician] who then got in touch with another police station from a nearby neighbourhood and they were the ones that investigated the case. They quickly found out that one of Florecia’s friends was the entregadora [lit. surrender, the person that “delivers” girls to the drug leader’s band].

Florecia’s father, when they knew the exact place where she was being held, went with the police of a different neighbourhood to the place behind the police station. However, because they did not have any legal permission to enter the building the police could not get in. Goria narrated how…

Like in the movies, my uncle said he could not wait so he broke in alone and heard how some people escaped through the roofs; he also saw a guy called Chino who sells drugs that was petrified and Florecia’s friend. (…) They couldn’t rape her because she was yelling so much and she was hitting them too. The policewomen checked Florecia and she didn’t show marks of being sexually abused.

This episode had a great effect on Gloria. It took time for the PCT to control her pain. Evidently, Gloria felt the events at her neighbourhood affected her. She told us “I could not sleep for a while, and I was sad and worried all the time.” This topic re-appeared in our discussions together after a person from a middleclass family was also abducted and it appeared all over the news.

Oncology kept complaining about the interaction between pain medicine and Gloria’s absorption of magnesium and potassium. At one point Marcos from the PCT told Gloria,

Tell your oncologist that you are fine now because we can control your pain. Do you remember how painful your pain was? Tell them we will do our best to slowly decrease your pain medication but as long as you need it you will receive it.
Gloria was fine after several weeks. Susana, after a month, was worried because Gloria wanted a piercing on the upper part of her left eye. Susana insisted she should not do it and told one of the members of the PCT that “We had to go through myriad of hardships, amputation, loss of an eye, but we did it for Gloria’s good.” Gloria insisted and Susana was afraid not only because Gloria had to overcome a removal of an eye but also because of potential infections. Thus, Susana went with Gloria to see their main oncologist. Susana wanted the oncologist to say no about the piercing but the oncologist told them, “Yes, she can do it. There is no problem. She went through so many things. If she wants a piercing she can have it.”

In Argentina, not every child will live under this extreme kind of violence. However, there are many stories of young women being kidnapped by mafias, with the compliance and co-participation of corrupt politicians, judges, and police forces. As we will see in more detail in Chapter 9, families are immersed in a myriad of hardships, from social violence to economic violence, that add to the challenges that children, caregivers and other key family members had to navigate while also taking care of a child with cancer.

Rubén: Experiencing the end-of-life

I saw Rubén, a four-year old boy from a rural area close to Ciudad del Este in Paraguay (bordering country) living with an osteosarcoma in his right leg, and his mother Miriam for about three months when I was conducting fieldwork with the PCT. I was told that Rubén had been in great pain and the oncologists had referred Rubén to the PCT to help ease his pain. He did not

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71 Currently, in Argentina, there is an increasing public concern in regards to growing different forms of human trafficking (sexual, forced labor in the textile and agriculture industries) that are often loosely targeted by the government. There is a new agency, the Office for Rescue and Caring of Victims of Trafficking that was especially designed to attack this. See, http://www.jus.gob.ar/areas-tematicas/trata-de-personas.aspx. Retrieved 20121113.
want to talk, smile, or do anything. The first day that I saw him, his mood had improved.
Rubén’s right leg was swollen but his left leg was better than before. When we were leaving the
room that first day Alex, a PCT physician, gave him some pats on the head and told some jokes
making Rubén smile. Alex told Miriam that it was a good sign if he smiled. Miriam talked to
Rubén in Guarani (an indigenous language spoken in Paraguay and parts of north-eastern
Argentina) and then we left. The next day his aunt from the province of Buenos Aires was
looking after him in his room, while his mother went to do some paper work. His aunt said he
looked better, with less pain. He could swallow better, but he didn’t want to see any one. His
pain medicine was apparently working, but still he was yelling for his mother, Miriam, and
weeping every time a doctor entered to his room. He was losing hair from the chemotherapy and
seemed tired of seeing doctors at the hospital. The moment we said bye and left the room he
would stop crying and yelling for his mother. While Rubén sat quietly in his room with his aunt,
Alex and Mariana peered through the window in to door. Mariana turned to Alex and said,
“sometimes it would better to see children from a door’s window without them looking at
you…”

I saw them again the following week and Rubén was feeling better, and his corticoids and
morphine had been decreased. He was starting a new cycle of chemotherapy, but oncologists
decided they could not give radiation. The oncologist told Rubén’s mother that they might need
to amputate the leg since cancer seemed to be restricted to the femur (no traces in the lung or
other parts of the body). The decision was amputation.

A month and a half after I first saw Rubén and Miriam, I met two staff from the PCT and
the resident who had been responsible for Ruben’s care. They said Rubén’s cancer was
“progressing irreversibly” and the Hospital Infantil’s Bioethics Board concluded that there were
no therapeutic options, no chemotherapy, radiotherapy, or even a possibility of amputation since cancer has actually spread and it became resistant to the chemotherapy and radiotherapy. Cancer had spread to the right hip and in order to amputate it they would have needed to take one third of the hip without any guarantee whatsoever that they could stop or extirpate the tumor. At the time they had not yet given Miriam this news. One of the residents told us that during the weekend an anaesthetist came to check if they could perform a nerve block. According to the residents, he wanted to decrease morphine and switch it to tramadol (another opioid use for moderate to moderately severe pain). Residents at the unit did not decrease nor switch morphine because he was still under a lot of pain. Indeed, following instructions from the PCT they had to give *dosis de rescate* (“rescue doses”) of morphine in between the regular doses the day before and that day as well.

We entered Rubén’s room where he was eating with his mother. He looked good, and his hair was growing again, now that he wasn’t receiving chemo. After some time while Marcos from PCT and Miriam were discussing his symptoms, Rubén started to feel and complain about pain. First, Marcos checked his legs and Rubén said they were fine but then he started to feel a lot of pain. Rubén complained to his mother in Guaraní. Marcos checked the IV bag with morphine to see how much was it dropping and to check the other medication as well. They had a rescue dose at 9:00 am, it was noon, so Marcos told them they were going to raise morphine 4.3 cm more. He went to the Nurses’ Room and asked one nurse to add 4.3 cm of morphine and added to the IV bag. Then we went to the Staff’s Room and Marcos started to update Ruben’s medical chart. Marcos asked for the anaesthetist’s cellphone number. Looking a bit angry, he said he was going to call him: “In general we are fine if the anaesthetist does his job (nerve block) and I do what I know (pain medication)”. On our way to the PCT office, Marcos called
the anaesthetist and told him he had been following Rubén for a while and that although he is now officially “out of treatment,” he is still with pain. Because of this they would actually need to increase morphine (not decrease it or switch it to tramadol). The anaesthetist said that his idea was to decrease morphine and switch it to methadone. Marcos told him that it was a good idea but in order to do that he first needed to be stable with morphine, something that had not yet happened. Marcos also told him that it was still not clear what the family would do with Rubén. His father was coming the next day from Paraguay and no one knew if the family would like to stay or go back to Paraguay. There was possibility of giving them morphine or methadone that they could administer in Paraguay. Marcos added that sending him to Paraguay with morphine was also unlikely because they would not be able to cross the border to Paraguay with a big bottle of morphine. The anaesthetist said that the nerve block might work only for eight hours maximum. Marcos said that was fine, at least with that they could be able to cut the pain circuit for a bit.

Two days later, I saw Rubén at his room with his mother, father, Alex and Marcos from the PCT and the fellow from oncology. The parents said that Rubén was fine. He did not have much pain when he was lying in bed but he could not move or sit due to the pain. During the visit, Rubén watched TV and did not look at us at all. Marcos asked the father how he saw Rubén, and he replied that Rubén looked just as he did before they came from Paraguay. Rubén’s father showed us pictures of Rubén who had been very swollen in both the leg and in the abdominal area where there were signs of bad blood circulation. His father said that they were still waiting to talk with the oncologists.

As we left the room, Marcos told me that when Rubén and his family came to the Hospital Infantil at the beginning, Rubén was improving, the tumor and swollen area were
decreasing, and he seemed to be improving. Then, he had a portacath infection, and his tumor became resistant to chemo and radiotherapy, and the tumor grew back. It was measurably growing day by day and was now untreatable with surgery. When we left the unit we met Dr. Victor, who is on the Bioethics Board, in one of the corridors. He said that the board was uncertain what to recommend for Ruben: should he stay where he could be cared for, but where noting more could be done, or should they recommend that he return to his home in Paraguay. The board considered whether they could send Rubén back to Paraguay. Marcos told him that they did not know how to do it because his pain was still not under control and they did not know how to send them with morphine to Paraguay, where there was no appropriate medical care. Victor said that before they came they were in a Clinic in Paraguay and they came here with the assumption that Rubén did not have to be amputated. They were told that the most likely outcome was that they would go back in Paraguay. Victor added, “I understood you were not able to control his pain.” Marcos told him that they were seeing him every day and were trying to control his complex pain, and described, in detail, the many drugs they were using. He also told Victor about the attempts to switch him to methadone, and the need to control and stabilize his pain, as of yet unsuccessful. Marcos also noted he had many doubts about giving him medication, like morphine to take across the border. Victor said, “Well, if we are not controlling his pain here, what’s the point of him having pain here or there. I think we need to ask them if they want to go back to Paraguay to unite the family together for whatever time left he has.”

The next day we went to see Rubén, but first we stopped at the Residents’ Office and asked the resident in charge of Rubén how he was doing. She said that Rubén was doing fine, with almost no pain while lying in bed, but they were considering what to do next. She also added that the day before, one oncologist, it was unclear whom, came and apparently literally
told Rubén’s father: “Your son is going to die. There’s nothing we can do to cure him.” The resident said she talked for a while with the father about what to do. They have an aunt in Moreno (40 km from the City of Buenos Aires) and they could try to go there and see if Rubén can switch from IV to oral morphine and then see if they can go back to Paraguay. But first they were going to try to give morphine via a probe by mouth. We went outside the room to the corridor to talk with the father. He told us he came only for a week, the maximum time off that he could get from his work in a primary care immunization program for the government. He was considering going back to Paraguay with his wife, and Rubén. Rubén repeatedly said he missed his grandmother and his brother and that he wanted to go back to see them. Marcos told Rubén’s father that the main issue was how to be sure that he was going to receive the medication he needed. He also added that it was difficult to control Rubén’s pain. Both the palliative team and the oncologists were working to control his pain. One of the oncologists told the father that they could try to come every two weeks to obtain the morphine, but the father said it was not possible. Marcos then asked the father if he thought there was a possibility of crossing the border with a big bottle of morphine if they gave them all the required papers, his clinical history, and a letter explaining they need it for controlling Rubén’s pain. The father said he thought it might be possible because he worked in an immunization program and knew people at the Ministry of Health. He also had a cousin who worked at the border. Marcos told him that they were going to simplify his medication (morphine + gabapentin + anticonvulsive) as much as possible to help him with his neuropathic pain, which made him feel like he was having electric shocks.

The next day Marcos talked with the pharmacy and asked them to prepare Rubén’s morphine, gabapentin, and a tricyclic for thirty days. We went to see them. The father asked if they could come here again were they to need more. Marcos told him that they could, but that it
might be better to go to Asunción (Paraguay’s city capital at 300 km) than to the City of Buenos Aires (2 000 km). In the medical chart he wrote the phone numbers of two palliativists in Asuncion who could prescribe morphine, and the number of the only pharmacy in the whole country were they could find morphine. When Marcos talked with the father and mother I played with Rubén with some cubes he had in his bed, he was grabbing them and pilling them in small piles. At one point he started to cry when he saw Marcos giving his father all the paper work because he thought they were going to perform more tests. He asked his father if this was the case in Guaraní. That morning one oncology fellow came and gave the father a blister pack of pills. He said that this is “chemo by mouth.” Rubén and his parents went back to Paraguay. Marcos called them one week later. They were able to get the medication through the border with the help of the father’s cousin. She said Rubén was able to see all his family and friends, and that Rubén did not feel any pain or symptoms. The medication they took from the hospital lasted until he died. Miriam said thanks to the palliative care team for all their help.

With these three examples, I want to direct attention, first, to the individual corporeal, subjective, and social experiences of Flor, Gloria and Rubén. They each went through intense chemotherapy for their oncological (Gloria and Rubén) and hematological (Flor) cancers, and in the case of Gloria, radiation treatment. Flor was a patient and mother without her child close by. Gloria had had an amputated leg and had lost one eye. Rubén’s standard treatment did not work and he individually and collectively experienced the end-of-life. The three children had corporealized the medical treatments and its consequences.

What did it mean for each of them to be treated for cancer? In the first instance, Flor was a rare case of a patient who was also a mother far away from her daughter, and a variety of staff showed great concern about how she was doing. In the second case, Gloria had her pain under
control but was influenced by the extreme forms of violence she was subjected to in her working class neighbourhood. In the third case, Rubén and his family had tried to overcome the disease. They had moved from Paraguay to avoid the need to amputate his leg, but they were not successful. The did not overcome the disease and they experienced the end of Rubén’s life. These three examples show how children and others conceived what children “are,” what should be “done” to them, and also what actions are taken. In the three cases we saw their physical pain and struggle, and the course of their treatments. We can also see how these bodies not only absorbed intense social influences like in the case of Gloria’s pain after her cousin was kidnapped. These children also radically affected others like in the case of hematologists mobilizing resources to find a way for Flor to recover her daughter, or palliativists and oncologists helping Rubén and his family to go back to Paraguay with the pain medication. Myriad forces always traverse children’s bodies.

They each became central nodes in these groupings of biotechnologies and bio-knowledge that aim to wipe malignant cells from their bodies. By doing so, they become crucial actors in these clinical dramas. For instance, Flor’s body, to the staff, signified a complex relationship between the roles of patient and caregiving mother, particularly to the doctors and residents with children who saw themselves reflected in Flor. She also highlighted the relationship between sophisticated urban patients and rural aboriginals. Gloria’s body was seen by oncologists and palliativists where they contested differences in their explanatory models. The oncological care that focused on maintaining magnesium and potassium levels for therapeutic purpose was posed against analgesia and pain control. She also exemplified the individualization of external, social violence. Rubén’s body was also seen as part of the tension between ongoing medical care to reduce physical pain and the family goals of reducing his social
alienation during the end of his life. This dilemma was only resolved by “smuggling” morphine through national borders in an international context of uneven access to quality end of life care.

These three children’s stories demonstrate what they and their families, often with the assistance of doctors, residents, nurses and other staff were able to accomplish during their cancer care and even as they met death.

Corporealities/subjectivities

Through the course of cancer treatments, these children are often surprisingly aware of their circumstances and the challenges they face. Emma was a 6-year old girl with acute myeloid leukemia who was under treatment for about a year and had finished the consolidation phase.

When I first saw her, I was conducting fieldwork with the Palliative Care Team and she was alone with her mother in her room. The palliativists were called to ease some of her painful symptoms which at one point had included a painful herpes zoster. She was on a waiting list for a bone marrow transplant. But, because she did not have any compatible close relatives who could be donors, she was expected to wait up to seven months, according to the transplant doctors said. Both the hematologists and palliativists found it “hard to believe she was going to make it.” Seven months seemed a long time to wait. I wrote in my field notes:

According to the hematologists, Emma had a relapse intra-treatment, which is a “very bad thing.” Ten days ago, after less than a year of treatment, hematologists decided to suspend treatment. She is OK but she can get worse at any moment. Mariana, one of the hematologists told Maria from the PCT “these kinds of cases se prenden fuego (get on fire) in two days.” According to Mariana “she has an acute myeloid leukemia in free-fall, although in fact we couldn't say she is in free-fall given that she never had a complete remission.” Both parents decided they wouldn’t go for more treatment. The head of the hematology unit wrote on her clinical history they will give “maintenance treatment,” and he also told Maria that Emma is “DNR” [do-not-resuscitate]. Emma is noticing that something has changed. For instance, before she was not allowed to eat hotdogs in the street and now when she asks for one she is allowed to eat it. She also asked her mother if they would give her more chemo and since her mother told her, “We are going to give
you only some little pills,” Emma replied to her mother immediately saying, “Ah, maintenance!”

In this vignette we can clearly see how a six-year old girl not only knows that her particular situation has changed –she could eat things that were banned before– but also she is aware that something in her treatment has changed as well. This is a simple example that shows how children are attentive to the constant interchanges between people, an awareness of what they say and do not say, and what they can or cannot do. Children were able to grasp changes by asking, listening, seeing, etc. Every little detail counts. Children’s subjectivities are informed by their own corporealities and vice versa. This is why I am naming it as “corporealities/subjectivities.” Children, like everyone else, want to make sense of their worlds so they ask themselves why certain things have changed (in themselves and in others). They ask, ‘Why am I now able to do something that I could not do before?’ Children and parents also triangulate information collected from the different professional teams they interact with. Often the mention of quimioterapia por boca (“chemotherapy by mouth”) is a signal of a more “palliative” use that tries to target a specific area or organ affected by the cancer, and often the treatment does reduce it a bit. However, most frequently it means they are not able to eliminar el tumor (“erase the tumor”), and a cure is considered less likely. Consequently, it frequently indicates that the main hematological treatment is not actually working. In the same field notes about Emma I also wrote that day:

Maria (from PCT) told me that Emma’s mother is not feeling well because her own husband has died from cancer three years ago and she is very sick too (she is Emma’s main and only caregiver). Emma’s mother got confused with the morphine dosages; she

72 During the maintenance phase, after induction and consolidation, children are given low doses of chemotherapy for certain period of time. When treatment does not seem to be working often oncologists and hematologists give similar chemotherapy by mouth but in this case the difference is the tumor has not been wiped out and that professionals are hoping it will help children despite the fact that treatment does not seem to be working.
was only giving her 0.06mg, which according to María was like nothing. María asked Emma’s mother to stop giving morphine to her because if Emma didn’t feel any pain that dosage wasn’t going to do anything. Apparently, I could not confirm it, one of the hematologists told Maria “with these lab test results, Emma may not live next week.”

This is just one example of the interconnections children, parents, and key clinicians develop among themselves, and how it directly affects children’s corporeality and subjectivity. Emma felt with and from her body that something had changed with herself but also her confused and logically fearful mother. We can see how her corporeality was influencing her subjectivity. Moreover, their perception of the situation was compounded by previously seeing her father die from cancer. Emma’s experience also shows how medicine has limitations and how difficult it may be for physicians when treatments are ineffective and they realize they may be failing a patient. Indeed, because these children have to go through these intense experiences of permeability the failure of treatment may bring feelings of futility in their hematologists and palliativists.

A variety of professionals, oncologists, communicative disease specialists, palliativists, residents, nurses, and psychologists all contributed in make sense of children’s bodies and their capacities to act. One of the things Telma, the psychologist at CCF, would repeatedly advise parents at every multi-family meeting, was to explain in their own simple words what their children have. Telma once told parents:

Even to a three-year old child you can tell her ‘You have a disease in your blood, because of that doctors have to prick you and take blood from you and they have to give you medicines.’ And you can tell this to help them understand more what’s going in their bodies.

At the same meeting, Juliana, one of the mothers, said that she thinks that very often children know more than what adults think they know. Sometimes they know even more than
their parents, nurses, and physicians. She emphasized that this may happen because children (under these circumstances) grow fast (although she did not use this word):

I don’t understand how but my three-year old boy, since we discovered his illness and we started treatment, he is smarter [más vivo] and more aware [despierto]. He is very alert. For instance, he can’t drink milk since his last hospitalization [nine months ago] so doctors have to pass milk and medicine through a gastric tube. Therefore, he knows that when he coughs he has to grab the probe so it doesn’t fall out and he does it every time he coughs.

This constant negotiation about treatment to children’s bodies lies at the core of the intersubjective relationships among children, family members, and several health professionals. Each of the three actors have ways of explaining what children “are,” what they “have,” and what needs to be “done” to them (Kleinman 1976, 1978). In this way we can see the interplay of corporeality and subjectivity, how each actor subjective perspective is anchored in the corporeal body. Still, this endless negotiation also requires continuous adaptation as they are immersed in new, emergent scenarios. Hence it is crucial to make sense of what is happening to children throughout the long treatment.

**Children’s growth under medicalization**

In this part of the chapter I will focus on how the long experience of treatment has a direct impact on children’s particular physical, emotional, and mental growth. There is a direct relationship between how long the medicalization process is experienced and the maturation process each child is going through (Bluebond-Langner 1978, Bluebond-Langner et al. 1990). Children still grow while being ill and experiencing illness and treatment. The process then of becoming an ill child is so powerful that needs to be examined closely, in all of its dimensions. Parents and children see myriad changes on children’s bodies occurring quickly. Julia, a second-year medical resident rotating at the Communicable Diseases Unit puts it in this way:
The child with leukemia had anemia, or it was a child who had fever, and suddenly he ended up in a super-complex situation, and very sick. And as a side effect of the chemo he ended up with a lot of infections. So it is very difficult for the parents to understand that their child [is getting sicker], that is, physically they couldn’t see much. Maybe with a solid tumor you can see it. But with leukemia, which you don’t see it, it is like they end up sicker than before they were hospitalized.

The progression of medical experiences parallels the readjustments and displacements that children, as well as parents, siblings and other family members, and professionals go through on an everyday basis. As Hardman (1973) argued back in the 1970s, ‘childhood’ is not a pre-rational or pre-adult stage; it is a ‘present’ that needs to be understood in its own right. The present I am talking about here is a present of hospitalizations and complications of children’s medical-life situations. It is a present of urgently needed medical interventions.

Significantly, the impact of the medicalization goes beyond the mere physical. Children’s whole lives are also medicalized at least in their adaptations to the biomedical entanglements and the weeks and months living within the Hospital Infantil’s. The “re-setting” of the bone marrow with chemotherapy also works as a resetting of their corporealities-subjectivities. Often it is difficult to “go back to normal life” once children are labelled as “free of illness.” Some parents told me that they could not have gone through whatever their children underwent (a topic I will return to later). They added that they consider their children to be smarter and more mature given the kinds of experiences they had to endure while being under treatment and medicalized. Certainly, these two points cannot be generalized. However, this leads us to consider the different kinds of growth children with hematological conditions experience throughout the many months and years of active treatment and the maintenance phase.

One of the things that many parents, and even clinicians, highlighted about children’s growth while being treated is the importance of the carácter or estado de ánimo (“mood”) in relation to children’s wellbeing and their capacities to overcome the multiple difficulties of
treatment. For instance, many parents told me a variety of things like “she is now changing her mood, after her treatment”, “she became more difficult”, “she was more docile and now she has a strong character;” or, “before treatment he was quiet and shy with his siblings, and now he complains all the time, and he doesn’t share anything, he is used to be alone.” Often, parents also expressed their need to manage and mask their mood and emotions. For instance, parents and siblings tried not to be sad or cry in front of their children in order to positively affect children’s therapeutic processes. I also heard how clinicians were encouraging parents to conceal their emotions as well in order to protect their children (the rationale is that if children see their parents sad they will become sad). It is clear that children’s growth during treatment is a fundamental concern for parents, family members, and clinicians. Thus, caregivers have to behave in particular ways in order to direct their children’s growth during treatment in certain directions.

The ups and downs of treatment, the different therapeutic phases, and the reconfigurations that happen within the family while children are being treated inevitably affect families. Small children took things differently than older children or adolescents. For instance, in many occasions during the multi-family meetings at the CCF parents made statements like one mother describing her child who had passed treatment and was in a maintenance phase, “it is hard to make them understand that they have already passed that (urgent) situation.” In another multi-family meeting, some parents discussed about re-adjusting to the situation of children being treated for a long time:

Eleonor (mother of 4-year old Fabricio, who has Leukemia –ALL B-, and is her only son): With the small ones the situation is similar. He sometimes talks to me as an adult and he scares me. This is similar with older children in that he is also growing in this way and if he grows without limits he will grow this way. I try to give him whatever I can. I let him eat whatever he likes. But the hardest thing is that he talks to me like an older child. He tells me “you don’t understand that I don’t like this.” The problem is with my
husband because he feeds him and he has to eat things that he doesn’t like and then he vomits them. It’s like he wants me to defend him from his father.

Another mother then added that “they learn things very fast, and they also learn to manipulate people fast…” As we see, there is a clear understanding among parents that these children experience things that other children do not. Thus, parents describe their children as “growing fast.” In the same meeting, Valeria, seven-year old Julian’s mother explains,

My son grew a lot, he knows a lot about the medication, the treatment. I told him he has leukemia [ALL-T] but I didn’t say cancer because it’s a terrible world, but I told him to talk with the psychologist at the hospital and not with me, that he talks with him [the psychologist]. For seven months we have been going to the Day Hospital [at Hospital Infantil] and he doesn’t talk with no one besides my husband and myself. He doesn’t have friends because he is afraid that if he becomes friend of other children he may leave them in the same way he left his friends in San Luis [their home province]

Children learn and absorb myriad things from multiple sources during the long hospitalizations and throughout treatment. For instance, parents try to control how their children are exposed to information about their medical conditions. In the same meeting I am referring in the last quotes Mónica told us,

When they [hematologists] gave me the diagnosis, I asked the doctors not to tell him the word ‘cancer’. But one day he saw a paper when we were going to the [National] Drug Bank and he started to read it and he learned he had cancer and he felt bad. Then the psychologist explained to him that it is not the same cancer of his grandmother [who died from cancer] neither the treatment…

When Mónica said that, Valeria quickly replied, connecting the word “cancer” with her child’s mood,

I didn’t want to say it [“cancer”] either because it has to do with his mood or I don’t want to demoralize him. I don’t want to tell him to avoid depressing him. Sooner or later we will tell him. When the disease will be left behind I will tell him because it depends a lot on his mood. My son is going well, he never needed a transfusion, and he himself alone recovered his defences. He has so much strength to fight it.

In the classic In the shadow of illness, Bluebond-Langner (1996) looks at two kinds of relationships inside a family experiencing Cystic Fibrosis (CF), those between well sibling and
parents, and those between well siblings and ill siblings. According to Bluebond-Langner, two issues dominate the discussion within the family: 1) the distribution of material and non-material resources (time and attention), and 2) communication about CF and the ill child’s condition.

Similarly, what we see in the quotes above is how parents and families in general are trying to make sense of their children’s medicalized bodies and what to do in order to help them and the family in general. It is crucial to understand how different resources are distributed and how things get communicated. In almost every multi-family meeting, or when talking with parents outside the wards in the corridors of the hospital, certain themes would emerge over and over again. Some of these themes were how to communicate what children have without “depressing” them, or the (a)normality of their children’s lives, or the accelerated maturation these children had to go through, or the need to put limits but at the same time acknowledge their sick children special needs and to take care of them differently when they are sicker or when they feel better.

**Different kind of growth and maturation**

Evidently, children living with hematological conditions and going through treatment experience a different kind of growth. Not only because it is liminal in the way they are temporary set outside their ‘normal’ development but also because it implies brusque and constant re-adjustments. In one instance, I observed during my fieldwork, Lucía, a twelve-year-old girl came for a routine check-up from a northern-east province six months after the end of her hematological treatment. She had overcome one year and a half of chemotherapy, blood transfusions, lumbar punctures, bone marrow examinations, and several hospitalizations. Lucía had recovered some of her normal life with her friends at her high school, although she had to repeat her first year of high school. She came with her parents just for a short trip to the City of Buenos Aires for a routine assessment. Once the test results were available, the hematologists
came and talked with the parents after asking Lucía to go to another room to watch TV while they discussed her condition. Because Lucía was excluded from the conversation, she became worried that something was not good. The hematologists explained to the parents that unfortunately the illness had indeed returned. They had to start all over again. Lucía and her parents had to readjust to start a post-relapse chemotherapy protocol. Later that day I saw Lucía and her parents at one of the corridors benches and Lucía was grabbing her mother’s left hand next to her chest.

One aspect of this different kind of growth or maturation that is often obscured is that children very often act as caregivers: they take care of parents, their main caregivers, and other family members. In countless occasions I observed, heard, or was told about children taking care of their parents. For instance, children who were often having a lot of pain when swallowing would eat food just to please their parents. They showed no pain or suffering though they most likely were feeling it. They also avoided certain topics so as to not worry their caregivers. In one multi-family meeting at CCF one mother described how her own 12-year old daughter, who had a rare cancer, calmed her and offered to take care of her:

Last year at one point I started to feel really bad. I did not have any energy, and went to see my physician for a check-up. When I went to pick up the results, she told me that I had to do an oncologic test. When she said that I wanted to die, I told myself “How this is happening to me?” I could not believe that it was happening to me, if I had a cancer whom was going to take care of my daughter? My physician told me it looked like a peak of stress and that I had to go back home and start doing something to be more relaxed. I went home and I could not stop crying. I cried when I was going to bed, and I cried when I wake up the next day and I kept on crying, I could not stop crying. I could not believe it. But, one day I was very sad and my daughter saw me and asked me what was going on so I said to her that I was sad, that I had a test done and it looked I was sick. She told me, “Come mom, sit down here” and she asked me to lay on bed and to put my head on her lap, she was siting on bed, and she said, “OK mommy, now it is my turn to take care of you.” And when I was like this on my daughter’s lap I found calm and it was like something clicked and I realized that I had to slow down and be more relaxed.
This mother subsequently confirmed that she did not have cancer and continued to care for her daughter. This small vignette nicely synthesizes what often happens between children and main caregivers, the kinds of interconnections, and mutual care that both perform on a daily basis. Children with hematological conditions have to go through myriad experiences that forced them to grow and mature in a different way and to pay attention to things that other children may not be able to perceive.

**Learning to live in a medicalized body**

When children were constantly subjected to medical interventions from very early in their lives, a different learning and teaching process is established. They were not only taught how to live in a medicalized body by different health professionals and their families, they also had to figure out for themselves how to live in a medicalized body. Children were aware of this dual process not only in relation to their own lives but also to the other children they encounter in the hospital. Their peer-peer learning came from witnessing the countless ups and downs, the myriad medical interventions, as well as the constant need to emotionally and socially adjust to parents, siblings, and other family members, and health professionals while going through the long illness/treatment process. When children are inside the hospital there is a pendulum-like experience between hectic procedures and quiet passages of time. Thus, children also had to learn how to navigate periods of waiting and boredom.

Children learned and experienced how to be inside the hospital, how to behave, and what is expected of them. I once accompanied Fabio, a five-year old child from the Greater Buenos Aires Area, her mother, and one of the hematologists to the “Image Department” because the hematologist needed an ultrasound to be performed on Fabio’s left arm to confirm or discard an
infection. During the ten-minute walk from the HU Fabio was screaming, kicking, and crying, “I want to leave, I want to leave.” The mother was holding him as well as she could. When the child, his mother, the resident and myself arrived at the Departamento de Imágenes (“Image Department”), we stayed outside while the hematologist talked with the technician and asked them to perform the ultrasound as soon as possible. There were thirty people, including parents and children seated on the benches on the narrow corridor, while technicians and doctors shuttled in and out of the examination rooms. Everyone was looking at Fabio. Some children came close to Fabio to see how he was doing. One child, a patient who was perhaps four years old, came with a small toy dinosaur and wanted to give it to Fabio to play, but Fabio did not want it. Fabio was inconsolable. Yet, the child insisted and tried to open Fabio’s left hand to put the small dinosaur in it while Fabio kept on refusing. Fabio’s mother told the child “Thanks, but he doesn’t want it.” The child then went back to her mother and kept on looking at Fabio.

This seemingly trivial anecdote shows the kind of learning that children individually and collectively learn from their bodies. Because it is in how children construct their worlds and put words to objects that we need to focus; “it is in play, in imaginary situations that children mostly reveal spontaneous meanings dominating over objects” (Hardman 1973:509). In this case, the other child showed Fabio that he could play to forget his pain and suffering for a little while. Children were constantly affecting other children either by crying, kicking and screaming, or by attempting to play and distract them from the distress they may be experiencing. On countless occasions I observed children playing with IV poles, plastic syringes, tubes, and other medical devices, and how they tried to comfort other children going through experiences similar to what they themselves had experienced. Children demonstrated that they were active social actors
attempting to influence others. They possessed a kind of knowledge that is corporealized by learning how to live in a (hyper) medicalized body.

This was also true in the story of Alejandro and Emilia at the beginning of this chapter. Alejandro, the ten-year old boy with acute lymphoblastic leukemia who finished his treatment (he had six years of treatment though if we count the regular checkups) had a tough time with his classmates at school. Emilia said:

He is always with his siblings, or with me, with his games, with the computer, his other friends have girlfriends. I didn’t see him moving forward. But now that he didn’t pass [the school year] he is happier, he never got along with his classmates, and now he is with his younger brother. May be now with this other group that thinks differently he will agrandar más (“grow more” and also “feel more confident”).

Emilia, and the rest of parents I talked to, were trying to figure out what was best for children like Alejandro. But Alejandro, and the rest of the children I observed and talked to, was also trying to figure out what was best for himself. In this case, it was best for Alejandro to repeat one school year to be with his sibling.

On the multi-family meeting at CCF that parents talked about children’s growth they also discussed about intelligence, Analia (mother of Belén, 10-year old with an auto-immune liver insufficiency since she was a year old) said:

Belén is fine. Doctors told me that there were no many children with what she has that haven’t gone to transplant. She is very clever. She failed three times to pass his school year. For some things, she is brilliant. Whereas other things she doesn’t understand them.

And Emilia, Alejandro’s mother added:

My son is the same, he is brilliant for math, but for literature no, he writes like a doctor. He learned to write taking eleven pills per day. Still he failed 5th grade because he had a very rigid and demanding teacher…

This is one of many aspects of children’s medicalized growth. Inteligencia (“cleverness”) and brillantez (“brightness”) appear in this context as a quality of the children unaffected by the
treatment while at the same time children have to develop new capacities because of the treatment. One key aspect of this intelligence is how to live in a medicalized body and manage their painful treatments. These are skills and knowledge that they teach to, and learn from, their peers, parents, family members, and doctors. In this way being children under intense treatment create “endurance.”

Children se la bancan: Becoming-endurance

I started this chapter by talking about a child that “can do everything” and then moved to discuss “children’s growth” to focus on how children’s bodies deal with the powerful forces of cancer, chemotherapy, their emotions, and the psychological and social forces of parents, siblings, other patients, and doctors aiming to cure them. As part of this process, children’s bodies resist these outer biomedical forces and push back. Parents, family members, and different health professionals from medical residents to staff told me on multiple occasions that children se la bancan (“could endure”) a lot more. Since hearing this for the first time I could not stop to wonder what this endurance actually meant: that children were tougher, weaker, more docile, that they could not or did not want to complain so much? What does bancarsela mean for all these people? Bancarsela (“endurance”) was used in multiple and at times contradictory ways. On the one hand, it means that children could actually tolerate more intrusive procedures, pain and suffering. Parents, siblings, family members, medical residents, nurses, staff doctors all witnessed children’s ability to tolerate extremely stressful and painful experiences. Thus, this relates to some sort of wishful thinking that children are tougher and can undergo whatever situation they have to.
However, on the other hand, it also means that children have developed the emotional and psychological ability to tolerate the personal, social, and emotional intrusions and indignities of their treatments. When I interviewed Malena, the head of the medical residents rotating at the CDU, I asked her about children’s endurance and her professional obligation in relation to children’s own bodies. She replied:

They have rights to everything. That is, in fact, you are… Sometimes you don’t realize but you are with their parents, I always tell the kids [the younger residents], when one is an R2 [second year resident] one doesn’t realize that when you come you have to tell the father, and the child [patient], you arrive early in the morning and you have to say, “Hello, how are you doing? Well, today we are going to take some blood samples because of this and that…”

Malena always stressed to the younger residents that they needed to explain to children and caregivers what they had done, were doing, and were going to do to children’s bodies. Knowing the why of these intrusive medical interventions seemed essential to build trust between residents, children, and caregivers. She said,  

Think about this, you are pricking his son, you are putting something inside his son, you are taking something out of his body, that is, you are taking blood, you are putting, I don’t know… a probe. You are opening his mouth, that is, you have to ask them their permission. You have to tell them why you are doing it. You have to explain to them what you saw. Because of this we always tell them [for the younger residents] that it is very important at the end of the day to sit and talk with them, I don’t know, half an hour, to explain what you did, why you did it and for what reasons…

Malena then gave me a very graphic statement that evokes an image of breakdown in a relationship. She said:

Because… it’s like if someone comes and touches you, they touch I don’t know, a boob, and no one say anything about it! Yes, like the feeling of watching me open you up and undress you, and not explaining to you why. And you are like a silly, no, you can’t! That is, you have to [explain why], even more to a parent, because if you are an adult maybe you endure it [te la bancas]. But for a parent, it’s like, his son is worth more than himself, it’s the same when a kid gets sick, it’s not the same that if the adult gets sick, because he cannot even explain what’s going on to his son, he can’t. And because he can’t show this, he suffers more…
In this quote we can see how children’s emerging endurance is connected with lack of proper representation of what is going on within their bodies, what others are able (or unable) to signify about these processes, and we see how this is related to a sort of micro-dignity that emerges in the process of interaction between children, families, and health professionals. In this case Malena was placing endurance on the parents not on children. But she was clear that as health professionals they needed to explain as much as they could what they were doing with children’s bodies, especially to their parents. Children’s parents are trapped between two opposing forces: they have to witness their children in pain, yelling not to be pricked any more, while at the same time taking care of them and aiding professionals to permeate even more to try to cure their children. Or, as Claudia another second-year resident at the CDU told me:

It’s all the pain. The parent is always stressed, because often the parent can’t stand to see his son suffering. And also the son is mad at the parent because it’s like he says, “Mother, how could you let them do this to me?”

But endurance can also mean that children are appropriating their situations, that they are painfully learning what to do and how to (re)act in these intense and invasive clinical procedures. Even small children, like two-year old Betty living with acute lymphoblastic leukemia, began asking for “Plaxul, plaxul” (wound healer ointment) for her back one day after she went through a bone marrow aspiration. But more particularly in relation to pricks, in one multi-family meeting at the end of treatment, different mothers of children were talking about their children’s playful relationships with catheters and needles:

Mother 1: My son’s catheter lasted about three years. I still remember, the day they put it in there were five children that were receiving catheters, and for the other four they had to removed them because they got infected, but for my son it lasted three years. Indeed, when they took it he kept it – he even kept his lumbar puncture and bone marrow aspirations needles. He knew everything about his treatment. He would discuss the drugs with the doctors and nurses, and if they forgot something he would remind them.

Mother 2: My daughter would also tell the nurse if something was wrong with the medication…

Mother 3: My daughter also plays with the needles; she pricks her doll with needles.
Mother 4: My two children (healthy and ill) pretend they are doctors: my sick child asks for
prescription papers from the hospital and takes them home and they play with dolls and they tell
the doll, “You have an otitis.”

This notion of endurance shows the kinds of struggles children (and caregivers) have to
face on a daily basis, they things they incorporate into their games are things common for them
but hardly present in other children who are not going through hematological treatments. In this
sense, they grow and mature differently and we will see this in the next section.

Collective embodiments, everyday resilience, and becoming-children

In this chapter I have looked at children’s intense bodily experiences from different angles.
During my fieldwork I paid special attention to how children were able to navigate their
experiences by bodily manipulating and expanding their capacities to do things. Certainly, age is
one clear distinction when talking about children, and how they are able to traverse their hyper-
medicalized experiences. Yet, as I noted before, it is not age in the abstract that helps understand
the kinds of experiences children face. Instead, it is age related to physiological and neurological
development and the temporality of the experiences of becoming a medicalized body what
counts more (Bluebond-Langner et al. 2010). From the professionals’ standpoint, there is a
higher chance that older children will “understand” more of what is going on. With respect to
younger children, there is a greater need to find other less verbal (or pre-verbal) ways to relate to
them and make them “understand”. Yet, what does it mean to go through countless
hospitalizations, operations, tests, and a wide variety of medical interventions from the
perspective of a child? When a child experiences a hematological condition, what does it mean to
have/be a body that is constantly intervened? Indeed, this is a particular group of children that is
constantly being “super hospitalized,” as Mila the senior resident in the CDU told me:
…They are children that are super hospitalized, so, for instance, they come and say ‘Look, I have an epidural catheter,’ or, ‘look, the IV has blood return.’ So you are astonished, because you say, this child is like a doctor! But he is still a child, isn’t he? That is when you forget they are children and you treat them like anyone else. But you never have to forget they are children, in spite of them having an illness or being super hospitalized.

Consequently, they are children *despite* being super hospitalized. Nonetheless, they are children *through* their own hyper-medicalized bodies. They are also children who are being collectively taken care of and treated. During countless opportunities, I was able to observe how children interacted with multiple actors within the hospital who measured how much they could do, tested how far they could go, and assessed how they could control their own lives. For instance, when a thirteen-year old girl named Julia, who was in maintenance phase for a recently treated acute lymphoblastic leukemia, went back to the hospital for a routine control, the hematologists found that she was relapsing and had to be hospitalized. She needed constant monitoring, which required regular blood tests. She refused to be pricked by just anyone, be they a doctor on the ward, a resident, or a doctor from the Hematology Unit. Hospitalization is more than becoming a dweller in a hospital; it also includes negotiating the boundaries of the body and the social relations that permeate bodies. In describing the exteriority and access to the body in connection with illness, Nancy (2006) strongly asserts something we all know but we tend to forget: we *do not have* a body we *are* the body. Consequently, it is important to consider what happens when you are a body that develops while enduring months of hospitalizations and years of medical interventions.

**Conclusion**

As Grosz (1994) argues, we need to look simultaneously at both bodies and personal experience. Indeed, corporealities/subjectivities are always functioning, interactively reacting to the shifting
inner and outer forces of cancer treatments. Corporealities/subjectivities are key to understanding children’s engagement with their social worlds from within their own corporealized subjectivities. During long, tiring treatments children recreate a new body able to do new things.

In this chapter, I have attempted to consider how different actors, including children, are making sense of children, as well as what they “are,” and what should be “done” with them. I focused only on children because, although they could operate independently, they where frequently outside the decision-making process. Early in my fieldwork, I started to see children as nodes of multiple webs and forces in constant transformation. I also began to realize that children with hematological conditions are able to develop and have lives even while being intensely treated. They can do many things with others, including their parents, siblings, and hospital staff to affect them and influence their own therapeutic trajectory. However, their development and growth was not only marked by conventional milestones, but also by the thresholds that they traversed during their long treatments and hospitalizations.

I have also examined the contradictory processes in which children, families, and key clinicians are materially, emotionally, and symbolically invested in “getting better” in ways that sustain this permeability process. There are countless instances in which children’s bodies are overwhelmed by being broken up into biological components and organic functioning. There are constant frictions between that which different professionals want/need to do with children’s bodies and the collective embodiment that results from children, parents and other family members living these medical interventions. Children and/or parents may frequently refuse to “adhere” to, and “comply” with, medical treatment, but that does not mean that children’s bodies would be less forced to become permeable and docile to that treatment. Children enter into complex social relationships with their parents, family members, and doctors during the course
of treatment. These interactions, mediated by their bodies (the focus of treatment) enable children to develop and create subjectivities that are unique products of their corporeal experiences.

In the following chapter, I will discuss in more detail children’s inter-corporeal pain and how these hematological treatments entail painful interventions and all sorts of experiences in which pain and suffering are fundamental occurrences.
Chapter 8: Children’s inter-corporeal pain

“It often happens that those who think are not sure of thinking: their thoughts, ranging between realizing and dreaming, are slipping from their hands. (….). On the other hand, one who suffers has never the slightest doubt, is always sure to suffer and therefore to exist.”

“The history of man is the history of pain.”

Children’s pain is a unique and intense experience that addresses the whole self and others as well. Pain has a complex nature, it is an affect that destroys meaning, it is a by-product of the ‘natural evolution of disease,’ and it is also a collateral effect of biomedical interventions in the forms of diagnostic and therapeutic procedures. In this chapter, I will discuss these two aspects of pain by focusing on the inter-corporeality of children’s pain.

One late afternoon in the Communicable Diseases Unit there was hectic activity at the residents’ office with fourth-year residents running in and out. I approached the scene and asked one of them what the commotion was about. Contrary to my expectation of some clinical crisis, she said that they were shooting video footages for their end of residency party. They were going to make a funny video in which Claudia, a fourth-year resident, would make fun of an incident when she almost destroyed the office during a rough night shift at the beginning of her second year. Claudia looked very angry; another resident came back, knocked on the door, entered and said she has another patient arrived in the middle of her night shift, while Claudia was pinning nails to a flyer that says “Grand Rounds.” Then she threw a whole shelf of stuff to the floor and yelled like she was possessed. They repeated this a couple of times.

Then, when the other residents left, and the room was calm again, Claudia explained to me:
When I was R2 [second-year resident] one night I had to prick a small boy, Leonardo (I still remember his name). I don’t remember well why or for what reason, but I had to pricked him not less than eight times [until she found the vein for the IV]. It made me so angry and made me feel incompetent because we don’t study to torture kids. So I went to the residents’ office and I began to throw everything, I broke everything. When another R2 who was helping me entered into the room to see what’s happening she saw me destroying everything… I mainly felt a lot of impotence, you know?

This vivid story is not unusual. In the Argentina’s context, medical residents, especially those in the first years of residency, are greatly affected by the constant exposure to children’s pain and suffering, particularly by inflicting pain though their own medical interventions on children (Donnenfeld 1994). Everyone is differentially affected. Third- and fourth-years residents, staff doctors, or nurses, witness or become regular producers of children’s pain. As Claudia said, medical residents and other professionals need to remind themselves everyday that they “did not study to torture kids.” However, in many ways they do. By attempting to cure children, they inflict a lot of pain and suffering. Certainly, health professionals are repeatedly and continuously exposed to others’ suffering. However, from children and families’ perspectives these are unique experiences. For doctors and staff, it is the pain and suffering of their patient; for a parent, the pain of their own child; for the sibling it is the pain and suffering of a brother or sister; and for a child, the pain is their own. Thus, how do they individually and inter-personally understand and are affected by these experiences? The experience of pain is more than its physical, neurological, and organic factors, although Western biomedicine has a tendency to reduce pain simply to sensations within a body (Scheper-Hughes and Lock 1987; Taussig 1980). Yet, pain occurs within the body, and permeates beyond it (Good 1992; Greenhalgh 2001). We can only attempt to imagine how Claudia felt when—in the middle of a busy night—as a second-year resident she had to prick Leonardo. Leonardo had already experienced three months of chemotherapy treatment for his acute lymphoblastic leukemia.
Claudia pricked Leonardo “no less than eight times” in order to find the vein for the IV. Though it was traumatic for Claudia, at the center of this picture was Leonardo, pricked eight times while his mother watched, and the other half-awake children and parents looked on and heard first Leonardo’s and later Claudia’s screams. Together, Leonard, Claudia, the children and parents in the room suffered the inter-corporeality of children’s pain.

Children like Leonardo, living with cancer were constantly traversed by flows of painful stimuli which families witnessed while also caring for their suffering children. Indeed, caregivers and family members were caught in an antinomy of loyalties between mitigating their child’s pain, and their commitment towards doctors to adhere to a painful treatment’s plan. In this context, dealing with pain is often a central part of the everyday life of children and families. Therefore, in this chapter, I will look not only at children’s experiences of pain within children’s bodies but also, and more importantly, in their corporeal and social relationships with family members and many health professionals.

Children, parents, and family members share a common desire to liberate children from their current and future suffering and pain. All are faced with the paradox of attempting to medically cure children’s bodies while inflicting pain and suffering in the process. Not only is this a tension faced by parents, it is an institutionalized tension between the active treatments of Hematology and Communicable Diseases, and the pain relief of Palliative Care. Thus, pain and suffering are indissolubly connected since both are part of the same process of de/re-stabilizing corporeal experience. Pain and care are part of the reconstituting, re-stabilizing process. In many ways pain can dislocate and/or block inter-subjectivity (Leder 1992). It also can collectivize and generate inter-subjectivity, the co-presence and mutual affecting influences of

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73 Some authors use both interchangeably and others differentiate pain from suffering depending variable factors. For looking at this distinction, see Burlea (2009).
concrete corporeal relationships (Csordas 2008), by channelling the processes of healing, generosity and empathy (Throop 2010).

In this chapter, I aim to examine the anthropological and socially inter-corporeal nature of children’s pain, as part of the “human experience” and as a key aspect of “social suffering” (Good et al. 1992). Thus, it is key to understand the attempts to give sense to how children’s pain is experienced at this particular clinical setting and how pain affects the lived experiences of children and those around them. In this way, I am interested in looking at children’s pain not only as a biomedically-mediated search for meaning or as a biomedically-produced affect, but as an inherent part of treatments aimed to overcome cancer.

Rather than discussing pain in its broad scientific dimensions, I will focus on what pain “does” for children, their families, and those health professionals that I worked with. How does pain “work”? Particularly, how does people trying to make sense of it contextualize pain? Children living with cancer experience “deep” pain and suffering (Frank 1995). They often live under untreatable chronic pain. When children go through long and distressing treatments, pain rebuffs logical and rational thinking. Yet, children’s pain forces everyone caring for children to do something about it, to (re)act to it.

During my fieldwork I observed or heard countless instances of children experiencing pain, and children, family members and staff discussed other instances with me. In some cases pain was or became chronic, or it appeared abruptly after a specific procedure. Sometimes it came because the analgesic effect of the drugs did not last until the next dosage, or pain appeared

74 There are some recent papers that suggest the children, particularly infants, feel more pain than previously thought, see Verghese and Hannallah (2010). Yet, focusing on the last decades of development on the “science of pain” is beyond the scope of this chapter. For a comprehensive review of the history of infant pain see Cope (1998) (http://anestit.unipa.it/mirror/asa2/newsletters/1998/09_98/Neonatal_0998.html; accessed 20130507).
as part of the end-of-life process. What we may call “pain” is not any single homogeneous entity, rather it is a cumulative experience. As a multifaceted process pain in children living with cancer usually almost never fully disappears, and instead (re)appears as a palimpsest of layers, an overlapping multi-causal bundle of painful stimuli. A cancer-survivor living in her late twenties told me that for her the worst, more painful memories she had about chemotherapy was the uncontrollable vomiting she had. Whereas for Agustina, a seven-year old girl with a rare anemia would cry and cry every time she would be hospitalized for a long stretch of time for “no particular reason.” Maybe the best example of this palimpsest of layers of pain is when children have to experience a lumbar puncture or bone marrow aspiration during their cancer treatments. Hematologists intellectually knew these procedures cause enormous pain, even when children are under sedatives. But children felt it. Older children told me they felt they had to put their bodies to these (and others) procedures to overcome cancer. They were not mere patients but active players in these healing dramas: they painfully knew and felt it.

During my work with the three medical units I was often amazed by how professionals would place children’s pain in different hierarchies but at the same time they would all be fully committed to curing and caring for children. Depending the therapeutic phases children were traversing hematologists, communicable diseases professionals or palliativists would interact with children to attempt to ease their pain from their different professional perspectives, using different frameworks, and having different sets of urgencies. Yet, when children experienced symptoms associated with either the main illness or the side effects of treatment, and when those symptoms were severe enough to be hospitalized, they often ended up hospitalized at the Communicable Diseases Unit since some of the major difficulties linked to hematological treatments are different kinds of infections. Thus, hematologists and communicable diseases
specialists are all the time in contact and while conducting fieldwork on both teams I was able to observe the different ways they deal with children’s pain. On the other hand, when a child experiences pain the usual specialists that would be called upon from any unit at the hospital for referral would be the palliativists.

I will divide this chapter in four sections. In the first section, I will consider the difficulties of assessing children’s pain and multiple strategies professionals have developed to get access to, and evaluate, children’s pain. In the second section, I will consider how pain is actually inter-corporeally produced. That is, how painful experiences are differently co-experienced by the sufferer and those around him or her. Then, I will focus on how pain is an affect that shatters meaning and something to be discovered. This dual nature of pain will be evaluated to show how pain ranges from pre-personal to inter-personal experiences. In the fourth section, I will reflect on how pain is not only created by illnesses but also by treatments. Thus, how pain can be experienced differently by children and families or by different health professionals.

**The inter-corporeality of pain**

Pain is a unique “equalizer” of life, to be human (in fact, to be a living being) is to be inescapably exposed to suffering pain (or, to witness others suffering pain) as an unwanted concrete bodily experience. Intrinsic to our everyday being-in-the-world pain is an experience that, even for a two-year old child, constantly questions the meanings, values, and aims of our (and our closed ones’) existence. In this way, pain is linked to many different contradictory aspects of our personal and trans-personal experiences; it is connected to our most empathetic relations to others and our most averted separations from others (Throop 2010). Thus, pain not
only transforms those who experience it but also those that are connected to the person suffering pain. Experiencing and witnessing other’s pain, (especially your own child) directly affects the witness, and, often when the one in pain is a child, it triggers different (re)actions. Things have to be done, and even recriminations arise between different members of the family (or between children and their parents). During a family meeting at the Palliative Care office the parents of Luisa, a six-year old girl with bone cancer, began to blame one another for things they did or did not do in regards to Luisa’s pain. At one point the father said “When I feel bad [when he sees Luisa in a lot of pain], I take my motorbike and go to the highway and I put it at two hundred [km/hour] and with all that adrenaline I feel better.” Evidently, he needed to do something with his daughter’s pain.

Although pain is a fundamental human experience it has historically attracted only some attention in anthropology. Yet, many anthropologists have stressed the intrinsic cultural ambiguity of pain (DelVecchio Good et al. 1992; Morris 1991). For instance, Throop (2008:254) says,

While noting that culture can play an important role in shaping pain along a number of dimensions – including its intensity, expression, response, and interpretation – many anthropologists have pointed to pain’s tendency to actively resist the cultural patterning of linguistic and interpretive frames.

Thus, on the one hand, culture(s) can influence in multiple ways how pain is individually and collectively conceptualized, classified, and narrated, on the other hand, it can also give the ‘script’ to resist those systems of coding, understanding, and narrating it. In other words, paradoxically, culture(s) can simultaneously build and destroy how we collectively and

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75 Though I am not saying that it has not attracted attention at all. See for instance Murphy (1987); DelVecchio Good et al. (1992); Good (1994); Jackson (1999); Kleinman (1978); Morris (1991); Mattingly (1994, 1998); Mattingly and Garro (2000). Yet, in comparison with other major human experiences it has been historically less studied in anthropology, I would say that it has been a minor issue.
individually map out pain. And, precisely, because of this ambiguity social scientists can see pain ultimately as un-objectifiable, un-expressible, purely subjective and un-transferrable experience, as in this passage by Scarry (1985:161-162):

Physical pain is exceptional in the whole fabric of psychic, somatic, and perceptual states for being the only one that has no object. Though the capacity to experience physical pain is as primal a fact about the human being as is the capacity to hear, to touch, to desire, to fear, to hunger, it differs from these events, and from every other bodily and psychic event, by not having an object in the external world. Hearing and touch are of objects outside the boundaries of the body, as desire is desire of x, fear is fear of y, hunger is hunger for z; but pain is not ‘of ’ or ‘for’ anything – it is itself alone. This objectlessness, the complete absence of referential content, almost prevents it from being rendered in language; objectless, it cannot easily be objectified in any form, material or verbal.

Alternatively, social scientists can see pain as a potentially meaningful, inter-personal, communicable experience, a “suffering-for,” as in this passage by Throop (2008:272):

Briefly stated, the process of fashioning pain into a meaningful experience, that is, transforming it from an instance of ‘mere-suffering’ to one of ‘suffering-for,’ is deeply implicated in a sufferer’s ability to situate such dysphoric experiences in a time frame that stretches beyond the present moment of pain. (…) This temporal stretching is at least partially accomplished through an articulation of ongoing painful sensations with the virtues of endurance, effortful exertion, self-governance, and compassion – all virtues that may provide a meaningful bridge to a sufferer’s history of past actions, as well as to possible future self-states in which his or her moral strivings may be potentially realized.

In both examples, it is the (im)possibility of going beyond the limits of the present moment of (individualized and somatized) pain what precludes or permits the making of a broader “purpose” to one’s pain. Yet, what appears less prominent in both approaches is the inter-corporeality of bodies-in-pain (though less so on Throop’s idea of ‘suffering-for’) caring one another, affecting and being affected by one another, and attempting to discover the meaning(s) (if any) of pain while being affected by other’s pain. Yet, it becomes evident that when children experience pain (and others witness it) is not only meaning what needs to be discovered from the cracks and gaps of chaotic existence, but also there is affect that mobilizes/traverses bodies and, by doing so, shutters meaning. Indeed, according to Deleuze
(2001) affect is a non-representational mode of thought: that is, affects are pre-personal intensities just-not-yet-personalized in feelings expressed in the social idioms of emotions (Shouse 2005). This is key, for pain is, indeed, an affect.

Precisely, as Livingston (2012:120) reminds us, pain cannot be disconnected from social context, we need to look at the “total situatedness of pain.” Following Asad, and criticizing Scarry’s work on torture, Livingston states that we need to move from a textual analysis of pain to the concrete experience of pain in wider social contexts. We need to recognize, as Asad (2003) did that the experience of pain escapes the observer. Ultimately pain, as cancer, is a relationship. As Livingston (2012:121) argues, and as the example of Luisa’s father demonstrates, “pain begs a response.”

There are many different cultural assumptions and (pre)dispositions attached to caring for, and responding to others living in pain. The expansion of the present’s horizon, the potentiality to relocate pain in a wider context, echoes what Crapanzano (2004) calls “hope.” Crapanzano (following Heidegger) claims, hope can be linked to care (sorge), which is rooted on an experience that “something is still outstanding” (2004:9). This notion of attempting to broaden the bleak present by those that are directly suffering pain, disability, and chronic illness also relates with what Mattingly (2010) calls as the “paradox of hope”: concrete, active, moral and practical thinking and acting by poor Afro-American parents and sick children in the U.S in the “borderland zones” of urban hospitals. For Mattingly, hope must be actively “cultivated.” Crapanzano’s and Mattingly’s notions of hope relate to what children and family members often expressed to me in different ways about the moral questioning that, indeed, there must be a

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meaning to children’s pain and suffering throughout treatment. The quintessential moral question “why?” is usually present in everyone’s mind (Good 1994). By talking with caregivers when looking at children’s pain it becomes clear that we need at the same time to consider care as part of the inter-corporeal collectivizing forces of pain. I will define care echoing Levinas’ (1979) ideas of a responsibility towards the other in a face-to-face relationship, an “infinite responsibility towards the other” in Levinas terms. Responsibility for Levinas was an affective, immediate response to the Other. One that helps to focus on how interconnected and mutually affecting pain, suffering, and care are. (I will further discuss issues of care when talking about families and “therapeutic relatedness” in Chapter 9.)

In a way, this operative definition of care can be seen in constant tension with biomedical practices seeking to cure bodies with its embedded here-now inherent violence and its tendency to de-collectivize, individualize, personalize, and biologicize pain and suffering (Good et al. 1992, Greenhalgh 2001; Scheper-Hughes and Lock 1987). For instance, Mariana, one of the fellows77 at the HU, recalled that one of the things that impressed her most when she started her fellowship at the HU many years ago:

…Was the aggression we had with children and with the parents because that [bone marrow] puncture needle is terrible, and (back then) we were not sleeping children almost completely like we do now, we only gave them one medication, which would make them forget about everything. That is, they didn’t remember but during [the procedure] they cried, yelled, [while] the parents [were in silence]. So then what happened is that we started to slowly add more medication (…) and with that the bone marrow punctures are more [comfortable]… but the truth is that you agredis (attack) children in such a disturbing way. They don’t remember after, that is, those that come back older, out of treatment, they actually don’t remember but in the moment you feel horrible. I think it is one of the worst moments.

77 At the time of my fieldwork she had finished the post-basic residency in Pediatric Onco-Hematology and she was a fellow (working for almost no pay) trying to become a full-time staff at the Hematology Unit.
Mariana seemed to rationalize the infliction of pain (inherently needed for the advancement of the hematological treatment) by stating that children “actually don’t remember” anything afterwards, but the actual moments in which children were the targets of painful procedures were indeed very “disturbing.” This is an example of how children’s suffering and pain become both a meaning-to-be-discovered and an affective experience. Feeling “horrible” about inflicting pain on children becomes part of the everyday practice of being and becoming a cancer doctor. It is a learning process to be able to navigate these intense experiences, and not only to give it a positive spin but also to be able to connect in a professionally way with each child (and family) living in a painful body during these inter-corporeal painful experiences.

Painful bodily interventions by health professionals are central, unavoidable aspects of medical practice, especially those professionals that deal with invasive treatment such as chemotherapy, radiotherapy, or surgery. Mariana also shows how the Hematology team (after being affected by children) decided to do more and give better analgesia to children when performing painful procedures. Hematologists were affected by children’s pain and found ways to affect children in less painful ways.78

Children also try to affect others when are in pain or when they project they will experience pain, for instance, a typical case is when children have to be pricked with an IV infusion of chemotherapy or blood transfusion. In those cases, I observed how children from early age such as four-year-old could tell the nurse which arm to prick and can attempt to choose the nurse or medical resident that perform the prick better. They try to find the people that inflict pain

78 During my fieldwork at the Hematology Unit many members of the team told me that they should perform the highly painful procedures such as lumbar punctures and bone marrow examinations at the “Intermediate Therapy.” They should give total anesthesia to children but that is not possible given the institutional constrains (Intermediate Therapy is always busy with other procedures) so instead they do it at the Hematology Unit Procedures Room and try to ensure they give children the best analgesia possible during each procedure.
them the less possible pain (usually more experienced fellows, the head of nurse, or staff clinicians).

In the US, Burt (2002) studied the social, medical, and legal ambivalence provoked by dying and death and he found that health professionals needed to constantly re-contextualize and re-signify their pain-inflicted interventions. He emphasized that, indeed, this

… process by which physicians come to a neutralized or positive professional attitude towards these interventions involves some relearning, some suppression, of the contrary, socially condemned meanings attached to the infliction of violent injuries (Burt 2002:99).

Yet, this suppression made by health professionals is, by definition, always incomplete. It has to be recreated all the time, especially in stressful and liminal moments like in the initial vignette with Claudia. Burt argues that often physicians find hard to believe in the “goodness and justice of their professional enterprise,” and this may be caused because “violent intrusions into other people’s bodies are intrinsic to the medical enterprise; and the goodness and justice of these interventions must continually be reasserted” (2002:105).

If the embedded violence in the medical practice and its ultimately goodness and justice need to be constantly reasserted by health professionals, then how parents and other family members would attempt to make sense of it, and, moreover, how children themselves would understand it? “Why me”? “What’s the meaning of this pain”? “Why my son”? As Frank (1995), Kleinman (1978), and Mattingly (1994) have pointed out people tell stories to make sense of their suffering. When people craft their illnesses into stories, they find (not always though) some sort of healing in it, at least some order in the chaotic lived experience. People should never be seen as passive, patient, receptors of medical knowledge and practices but as active,

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79 Maybe by creating this darkly funny video clip for her end of residency party I described at the beginning of the chapter Claudia was attempting to re-signify her individual experience and to re-collectivize it by affecting her fellow medical colleagues.
transformers, and (co) producers and defiant of biomedical interventions. Thus, children and parents need to contextualize these painful everyday experiences navigating between professionals’ narratives of cure and improvement and children’s and parent’s narratives of pain, suffering, healing and mess, or what Frank calls as restitution, chaos, and quest narratives (Frank 1995).

Both Crapanzano (2003) and Mattingly (2010) have highlighted the importance of imagination in the creation of “imaginative horizons.” Parents use their available resources to ease some of the (inter-corporeal) pain and suffering children undergo. For instance, Rosa, the mother of four-year boy Carlos with congenital anemia told me that she used to play a lot with him, especially when he started to get sicker and needed to be hospitalized more often. Given his condition, he needed many blood transfusions. He was encerrado por meses (“trapped for months”) hospitalized or at home, without the possibility to go out and play in playgrounds como cualquier chico (“like any normal kid”). Professionals needed to isolate Carlos in order to avoid injuries or infections, worsening his condition. Thus, Rosa would find her own way of dealing with Carlos’s distressing experiences and giving (other) meanings/affects to these medical procedures. Rosa told me:

I play with my son a lot. I tell him that the blood he is receiving is from the spider man. Sometimes I don’t know how to explain to him [what he has] and for me the best way is with the toys he uses and the games he plays. To me is the best psychology. I think with small kids it is better because then when they grow and become adolescents it’s harder because they complain a lot and they know more.

Rosa was using Carlos’ own imagination to affect him and find meaning to what he had to go through. In different ways both health professionals and family members are trying to,

80 For the creative use of games and toys by family members and health professionals in the context of children with terminal illnesses, see Bluebond-Langner (1978), Johnson et al. (2012), and Vindrola-Padros (2009).
given the circumstances, ease current children’s pain and suffering, and frame these experiences in a positive light. Nevertheless, these attempts can often clash and, therefore, parents and professionals need to navigate and negotiate their efforts to aid children. While hematologists and communicable diseases specialists were trying to understand the causes of Carlos’ anemia and were administering drugs and blood transfusions to ease his condition, Rosa was trying to comfort her son and expand his present (and Carlos by believing his mother was potentially re-contextualizing his own pain, though I will never know what was going inside his mind). Rosa was attempting to discover another layer of meaning to his current here-now and to the intercorporeality of Carlos’ pain.

Indeed, palliativists (and others) have been saying for quite a long time that not only cure and care are both part of the biomedical enterprise from its inception (Twycross 2003) but also both aspects include imaginative less “concrete” (that is, somatic/organic) forms of dealing with the body/self’s recovery and healing (Kleinman 1992; Mattingly 1998). Indeed, Rosa’s way of caring for his child was giving strength and confidence by using imagination as a therapeutic tool (“you will be spider-man”!). This is also something the health professionals I was in contact with during my fieldwork on one way or another were aware of: they were looking for ways to ameliorate children’s and parents’ here-now dire situation. Yet, in some cases, there were a lot of frictions and conflicts between what some doctors or team thought were the best way to do it. For instance, Lisandro, the head of Hematology, told me that he not only tries to explain what they would do but also tries to use different strategies like games or sense of humor to communicate with children. He said,

…to children I try to explain them with games or other methods everything we will do to them, why [we will do it], and always, since they are three or four-year-old, when they talk and ask, I always tell them, “Look, I will never lie to you.” And this is a legacy I impose to myself: “I will never lie to you. I can make mistakes but I will never lie to
you.” That is, I can tell you that tomorrow I won’t [lumbar] puncture you, and then it occurs that I need to do it (…) I had an eight-year old girl that I remember she told me, “And if you say now no, and then you say yes?” And I replied to her, “It is because I made a mistake… but not because I lied to you.” Why? Because maybe you have a problem, your platelets went down, and I have to rush and do a bone marrow [examination] that I hadn’t programmed.

Lisandro as the head of Hematology is acutely aware of the kinds of pain and suffering hematological treatment can entail. Because of that, he was connecting to, and building trust with, his patient by attempting to tell her always the truth. He was explaining to the child what he was going to do to her body with these stressful and painful procedures. This is an important aspect of patient’s autonomy in a very hierarchical institutional context. Lisandro was building trust with her. As Bluebond-Langner et al. (2010:338) have argued, “There are several values that need to be respected in the decision-making process with children. One is that it should be conducted without deceit.” This is one way of recognizing the other’s (present or potential/projected) pain. This is also another aspect of children’s inter-corporeal pain. By legitimizing and recognizing other’s pain health professionals or family members become more open and vulnerable: they become more permeable to children’s pain. As Alex, from the Palliative Care Team, told me

Because when you legitimize other’s pain you have to put up with the possibility of share it, if you say, “So, you are sad, aren’t you?” (…) I remember a girl that is at Communicable Diseases [Unit] and so they told her that her toes had to be amputated (…) and she went from being happy to the next day not talking to you at all. I asked her, “Are you sad?” And she told me, “Yes.” And I said, “Are you sad, or, are you very sad?” And she said, “I am very sad.” What happened then it was a shitty time that happened between she and me. But it is very interesting what happens when you take the courage, because it doesn’t happen often, usually one becomes a membrane without porous. But when one legitimizes other’s pain, when you say, “I see you’re sad”, “Yes,” “Very sad, are you very sad, aren’t you?” Versus “OK you are sad but it will pass.” (…) You are taking the night shift with a dying patient, “Are you scared, aren’t you?” “Yes.” “Very scared? Tell me…” What are you gonna say instead? “It’s OK to be scared but who wasn’t?” Wow! You know, all this is happening all the time. And I think that [if we do this] we let run this bluff, this lie that we are all hugging one another when we are all totally separated [from one another].
At the core of what Alex said is the issue of the inter-corporeality of pain I am attempting to address. The inter-corporeality of other’s pain that can be legitimized and recognized or can be avoided and invisibilized. Other’s pain can make you a “membrane without porous;” that is, an impermeable body. Alternatively, as we saw, other’s pain is not only children’s pain; it is something that is affecting everyone. In this way, children’s pain can simultaneously be inside and in-between children. For instance, it can be in-between a dying child, the inexperienced second-year resident at the Communicable Diseases Unit during her night shift that was anguished because she did not know what to do with her dying patient, and the child’s parents. In myriad ways pain and suffering traverse bodies and everyone is (differentially) affecting and affected by children’s pain (more so when dealing with the end of life). In addition, yet, knowing about what kind of illness you ‘have’ can certainly affect you. Alex, from the Palliative Care Team once told me

I try (within certain minimum age) to make children understand their illness. I ask them if they can explain it to me. I try to be attentive (to have certain inner register of alienation), I am out of synch when for instance I don’t care that the other understand what’s going on [to his/her body]. It’s clear to me there is a red flag when I lose interest in explaining it [to him or her] or to check how much [he or she] is understanding.

In my MA thesis (Wainer 2008) I analyzed the palliative production of “accompaniment,” this idea that palliativists have to construct certain ways of accompanying (easing all sorts of symptoms to) patients and families during illness and especially at the end of life. Palliativists told me about the need to develop communicative and attitudinal skills. Alex from the Palliative Care Team pointed out to the need to learn to listen “it is very important the ability to listen to and absorb, to listen to what they say and do not say. What people say when they talk?”
As Claudia said at the beginning of the chapter, health professionals do not study to torture children or to be a mediated factor of those intense concrete forms of inter-corporeal pain. Neither parents nor other family members want to witness children’s pain and suffering. Needless to say, children do not want to experience a painful body. Yet, children yell, and scream, and expose their pain in countless ways on a daily basis. Therefore, all the actors of these dramas are in one way or another invested in elucidating not only the causes and consequences but also the impacts of children’s pain. Since pain is an ever-present aspect of these medical encounters. Every single day at the Hospital Infantil there are countless instances of high and low doses of suffering and pain inflicted not only to children’s bodies, but also indirectly to others who accompany and witness these experiences as siblings, parents, aunts, and friends. Additionally, medical residents, medical staff, nurses, psychologists, also participate in this pain. Everyone is affected on one way or another by children’s painful bodies, and by witnessing children’s pain and suffering on a daily basis, included, health professionals (Sork 2005).

The same day that Claudia was rehearsing for the video clip her experience of anger and impotence for having to prick Leandro “no less than eight times”, as a fourth-year resident, she was helping a second-year resident to take 2.7ml of blood from Ricardo, a six-year old boy with an endocrinological disorder. Ricardo had a spike of 37.8 of temperature the night before so they needed a lot of blood for a battery of tests to figure out what was the cause of Ricardo’s fever. Yet, Claudia complained at the residents’ office, “Endocrinology asked for a bunch of tests, we have to take 2.7ml of blood from Ricardo! 2ml just for them and the rest for our regular blood test.” Claudia looked at me and said, “You know… sometimes… doctors can be very cruel.” In fact, when considering children’s pain, this unintended medical “cruelty” also needs to be
unpacked in order to understand not only how children experience pain, and how parents and other family members witness it, but also how professionals experience both inflicting and witnessing children’s pain. Pain must be examined as both the affect that shatters meaning, and the meaning to be discovered. Children living with cancer show the inter-corporeal quality of pain. Pain does not only reside inside their bodies, but also beyond the individual bodies. Pain-as-affect traverse bodies. Thus, it is children’s inter-corporeal pain and suffering in which bodies are at once victims and witnesses, weapons and-wounds, objectified and subjectified.

**Assessing pain**

Pain assessment is a constant and essential part of total pain management particularly in children, and consists of such approaches as distraction, evaluation, reassessment and medical intervention (Eichenfield et al. 2002; Taddio and Katz 2005). When looking at pediatric pain there are multiple ways in which different health professionals attempt to measure children’s pain perception in order to estimate the best pharmacological and/or non-pharmacological treatment. Some of the main elements they use are: questionnaire-based survey tools, numerical rating scales, faces scales, visual analog scales, adjective scales, and color scales.

For many health professionals, especially palliativists and other pain specialists, the Visual Analog Scale of Faces (VASOF) is seen as the gold standard for pain assessing in children. Usually while assessing pain professionals want to know “pain onset, location, intensity, quality, duration (or frequency, if recurring), spatial extent, temporal pattern, and accompanying physical symptoms [because they] are the key pain characteristics for assessment” (McGrath and Brown 2003 cited in Charlton 2005: 4). These features are obtained from a child (when possible) and parental report during the diagnostic interview and clinical examination. As
in the case of the Palliative Care Unit at the Hospital Infantil, professionals also obtain a quantitative rating of pain intensity (being 0 no pain, and 10 the worst pain ever experienced). There is a huge difference for health professionals dealing with pain between verbal and pre-verbal children. Mila, the head of the medical residents at the Communicable Diseases Unit reminded me

> With a baby, you, realize that, you know, he is distressed, that he is irritable or whatever, because you see it in his gestures, the way he is frowning, he has pain, whereas with an older child he just tells you…

> When looking at the specificity of pediatric pain it is worth looking at the new updated definition of pain by the International Association of the Study of Pain, which in 2011 updated their definition by adding this note:

> The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. Biologists recognize that those stimuli which cause pain are liable to damage tissue. Accordingly, pain is that experience we associate with actual or potential tissue damage. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience. Experiences which resemble pain but are not unpleasant, e.g., pricking, should not be called pain. Unpleasant abnormal experiences (dysesthesias) may also be pain but are not necessarily so because, subjectively, they may not have the usual sensory qualities of pain. Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually no way to distinguish their experience from that due to tissue damage if we take the subjective report. If they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain. This definition avoids tying pain to the stimulus. Activity induced in the nociceptor and nociceptive pathways by a noxious stimulus is not pain, which is always a psychological state, even though we may well appreciate that pain most often has a proximate physical cause.\(^\text{81}\)

> One should ask a child that has gone through the cumulative effects of hundred and even thousands of pricks throughout their entire treatment if pricks are “experiences that resemble

\[^{81}\text{http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698 - Pain, accessed 20150130; my emphasis.}\]
pain” and thus only “psychological states.” Leaving aside that small detail, by reading this updated definition I wonder if we are still trapped by the Cartesian thinking here and its necessity to see a clear damage tissue to call a certain sensory event as pain. The definition “avoids tying pain to the stimulus,” and emphasizes that even if there is no way to probe that pain is not caused by tissue damage, and “[I]f they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain.” Still it seems the definition reinforces the division between body/tissue and mind/psychological state. In order to call pain any stimuli there is always a need for a “proximate physical cause”? Studies on children not only have shown an equivalent plasticity and increased excitability in the developing nervous system in contrast to adults, but also young infants have intensified reflex responses (that is, lower thresholds and longer-lasting muscle contractions) when considering certain types of trauma such as needle insertion (Andrews and Fitzgerald 1994). I am pointing out the contradictions in the above definition, but it is also striking how little access doctors or anyone else has to the pain of others. We need to “see” it somewhere in the continuum of internalized exteriorities / externalized interiorities (Grosz 1994) in order to call it “pain”? How do children, from their own lived bodily experiences, feel pain and how difficult is to assess it, to relate to it?

Each of the three groups of professionals I worked with showed a deep sense of commitment and an urgent need for learning and keep updating within their own field. They all have bibliographical discussions in relation to their own field new issues. The palliative care team was constantly fine-tuning their knowledge about pediatric pain and ways to ameliorate it. But in between these (and other) professional teams dealing with children’s pain were children and families. They also know about pain, they know with and from their own bodies. Yet, in some cases there were clashes and frictions among the different health professionals and their
different perspectives in regards to how to treat children’s pain. In many ways this happens because professionals and teams, according to their particular specializations, tend to focus on each particular field of knowledge within biomedicine. When I conducted fieldwork with the Palliative Care Team I observed a team meeting in which they complained about how other units mismanaged children’s pain. Marcos, one of the palliativists said,

> Often patients are referred to palliative care when illness has advanced so much, when they are in the last days, or when residents do not know how to treat them, and the staff doctors do not help them at all. For instance, we have the case of the fourteen-year old girl from San Juan [western province that limits with Chile] that had so many issues after her operation, she now has bone metastasis and now the Head of Neuro[logy] said, “That’s it, it’s over.” I say, that’s it what? We know how to do palliative care but the problem is that there are plenty of sick children to whom doctors do not know how to treat pain or other bothering symptoms.

Many things have changed at the hospital since then and now the palliative care team has a bigger presence in the everyday work of the hospital. Since my fieldwork the palliative care team has expanded considerably in terms of its number (from two to four staff) and in terms of the general knowledge and acceptance from other specialists. During all these years, countless medical residents from the children’s hospitals and other hospitals throughout the country have rotated at the team as well. More children, families, and health care professionals are aware of palliative care techniques and knowledge to deal with pain and other uncomfortable symptoms. But the truth is that pain is a pervasive experience that almost every day is either directly experienced by children living with cancer or witnessed by family members, and professionals.

One day I was conducting research at the Communicable Diseases Unit when a 15-day-old baby was hospitalized. When the mother and baby entered the unit for the first time I followed one of the medical residents who received them and filled the clinical history. I will describe these first moments to show the complexities associated with children’s painful experiences vis-à-vis with others (in this case her mother and two residents) witnessing her pain.
The name of the baby was Elena. She was a 15-day old baby born in term on the 41st week with good weight. The mother, Alejandra, was a 21-year old girl from a working class neighborhood some 30km from the City of Buenos Aires. When we arrived to the room she was seating on a chair next to the bed in an isolated room holding her baby on her arms. According to the mother everything started with a small bump that then it became a 4x4cms abscess in the left chest region. Alejandra took the baby to the nearby hospital in San Miguel (Province of Buenos Aires) but they she was not happy with the treatment so she took her baby the same day to the Hospital Infantil. They arrived by local bus at 4:00 am the following day. José, the second-year resident, asked how her pregnancy was and the mother said it was OK but she didn’t have many controls. The baby was being breastfed. Alejandra then said, “I have to tell you that I am epileptic.” José asked her, “What kind of medicine do you take?” “Phenobarbital,” Alejandra replied. She then added,

I took it during my pregnancy, a doctor recommended me to take it. I only went to controls in the last trimester of my pregnancy and the doctor told me that it was a risk to take this medication but it could be worse if I had a convulsion and maybe an accident with consequences to my baby or to me.

Alejandra was alone, the father left her when she was four months pregnant. The resident then told Alejandra he was going to check something and left the room. I followed him. He then discussed with the head of residents and one staff doctor what to do. They said that the initial treatment was antibiotics and acetaminophen since the baby did not have fever. The head of residents asked for an ultrasound and a complete blood sample. The staff doctor said that it might need a lumbar puncture (LP) as well. Another second-year resident disagreed and asked the staff doctor for the rationale for it. The staff doctor explained, “It’s a neonate, plus bacterial infection, and plus she has 22 000 white blood cells.”
Then, we went back to the room with the baby and the mother. José took some gloves and a tiny needle-syringe to take blood from the baby. With this special needle, he had to find a vein in Elena’s left hand. The hand was so tiny I thought the needle would traverse it. The mother looked at the procedure in complete silence. I stood close to José and the baby. At this moment Cecilia, another second-year residents, came and offered help to José. Then José held the baby and Cecilia punctured the baby with the needle. The baby cried a lot. When Cecilia performed that José put his little finger inside the baby mouth and both José and Cecilia explained to me, and the mother, that “when they are this small just to suck something would calm them down, they will not feel any stress at all.” The baby cried less but still she showed signs of what I would describe as pain. Since Elena was so small they had to take blood drop by drop. It seemed it lasted a lot. The mother kept in silence during the procedure. While Cecilia took blood José asked more questions to the mother. José asked Alejandra if there was anything more she would like to add to the clinical history. Alejandra said,

Yes, there were three events during my pregnancy that I should tell you. First, at one moment I was very depressed, I don’t remember at what point of my pregnancy, may be when I was five or six months, and instead of taking two pills [of Phenobarbital] I took a whole tube of twenty pills. They took me to the hospital and had to perform a gastric lavage. I also had low blood pressure. And, as I said, I am also epileptic. I came here because I had to do something…

Cecilia, then told Alejandra they had to do some tests and also needed to know as much as possible what she had been taken for her epilepsy during pregnancy and since Elena was born as well. She said, “The blood taken from you and your baby will help us understand more what Elena is having.” José then added, “I am afraid we will have to take some sample from the abscess to study it too.” Alejandra agreed in silence by shaking her head. Then, José came with another set of needle and syringe to perform a puncture in the abscess. He punctured the baby very slowly and almost parallel to Elena’s chest in order to avoid going deep with the needle.
Alejandra did not look at her baby during the procedure. Some dark thick liquid came out the abscess. Elena was very silent. Elena cried a little bit while José was putting the tip of his little finger inside her mouth. Then, José collected all the tubes and disposable material and we both said goodbye to the mother and baby. The mother looked very worried and attempted to shake her right hand to say goodbye.

With this example, I want to focus not only on the baby’s pain but also on the mother’s, the residents’ and my own discomfort by witnessing it. This was the context in which not only Elena experienced pain but also medical residents caused it, and we all witnessed it. This example can orient my discussion about everyday forms of pain and suffering, sensations and subjective experience, representation and non-representation. Throughout the chapter I focused on how pain is assessed and treated, and how it differentially affects children, parents, and different kinds of professionals (palliativists and others). It is fundamental to differentiate this because like in the above example even newborn babies are experiencing pain and expressing it in particular ways. I also bring this example to attempt to show the inter-connections and mutual influences that were present in that room. The resident seemed concerned with the baby’s pain. Yet, he was trying to understand what the source of that abscess was, and in the process of understanding it he was inflicting pain to the baby. The mother looked very worried and she was trying to figure out what was going on. As the ethnographer I tried to observe the situation, remember it, and I was also a bit shocked by what it looked as an immense syringe in relation to the small baby’s body. Though we could only represent some part of what was going on in that room.

As Livingston (2012) and Asad (2003) argue, above all pain is a relationship. Being traversed by your own or other’s pain solicits a social response. Thus, what happens at the
“interior” of the body or, in the endless process of “interior” meeting “exterior forces”? Canguilhem (2008:16) argues, “Properly understood the concept of interiority conveys a spatial image. Interiority is exteriority turned inside out, but not abolished.” These exteriorities turned inside out are at the core of children’s permeable (medicalized and hospitalized) bodies. Indeed, they are a fundamental aspect of this inter-corporeal pain and the ways we live our bodies. Though, as Grosz (1994) reminds us, subjectivity should not be equated with interiority. Jackson (1992) has shown how constant chronic pain creates tensions and frictions between the body as subject and object.

Yet, in spite of all the vast recent scientific research pain seems to exceed any effort to reduce it to a clear-cut object of biomedical gaze (Illich 1974; Jackson 2005). In their revolutionary study Melzack and Wall (1965) recognized that pain is a multidimensional experience determined by physical, psychological, cognitive, and sociocultural factors. They led the reconceptualization of pain as a phenomenon with multiple facets that need to be simultaneously dealt with a multidisciplinary approach. In particularly, chronic pain is a fundamental problem for social and medical investigation because of its unclear place in the classificatory system in Western biomedicine (Honkasalo 1999) and because of the stigma and liminality attached to those suffering pain (Jackson 2005). Pain although theorized in biomedicine as occupying a clear niche in the everyday lived experience is part of multiple disruptive processes that at once distort biomedical categorization and blur diagnostics (Honkasalo 2001).

Going back to the vignette I presented above I could see how the mother, following the residents’ questions, tried to make sense of the current situation for her baby while in silence witnessing (and being affected by) the painful procedures being performed to her daughter. She
had quickly decided to take her baby from the close-by hospital to the Hospital Infantil in the City of Buenos Aires. She could see the growing big abscess on Elena’s chest and she felt something had to be done, quickly. Of course, the residents also tried to elucidate what events in the past could have caused the baby’s conditions but in the process they were all embarking on a meaning-making process that was transcending the mere Cartesian dichotomies of an individualized body-mind. The mother’s separation from the father, the mother’s epilepsy and her medication, her event of swallowing twenty pills, the baby’s abscess, and the baby crying were all being actualized in that room in that moment in which the residents were performing a painful procedure to the baby. I am sure the baby did feel some relief by sucking José’s little finger as the resident wanted to believe. But also the mother and baby were both under enormous stress, and we were there causing and witnessing that. As many authors have argued before (Czordas 1994; Good 1994; Kleinman 1995; Jackson 1994; Morris 1991; Throop 2010), pain is always contextualized. Thus, in this case both the act of inflicting pain and witnessing the act of inflicting pain were contextualized under the rubrics of “biopsy” and “blood sample” for the medical residents and of “I have to do something” for the mother. We will never know what kinds of long-term imprints these experiences had create on the baby’s corporeality/subjectivity and biomedical sciences are far from understanding how a series of painful events are located in the continuum of a growing body. Needless to say, I am not criticizing the medical residents for thinking that by letting the baby suck the little finger their

82 Oral stimulation such as breastfeeding, the use of a pacifier, and the administration of sugar orally has been proven to reduce the signs and probably the experience of pain in babies (Carbajal et al. 2008, American Academy of Paediatrics and Canadian Paediatric Society 2006).

83 Although there are a growing body of research suggesting that the more painful procedures a child experiences, the more brain-development and behavior challenges it suffers (Brummelte et al. 2012).
intervention was less or not stressful at all. This shows what they have learned at medical school and during their residency in relation to the management of pediatric pain. The question, however, we need to ask is how pervasive pain can be and what kinds of effects co-produce in the sufferer and those close to him or her witnessing that suffer. During my fieldwork I was able to observe how medical residents, especially those rotating at the Communicable Diseases Unit (second-year and fourth-year) were very receptive to the palliative care knowledge. In fact, they were calling them and asking them all sorts of questions about drugs, treatments, and tips on how to better treat children’s pain. Assessing and treating pain is a complex task. Newborn babies, small babies, toddlers, older children or adolescents (and their social circles of care) experience pain and affect others on a daily basis.

**Pain as an affect that obliterates meaning**

For children and families, it is hard to believe that some pains are inevitable, for them any pain is not good. Cassell (1982) states that patients and their families can often experience suffering from therapies as worse than the suffering of the illness itself. How do children, health professionals, and family members attempt to give sense to, and affect/are affected by, children’s pain? These are two interrelated processes. On the one hand, to consider pain as affect is to locate it in a pre-personal zone. On the other hand, to think of pain as shattering meaning (or, even as something meaning-less) is to put it in the blurry personal realm of sensations, perceptions, feelings, thoughts, and consciousness. In many ways, pain is pure affect, and attempts to find “meaning” in pain are efforts in rationalization that try to represent the unrepresentability of pain. Of course, health professionals are not the only one observing and attempting to elucidate pain. Children know it with/from their bodies. Caregivers are painfully
aware of it. In addition, family members absorb information that different doctors share, which they pass along to other family members. They also observe and draw tentative conclusions. The meanings and affects associated with children’s pain are situated, localized in particular bodies. As Frank (1995) argues, the stories people tell about their illness are told through a “wounded body”: they are not about their bodies but of them.

Lakoff and Johnson (1980) have argued that we live by metaphors; we think and perceive the world using metaphors as heuristic devices. When children and adolescents refer to their own pain, they do it in different ways and using different metaphors (often taken from health professionals, often made up by them). I will give two examples extracted from my field notes to show the enormous arsenal of metaphors and images children and adolescents use on a daily basis when referring to their own painful experiences.

While working at the Palliative Care Unit I once observed a follow-up between Pablo, a 19-year old boy from Perú who was living in a working class neighborhood near the City of Buenos Aires and Elizabeth, the head of Palliative Care. Pablo had come five months earlier to Argentina to find good and free treatment. The Neurology Unit referred him to Palliative Care. Pablo had an undiagnosed condition that caused him intense pain that radiated from his waist to both legs, both knees, to the soles of both feet. When Elizabeth asked Pablo how his pain was Pablo told us, “It is like burning in my legs, like bubbles when the water or soup is boiling, like bubbles going down from my waist to my legs.” Pablo was very worried because doctors were thinking that could be genetic and he told us that both his parents had these intensely painful experiences, and he did not want to go through the same experiences. Pablo wanted to know the cause of his pain was and what to do about it. His pain needed an explanation and ways to (counter) affect it.
On another occasion, Silvina, a 6-year old girl with acute lymphoblastic leukemia came to the Palliative Care office for a visit. On her pervious visit, she drew a picture of herself with pain depicted as little ants walking insider her body. The picture hung at the entrance of the office.

Elizabeth: And those ants that you’ve drawn are they gone?
Silvina: Yes, they are gone, sometimes they come, and sometimes there are ants and cockroaches that walk all inside me. But now I am fine.
Elizabeth: So now you are fine. You don’t have any pain at all?
Silvina: No, only a little pain, it bothers me a little, like when they walk here [and she points to her throat] but other than that I am fine.

Palliativists and other pediatric specialists are aware of this rich use of images and metaphors and they encourage children and parents to describe children’s pain in their own words. With those verbal descriptions, they can better understand the different kinds of pain (somatic, visceral, or neuropathic according to the biomedical categorization of pain) and they can better orient the kinds of pharmacological or non-pharmacological treatments they would suggest. However, palliativists (and others) are also trained to discover signs and to listen to what patients are “saying” with or without words. While conducting fieldwork with the palliative care team I observed how, using a biomedical model, they attempted to pinpoint the exact causes of pain. Thus, when children could verbally express pain, palliativists would ask children if the pain was like stabbing, piercing, cutting, and drilling pain. Or, if the pain was como algo que presiona (pressure-like), que apreta (deep squeezing), quieto o difuso (dull or diffuse), en todas partes o localizado (if it was vague or well localized); or, muy doloroso (if it was like aching).

84 The Palliative Care Team has two permanent volunteers that offer different kinds of “non-pharmacological” assistance to patients and even caregivers. They provide sessions of visualization, mandala drawings, breathing techniques, crystal bowl singing, and other so-called “alternative therapies.” The team also has two renowned artists who help children do art-therapy.
With these approximations to children’s pain palliativists attempt to map the causes and pathways of pain within each child’s body and they suggested plans to ease their pain.

When talking with children, palliativists also wanted to know if the medication lasted until the next doses, or, if the pain medication was working but generating undesirable side effects (often painful and uncomfortable) such as constipation or rash. Indeed, palliativists, hematologists, and communicable diseases specialists have to consider the interactions of myriad drugs they (or others) were prescribing to each particular child (often more than dozens), their side effects, and the potential ways to reduce the negative interactions among drugs (which is not an easy task). Pinpointing how pediatric pain works is a complex process for the different health professionals dealing with children with different forms of cancer. It requires different sets of knowledge and ways of understanding the relationship between visible and invisible clues and symptoms, and, between individual(ized) bodies and collective bodies. (Indeed, one could ask: we may “know” the source of pain (cancer, pain receptors, etc.), but does this knowledge give “meaning” to children’s inter-corporeal pain?)

Thus, verbalized expressions that attempt to make sense of children’s pain are one part of the broader communication among children, families, and health professionals. Indeed, there is a rich tradition of social scholars looking at the narratives and the storytelling strategies that people experiencing pain create to attempt to put into words their inner/isolated experience (Frank 1995; Good 1992; Mattingly 1998). In fact, pain’s sufferers in order to transmit their experiences they need to externalize it by making their inner pain audible and visual. Thus, non-verbal clues such as gestures become also important in this communication. Besides, when patients use gestures to

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85 When I was conducting fieldwork with the Palliative Care Team roughly 50% of their patients were children with different forms of cancer and also approximately 50% of all their consultations were referred by other units and specialists because of pain.
externalize their pain, they “construct chronic pain as a ‘object’ in the intersubjective space” (Hydén and Peolson 2002:328). It is this “intersubjective space” what I refer as the intercorporeality of pain and where gestures and verbal expressions are used as means to communicate and conceal painful experiences. In fact, in-between meaning, affect, and bodies lay the gestures of pain. Gestures that can have pointing, iconic and symbolic functions (Hydén and Peolson 2002) show not only how the body becomes the terrain of pain but also how pain creates the fear (terror) of future physical and mental pain.

Thus, in-between bodies, there are also inter-corporeal contact zones in which touch becomes a threshold and border of bodies constantly dissembling and reassembling. Medical, familiar, inter-personal touch becomes the territory of painful affect(s). Hence, which is the place of touch/being touched and culturally mediated patterns of contact in the early development of children, especially the central nervous system? Which is the place of touch in the everyday lives of children living in pain? How much and in which ways children resist to be touched when they are in pain? When we talk about gestures of pain, when children are using their bodies to signal where it hurts, they are using touch as a language the same way health professionals use touch as a semiotic/heuristic tool to distinguish the normal from the abnormal/pathological (Canghuillem 1991). In some way, touch works at the micro-level of the structure of biomedical ensembles, connections, and networks myriad actors (re)produce at the Hospital Infantil. For Latour (1987) the notion of network came from Diderot who wanted to get away from the Cartesian lineage of matter and spirit. Instead, he proposed a relation between matter and bodies. In this sense, touch is central to this network of matter and painful bodies that using Deleuzian’s terms work rhizomatically; that is, work continuously, contingently, heterogeneously, immanently, and affectively.
I once followed María from the Palliative Care Team to the Communicable Diseases Unit to see Carola, a five-year-old girl with acute myeloid leukemia who had experienced intense pain the previous day. When we entered the room, Carola was on a fetal position, covered with blankets, and refusing to be uncovered. Carola’s father was next to her. María told me that the whole unit feared and avoided him, because he had many tattoos and piercings all over his body. Apparently, he was violent with his wife and Carola as well. When we entered the room Carola and her father were quiet and looked calm. María sat next to Carola and while she was touching her left arm, asked her “How are you doing little princess?” Then María asked Carola, “So, how do you feel today?” but she did not reply. María insisted, “I bet you are tired of so many people coming to talk to you, so many people touching you, but we won’t prick you, we won’t do anything to you, I promise.” Her father said, “I think she is more comfortable with what you are giving to her. She seems better, she can sleep better, and she doesn’t complain so much of pain.”

This is just one small example of how pain can be seen as an affect, as a non-representational mode of thinking and being-in-the-world in which children place their bodies in fetal positions to avoid being touched or pricked. Of course, pain is (a pre-personal) affect, however, the moment it emerges on the consciousness of “I” it becomes something to be discovered. Though it constantly defies meaning.

At the Communicable Diseases Unit staff professionals and medical residents were in close contact with the Palliative Care Team. Especially, second-year medical residents at the Communicable Diseases Unit who work all day, and have to take one or two night shifts per week, were more prone to call to the palliativists (at any time during the day or night, weekdays or weekends) or ask them to come to help them with the pharmacological and non-pharmacological management of children’s pain. In fact, a very common scene that I was able to
observe at the Communicable Diseases Unit was by the end of the regular week day, around 5:00
or 6:00 pm, when the staff, the head of residents, the fourth-year residents and all the second-
year residents were leaving the unit, and only one second-year resident was going to stay during
the night shift (or, on Fridays when two were going to take the weekend shifts). Usually the head
of residents would ask the resident in charge of the night shift what she/he would do if X
happens to Y child (usually those in critical situations). For instance, once they were talking
about Marcela (a 13-year old girl with a rare, undiagnosed anemia):

Cristina (second-year resident in charge of Marcela): She had a post-diagnostic sepsis that they
think it is caused by her anaemia. She has dipyrone (non-steroidal anti-inflammatory drug) for
her pain in her left leg, Teico[planin] (antibiotics, 2nd day), portacath (11th day), she has a lot of
pain in her left leg but at the physical exam there is nothing. Her parents are all the time with her,
the father said “it seems you are forgetting Marcela.” They have an older son. They are from
Chaco [far away Northern-east province]. Until Wednesday she will be with all the antibiotics.
Today she has 2 900 white [blood cells], 10 of hemoglobin, and 11 000 platelets.
Tina [head of residents]: So what happens if Marcela gets septic during the weekend?
Cristina: We will have to cultivate her [take blood samples to find the cause of
the infection],
give oxygen, lock the portacath, or, if we can’t lock it pass the less possible fluid through it, put
another intravenous access, put a bigger access (from 20 to 22) so you could expand her faster.

As we can see the medical residents were trying to foresee what would happen if Marcela
were going to get worse during the night. Certainly pain for medical residents (and many staff) is
something that affects them more than something they can clearly understand and give meaning.
On the usual overwhelming scheme of things pain was one of the many aspects they were
considering. And if pain got worse they would most likely end up calling the palliativist on call
to help them overcome this affect that obliterates meaning. Yet, it seemed that what Marcela was
referring as her own experience of pain did not match with what her medical resident considered
as “pain,” Cristina noted “she has a lot of pain in her left leg but at the physical exam there is
nothing.” These frictions between self- and alter-narratives of pain are constantly occurring and
at the heart of it is this tension between pain as affect or meaning. On many occasions I noted
how medical residents were pondering if Marcela’s pain was “psychological” (they thought she was depressed) or “neuropathic” (pain induced by injury or disease of the nervous system).

Sometimes, professionals were drawing a clear line in their everyday practices and interactions with children and family members between “real” and “concrete” pain and “not-so-concrete” or “less real” pain (Jackson 1992) which often was characterized as “psychological,” “emotional,” or even “social”—anything that was not clearly-cut organic. Yet, this line very often became blurry and messy. On the other hand, children and families absorb and observe biomedical interventions into children’s bodies. They absorb biomedical knowledge and practices by (re)asking, questioning, resisting, sharing information among families, listening to what doctors say to other families, among other strategies. They observe professionals’ reactions, their silences, who treat children better, who prick children’s arm less harmfully, who listen to children’s and family member’s complaints about pain and do something about it or who does not trust so much on children’s expressions of pain. These are not only forms of conceiving pain (and the actions around it) as a meaning to be discovered, as something that can be understood, but also as a way to affect others: pain-as-affect.

Thus, children and families also affect, and are affected by, children’s painful bodies. Children and/or caregivers scream with all their strength or se tragan (“swallow”) painful experiences, they do not show signs of pain to protect others, they cry or do not cry in front of their close social circle and/or in front of the different health professionals, and they ultimately need to (re)learn how to live in a often constantly painful body. Indeed, professionals sometimes even explicitly try to channel or confine pain-as-affect when ask parents “please do not cry in front of your children” to avoid “depressing” them more.
Obviously, age is a key factor in relation to how much children can verbally express themselves in regards to their own painful bodies. Also, the number of months or years that children have been treated or socialized with other sick children, or the intensities of painful experiences can be a major factor (children’s own experience with their illness) in children’s awareness; more so if children have gone through experiences of relapses and recoveries. For instance, a younger child going through bone marrow transplant may know more about his/her options than a newly diagnosed older child. Moreover, children show different understanding and present different views to different individuals on different occasions; they craft their messages according to the different audiences and contexts (Bluebond-Langner 1978, 1996; Zeman and Garber 1996). In some instances, children, particularly adolescents become frustrated when professionals do not acknowledge their pain (Dow et al. 2012).

But often children’s pain is evident, something “easily accessible” to the senses of those who interact with them. One could say that often pain is “shared.” The very first day I began my fieldwork I was working with the palliative care and I followed Marcos, at that time one of the two palliativists working at the hospital, to Neurosurgery Unit to see Javier, a twelve-year old boy with an advanced brain tumor that had taken half the brain and pushed out his right eye (and half the skull). We arrived to the room when a nurse was introducing a nasogastric tube into Javier’s nose. Some minutes before we arrived Javier had a convulsive episode, which according to Javier’s mother lasted for about fifteen minutes. But when we arrived Javier did not look so uncomfortable. He had half his brain swollen and the tumour had pushed out as well as his right eye. His left eye had a blank stare. Marcos asked the parents how he felt during the day and the mother explained he had several convulsive episodes and after those episodes his legs and arms would become stiff. Marcos asked the parents if he could check Javier and they said yes. Marcos
assessed Javier and found that Javier had pain when touching his abdomen. Marcos asked the parents what else was causing him discomfort. Analia (Javier’s mother) replied that besides the convulsive episodes he had dyspnea [feeling of lack of air], “He wakes up in the middle of the night because he feels he lacks air and then his breathing accelerates. I am worried about this.” Marcos ensured them he could give more medication to control that symptom. Then, Marcos offered parents to go to another room to talk a little bit.

Marcos: I know seeing Javier in this way is not a very pleasant image.
Analia: This whole process is like a nightmare. I can’t describe what I feel. But I am more worried about these moments in which he lacks air.
Marcos: I think the neurosurgeons at this unit have already told you that this would not improve, instead it would get worse. The tumor has spread and taken some parts of the brain that control the nervous and breathing systems. Still we can help Javier by decreasing the sensation of lack of air. With some medication we will be able to help Javier to feel less this sensation, although this dyspnea would likely continue… (long silence) … What is that worries you most?
Pedro (father): We don’t want Javier to suffer…
Marcos: We will do everything that we can to help him ease his pain and suffering. Now with the nasogastric tube we should not worry about feeding him.
Analia: But we are worried, he is not eating much.
Marcos: At this time it is less important feeding Javier, it is not something he needs. I understand the values associated to food and that you as parents want the best for him, but he does not need so much food now. But what he needs is some fluids, that you clean his mouth, you can give him a little bit of water with lemon juice, that you can clean the excess of saliva and mucus.
Analia: OK. We can do that. The other thing that worries us a lot is what we should do with our three daughters; they are 16-year old, and 14-year old, and 13-year old. The older is in her own world, the middle one is depressed and crying all the time, and the youngest is the one in charge of everything, and the one closest to Javier.
Marcos: You know, either at home with good nurse support, or here Javier could be well treated.
Analia: We know that.
Marcos: If you want you could talk about it with your daughters and see what they say [about taking Javier home].
Analia: Yes, we could. I want to be all together and at home but I don’t want them to see Javier as he is now. Because of this I would prefer him to stay in the hospital. But we will think about it.

It is this inter-corporeal space and relationship of pain what was central for the parents and the palliativist doctor. In this room Javier was evidently feeling a lot of pain, the tumor had advanced and we could all see that he was dying in front of us. The parents did not want him to
suffer, but also they did not want their daughters to see him dying in this way. It was this connection to Javier’s pain, the concreteness of Javier’s pain, the attempts by Marcos to ease it and to aid Javier (and his parents) to navigate the best possible way during this agony phase, what was at the core of these affective processes. More than a meaning to be discovered pain was an affect shattering meaning. This vignette shows a lot of issues that need to be unpacked.

The complexities of pain at the end of life were doubled by the parents’ fears and anxieties of not knowing how to handle the end of life and the way Javier’s sisters would handle it. In this case on top of Javier’s pain during his agony phase and the technical difficulties faced by the palliative team to efficiently deal with his pain (to ease his pain, to make him comfortable during the dyspnoea episodes, to help Javier’s parents decide where to experience Javier’s last days of life, etc.) there was the inter-personal nature of his pain. This was a kind of pain that was existential, it was manageable (to a certain extent) but even though Javier was not able to describe his pain his body was affecting others and sending ‘signals’ that could be differently decodified by the palliative team or the staff at the Neurosurgeon Unit.

Pain resists, and in the end obliterates the ability to express and communicate any interior painful experience (Scarry 1987). Taussig (1987) has also pointed to the relation between pain and terror as something that shatters meaning. According to Scarry the person in great pain experiences his or her own body as the agent and perpetrator of his or her distress. The constant, self-proclaiming sign of the body in pain holds not only the message “my body hurts,” but also the certainty that “my body hurts me.” Her body-as-object-in-pain is indistinguishable from her body-as-self (as simultaneously a weapon and a wound). Yet, there is more about pain in just seeing it as an opaque experience. Livingston (2013) has rightly criticized Scarry for her narrow
view of pain as an entity to be defeated by an agentive individual instead of looking at pain as a social relationship embedded in a particular social context.

Yet, what happens when the body-as-self cannot verbally express her pain? It will eventually express it through other (non- or less representable) venues? What happens when others are witnessing this painful allegedly inexpressible experience, particularly parents (Hayes and Kjiox 1984) or health professionals (Sork 2005)? How distant/close is the “victim” from the “witness” and what are the limits of our personal responsibility to, and our ability to understand from, the pain of others (Sontag 2004)? And as Sontag (2004:7) vehemently reminds us, “No ‘we’ should be taken for granted when the subject is looking at other people’s pain.” These are in fact tough questions for children-in-pain and those involved in caring for children.

To summarize, what do I mean by pain as an affect that shatters meaning? Schematically speaking, I mean that pain is an affect when we consider the pre-personal, non-representational aspects of pain, when there is a dynamic catalyst decreasing the potency of one’s body. On the other hand, pain can also be seen as an enigma, as an illegible manuscript that needs to be decrypted, especially, by those trained in deciphering the mysteries of the body but also by those that directly suffer those pains (children and their close social circles). But, ultimately, as Livingston (2012) argues, pain is a relationship that begs a response, a form of affect/being affected by it.

**Pain from illness and from treatment**

Children and adolescents often depict invasive procedures and their associated anticipatory anxiety and fear as the most painful and worrying aspect of illness or hospitalization (von Baeyer et al. 2004). I heard multiple times how parents and children complained about the pain inflicted
by doctors, nurses and technicians during diagnostic or therapeutic procedures. Venipuncture was one of the most feared, violent, and excruciatingly painful experience children have to go through during treatment (McMurtry et al. 2011). It is also one of the most common, daily, routinely permeabilizing procedures. Almost all children with cancer suffer painful events during their illnesses. Professionals tend to assume that pain inflicted by treatments, or by diagnostic or therapeutic procedures are somehow acceptable given their actual professional and institutional circumstances. Although, as I showed before with the hematology team improving sedation for painful procedures, professionals try their best to decrease its presence during treatment.

On multiple occasions, when I observed multi-family meetings at the CCF, parents complained about the painful treatments. Parents narrated different stories in regards to their perceptions of children’s pain. One mother, for instance, told us that when her worried son asked his main hematologist how long would he need the semi-implantable port the hematologist told him “For two more years” and immediately left the room (and the mother then told me how she feared for more infections and painful interventions). Or, another mother told us how her daughter did not want any nurse or doctor to prick her besides the head of Nurse at the Onco-Hematology Unit because he was the only one that would not make her veins explode (and she never wanted a semi-implantable port precisely because of fear of infections). Or, yet, another mother told us how her ten-year old son would indicate the specific place on his arm, the precise vein where he wanted the prick. He would say, “Prick me right here,” and complained in a loud voice if the nurse or resident did not prick him exactly where he wanted.

On one occasion, one Monday in one of the early meetings at the HU they discussed about a four-year-old girl with acute lymphoblastic leukemia hospitalized at the Communicable
Diseases Unit. The girl had fever on Friday, Saturday, and Sunday and did not receive any antibiotics. The hematologists began to talk frantically about the case:

Alejandra: I went with Muriel, and Cecilia to the [communicable disease] unit on Friday afternoon to ask them to give antibiotics but they didn’t give it to her.
Brenda: But she is on the induction phase!
Alejandra: Yes, we know that.
Brenda: I will go and talk with Alicia [one of the staff at the CDU].
Alejandra: Alicia told me that in adults they would treat it but in children one event of fever is part of the illness.
Brenda: I talked with another doctor that works outside the hospital with Alicia and she told me that at her unit Alicia can’t talk with no one above her or below her…
Claudia: I went to the unit to talk for another case and I had to listen to the “petisa” (“shorty”) giving me a lesson about candida tropicalis but the girl was getting worse…
Brenda: We have an historical problem with communicable diseases unit, they can’t say that if [a child] has a[n] [fever] event per day is part of the illness.
Flavia: I thought she was joking when she said they were not medicating her. I asked her why? Which were the criteria? And they said what they told Alejandra, “Because in children it is part of the illness.”
Claudia: “Because in children it is part of the illness” during induction [phase] is a conceptual mistake.
Brenda: On the first month of induction if [the child] experiences fever you must medicate. We have three times more mortality caused by infections during induction [phase] that other places.
Rafael: It is like two circles that don’t touch one another…
Alejandra and Brenda: Yes!
Brenda: Every time you see fever in these kinds of children you have to think first that is an infection and then that is part of the illness.
Alejandra: I always have issues with Roberto [head of Clinics Area], I don’t think he likes me, but we will keep seeing children dying because they don’t understand that with these children we can’t wait, we have to assume that fever equals infection and we have to start treating them with antibiotics right away…

This discussion not only shows the native perspectives of conceiving an uncomfortable symptom (fever) as either part of the illness (communicable diseases) or as a by-product of treatment (hematology) but also the inter-units’ frictions. Often it is not a straightforward distinction what is caused by the evolution of illness or the intervention of treatment, unless it is clearly evident like an abscess caused by the insertion of a lumbar puncture. In many aspects illness and treatment are intertwined, and often there are conflicting ways in how different specialities see this. Yet, for the hematologists every little symptom (or even something like a
“pre-symptom”) is a source of worry. On the other hand, I heard Communicable Diseases staff and residents said that hematologists push children’s bodies to their limits, the thresholds of life, and so they need to run many tests to be absolutely sure which is the source of infection (bacteria, fungi, and/or viral) to start the right treatment. In these contradictory views we can also see the different sets of knowledge, practices, and notions in regards to children’s bodies and what should be done to aid their situations and ease their pain and suffering. When I think about children’s pain I also see differences in how palliativists, hematologists, or communicable diseases specialists understand the causes of pain as if they are part of treatment or illness. The above example also shows how different doctors consider fever as either part of illness or part of treatment. The same can be said about pain, since both illness and treatment are sources of pain, and different health professionals, children and families differently consider both.

I remember the story of Hugo, a five-year old indigenous child from a northern-west province. He was derived from the main pediatric hospital in his province for a rare autoimmune disease (they suspected he had an X-linked lymphoproliferative disease). The first time I saw him he had just arrived to the hospital with his mother. They were almost all the time in silence inside their room. In fact, since I was “the ethnographer” and they were the “indigenous” I was the target of many “cultural questions” in regards of their different social and familiar patterns of behavior; especially, in relation to the “mother-child bond.” I tried my best to answer to medical residents, psychologists, and staff doctors at the Communicable Diseases Unit what I knew about their ethnic group and the people of the Chaco region in general. I tried to emphasize to health professionals how important for these groups is the bodily fluids since they carry elements of personhood (Tola 2004) and how stressed they might felt by witnessing myriad procedures being performed onto Hugo’s body. During the many months Hugo was hospitalized he was subjected
to multiple diagnostic and therapeutic painful procedures. Hugo and his mother (then, after a 
month his father came as well, leaving four children alone in charge of an aunt) were taken from 
a small, rural indigenous community and placed in one of the most complex pediatric hospital in 
the biggest city of the country. And Hugo’s body was endlessly permeated for liver and lung 
biopsies, bone marrow examinations, lumbar aspirations, CAT scans, and many other extremely 
painful procedures. I can say that he experienced different forms of pain throughout the months 
he was hospitalized. And his pain was caused by a combination of illness and treatment’s side 
effects. I remember the first day at the Communicable Disease Unit I was at the medical 
residents’ office when I started to hear a boy crying very loudly, the boy was crying and saying 
“Mommy, mommy, mommy.” All the medical residents were coming and going hectically. I 
asked one of the residents, “Who is crying?” And he said the boy was Hugo. He was crying 
because the resident in charge told him they needed to perform a lumbar puncture (he explained 
it to him and his mother). One of the staff doctors came to the office while I was taking notes and 
I asked her if they give analgesic to Hugo and she said, “Yes locally, but not general sedation 
because with children sedation is risky. In general, we don’t want to sedate because it can 
produce serious consequences.” Hugo kept on crying. I stayed inside the office taking notes and 

86 After two months of countless tests and procedures immunologists and communicable diseases 
specialists came to the conclusion that he had a rare disease and the experimental treatment 
he was receiving was only buying some time (with multiple side effects). The final 
therapeutic decision was to perform a bone marrow transplant and he had at least two of his 
four brothers histocompatible. But the family declined to perform the transplant and so they 
took him back to their rural community and I lost track what happened with them after. I had 
a good discussion with the medical resident in charge of Hugo at the Communicable Diseases 
Unit after the family took Hugo back to his place and he understood the family decision for 
many reasons but especially because he was going to be a post-transplanted child needing 
multiple drugs for life and unless they were going to move to a bigger city it seemed less 
likely they were able to manage Hugo’s post-transplanted life. I also wondered at that time 
how much Hugo and his family understood about Hugo’s conditions and the different 
diagnostic and therapeutic strategies different groups of professionals developed in order to 
understand and treat what was going on Hugo’s body.
other residents were also writing clinical histories and doing other stuff. Then, after awhile, he stopped crying and we asked ourselves if he had been sedated. Another resident came and told us he was given midazolam (sedative and amnesic before procedures) and ketamine (analgesic and anasthesic) to sedate him. Then, the medical resident at the hematology unit who performed the lumbar puncture told me that Hugo,

   Was crying all the time, before I touched him he was crying. Just by mere looking at me and the other [medical] resident [at hematology] he began to cry. There was no other option to perform the [lumbar] puncture than sedating him.

   I bring Hugo’s example to show how diagnostic and therapeutic procedures often become layers and layers of painful experiences, especially, when professionals cannot understand exactly what is going on and so perform even more procedures to find a diagnosis. In this sense pain is both produced by illness and treatment.

A brief conclusion about children’s pain

The central question of the chapter was a not-so-simple one: How much do children, families, and different health professionals know, (can) understand, and do about children’s everyday pain and suffering? In particularly, how does pain appear to be understood and approached in the clinical context of this pediatric hospital in Argentina? What does pain do when looking at its inter-corporeal nature? These are important questions indeed. Understanding pain and the (re)actions upon those painful experiences are central concerns for sick children and everyone involved in their treatments. We could ask these questions theoretically in relation to the recent development in the field of pain management in biomedicine or particularly in pediatrics (Verghese and Hannallah 2010). But we need to reflect on the ground, ethnographically, on how pain is not only understood and endured but also how it becomes inter-corporeally collectivized.
Because these are also questions that every child and every subject involved with sick children (siblings, parents, grandparents, nurses, psychologists, hematologists, palliativists, etc.) are constantly thinking about on a daily basis. Therefore, how does everyone assess and relate to children’s pain and attempt to treat it?

In fact, within biomedicine the evaluation, management, and overall understanding of pain not only in its organic, behavioral and physiological complexity but also in its personal-emotional and transpersonal qualities have a relatively short history in comparison with other medical fields of knowledge. It was only in the 1950s and 1960s when many different paths (existentialism, movements of social disobedience, women’s and people with disabilities rights, to mention some) came together to influence the search for understanding and practicing a more humanistic medicine more respectful to patients’ needs and suffering (Clark 1999). Yet, in spite of more patient-centered approaches, we have to keep in mind that modern biomedicine is still a direct inheritor of the 17th Century’s Cartesian model of embodiment with its mechanical understanding of the human body. This model tends to overlook subjective phenomena as by-products. That is, the biomedical clinical gaze tends to concentrate on the internal medium with its mechanical forces. Leder (1992:122) has argued that:

Within this framework, human sensitivity to the suffering of a fellow human being remains possible, but is hardly encouraged. In fact, it demands an almost schizophrenic shift between, at one moment, examining the machine-body, and at the next, acknowledging the person to whom it belongs.

Certainly, this hard-core model of biomedicine may have influenced concrete medical practices but it seems to be losing some ground to a more sensitive approach to human illness and suffering (Kleinman and Benson 2006). Still this “schizophrenic shift” on varied degrees is very present when looking at children as objects or subjects of medial knowledge (remember Claudia the resident at the beginning of the chapter with her anger for treating Leandro as both a
medical object and subject). In fact, there is an increasing recognition that it is of fundamental importance to move beyond the Cartesian dualism to understand the complexities of the psychophysiological, social, affective, and developmental factors present in all children’s pain perceptions and behaviors. We know that child’s and adolescent’s pain intensity is very often affected by contextual factors in particular cognitive, behavioral, and emotional factors (Eccleston 2001). Thus, when we look at the body-in-pain there is, however, a constant process of “intertwining” (Merleau-Ponty 1968) in which the “lived body” is not only at once perceived and perceiver, will and matter, but also part of a social relationship (Asad 2003). Concrete painful medical interventions on concrete lived bodies would directly affect children’s pain perception. Thus, for instance, as I have argued, children’s age and developmental level strongly influence their perception of pain (McGrath 2001). Moreover, the influence of age also varies depending on the kind of pain and the characteristics of children’s previous pain experiences. In addition, children’s recollections of past pain experiences and pain-coping efficacy also affect how present pain situations are actualized. That is, previous struggles can destabilize active efforts to deal with pain and could in fact amplify anxiety and destructive thoughts (Chen et al. 1999, 2000). Thus, as pain’s specialists argue, successful early intervention for children at risk is vital because it not only affects the child’s current pain experience but also expectations of, and plans for, dealing with future pain conditions (Charlton 2005).

To conclude, in this chapter I have reflected on the centrality of pain and suffering for children living with cancer following hematological treatments and for their parents and key health professionals. I have analyzed how pain can be conceived as an affect that shatters meaning and as a social relationship. I have also considered how pain is hard to be separated out
since its not only part of both illness and treatment but also is something that happens between people.

In the following chapter, I will consider the role of caregivers and families in their support of children living with cancer. I will look at the kinds of “therapeutic relatedness” they are able to build by sorting out those that are helping them from those who do not help, and, do not support them throughout the long and taxing therapeutic process.
Chapter 9: Therapeutic relatedness

“If I had to chain myself to the hospital I was going to do it, I don’t have any problem. I will do anything for my daughter’s health. In fact, I already chained myself [to a hospital’s door] once to receive a house [from a social plan] for my daughter to have a better life and I got it.”

Gloria, mother of 8-year old Susana living with histiocytosis (a rare disease)

“I will wear a mask and I will keep on moving forward, and those who want to follow me are welcome.”

Mariana, mother of 4-year old Luis living with acute lymphoblastic leukemia

In this chapter, one of my aims is to elaborate on the notion of “therapeutic relatedness” by looking at the broader medicalization of social relations. Particularly important here is how the family as a collective actor is transformed by the multiple dislocations and adaptations they need to endure while pursuing treatment. Some of the questions that need to be asked are: How does a lengthy cancer treatment affect families? In which ways domestic relationships and family roles that were taken for granted become unfamiliar, open-ended, and subject to constant reorganization? How do children’s illnesses and treatments create financial and economic burdens (to already vulnerable families) and impel new modes of multi-sited care (at hospital and home)? In many ways, children’s illnesses disintegrate family organizations. And, by doing so, it requires new forms of reintegration. Families face all sorts of challenges and have to reconsider who counts as “family”: who is “with us” in these long therapeutic journeys? Moreover, families have to navigate an uncertain present, as I will explain later parents live with the fear of not curing their child, the personal fear of not knowing what is coming next. Caring for children living with cancer requires an affective/emotional work throughout inter-personal displacements (concrete potential limits to our notions of personhood). Therefore, one thing I will stress
throughout this chapter is how families are dynamic entities that place children living with
cancer at the center of family reorganizations while navigating the impact of children’s treatment
to the whole family system. By de-naturalizing what was taken for granted it reconfigures the
mere notion of “family,” or in Carsten’s (2002) terms, each particular “culture of relatedness.”

In many ways children living with cancer need to map and navigate new and emerging
territories and they have key actors, like parents, that help them traverse their own paths. Deleuze
defines “parents” in a very particular way. For Deleuze (1997:62):

…parents are themselves a milieu that children travel through: they pass through its
qualities and powers and make a map of them. (…) There is never a moment when
children are not already plunged into an actual milieu in which they are moving about,
and in which the parents as persons simply play the roles of openers or closers of doors,
guardians of thresholds, connectors or disconnectors of zones. The parents always occupy
a position in a world that is not derived from them. Even with an infant, the parents are
defined in relation to a continent-bed, as agents along the child’s route.

Then, who are, along with parents, those “agents along the child’s route” that “play the
roles of openers or closers of doors, guardians of thresholds, connectors or disconnectors of
zones” in the case of children living with cancer? Who are next to, or nearby, these children
when they are hospitalized for months and intermittently isolated from their broader social
circles? How do these different agents relate to one another and what sorts of connections are
built in these daily interactions?

Throughout this chapter I will use “therapeutic relatedness” to talk about those “agents
along the child’s route”. I will concentrate on everyday life and the ways that people explain and
(re)create the connections that matter most to them, and the processes by which these
connections are (re)made during long hospitalizations and years of treatment. Drawing from
Carsten’s (2000) notion of relatedness, I defined “therapeutic relatedness” as the knitting of
social and medical relations that matters through a temporal, affective, and spatial dis/continuity
during lengthy children’s cancer treatments. During the one to two years of cancer treatment these “cultures of relatedness” are dramatically transformed by children’s cancer treatments, and, thus, in a sense, children, caregivers and the family structure are all influenced by the interweave of medically organized connections that I refer to “therapeutic relatedness.” Thus, this chapter will focus on the everyday hardships and struggles within and outside the hospital not only for the nuclear group that surrounds children but also to the broader social world of children.

Many family members, especially mothers, told me plenty of times they have to “keep on fighting for their children.” Thus, within this notion of therapeutic relatedness an important point I analyze in this chapter is what I call the ethics of “keep on fighting.” Closely related to the notion of children’s “endurance” (described in Chapter 7) this family’s ethics of “keep on fighting” seems to be a central locus on how caregivers and other family members define their active caring role at the interior of the family network and to outsiders like me as well. Indeed, how different family members understand both illness and its treatment is not only central to the dynamic of each familiar constellation, but also essential to mobilize resources at home, at the hospital, and at other related places such as NGOs like the CCF. Thus, it is crucial to understand how the social world of children changes through the medicalicalization of their social relations into the social world of families taking care of children living with cancer.

The whole family is rearranged when pursuing cancer treatment for their children. For instance, fathers of children with chronic illness such as cancer, according to May (1996), are “the forgotten parent” and professionals need to engage them more in the lives of their children. On one occasion, Telma, the psychologist in charge of the multi-families meetings at the CCF told me that she always asks the mothers to bring, if possible, their husbands and male partners to the meetings. She said,
I understand how mothers think they do everything for their children, and that they may feel they are the only ones that understand their children, but very often fathers are set a bit aside, and it is always useful to have at least one father in the meetings because the group dynamic changes. Because they also do a lot of things, it is like mothers have a hard time letting go of that self-imposed role. Of course, it is true they do a lot of things, but they are not the only one that does things.

I agreed at that time with Telma: both parents do a lot for their children. Yet, during my fieldwork the majority of the main caregivers secluded for months at the hospital were women, and within these women the majority were mothers. At the twenty-two multi-families meeting I participated at the CCF approximately 80% of the participants were women; they were mothers, aunts, grandmothers, neighbours, and friends. Roughly the other 20% were men; they were fathers, uncles, and grandfathers. I did not observe male friends joining these meetings. In many cases fathers had to work hard to sustain the family. Employers determined if a male parent could accompany children and mothers to the different tests, procedures, and hospitalizations. If they lived in the city, they came after work or during the weekends. The situation was more difficult if the parent was single, or if the family lived outside of the city. I observed once a single father taking care of his daughter living with leukemia while he managed to keep his job. Yet, the majority of the main caregivers were women and mothers.

Often employers did not allow parents to take time off, or they would allow them to go for few occasions. If fathers were working under the table, they could not jeopardize their jobs by asking to accompany children and wives to the hospital. In other instances, fathers were very much present in the overall decision-making of the treatment and were able to help their partners in different things related to their child’s treatments. It is likely that in some instances mothers, due to their closeness to their children and the overall medical process, saw themselves as “gatekeepers.” That is, they developed an ambivalent feeling towards the active involvement of men with “their” children, because it could threaten their sense of control over this specific life
domain (Doherty, Kouneski and Erickson 1998). However, at least according to some of the women I talked to, women welcomed any help they could receive, not only from their partners, but also from other family members and friends. In some cases, it was more the general dynamic of the family that would produce the presence/absence of mothers and/or fathers and/or other members of the family as the main caregivers of children secluded for weeks and months at the hospital. In other instances, it was a deliberate decision by both parents to be the only caregivers. I once was following two members of the palliative care team and one asked the father of a 5-year girl with acute myeloid leukemia if there were other family members besides him and her wife (that day she was taking care of their other son) taking care of her daughter. He replied, “ni en pedo (“by no means,” note: informal), only her mother and myself take care of her.”

Thus, families decided how to take care of their children. Then once they begin treatment, they became secluded for long periods of time at the Hospital Infantil. These long hospitalizations socialized them into the Hospital Infantil’s dynamics and what is expected from children and parents while pursuing cancer treatment. During the long hospitalizations parents and children were often concerned with just “simple” things such as being able to eat, sleep, urinate, defecate, or drink; they were also worried about children losing their hair. For healthcare professionals it is common to see these normal bodily (mal)functions as unwanted side-effects of the treatment, something that would eventually be quickly recovered. But in the case of children and parents these concerns about the (in)capacities of the body are, as far as I can tell, an intrinsic and central apprehension and not just a by-product of being treated and hospitalized (cumulatively) for months and years. Children, sibling, parents, and concerned others have not only to re-signify the usefulness of invasive treatments but also develop a new understanding of children’s (ab)normal and permeable bodies. Indeed, there is a clear clash in how this is viewed.
It could be seen as a minor concern; for instance, for a teenager to be able to eat alone without others’ aid, but in a context of going through a cancer treatment a simple thing can become a very complex and stressful condition with huge consequences for the inner social circle. Basic physiology concerns such as the falling of hair or the temporary incapacity to eat solid foods are not only problem in itself but also in relation to other potential or past problems. Every problem is connected with previous ones, and so there are cumulative worries constantly co-developing and re-emerging during these long hospitalizations.

Another important question I will explore is: Who counts as family in the midst of these long and tiring treatments? In other words, what constitutes a close relationship and who become therapeutically related with children’s everyday struggles? In the context of a family with a child living with cancer it is not an insignificant question for parents, caregivers, siblings and other family members to ask: who are “family”? Because this question implies how “family” is re-organized by having a child living with cancer. While the children are being treated, their social groupings will need to be reorganized in myriad ways according to multiple factors (and constantly adapting to emerging changes). First, there will be some reorganization according to the capacities of the main caregiver(s) to stop working (at least for some months) to become a full time main caregiver. Second, the family will need to be rearranged according to the distance from home to the hospital (can they travel by public transportation? Do they need a local ambulance?). Or, do they need to partially or fully relocalize in the City of Buenos Aires at least for some potion of treatment? Third, the child’s age (and the presence or not of siblings) will also become a crucial factor (is it an infant or late teenager?). Fourth, the child’s specific condition and particularized treatment will frame these familiar reorganizations in terms of whom they will interact with at the Hospital Infantil and what procedures should be followed. Fifth, long
Hematological treatments will have a direct economic and financial impact on families. That is, families will need to find ways to sustain the long treatment without one or two parents working for a substantial period of time. Sixth, the emotional work needed to care for children and the rest of the family grouping will also become crucial. As I further develop in this chapter, how family members will be able to support one another becomes critical. These multiple factors will directly influence each family therapeutic trajectory.

Thus, this chapter will deal with the fragmentary, dispersed, and endless forms in which social and family care is put into practice. Very often families become disjointed and thus they need to develop a “multi-sited” care. The main caregivers will often be secluded for months beside the children at the hospital while the rest of the family will need to re-adjust to these massive changes in their everyday lives (and the absence of two members). Very frequently the main caregiver(s) cannot work (caring is often a 24/7 unpaid work) so they would become economically dependent on their partners, family members, friends, and social programs for sustaining the long and tiring treatment, and for sharing the burden of care. Indeed, many families have to live under extremely hard economic conditions, which will likely impact the therapeutic trajectories. This chapter will show the kinds of work that families and their broader social world carry on while caring for their members, especially children at the hospital and while trying to continue a “normal life” irreversible changed. Thus, this chapter is crucial to understand the “non-professional” work that is also a central part of the long treatment and care for children living with cancer in this clinic setting. To put it boldly without the family work (beside the professional work) there will probably no chance of cure. But in order for the family

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87 And this was clear for some professionals in the past. At the same Communicable Diseases Unit in which I conducted fieldwork, Dr. Florencio Escardo, one of the most famous and revolutionary Argentine pediatrician, after decades of institutional fights in 1958 succeed in
to produce this type of work, we need to ask questions aiming at interconnectedness between professional and family care and the reorganization of social life families face during the long treatment. In fact, as Livingston (2013) argues cancer is something that happens *between* people.

Thus, it is important to pay close attention to how these processes of therapeutic relatedness are embedded not only affectively and emotionally but also how dynamic and productive (or disruptive) these highly medicalized forms of relatedness can be, in spite of, and because they are under constant stress and crisis. As Carsten (2000) noted in her influential introduction to *Cultures of Relatedness* new studies of kinship have on gender, personhood, and the body as the three central features of these cultures of relatedness. Indeed, these cultures of relatedness also describe the kinds of relationships that are knitted in the long and exhausted therapeutic processes within and outside the clinical setting. In a broader sense children and families are creating new relationships and knitting new networks, they develop relationships with particular medical residents, staff doctors, and others. They all become part of “other kinds of social relations” (Carsten 2000:5), which suddenly turn into crucial forms of therapeutic relatedness.

Yet, in order to approach to these particular cultures of therapeutic relatedness embedded on children’s medicalized everyday lives we need to recognize that neither “nature” nor “culture” can be taken for granted (Carsten 2000; Schneider 1980; Strathern 1992); that gender, personhood, and the body are contextual to particular knowledge practices (in constant frictions and negotiations). In other words, not only how people make sense of their “natural” and “cultural” bonding in specific time-spaces using the idioms of kinship (or, relatedness) is constantly shifting according to myriad factors, but also, and more importantly, they produce

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letting mothers stay in the same isolated rooms with their children (something that was not allowed before) which dramatically increased the rate of cure (Escardo 2007).
these particular knowledge practices with and from their bodies in particular contexts of action. Following Strathern (1992), I focus on these specific destabilized knowledge practices in which nothing (neither biology nor culture) can be taken for granted and in which children’s bodies are at the center of multi-vectorial (biomedically mediated) forces. But before looking at the triad gender-personhood-body within this therapeutic relatedness it is important to understand the transformations and reorganization of family life by focusing on how families distinguish between those who help and understand them and those who do not.

**Therapeutic relatedness: Filtering out “who is with you and who is not”**

Many caregivers told me that throughout treatment they needed to find people who would understand and help them, people who would be on their side. Thus, through the sifting of “who’s with you from who’s not”, the reconstitution of community means the temporary distancing or loosening of kinship relationships. Sometimes other people outside the “family” were brought in into the “community of sufferers” (Turner 1967) whereas people within the “family” were temporarily or definitively cut out of the familial network when they could not understand nor help what the family was going through. In this way, one can see how each child’s long illness and treatment impact in different ways family’s dynamics. In the following excerpt taken from one of the multi-family meetings at the CCF two mothers of young children with different kinds of cancer discussed about the lack of support from other family members,

Elena (late twenties, from the Province of Buenos Aires, her daughter Ruth was diagnosed with a neurofibromatosis when she was five months old, now she is 4-year old): I am the oldest of four brothers, and the only one that have kids. And, I tell you it is not the same children of daughters than children of daughters-in-law. But my mother doesn’t understand what’s going on with Ruth. It’s like the old saying, “one is not prepared to lose a son, less so to lose a grandson.” Because of that she denies everything. Although, I have to say, she is close to me all the time.

Mariana (late twenties, from the bordering country Bolivia, she quit her job to take care of her son Luis who was diagnosed with acute lymphoblastic leukemia three months ago, he is 4-year
old): My parents-in-law don’t care; they only came once to my home. And he is the first
grandchild from both sides! My father says that he doesn’t understand how they don’t want to
see their grandchild. My father says that looking at your grandchild is like looking at your future.
When this happened to my child I told myself, “I will wear a mask and I will keep on moving
forward, and those who want to follow me are welcome.” That’s the time when you see who is
with you and who is not.

As Mariana noted, during these life-changing months and years sometimes gradually,
only drastically, parents are able to see “who is with you and who is not” and by doing that they
are building therapeutic relatedness with some people (and not with others). This realization,
often, helps them to (painfully) figure out how to draw a line and to focus their scare material,
emotional and symbolic resources. Needless to say, parents and other family members have to
keep on raising their families with other healthy siblings while accompanying their sick children
during a one-to-two-year intense life and family-changing therapeutic process. Given the
intensity of this task they also need to figure out how to keep couples together (which is not
easy) and how to relate with those other family members, friends, and concerned others who are
willing to give a hand and help rather than being detrimental.

When parents talk about sifting “who is with you and who is not,” they are dealing with a
temporary and spatially separation/reintegration process. In a sense this is a “liminal phase,” this
mid-point, social threshold, borderline situation in-between social positions, what Turner
(1995:95) defined as “neither here nor there.” When parents and caregivers are pursuing cancer
treatment for their children they are often in a sort of limbo, a sort of threshold between what is
normal and extraordinary, who counts as family, and who does not. On the one hand, the sifting
of social and family relationships, the radical changes introduced by children’s illnesses and
treatments, and a whole range of stressors may influence caregivers to try to be surrounded by
equals (those that are with you, or who go through similar experiences and can, therefore,
understand you). On the other hand, it may push caregivers to distance themselves from those
unhelpful and unsupportive. In this way, the child’s therapeutic trajectory may influence new forms of therapeutic relatedness (which can or cannot intensify pre-illness/treatment tensions with the family dynamics). The sifting of who is with you can create a sense of *communitas* among those who are going through similar situations, it can equalize parents and children experiences with those who are suffering comparable hardships. Yet, as Esposito (2010) argues, *communitas* is less a sense of blending with others who are similar but rather it is a gift or an obligation to the other who reminds us of our essential otherness with regards to ourselves. This is a tension I too found among parents and caregivers between sameness and otherness (especially between caregivers enhanced intimacy with the sick child and those partners that stay at the “rearguard” taking care of the rest of the family). We will see later how many experienced parents felt a sense of debt, they needed to give back (information, tips, support, hope) to those at the beginning of the therapeutic processes. Yet, we can also loosely point to the fact that, according to what parents told me, a certain community of suffering is built while pursuing cancer treatment for their children. Re-constituting this community is part of this process of knowing what you have to do, where, when, and, particularly, whom is part of your culture of therapeutic relatedness. A sense of belonging, the creation of new routines and habits, and, especially within the *Hospital Infantil* the slow knowing of people who are experiencing similar issues are things highly valued by the family members. There is often a sense of retribution, of giving back to families that are starting the process the knowledge and advices given to them by others.

But sometimes people outside the family, even strangers, helped and the much-needed aid came from unexpected places. Parents waiting together became related though the therapies

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88 Neither parents nor clinicians used this notion of *communitas*, although parents constantly referred to the sense of community with other parents going through similar situations.
performed on their children. For instance, in one multi-family meeting at CCF one mother shows the reorganization of the family (older siblings as caregivers) but also she highlights the help of neighbors,

I am lucky to have a beautiful family, as I said, my older son had to take care of the other siblings, but I also received a lot of help from my neighbours, people that I never expected any help came to help me. Once a neighbour with whom I had never spoken to before knocked my door and asked me “Does your daughter need blood donation?” And I said yes and the next day she went and donated blood. These little things are very valued and because of all this I am very thankful.

Throughout the rest of the chapter I will tease out what these different forms of medically mediated interconnectedness, or what I call therapeutic relatedness mean for particular people. I will do so by considering how the triad gender-personhood-body works in the context of family care.

The work of “therapeutic relatedness”: The burden of care

At least since Janzen (1978) anthropologists have focused on medical systems in the broader socio-political context in which there are constant negotiations of meanings in real life situations between medical (western and traditional) practitioners, patients experiencing illness, and concerned others. Nichter (2002) revisited the notion of therapy management group to highlight that within the therapy management there is both consensus and dissent.

Thus, it is crucial to be attentive to these negotiations and disputes in relation to how families handle the treatment of one of the member of the group that is affecting the overall system(s). I am here concentrating on the particular circumstances of specific households, extended kin, and social networks. Many of the stories I heard and the interactions I observed were not only about re-arranging priorities (between home and hospital) and revisiting social
relationships but also about separation, disputes, and even domestic violence prior, during, and after the irruption of children’s illnesses within the close social grouping.

Similarly to what I observed at the Hospital Infantil in Buenos Aires, Levine’s (2000) collective book in a pre-“Obama care” context shows how there are new responsibilities for family care giving. The authors analyze the complexity and the impact of the care giving experience to families, and they emphasize the need for building better partnerships for change and fostering improvement in care; for instance, on the financial burden of care. Needless to say, in a broader sense care giving is not solely a professional activity; it encompasses family and non-family caregivers, health professionals, health administrators, health policymakers, religious care providers, patient and caregiver advocates, and human resources professionals, among many others. Thus, we need to understand how family care giving is situated in particular contexts. In the United States, it is rapidly becoming a politicized arena in a privatized economy in which families are expected to be “always on call.” In a very different context in Argentina where there is a long tradition of seeing access to reliable healthy care as social rights of citizenship I also see families of children living with cancer as always “on call.” They have to be ready to take their children to the hospital as soon as possible on the minor clue of infection, or, caregiver and children have to stay hospitalized for months if need be.

As I already mentioned, parents and other main caregivers recognized a shared relationship through the hardships and struggles of their medicalized lives. These experiences clearly distinguished those who “are with you” than those that “are not.” In order to sustain the treatment an immense web of people, resources, and practical knowledge have to be set in motion. Especially, during the long hospitalizations and the months and years of treatment parents and other main caregivers got tired and often burned out. But, still, they are expected by
health professionals to painstakingly learn their role as (main) caregivers, and to be always on call to support their children and families. Sometimes children had only one, often two real main caregivers for a very lengthy treatment. For instance, when a mother and child come from a far away province to the City of Buenos Aires they often find themselves going through the main part of treatment with its usual complications and hospitalizations without the chance to go back home to visit fathers, siblings, friends, etc. This disconnection can last months or years sometimes. In this long period of time family members worked 24/7 as caregivers, and unless they found ways to lighten their load or develop skills to manage stress, the burden of care grew heavier and heavier.

Indeed, it often took time for each family, for the main caregiver(s) to figure out how to navigate the medical and social bureaucracies that affect their everyday experience of cancer treatment. Therefore, depending on their available resources, the sooner they understood the different processes, bureaucracies, and systems the quicker they gained access to different webs of support inside and outside the hospital. Of course, this is not a one-time sort of understanding: the practical knowledge comes by waves in a non-linear way. It is a cumulative process with multiple obstacles and bumps on the road. And we can see how this gradual, contradictory, cumulative understanding shapes and impacts each family and the social world of children living with cancer. What is interesting here is not so much to look at a cognitive and disembodied notion of knowledge-making but rather to look at “knowledge-in-practice” and “knowledge held in common with others” (Shotter 1993:19, cited in Thrift 2008:122). When looking at the triad gender-personhood-body within this notion of therapeutic relatedness we can see how the practical knowledge gained by children and caregivers is always contextualized in the group that
take care of each child. Paraphrasing the famous saying, it takes a village to take care of child living with cancer. And a key aspect is the gender of care.

The gender of care

Many studies have shown the gendered division of care, in particular in relation to children with acute and critical medical conditions (Elliott Brown and Barbarin 1996; Yeh 2002). Specifically, it has been noted in multiple studies both in the global north and the global south the key role of mothers and other female main caregivers in relation to practices of care for children experiencing pediatric cancers (Young et al. 2002). It is important to explore gender differences in care behavior no as static but as dynamically shifting according to different clinical contexts. In particular, scholars have highlighted how mothers of children with cancer traverse all sorts of parenting crisis and intense emotional interdependence with the sick child while also having to balance the needs of the whole family (Young et al. 2002:1841). Though, these studies have paid less attention to the role of fathers in relation to the everyday care of children with pediatric cancers. In fact, as many studies suggest there is a tendency to assume mothers as the children’s main caregivers by default, which is not always the case. Yet, as I mentioned before, during my fieldwork the great majority of main caregivers were women, especially mothers. However, fathers were also very involved even if they could not be nearby their children all the

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89 See, Gerstel and Gallagher (2001) for men caregiving, and MacDonald et al. (2010) for pediatric palliative care.
90 MacDonald et al. (2010) conducted a meta-analytic literature review on gender imbalance on parental perspectives on pediatric palliative care in the North America context and found that mothers constituted 75% of the overall samples of parents. Thus, they suggested that gender imbalance in study samples, designs, recruitment strategies, and data gathering techniques should be further considered.
time, in fact, their work was influenced by overall gender roles and gender identities (see Chesler and Parry 2001).

On many occasions, I was able to observe negotiations of different gender roles and division of labor in relation to care. In the following example we can see parents that try their best to divide equally the responsibility of taking care of their children. This is a family that moved from Paraguay to pursue hematological treatment for their three-year old child. In this case both parents try to divide the tasks of caring for both children (the sick and the healthy one). We can see how they need to balance their workload and find some mutual support in the intense and demanding work of caring for both children:

Guillermo: She [for his wife] comes always to the hospital and I try to come as much as I am able but that depends on my work. Now my boss understands me and lets me come without a problem. I tell him that I have to come for a [lumbar] puncture or whatever else and he lets me come and I always have work after [he works in construction under the table]. But now it got a bit complicated with the older brother because he started primary school. So I have to take him to school at 12.45 and then pick him up at 4.45. We didn’t have any vehicle before and it was difficult but now we bought a scooter and I have no problem to take him to school. So my wife comes to Buenos Aires with Juan early and I stay home, I then go to work, come home to take my other kid to school and if there is time I go back to work and then go to pick him up at school. But when we used to come both here [to the City of Buenos Aires] we used to take turns one was in the room with Juan and the other with the older son, and when one started to cry we would call the mother to take care of him and I would take care of the other. The same thing with the paper work, she always comes with Juan to the hospital but the one that takes notes of everything and is in charge of the paper work and keep them in order is me. If she goes alone to the hospital tomorrow I will go to the terminal and buy tickets today. As I always say all our money goes to Chevallier [long-distance bus company] [laughs]. This is all very hard because every day you have three hours one-way and three hours the other way. We get up at four in the morning, drink some mates [Argentine type of green tea], and by 5.15 they are taking the bus to be at the hospital at 8.30, and they are back home by 4 or 5 in the afternoon.

In the above example we see how having a child experiencing a chronic-potentially-curable condition drastically changed not only the mother’s but also father’s roles and biographies. They took the decision to leave Paraguay to pursue treatment for their child in
The father, back in Paraguay, used to work in an office in a managerial position and the mother was a housewife. When they moved to Argentina the mother became the one that would accompany the child to the hospital and the father had to work under the table as a construction worker although he also tried to be as involved as possible in everything related with his sick child. They pursued a major change in their lives in order to get access to better therapeutic options. Still, within these options, gender roles (and the particular socio-economic conditions) played an important part in determining who did what. What is remarkable is the mixed nature of their new configuration: in some ways they hang on to the roles they have always had, but they negotiate and perform them in different contexts, which necessarily changes them. They creatively engaged in new ways of parenting and caring for their children. One example from the quote above is how the father asks the mother to tell him “exactly what the doctor said,” what Mattingly (2000) called a therapeutic emplotment process. That is, the need of family members to understand what professionals were saying and be able to communicate it to others, a mutual need of finding a common ground between parents and between professionals and family members.

In many instances I was also able to talk with mothers and observed them talking at the multi-families meeting at the CCF or hearing them talking at the corridors of the Hospital Infantil and they would often refer that their children’s need would come always first. Often, according to some mothers, their own needs were set aside for the greater good of helping their

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91 The health care system in Paraguay is not reliable, especially for middle-lower and lower-classes families, particularly outside Asuncion (the City Capital). As the majority of the countries in the region it had experienced a neo-liberal agenda imposed by international organizations such as World Bank, IMF, and agencies like USAID, and JICA that had reconfigured the healthcare systems in Latin America (often pushing for further privatization). See Homedes and Ugalde (2005) for an example in Latin America (Chile and Colombia).
children recover. Young et al. (2002:1845-6) argue in their study of mothers of children with cancer that:

The reluctance of women in our study to give voice to their own needs can be understood as a means of demonstrating their adequacy as mothers of an ill child, and as a means of avoiding drawing attention away from their children, but may result in health professionals failing to recognise or meet mothers’ own needs. Our findings point to the importance of supporting mothers in ways that enable them to fulfill their role as parents of a child in crisis, to the part that services such as information provision can play in helping them meet their obligations, and serves as a reminder that help that might be construed as undermining their role and obligations is likely to be less than welcome.

In this context of care, of gendered care, where we should pay attention not only to the gender division of labor within the family but also to the divergent roles mothers and fathers play in the everyday lives of children living with cancer? Mothers and other female members of the family play different functions in the quotidian world of check-ups, procedures, paperwork, referrals, shopping for medicines, navigating NGOs and state agencies such as the National Drug Bank, etc. Even more important is the role they play during the frequent medical travel/relocalization and the long and tiring hospitalizations. In this way we can see how important is gender to understand these particular forms of therapeutic relatedness.

**Personhood and rearrangements: The multiple experiences of inner/outer displacements**

Further elaborating on the notion of therapeutic relatedness in this subsection I will reflect on the varied and manifold personal experiences of displacement children and their close social circles have to go through by looking at personhood. Thus, I will look at how personhood is constantly reshaped through (in a broader sense) personal displacements. One level of displacement is the physical spacing and discontinuity between sick children, main caregivers, siblings and close relatives, as we will see when discussing medical travel and relocalizations, this idea of ‘multi-
sited’ care. But displacement in a more affective and non-representational sense has also to do with the emotional/affective work children, parents, siblings and other family members do when shaping their present while dealing with children living with cancer and their potential shared futures. As Cassell (1982:42) points out, the personal meanings attached to illness and treatment emerge from both past and present experiences. Indeed, often “people [with cancer] frequently behave as though they were physical extensions of their parents” since “No person exists without others.” Thus, when considering personhood in the context of cancer treatments we have to think on both the potential to do things (expansion) and the vulnerabilities associated with illness (contraction).

In fact both processes the ‘outer’ and ‘inner’ changes, are intermingled and are often hard to separate. For instance, in the following multi-family meeting at the CCF we can see how Guillermo is narrating his experience of physical relocation from the bordering country Paraguay and their struggles for a place to live. And, then, we will see how two mothers are talking about their emotional/affective work while navigating intense forms of fear in relation to their children’s illnesses.

Guillermo [father of three-year old Juan]: So we are finishing Juan’s treatment. For us it is very hard the treatment, because it takes a lot of time. We had a rough time, at one moment we didn’t have a place to stay, I am constructor and for a while we had to live in the places I was building until we finished the work and the owners asked us to leave the place and so we ended up in the street. One day we had to take all our stuff to the street and we called a moving company but we didn’t know where to go because we didn’t have any place to go! [he laughs]. And, luckily, because the people in Baradero [a city 150kms from Buenos Aires] treated us well, a neighbour came and he told us that he heard that we are on the streets and we needed a place to live, and he said he had a small piece of land outside the city and if we wanted we could go and take a look at it. We went, of course, since we didn’t have a place to go! And when we arrived he told me to stay calm that no one was going to take us from this land so I built with my own hands a little cabin and we started to live there until about eight days after came another person that said that he was the owner and he asked me what was I doing there and what brought me to Baradero. So I told him our entire story and I told him my son had leukemia. The man listened to me and he told me he had a son who died of leukemia. So he told me to take a tape and to measure a 10 meters for 45 meters perimeter. That piece of land was going to be mine. So we lived there and
then after a while, when I wanted to build something more solid and I wanted to be sure about the land in order to avoid building something that then was going to be taken away by someone else I went to the Municipality to find out about that land and they told me that in fact it was owned by another person. The secretary at the Municipality told me that she knew the owner and that she was a good person so everything was going to be fine. She gave me her address and told me to go and talk to her. So I went to talk with this person, I found her and I told her our story, I told her we were living in a piece of land that belongs to her, that my intention was to pay it but that I didn’t have money now, I told her I wanted to pay it back in small instalments. She first told me she didn’t have any idea that land was hers. She asked me what brought me to Baradero so I told her my story, that Juan was having leukemia and we had to travel often to the City of Buenos Aires, that I was working in construction and how I ended up living in her piece of land. At the end this lady told me that she owns apartments and houses in the City of Buenos Aires and so she doesn’t need that piece of land so she was going to donate it to me. The following day I talked with the Municipality and everything was OK. Now we own that piece of land and we live there.

This is a clear example of the kinds of personal displacements many parents and families have to go through. It is not only the relocalization from Asunción (Paraguay) to Baradero (Argentina) but the multiple complications and adaptations and the economic and financial burden. The family had to experience all sorts of struggles from living in a construction site for a while and then facing the real possibility of living in the streets. If those people that helped them to find a piece of land where to build their house were not willing to give a hand the story could have been very different and thus the experience of Juan recovering from his leukemia and living without illness could have had a totally different outcome.

Yet, this is also a striking example of the extended relationships in which the family becomes embedded in particular forms of therapeutic relatedness because of the illness. In this case the family had to start all over from scratch in order to pursue treatment. It seems to me that we need to use a language of rearrangement of subjectivity and social groupings not only in space but also with regards to emotions and who takes care of whom. We can see the creation of a series of relationships for parents and children to take care of their volatile affective states.
Subjectivity also implies a reflexive sense of self, some kind of moral evaluation. In his story Guillermo was also implying that as a person, and as parents, “We did everything.”

Going back to the triad gender-personhood-body, in this case new gender roles, forms of personhood, and bodily actions were developed. When I think of the multiple experiences of displacement, as I said, I am also considering the inner changes that come associated with the displacements and the reterritorialization in other space-time. In fact, when Guillermo was talking about finding a new place to live, the psychologist told him, “How difficult everything must have been, but at least it has a good ending.” He then started talking about a fear that suddenly appeared to him. He said, “After a while I started to feel tachycardia and heart palpitations and fear, a lot of fear.” Therefore, he went to a cardiologist who did a lot of tests with no clear results. Guillermo had an irresistible desire to cry, often he could not stop crying, and after that he would feel better. Guillermo did not want to go outside in the night or to go to empty places. He also felt he was going to die. He said, “I felt I was going to die. I felt that all the time and the cardiologist would tell me not to worry that I was all right, but I nevertheless would feel that fear. And to be honest I don’t know why I would feel that fear.”

After Guillermo narrated his fears other mothers began to talk about their own fears as well. Julia, the mother of 12-year old Armando who had a testicular cancer when he was a baby, looked at Guillermo and said,

I totally understand you because I also feel that fear. I felt that fear all the time that Armando was sick, then when he got cured it was like the fear was gone, for many years I didn’t feel it, but now last Saturday when he showed me this little bump on his chest and we have to come back to the hospital that fear came again. And I think that that fear has to do with the fear that my son could die. But when I feel that I say to myself that I don’t know, no one knows when is going to die, it may happen but I don’t know, and if it is going to happen it will happen. Sometimes I am not sure if I fear that he will die, or that I will die. It is like I say, “OK, or he dies, or I die.”
Then, Susana, the mother of three-year-old Azul living with a retinoblastoma since she was two, nervously laughing, in low voice, said “… or she dies or I die…” And Julia replied, “but it’s like one has to live with that fear…”

As Susana stated it, “one has to live with that fear.” This is the personal fear of not knowing what will happen next, which Julia puts in a very dramatic, but not less real feeling of, “or he dies, or I die.” This is indeed not only an intense and extreme form of affective/emotional work but also of inter-personal displacement (concrete potential limits to our notions of personhood). In fact, seldom during my fieldwork at the Hematology Unit parents were able to address at least some of their deep uncertainties and fears in relation to the potential outcomes of the treatment. However, there were some discussions and talks about the specificities of each therapeutic phases and the need to go “step-by-step.” For instance, on multiple occasions I was able to hear how members of the Hematology team would give certain information to parents in relation to the exact moment in which their children were during the phases of the hematological treatment but would not go into more detail since it was “too technical.” The point is that often parents could not talk about their fears with their main doctors (oncologists or hematologists). Still the kinds of communication I observed between parents and hematologists were somehow dislocated, like out of synch. There were some frictions and displacements in the content of the communication as well. Lisandro, the head of the Hematology team told me in an interview that he always makes sure that he gives the relevant information in regards to the child’s diagnosis, prognosis and therapeutic strategies to those who are “affectively in charge” of children. He said,

What I do is that I would have a meeting with the parents, or those who are affectively in charge of children, sometimes it is a grandfather (…) I generally give the information to the parents, and I don’t let other people get in. And if someone stops me in the corridor I tell him or her, “Look, I already informed the parents, I don’t have any problem that they pass the information to you, but I can’t talk with everyone.” Because I think that the information would diversify and it would lead to a broken phone conversation. Also, I
don’t know the inner family quarrels, I don’t know if the mother-in-law or the father-in-law is a dominant figure…

Still, one has to bear in mind that Lisandro the head of the Hematology Unit and a father of a child with leukemia would likely perceive the communication of diagnosis, prognosis and treatment options differently. As Jain (2013) says the “evidence” is seen differently when one has too much at stake, in this case your child embodying the illness, or someone who in a professional manner delivers “information.” Parents would ask, “But where is my son at in relation to his treatment?” And hematologists would respond (like this response from an hematologist staff taken from my field notes):

Ok. This is very technical and you don’t need to know all these names. Your son is now on the phase one, protocol two, with L-Asas [Aspergisnase]; but you don’t have to worry about all this. We will be telling you what phases he will be going through and the main thing is to try stick with the plan and avoid any complications such as infections or other issues.

Even when looking at children going through remission, “deeper fears” could hardly be discussed between parents and professionals. Often professionals told me they felt they had no time or the context was not appropriate to discuss their fears. As Comaroff and Maguire (1981: 116) said more than thirty years ago when treatments were starting to improve children’s “years of survival” there were “urgent questions about the psychological and social implications of survival under improved clinical regimes.” I think this is still true nowadays, at least in the clinical context of this study.

There is something profoundly disturbing about a health condition and its suggested treatment that cannot be easily understood by children and their parents. Particularly, in relation to the ambiguity and uncertainty it brings on a daily basis, even for those who have passed the
maintenance phase and are on “remission” or living a “life without illness.” As Comaroff and Maguire (1981: 117) argue,

While the longer the child survives, the better his chances, relapse can occur at any time; and statistical attempts to factorize the risk of such occurrence are as yet of little help in particular cases. Hence prognosis is difficult to fix, and the illness is neither clearly ‘acute’ nor ‘chronic’ for much of its course, a pattern which does not fit established cultural categories. Like other forms of ‘acute’ illness, this one is threatening on impact; yet no defined phase of resolution follows. For the very meaning of the term ‘remission’ (i.e. the retreat of symptoms) is profoundly ambiguous, both clinically and experientially. Is it partial or total? When does long-term survival become apparent ‘cure’?

Often the “ever-present threat of relapse” stays at the backdrop while parents take care of the “mundane uncertainties of chronic illness,” or as Julia above puts it, “one has to live with that fear.” In this section, I touched on geographic and emotional displacements. These two aspects become crucial components of the rearrangements of family’s social worlds and have direct impacts on the diverse form of interconnectedness family experience. In this way, in the face-to-face or broader social contexts in which these families are embedded therapeutic relatedness has to do with these double inner/outer displacements.

**Therapeutic relatedness and embodiment: Long hospitalizations**

During long periods of time children and their main caregivers, often mothers, are secluded inside the hospital. Gradually, both children and mothers (or other main caregivers) learn the intricacies of being fixed in one location inside a giant hospital: now they are hospitalized bodies. Mothers and others also learn how to be a main caregiver, and what different professionals and other dwellers of this institution expect from them, and vice versa, what they can expect from their different professionals and staff they interact with. Like characters of Thomas Mann’s *The Magic Mountain* children and caregivers often find themselves between
moments of boredom and paralysis and moments of bright insights. Children and caregivers learn about the biology, physiology, and pharmacology of cancer in their long hospitalizations. In that sense during the long hospitalizations they embody someone else’s time and space, they internalize with their own bodies the cyclic rhythms of cancer treatment.

In many ways during these long hospitalizations mothers and others have to learn how to perform their roles as caregivers. When talking about disability and the reconfigurations of the domestic sphere Das and Addlakha (2001: 512) show how “domestic citizenship” can be explained from the political performance of kinship:

The domestic sphere we present, then, is always on the verge of becoming the political. A focus on kinship not as the extension of familial relations into community, but as the sphere in which the family has to confront ways of disciplining and containing contagion and stigma yields startling revelations about disability and impairment as located not in (or only in) individual bodies, but rather as “off” the body of the individual and within a network of social and kin relationships.

In many ways within networks of social and kin relationships children and caregivers throughout long hospitalizations are domesticated and disciplined into patients and caregivers in the institutional context of the Hospital Infantil. In fact, one essential place in which these performances of kinship occur is the hospital (Das and Addlakha 2001:512):

We identify the hospital as one such site, at which the domestic is instantiated performatively in relation to both state- and kinship-bounded figurations of community.

It is precisely during these long hospitalizations, when “domesticity and kinship are enacted in relation to disability and impairment” (Das and Addlakha 2001:514), when I see the reconfiguration of the domestic sphere strongly influenced by both the medicalization of children’s and family’s lives and the institutionalization via the multiple hospitalizations. The exact moment a child with cancer needs to be hospitalized for some time can vary, but often it is

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92 They even a bit of anthropology. I particularly remember the long conversations I had about what anthropologists do with seven-year old Fito.
during the beginning of treatment. In many cases on the first day of treatment, or “debut”, children and caregivers are hospitalized. As I showed in previous chapters when treatment begins, a chain reaction is set in motion. Multiple re-arrangements need to be done. And even if nothing big happens, just going to the hospital for a day to receive chemotherapy would imply an array of domestic adaptations. Who takes the other children to school? Who does groceries? Who cleans the house and prepares food? Who goes to the National Drug Bank to ask for drugs for the following chemo? When children and caregivers have to stay for a period of time at the hospital others would often have to step up and perform their domesticity in relation to “both state- and kinship-bounded figurations of community.” The situation is different though when we look at families from faraway places, or single parents, or parents with narrow networks. In this way the long hospitalizations are not only an important source of socialization for building new social relationships “off” their bodies but also of “domestic citizenship”. Families, especially mothers, begin to relate to others in similar situations. Families also begin to know more closely the medical residents that treat their children during these long hospitalizations. These are bodies in close proximity, residents and children become more aware of one another, children influence residents by yelling, crying, laughing, ignoring them.

During long hospitalizations different kinds of worries over children’s bodies emerge. As I mentioned at the introduction, often caregivers and families are worried about children’s basic physiological needs such as eating, or sleeping, or hair falling. They are also worried about parents’ social and medical expectation of care. For instance, the common belief that eating homemade food is better than hospital food (see Skolin et al. 2001); the relation between the ill child and other healthy siblings (Bluebond-Langner 1996); the distance from home to the hospital (whether they can go back to the hospital or not if needed) and the possibility to rush to
the hospital at night if there is an emergency; the need to travel to another city to seek treatment (Vindrola-Padros 2011); the relation between parents and their capacity to take care of the sick child; the key role of mothers as caregivers; the length of treatment and its economic and financial burden on the family system; the level of trust to different doctors and their proposed treatments; all these issues are constantly emerging and are connected with parents interpretations of children’s basic physiological needs. In other words, although these basic bodily processes could be seen as secondary in importance from the health professionals’ perspectives focused on continuing with treatment and not delaying the next cycle of chemotherapy, from the children and families’ sides they become something of great importance. These are familiar worries that are interconnected with other classes of concerns and discomforts like the nausea pre-chemo session. I am not saying that professionals underestimate these concerns; they know that children and families are constantly worried about them and try to ease children’s symptoms and provide an answer for general concerns with treatment. But children and families are concerned both with the present, the here-now (the phenomenological lived body, the continuous experience of being treated and intervened) and the future outcomes treatment could potentially bring. As Williams (2000) argues they are concerned with children’s cancer as a “chronic illness” as a “biographic disruption”; that is, the need to constantly redefine the child’s anticipated biography.

An important aspect related to the embodiment of long hospitalizations is how much children and parents are aware of what is going on within children’s bodies and what tools and information they have in order to let children feel –according to the circumstances– they have some control to what is happening to them. Some parents (not all) would request medical residents, nurses, staff doctors to explain to children why they have to take blood from them, or
why her hair is falling, or why they feel nausea and cannot eat solid food, to mention some of the
main worries. Still, some parents believe that their children do not know, or do not know enough.
But as Bluebond-Langner (1978, 1996) has clearly showed children with cancer know what they
are going through (even very young ones) and they know it with their bodies. Just to give two
small examples, in one of the multi-families meeting at the CCF two mothers said,

Sonia: In the last [lumbar] puncture we did for control [the child has finished treatment] I didn’t
want to worry my [6-year old] daughter so I didn’t tell her we were going to do it, but as soon as
we arrived to the [Hematology] unit she told me “Ah, they are going to do a [lumbar] puncture
on me,” and became uneasy.
Monica: The fact is that children know what they are going to do to them or what they are
actually doing to them, and so sometimes they say “they drunk me” or “I am a little drunk”
because of the sedation they received for the LP [lumbar puncture] or BMA [bone marrow
aspiration], or they laugh, or they say they cannot find one of their eyes, or they see two
mammas…

Yet, in other cases it is a non-intentional communication, the things fragmentary heard on
the corridors, or when office’s doors are half-open, or the rumours spread among caregivers what
is also inadvertently transmitted and wildly-imaginatively perceived. Sometimes it is just one
word. I remember one day I was following one of the staff at the Communicable Diseases Unit
when she met another staff,

We were going to leave the unit with Claudia when Florencia stops Claudia in the middle
of the entrance corridor next to the nurses’ office. Florencia tells Claudia how Karina is
getting worse and how Mariana has been hospitalized. Claudia says, “I had this fear this
was going to happen to Karina.” Precisely at that time Mónica (she has a rare,
uncharacterized anemia) and her mother were entering their room and when Claudia
pronounced the word “fear” I clearly observed how the mother kept looking at Claudia
with her eyes wide open…

This is a quotidian example not only of how things get (involuntarily) transmitted but
also of how long hospitalizations generate new corporealized knowledge and new relationships
among children, caregivers and several kinds of professionals. In many ways there is a labour, a
production of being hospitalized, long hospitalizations are a particular kind of physical/affective
work. Children and families are not merely re-producing and passively accepting what professionals want them to do, they are also producing and actively engaging with their situation under these long hospitalizations, they are putting their bodies while being hospitalized.

Within the hospital children and families are directed towards certain teams, units and specialists. Thus, they connect and relate with specific professionals and are able to mobilize resources within and outside the Hospital Infantil that can make a difference in their lives. Many parents told me that at the beginning they did not know about their children conditions and when treatment was ending they knew more, they understood why doctors were doing certain things, they also created new (often temporary) relationships with other parents with whom they had synergic exchange of information and advices. Children also create connections among themselves. Especially, older children and teenagers that often are hospitalized in the same unit or coincide on their long chemotherapy or blood transfusion sessions at the “Day Hospital” at the HU. Sometimes I was able to see how teenagers were chatting among themselves, though often they were often in a mood of not seeing anyone and they would cover their faces with hats or towels and tried to sleep.

During the long hospitalizations another type of therapeutic relatedness I was able to observe inside the hospital were the connections children and family members developed not only with particular nurses, residents, staff, social workers, and psychotherapist (to mentions some) but also with other children and caregivers. In a sense, these are ways of creating new networks (kinship/family/extra-family). This is precisely what gets rearranged—the social world in which sick children and parents are surrounded not only by other sick children and parents/caregivers but also by particular residents, nurses, staff, social workers, and others—they create a customized network within this massive institution. Indeed, in these particular forms of
therapeutic relatedness is where children and families knit their social networks with key social actors within the institution. These particularly intense medicalized social relationships during the long hospitalizations provide the substratum in which a family is reshaped by children’s illness and treatment. But there is a spatial-temporal component to this experience, which is often the need to relocate in another place such as the Hospital Infantil I have studied.

**Medical travel and medical relocation**

In the literature about medical travel there is often an emphasis on the movement of patients as if they were freely moving from places as tourists visiting new places (when in fact they often go from expensive to cheaper health care systems or from broken to working health care systems). In the last decade there has been a critique of the term “medical tourism” which often implied certain equivalence with other forms of tourism (Kangas 2010; Sobo 2009; Vindrola-Padros 2015). Even the term “medical travel” with its neutrality frequently does not represent the particular practices associated with medically produced displacements (Sobo 2009; Whittaker et al. 2010). Multiple practices can be associated within the medical travel general umbrella.  

What I observed during my fieldwork is that there are two big groups of medically produced displacements: there are medical relocalizations (the majority within the national boundaries and few from outside the borders), and there are medical travels of those who live in a relatively close distance from the Hospital Infantil. In all these relocalization processes there is a need to

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93 From medical euthanasia (Switzerland is one of the “booming” destination for “suicide tourism”, see Tuffs 2007), to fertility travel (Inhorn 2003), from organ transplants and organ selling (Schepper-Hughes 2001), to cheaper treatment in foreign countries (for instance, for dental care, Argentina and South Africa attract expatriate from developed countries with expensive dental care), to mention just a few.

94 In some cases, the international medical relocalization implies some sort of “undocumented migratory status” (Vindrola Padros 2011:435).
find a proper housing and other services when not being hospitalized. I agree with Milstein and Smith (2006) that some cases, like the one I described about the family that moved from Paraguay to Argentina primarily for medical reasons, we could call them as “medical refugees”, since they had to literally flee their country for medical reasons and start all over in the host country.

The unequal distribution of resources throughout the country and the pulling force of few tertiary level public hospitals are at the root of these medical movements, which are the effects of social and medical inequalities. As Vindrola-Padros (2011:439) argues in her work with children with cancer who had to travel to the City of Buenos Aires in order to be assisted,

The need to travel to Buenos Aires in order to access medical attention was an issue that created further disruption in the child’s life. In the case of the Argentine children, this migration was produced by the unavailability of paediatric oncologists and medical equipment in their place of origin due to the centralised organisation of the public health system.

As we see, centralized care is a paradox. On the one hand, it makes the health care system more efficient (from a rational biomedical perspective). On the other hand, it creates an endless set of hurdles for children and families. I think it is important to differentiate those families that live within certain proximity to the Hospital Infantil and thus have to travel back and forth to the hospital (even when they would be temporarily secluded for months at the hospital), from the more “stable” displacements that I call as “relocalizations.” When some members of the family, especially lower-income families, have to relocate from their own places to the City of Buenos Aires the kinds of experiences children and main caregivers go through are very different than those that can go back and forth from their house to the hospital and have an intermittent but still

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95 Here I am referring to centralize care in relation to the few tertiary level hospitals dealing with pediatric cancer. As I already mentioned in Chapter 1, the Argentine health care system, especially its public sector has been de-centralized and therefore the majority of the public hospitals were transferred from the federal level to the provincial and municipal levels.
easily accessible connection with the rest of the family. I was able to observe families who had to travel from places 150 km away from Buenos Aires everyday on bus and/or trains and/or subways (some three to four hours only one-way). Usually families from places beyond 200 or 300 km would need to relocate (at least temporary) near the Hospital Infantil (friends, distanced relatives, acquaintances, anybody would be approached to ask for a place to stay). In many cases the main caregiver and the child would do that, but often other members of the family will (temporarily) accompany them if not the whole family.96

On the other hand, in multiple cases I interacted with parents from far-away places (some more than thousands kilometers away) that had to leave their families for one year or more and could not see them throughout the entire treatment (at least the first two phases of chemotherapy) because their children could not get out of the hospital for a long stretch of time. Or, they saw them very sporadically during that time because they did not have the resources to go back home. In the majority of these cases children and their main caregivers, seldom the whole family, would live in cheap hotels rented by the Provincial House in Buenos Aires (some sort of “consulate” each province has in the City of Buenos Aires, the Capital of the country). In many instances healthy siblings, the second parent and other family members and concerned others would come to visit the child and the main caregiver during the long hospitalizations. Yet, as I have showed before, in many other occasions children with their main caregiver would come from far provinces or bordering countries to treat their children and would be dependent on their family’s resources and the different forms of state welfare. These different kinds of medical

96 A big difference between families from the Greater Buenos Aires Area and families from the rest of the country is that in many cases the latter families have access to certain kinds of resources (it varies though) through their Casa de Provincia (Provincial Houses) in the City of Buenos Aires, whereas the former often cannot have that help, though they may approach the Casa de la Provincia de Buenos Aires for some aid.
travels and medical relocalizations bring all sorts of experiences, not all of them negative. Of course, starting from scratch is hard in itself, but also children and their main caregivers would be exposed to different things, different people. The mother of a child from a northeastern province who came to be treated in a provincial hospital close by the City of Buenos Aires once told me,

Slowly, very slowly I started to know the hospital and the places, and then I began to know other mothers that helped me and gave me good advices of how to do this or that. We were lost at the beginning, Martin wanted to go back to our home, he would always say to me every day, “Mammy, I wanna go home.” I was very hard at the beginning, but we then slowly started to know more, and we also saw that Martin was getting better; he was overcoming his treatment and the chemos.

Of course, they had to learn how to live far away from their families. They could not see them often, or as often as they needed/wanted. Parents may think they are not good enough parents, or they may blame themselves or the other parent for things they could have done but they did not as some parents often told me. As we will see in the next section, it is by no means an easy task to take care of children living with cancer. As a family there are countless struggles and hardships that need to be overcome, but there are certain core believes families develop while caring for their children.

**The ethics of “keep on fighting”**

In my talks with parents and other main caregivers one of the multiple issues they highlighted was their long experiences of seclusion within the hospital, and, related to the latter, the experience of waiting. This is a particular form of waiting experienced by lower working classes in their relationships with state agencies and institutions like this Hospital Infantil which is comparable with a general experience of waiting corporealized by lower and working class
families (see Auyero 2011). Long periods of wait and isolation are often not perceived as the mere passive experience of (abstract) time passing (though children and families often told me they get tired of waiting) but as a productive and creative time in which new connections and associations are made. Auyero (2011:15), writing about poor people waiting in an Argentine welfare agency, says,

While they wait, welfare clients keep themselves busy. They play with their children, they feed the little ones and change their diapers, they walk around, they leave the building for a smoke break, they buy snacks from the stand and negotiate with their children about prices and portions, they play games on their cellular phones, and occasionally they read the newspaper (we twice saw clients reading paid newspaper editions; for the most part, they read the free newspapers available throughout the city in subways and kiosks). In other words, their waiting is active and relational.

I have found a similar situation within the Hospital Infantil or outside it at the CCF, or at the Provincial Houses where parents from the far-away provinces go to do paper work, or when parents have to mobilize resources in welfare agencies, or when children and caregivers are waiting for a procedure to be performed.

Waiting at the Hospital Infantil is also productive because there are a lot of things going while waiting. There is always a test to be performed, blood to be extracted, or a new specialist that need to be seen in the opposite part of the hospital. These are “things to do” scheduled and arranged by health professionals. But the opposite can be said in regards to the “things to do” from the family side: from registering what doctors said to clearly transmit it to other family members to following particular tips other parents passed onto them, from doing paperwork at the hospital to supporting children who are worried or sad, from entertain children when are bored to keep track of the tests and studies done to children, families are also busy doing myriad things.
As Auyero (2011) makes it clear, this is a productive and busy time. Many parents told me that they feel they cannot relax because there is always something to do (for instance, I observed how medical residents at the Communicable Diseases Unit would ask parents to do some small errands for their children and/or others like taking blood samples to the general laboratory) or because they feel they need to do something. This localized, institutionalized, active and relational waiting creates the substrate from which families build relationships, discover knowledge, and prioritize resources. But this active waiting throughout long hospitalization is part of a larger context of care, often among several kinds of crises.

The great majority of families I observed at the Hospital Infantil had to learn to manage a wide range of crises that are simultaneously co-occurring and, thus, put their children’s illnesses and treatments in the context of opposing and often contradictory forces. Let’s take for example the financial burden of not being able to work and having to sustain a one to two-year treatment, which is very often the case for the mothers that become the majority of the main caregivers. The following conversation with a father provides a good insight on how a pediatric cancer becomes a crisis within multiple crises. This is an excerpt from my field notes on September 1, 2010 at the CCF’s ground level:

I was chatting on the room with computers at the CCF with a father. Adrian showed me some pictures on his Facebook webpage of Juan when he was 2-year old. He showed me how the tumor grew really quickly in one month on his neck. He showed me pictures when Juan was operated and when he went through radiotherapy. Oncologists gave radiotherapy twice, when he started treatment and some months ago after his first relapse.

Alejandro: Today is a very important day. Juan eat a burger at 10:00 am but since then he is fasting [it was 1 pm] until 5p when he is going to have an MRI. If the MRI comes clean that means the end of his treatment and we will finally be able to go back to Tandil [430 km from the City of Buenos Aires].

Rafael: That’s very good news! How long have you been living here (City of Buenos Aires)?

Alejandro: We came here when his treatment started. We are from here but we went to live in Tandil because we wanted to be out of this massive city and we like Tandil. So throughout all this time we have been living in my parents’ house.
Rafael: Did any of you worked all this time? How did you manage to support yourself financially?
Alejandro: That was hard, really hard. My wife is a school’s director there in Tandil. So she took one year off with a full paid license because of Juan’s illness. But the license was only for one year so she had to come back to work. It was insane all the paperwork and things we had to do. Particularly, because this is not an easy illness that within a year you are sure that he will get cured and everything we’ll back as before. Unfortunately, he relapsed so that made things even more complicated. So, after many negotiations, IOMA [the Teachers’ Union-run health care] told my wife to take a psychiatric license without any timeline. The people at the Union told her “We know this is not right, but this is the only thing we can do to let you be with your child and not lose your job.”
Rafael: What? That’s crazy.
Alejandro: Yes, it sounds crazy but she had to take it otherwise she would have to come back to work and we were not done with Juan’s treatment. It’s crazy that she has to pretend she is crazy to be with her sick child. So, to answer your question, we are still living with my wife’s wages because I can’t work. We are also lucky that we live with my mother and she also can help us a bit. I don’t know how we would do all this without my wife’s salary and the help from my parents…
Rafael: And how is your everyday life? You know, how does Juan’s treatment affect your family? This is something I am intrigued about.
Alejandro: Now it’s fine. We had a very rough time. But now everything is OK. My older kid goes to school and then comes back to my parents’ house. At the beginning we had to pelear por todo (“fight for everything”). For instance, the first three chemo cycles we had to fight with IOMA. So oncologists at the Hospital Infantil gave it to Juan but then we had to harass IOMA to give them back to the Hospital Infantil, which they did, slowly, one by one. After the third cycle everything was better and we had the drugs on time.

As we see in this excerpt Alejandro tells a particular but somehow common story for many families. They experienced radical changes in their lives. In order to secure a cancer treatment for Juan they had to move back to the City of Buenos Aires, live with his parents, move the other child to another school, ask first for a one-year license for his wife, and then a psychiatric license in order to support and care for Juan throughout the two years of treatment. These are massive changes that imply, first, relocalization, then, re-organization of the family’s dynamic, and, finally, exploration and appropriation of old and new resources (for instance, living in his parents’ house and the discovery of the CCF). It also highlights that they, as a family, had to pelear por todo (“fight for everything”). Alejandro’s story also shows how the Argentine health care system is organized in terms of central and peripheral places. Many of the
children living with cancer that receive efficient treatment have to be dis/placed and temporary relocated close to key main hospitals.

Alejandro’s story also highlights this notion raised by countless parents of “keep on fighting.” When caregivers and parents refer to it they were talking about some sort of guiding principle that, undeniably, is not disconnected from what these families (usually working class) face on their daily basis outside the hospital and prior to their child’s disease. I call it an “ethics” to emphasize on this dual nature of values and beliefs (to fight for their children and to do everything they can for them). In many cases this “ethics of keep fighting” is linked to a will to mobilize every possible resource to reach the land of survival without illness. A typical case of this is when parents have to ask and negotiate resources with the different bureaucracies within and outside the Hospital Infantil (Union-run health plans, National Drug Bank, Ministry of Social Development, etc.). Parents learn how to navigate these multiple institutional fights.

Silvia, a mother of a six-year old child with leukemia told me,

You always have to talk to them [state agents and bureaucrats] very politely, but you have to be assertive about that what you know and do is correct. You cannot surrender or doubt because if they ask you something and you say you don’t know they will hold on that and they will delay everything.

In many ways, this “ethics of keeping on fighting” has to do with finding meaning to “what you have to do.” Children and families become entangled in a relational construction of subject-as-patients and the things that need to be done to them in order to cure them. In the middle of these processes that have children’s bodies as the source and target of medical interventions, there is the mediation and witnessing of children’s parents and other close family members and friends. Often parents find themselves trapped in-between their loyalty to their children (and their moral obligation to do anything to avoid them suffer) and their forced compliance (not without resistance) to their children’s doctors that would do anything to cure
them. This dual loyalty implies an intense form of affective work, especially for mothers who are most of the time accompanying children during their long hospitalizations and the several painful medical procedures. Young et al. (2002:1845) argue that, in particular mothers of children with pediatric cancers tend to overprotect their sick children, because

Having a child made vulnerable by cancer augmented mothers’ obligations to protect their children and prioritise their interests. However, with the reordering of meaning prompted by their child’s severe and life threatening illness, these obligations required that mothers accommodate to the demands of medicine even though this meant submitting their children’s resistant bodies to unpleasant treatments and manipulating their wills in ways that threatened the entitlements of childhood. The enormous internal conflict and emotional work these opposing pressures generated for mothers was one of the most striking features of their accounts.

Mothers at the multi-familiar meetings at the CCF discussed their problems and concerns in relation to how to fine-tune their care to their children without losing their authority and setting clear boundaries and limits when needed. But, in many instances children are the ones that give strength to parents and other concerned others to “keep on fighting” not matter what they have to go through. For instance, Luisa, a mother of a 12-year old Ricardo with acute lymphoblastic leukemia told me:

My son is the one that gives me strength, many times people told me “I don’t know how I would do what you do, I would be all day crying in bed.” But you have to do what you have to do for your children. One does what it needs to be done in order to make them feel better and avoid them suffering. I suppose other parents would do just the same if they were in our situations…

Myriad people constantly intervening, thinking, and taking therapeutic decisions about the children’s bodies and lives for a long period of time often intensify this internal conflict. In the social world of children living with cancer parents, aunts, uncles, grandparents, friends, neighbours, and siblings are also central in their lives and they are also embodying these enormous internal conflicts and emotional work. And as Bluebond-Langner (1996) showed, healthy siblings are often in a complicated position, not only adapting to the natural prioritization
of care for the sick sibling, but also, as I showed before, they are often developing responsibility
to take care of other members of the family (Zebrack and Chesler 2000). Mothers (and fathers)
would tend to overprotect their children during the long treatment but they may have other kids,
and when treatment shows signs of erasing the tumor or malignant cells from the ill child’s body,
these other children would start asking their attention. Indeed, many mothers told me that it is
difficult to “switch” from a normal life as a mother with a normal child, to a mother of a
“leukemia patient,” and, then, back to “normal” again once the child is living “free of illness.”
Every movement during treatment, from the first contacts with the Hospital Infantil, takes a
different spin according to the information they are discovering and the feeling they are doing
things because “you have to do what you have to do.” In this sense, they are cultivated,
indoctrinated and taught in how to properly care their children living with cancer.

Indeed, there is a big difference between the notion of “installing hope” to patients in
regards to cancer treatment (Good and Good 1990), the hero-storytelling and the quest for cure
(Frank 1995) versus the “ethics of keep on fighting” that numerous families referred to during
my study. The former is associated with the idea of “positive-thinking” and the usual military-
driven metaphors of fight, struggle, and conquer (Sontag 1978). The latter is connected with the
real, particular struggles that parents and other family members have to go through in order to
sustain care and the life and wellbeing of all their members included their sick children. “Keep
on fighting” in this case gets actualized and re-contextualized every day. For instance, every time
the main caregiver and the child have to take two buses and a train and travel three hours to get
to the hospital to put children’s bodies to more painful procedures and chemotherapy treatments.

Families, especially mothers, have to “keep on fighting” for myriad things for their
children. Susana, Gloria’s daughter, an 8-year old girl living with rare condition is a good
example of all the things parents, often mothers, have to go through in order to find a diagnosis and start treatment. In this particular case things got more complicated because Susana had a rare disease that was difficult to diagnose (and then to treat). Susana started with repetitive ear infections, she had multiple otitis, and she was all the time thirsty. Meanwhile Gloria got pregnant of Luis, and so those nine months delayed the process of finding Susana’s diagnosis in spite the fact that the professionals at the pediatric hospital in the City of Buenos Aires (not the one I conducted research) could not find what Susana’s problem was. After Gloria insisted many, many times they did a puncture close to her ear where she had like a granule. And there it came that she had 60% of chances of having a tumor. Many months passed and with the medication they gave to her she was still experiencing big headaches and a lot of pain. Then, Gloria told professionals they had to do another puncture, this time inside her ear. Everyone told her no, that it was going to be incredibly painful for Susana, and no one wanted her to go through that suffering. Gloria told herself that she would rather prefer to put her in that intense suffering but know exactly what she had. Professionals asked Gloria to sign paperwork that she was in charge of this decision, she even had to go to talk with the director of the hospital. Gloria said,

If I had to chain myself to the hospital I was going to do it, I don’t have any problem, I will do anything for my daughter’s health, in fact, I already chained myself once to receive a house [from a social plan] for my daughter to live better and I got it.

At the end they did it, Gloria’s husband had to leave the room because he couldn’t stand Susana’s shouts and crying, but at the end they took two tiny balls from her ear. They analyzed them and it showed 99.9% probability of tumor. Once they confirmed she had a tumor or something similar to a cancer they started to search what she actually had, they did more tests, until they figured out what she has: Histyocitosis.
Of course, knowing what Susana had was just the beginning of a long journey for this family. Gloria clearly remembered what happened when she received the phone call asking her to go back to the hospital for the diagnosis, her doctor said, “Mother, we were able to find the diagnosis, your daughter has this [histyocitosis], the problem is that there is no one in the country that can treat that, it is a rare disease that no one knows much about it. The only person that knows about it is in Canada.” The, Gloria insisted until one day the Argentine expert living in Canada came for a conference and she was able to meet him. He looked at the results and said,

Look Gloria, it is confirmed Susana has histyocitosis, this illness is rare, we know little, there are few therapeutic options and the path will be hard, very hard. Now I can tell you that your daughter has 2% of survival. She will have to go through strong chemos, she will have all her immune system compromised, you will need to take care of her and be sure she won’t get infected, she will probably go through multiple relapses, but if you want to fight this I will be right with you.

Gloria said that she did not think it too much, she told him that they were going to do everything, that they were going to fight, and if there were a slight chance of making they were going to keep on fighting. Gloria told me that from that moment until that day I saw her “we had gone through multiple experiences, and now my daughter is there outside, and she is eight years old now.”

I find Gloria’s story clearly shows the ethics of “keep on fighting.” It also highlights the theme of the chapter, which is children’s medicalized social world and its rearrangements. I think it is important to underline the idea that parents’ (and other family members’) role changes—and that, perhaps more significantly, the way they narrate their relationship to their child and their families changes as well. Thus, parents, like Gloria, are making sense of themselves and their relationships with their sick children while narrating the hard experiences they went through. Indeed, as I mentioned before, Gloria told us in that meeting how she became an activist for the rights of people with disability, helping people to obtain disability pensions or complaining to
school boards for children who had been bullied for having a disabled parent. In this way, her own notion of keep on fighting for her daughter was politically and militantly transformed in keep on fighting for others as well. Yet, another aspect that needs to be considered is how the whole family gets reorganized not only for those children and caregivers that have to relocate themselves at the Hospital Infantil but also for families that live close by and still will have the sick child and usually one main caregiver secluded for months at the Hospital Infantil.

Rearrangement, and transformations: Re-organizing the family at home

Similarly to what Bluebond-Langner (1996) found in her study children, parents and other family members at the Hospital Infantil first of all have to find ways to control the irruption of the illness within the family. Bluebond-Langner talks about the different phases in which families are able to contain the irruption of the Cystic Fibrosis (CF) within the family dynamic. Especially, how the illness of one sibling affects the other siblings within the family. Healthy siblings slowly understand what they can expect from their parents and siblings, as well as what they must do. Families follow several phases from the irruption of the illness, and each phase has different impacts on the ill child, well siblings, and parents. First, there is the diagnosis and first examination. Then, there are the first months and years after the annual examination. After that, there is the recovery from the first major exacerbation until the increase of hospitalizations and loss of predictability. Then, there is the increase in complications and discussion with the physician about the advance of the disease. And finally, there is the increased deterioration and the physicians must tell the parents that the child’s condition “now” is terminal. One difference with what Bluebond-Langner found working with children (and families) with CF in the US is that CF is a chronic condition that at one point will inescapably become a terminal condition
impacting the whole family whereas children with hematological conditions in the Hospital Infantil setting are mostly experiencing chronic conditions for many years that seldom become terminal conditions. Yet, this need to control its irruption within the family, and to rearrange the family dynamic, is somehow similar. Chronicity is not only biomedically labelled, it also becomes the identity of the child suffering the disease (and those surrounding the child). In this way, we can see how the chronic rather than terminal nature of each hematological condition shapes families’ dynamics. We can see how chronic conditions transform children’s (and others’) identities:

Chronicity consist of a fusion of identity with diagnosis, a transformation of self to self and with others (…) a constriction of social roles and identities to a core of patienthood and disablement, and an engulfment, loss, and often unauthorized but nonetheless demoralizing change of self from a person who has an illness to someone who is an illness or diagnosis (Estroff 1995:221).

Sometimes family roles have to be drastically changed because of cancer. Carolina, the mother of 12-year old Brenda with acute lymphoblastic leukemia, also told me:

My older 18-year old son he didn’t have any option than to be the father and mother at once, he lost one year of school because Brenda’s problem started in June of last year and he lost the second half of the year. He had to stay at home and prepare the food for the other siblings, he had to take them to school, and do other things. But he never complains, indeed, we have nothing to complain because we have a very loving family. My children take care and support one another, the same with the father, while myself I am here at the hospital with Brenda. We take turns, from Monday till Friday I am here at the hospital with Brenda and the weekends the father comes so I go back home, I cook, clean, iron, and prepare everything for the next week. On Monday I am back here at the hospital.

Through these two quotes one can see how everything has to be re-organized in order to balance the needs of the sick, healthy children and of the parents and the whole family as well. There is an emotional work that parents, siblings, and other members of the family have to perform, a sort of emotional engagement, in order to understand what everyone has to do. This
work has to be done collectively with those that are willing to work with the main caregivers (or negotiating with those who are less helpful).

Some examples of these rearrangements can be seen as trivial or insignificant. Yet, they are all part of a constant adaptation within the family. One example is when treatment is working and children are going back to certain normal life. For instance, in this dialogue at one of the multi-family meeting at the CCF these two mothers talk about how hard was to go back to "normal" with their children:

Mónica (mother of 13-year old Daniel, only son, he has Hodgkin’s lymphoma and is in the consolidation phase of chemotherapy): It is difficult for me to ask him to do things; he asks me all the time to do things for him. When he was on chemo I was doing everything but then it’s hard to go back to put limits to him…

Hilda (mother of 17-year old Rita, she has acute lymphoblastic leukemia and Down Syndrome): It is also hard for me, my other older daughter tells me that she needs to know that she has to do some things at home, that I have to put limits to her, and she says that I over-protect her too much. She also says that I have to make her do some things at home, even if it’s not that good for her, but she needs to learn to do certain things...

As we see in this quote families are constantly adapting to these ever-changing transformations that cancer treatment brings not only to children and caregivers but also to the whole family system. As Bluebond-Langner (1996) shows in general healthy siblings understand what they can expect from their parents and ill siblings, as well as what they must do. In many cases, families are constantly going through processes of re/dis-placement, even those families from Buenos Aires, since usually the mother is most of the time with the ill child, the father or other guardian may be working, the other siblings are often alone or being taken care by someone else (an aunt, a neighbour, others). Or, the parents may take turns to do certain paper work or be at the hospital certain days. In the majority of the cases at least one of the parents often cannot work so this brings more stress to the family. These are also important aspects of how children’s growth is medicalized too. Indeed, when looking at the family dynamics and each
family’s readjustments we need to consider how both healthy siblings and non-main caregiver parents are often in the “shadow of illness”. At a multi-family meeting at CCF a mother talked about how she realized that

I was with the main doctor and he was saying that we need to take care of my daughter [with a rare disease] and all of a sudden my husband said, “but you also have to remember that when you [mother] went running to take care of my daughter, which I will for ever be thankful and it is priceless what she did, I had to stay with our son, who was a baby, I had to change his diapers, take care of him, feed him, take him to bed at night. My wife was next to my daughter day and night but I was the one who was next to my son day and night watching him grow."

This quote also shows how the distribution of resources within the family is constantly changing and it is directly affected not only by the need to care the sick child by the main caregiver but also by the ones that are left “at the backstage” who are also taking care one another.

**Conclusions: Transformed family, redistribution of care, and new roles**

The disruption of a hematological condition alters the fabric of the “family.” The usual roles are upset, expanded, or relocated. For instance, not only adults work as caregivers but also children perform that role as well, and not only healthy siblings but the sick child too (Bluebond-Langner 1996). And children and adults have certain knowledge of what is going on, especially in relation to children’s bodies. So how does all this affect the family?

Throughout this chapter, I have analyzed how the different members of the family are affected by illness and its treatment. For instance, members of the family who usually do not go to the hospital or talk with health care professional ask the main caregivers to tell them about their children’s illness and treatments, older children take care of younger children, parents are physically separated for long stretch of time. In this personal and familiar biographic disruptions
family members have to find ways to take care of one another, to rearrange their priorities, and for how long treatment will last. I have considered how this therapeutic relatedness was conceptualized by looking at gender, personhood, and the body. Following Deleuze’s definition of parents, I asked who are the agents along children’s paths that accompany them in all these weeks, months, and years of treatment?

I have also shown some of the different experiences children with life-threatening conditions and the surrounding social worlds they traversed. Families were transformed. Months and years passed while caregivers (usually mothers) are far-away taking care of their sick children and while siblings, husbands, and other family members are also living their lives. Couples often cannot handle the stress and burn out and so they split. There is a constant re-adjustment going on according to the different phases of children’s treatments. Families’ whole lives are rearranged and the experience of care giving is constantly revisited.

I have reflected upon the impacts of hematological conditions and other life-changing conditions on the social groupings and the ways different kinds of families (not without frictions) re-arrange their priorities and inner tasks putting at the center their children, especially their children’s bodies, when trying to understand their own circumstances and their roles as caregivers and care-seekers. Therefore, I chose to focus more on the disruptive socio-medical processes families needed to go through. By doing so, I attempted to map how social groupings open/close, fold/unfold while pursuing treatments and reconfiguring their therapeutic relatedness. In the next chapter we will look at permeability in relation to children’s (and others’) dignity of life.
Chapter 10: Permeable bodies

“I think children are extremely permeable, way more permeable than adults, no doubt about it”.
Mariana, hematologist

In this chapter, I address the role of children’s bodies in the relationship between social and medical care, and the experience of children with hematological conditions, their families, and health professionals. I will also consider the differences among children, families, and professionals in relation to their own forms of (im)permeability. In the final section of this chapter, I will consider how children’s (im)permeability is central to the pursuit of treatment, and as a consequence, how it affects children’s personal dignity.

As I discussed in Chapter 7, during treatments children’s bodies experience both constrains (medicalization, hospitalizations, and the ever-present hematological and communicable diseases gazes) and new possibilities (growth, endurance, getting smarter). These processes raise questions about their impact on the personhood and dignity of these children. Rather than attempting to appeal to universal definition of dignity (Glen 2011; Levinas 2006; Taylor 1989), I examined children’s quality of life during cancer treatment and how they and their parents lived through the treatments while maintaining dignity of life. It was expressed and conceptualized by parents and doctors in different ways. While Mattingly (2014) describes how Afro-American families with children living with cancer and other serious chronic medical conditions search for the “good life” in the clinical borderline that become “moral laboratories,” I also found that children, parents, and clinicians constantly faced ethical dilemmas to maintain dignity. Medical interventions into the bodies of children, burdened with life-threatening conditions such as leukemia, challenge dignity and cannot be understood without looking at children’s bodies and the social relations constructed around children. Dignity in this context means not only what is good for each person from his/her own perspective but also for the
relations that each person has with others. Thus, in this chapter, I will talk about “dignity” in a broader sense not only to point out to how these “permeable bodies” are constructed but also to reflect on children’s (and others) dignity of life.

Since dignity of life is related to bodily capabilities, I use two central conceptual frameworks to understand the distinctive types of experiences faced by different actors in relation to their bodies’ (im)permeability. I focus on: 1) the transformations of the body as they become ‘permeable bodies’, by analyzing the kinds of relationships that develop and transform between children’s bodies, several health professionals, and family members; and 2) on the making of ‘subjectivity’ as the field where dignity is reconstituted via the double processes of the internalization of exteriorities (especially the internalization of power relations in the form of medical interventions) and the externalization of interiorities.

**Breaking into the body**

Biomedicine has historically looked at the body as if it was dead, disconnected, and isolated. This disposition creates the space where biomedical knowledge and practices work. Children’s bodies must become permeable for health professionals to gain access to the body. A series of mediations made possible by bone marrow examinations and other kinds of tests results ensure that health professionals have direct access to each child’s body. As we have seen in the previous chapters, once children enter into the Hospital Infantil’s procedures their bodies become the center of medicalizing processes. Thus, children, learn from what they live. If children live among needles, tubes, blood transfusions, chemotherapy, lumbar punctures and bone marrow aspirations, these procedures teach them about the permeability of their bodies – their corporealities. They learn to live in a body made permeable and extroverted (open from the
inside out) to medical intervention. In addition, a long series of events disrupt children’s lives, their family’s lives, and their social world (Bury 1982). There are major and minor changes, all marked by the entangled development of maturation and children’s diseases and medical treatments. Therefore, as we saw in previous chapters, this medicalization of children’s bodies has a direct impact on the personhood and dignity of children’s lives as well as the lives of others.

Children, their parents, and the physicians each have somewhat different experiences of treatment, mediated by the children’s bodies. Blood extractions, lumbar punctures, and bone marrow examinations are central to the creation of children’s bodies (im)permeability. The material aspects of these deep bodily interventions are of fundamental importance to children and their social worlds. Children are intimately aware of their corporeality of treatment over which they have some limited control. Parents also vicariously experience the pain and suffering of their children, as Valeria recounted in the quote that framed the opening of this dissertation. One or both parents are consulted and asked for their consent for treatments, weighing the pain and discomfort of tests and therapies against the uncertainties of prolonged life and cure.

The physicians who are responsible for treating the children also have different perspectives from those of the children and parents. Even among physicians, their points of view vary, depending on their specialty and level of training and expertise. Residents at Communicable Diseases Unit (CDU) and fellows in the Hematology Unit (HU), who provide much of the care, are both learning and responsible for procedures such as venipuncture at the CDU or bone marrow examination at the HU using a variety of needles and tubes. Fellows in the

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97 This should not imply that I take for granted that children would assimilate this situation easily. There is a wide range of responses to the medicalization of their lives, and some children probably never get used to it.
HU need to learn the subtleties of how deep the long needle should be inserted in-between two specific vertebrae for the lumbar puncture and how many drops of cerebrospinal fluid are let fall into the tubes for analysis. They also need to learn how to properly aspirate the bone marrow and how to smear it for analysis.  

In the “Procedure Rooms” labels with children’s names are affixed to the tubes that hematologists must handle them with care. Then, they take these tubes to the upper floor to be examined under microscopes. There are protocol-defined steps that need to be followed in this particular biomedical scenario that begins with the material of children’s bodies. Every aspect of these material interventions into children’s bodies by physicians is central to our understanding of children and caregivers’ responses to treatment outcomes. These choreographed treatments modulate children’s lives.

Perhaps more significant in making children’s bodies permeable, is the insertion of the semi-permanent ports, or Port-a-caths under the skin, to provide continuous external access to veins, as described in Chapters 5, 6, and 7. These ports are not only the gateways to veins for multiple procedures; they also prevent the need for continual punctures in children’s arms, which could lead to collapsed veins in children’s arms and legs. The ports make the interior accessible to the exterior for tests and the exterior accessible to the interior for treatments (chemotherapy, blood transfusion, fluid expansions when on septic shock). The port is the symbol of permeability and the persistence of accessibility during the course of treatment. As Alex’s story reminds us, the Port-a-cath became part of him, something that he did not want to dispose of, even after treatment was complete –something he wanted to show to his own children.

98 There is a technique that has to be learned on how to smear the sample of the bone marrow onto the tiny rectangular glasses. Some drops of the sample are dripped onto the first glass and then from it smeared into other glasses. According to the fellows that showed this technique to me, the final outcome should not be too granulated in order to be observable in the microscope.
This leads us to ask, what happens when the body is turned into a field of interventions? How does the initial seek to diagnose a condition before stopping and reverting the disease impact children’s bodies? Here we are presented with a paradox. Those interventions, dependant on often profound degrees of invasiveness and permeability, are essential to maintaining and prolonging the child’s life and also contribute to restoring the child’s dignity of life. What are the limits of invasiveness or interventions, before they threaten the dignity of a child’s body? Indeed, both lay and professional constructions of dignity are relationally produced, through the micro-processes of interactions among patients, family, and professionals against the backdrop of macro-processes, including juridical systems, Argentine Pediatric Association practice guidelines, and regulations within the Argentine health care system. How is dignity produced in these corporeal inter-personal relationships? How is dignity associated with keeping a relative control over your own body and minimizing the amount of suffering, in the accepted context of medical procedures and practices? Therefore, dignity has to be understood within a wider context, of the permeability of the child’s body, and the social and medical relationships mediated by these children’s bodies.

**Children with Leukemia**

The words ‘cancer,’ or ‘sickness in the blood,’ or ‘leukemia,’ have social affects. The mere sounds of these words produce resonances socially and subjectively in North America (Johnson and Lakoff 1980; Sontag 1978) and in Argentina (Luxardo and Alonson 2009). In the Argentine context, Luxardo and Alonso (2009) have shown how the process that begins with a diagnosis of cancer and continues throughout a painful treatment produce both an erosion of the self and a material tension between body and mind; a contradictory process in which suffering and pain can
be seen as both an other/external or an essential part of patient’s subjectivity. Leukemias are distinct from other types, such as the solid cancers, because of their often-invisible undetectable quality.\textsuperscript{99} As I showed in the previous chapters, I frequently heard parents, most often at the beginning of treatment, telling me that they did not consider their children to be sick, and that they had to deal more with the side effects of the treatment than the disease itself. How can that be? One aspect of the moral dilemmas faced by parents and children is that permeability actually does result in a high rate of cures that justifies parents’ decisions to subject their children to the extremely difficult treatments. We need to remind the reader that the great majority of children treated at institutions like the Hospital Infantil overcome their leukemias. Depending the type and sub-type of leukemia the majority of children will survive it and, although drastically affected by it, will carry out a continuum degree of chronicity in their lives. Parents need to make sense of these extremely painful flow of procedures when they cannot see that their children are actually sick.

When a child is ill, when is suffering and under pain, and her dignity and life are compromised at both the individual and collective levels we need to look at how this is produced. Children’s bodies and their medically orchestrated experiences of (im)permeability lie at the heart of the experience of pediatric leukemia. Thus, the question we need to ask is as follows: How can we talk about dignity of life when children undergoing treatment often experience a lessening of their capabilities (to affect and be affected) and, ultimately, to influence what is good for them (and others)? Particularly, in the case of children dying from leukemia, the question that authors like Lawton (2000) and Kaufman (2000) (and before them

\textsuperscript{99} As explained before cancers, or tumors, are divided between solid cancers (oncology) and liquid cancers (hematology). This division of labor is based on the distinction between cancers occurring on organs or tissues, or on the blood.
Saunders [1990] and Kübler-Ross [1973]) have asked is what can dying patients do with their own end-of-life? Lawton (2000) talks about “social death” often occurring before the biological death to patients experiencing palliative care. I have shown in Chapter 4 how the death of Laura, a thirteen-year old girl living with acute lymphoblastic leukemia, not only affected intensely affected her family but also the hematologists that were treating her at the Hematology Unit. They were not expecting Laura to die because her acute lymphoblastic leukemia B-cell had a good prognosis. Yet, a combination of unfortunate factors such as her compromised immune-system, her place of residence in a working class neighborhood in the Province of Buenos Aires, the hectic workload of the fellows at the Hematology Unit, the lack of beds at the Communicable Diseases Unit and other clinical units to hospitalize Laura right away, the three hours that took a fellow to find one nurse from the Hospital de Día (“Day Hospital”) to introduce an IV to start with antibiotics, among other factors, created the conditions for her septic shock and final hospitalization at the Pediatric Intensive Care Unit (PICU) where she ultimately died. Laura was supposed to come for a check-up the day before but someone wrote the day wrong and the mother was going to bring her the following day. One of the staff hematologists had to call and ask her to urgently bring Laura that day (they knew she was not good when the mother told them by phone she could not eat for two days because of the oral mucositis). By 3:00 pm Laura had a septic shock at the “Day Hospital” within the Hematology Unit where children receive chemotherapy and blood transfusions. At that time there was a seventeen-year old boy receiving chemotherapy that saw how nurses and residents started to expand Laura with fluids, gave her oxygen, and had to transfer her to the PICU. He witnessed something that could potentially occur to him. One of the hematologists told me that it happened once at the “Day Hospital” that

100 When a patient has a massive septic shock the first step health professionals take is to ‘expand’, which is to introduce IV fluids into the body so the blood volume is expanded plus giving oxygen. This is done because there is generalized crisis, a ‘systemic inflammatory response syndrome.’
one child got a crisis, and then as a domino effect another child got a crisis, and another, and another. And when they were able to stabilize one, another was getting a crisis. She said, “when they see what is happening to the other children, it’s like, it affects their mood and they get worse.” After three days at the PICU Laura died unconscious. A relatively few number of children like Laura die of leukemia. But as Laura’s death shows, children either surviving cancer or dying of it are able to influence others in countless ways. The question we have to ask is how we can think of what is good for children (and others) when going through these intense experiences, including the end of life?

The purpose of this last chapter is two-fold. Firstly, I analyze the interconnections of children with hematological conditions as subjects and as actors within patient-doctor-family relationships, in the context of life-limiting situations. Secondly, to illustrate how this analysis offers a foundation for theorizing about the dignity of children’s lives. I will argue that there is friction between prescriptive and non-prescriptive forms of understanding the dignity of life. I include as prescriptive forms the mass corpus of bills, acts, and bioethical and juridical interventions that locally and globally aim to define and prescribe what a life and/or death should be, and particularly the value of end-of-life processes under the guidance of medical expertise. Without disregarding this, I emphasize the need to consider non-prescriptive forms of understanding dignity of life, particularly children’s dignity of life, that emerge from the actors, their bodies, and social relationships. Through this chapter, in order to further reflect on permeability, I will examine dignity of life as an ongoing, contested and essentially unfinished process: it is for this reason that I will speak of (im)permeability as a critical aspect of children’s life experiences. To do so, I look at children’s bodies and the relationships they create with other bodies, and demonstrate that children’s dignity of life has to be considered simultaneously as
arising from the body and from the social relationships that sustain those bodies. I, therefore, emphasize the connections established between children’s bodies, their (im)permeability, and dignity of life.

The clinical gazes

For better or worse, children (and their families) are enfolded under the clinical gaze. In *The Birth of the Clinic* (1994), Foucault demonstrated how the clinic brought the body up to the surface and, simultaneously, how the art of dissection ranks among the most profound epistemic turns in the history of biomedicine. Dissection presented new ways of observing, understanding, and, certainly, breaking up the body. This newly equipped medical gaze consequently generated new kinds of knowledge and, eventually, bio- and socio-political power. According to Foucault, in the development of biomedicine as a cultural discourse, the patient became an objectified and unnecessary part of the treatment process: the culturally bounded gaze of medicine was focused on localizing disease in the fragmented tissues of the human body. Deleuze argues that Foucault showed “how pathological anatomy subsequently introduced into the body deep foldings which did not resuscitate the old notion of interiority but constituted instead the new inside of this outside” (2010:80-81). In the case of the children at the *Hospital Infantil* there is an obvious line that leads from subjectivity, which is part of and forms the body’s corporeality and here is subordinated to the different medical gaze, to things impacting the body, and thus subjectivity-construction through permeability. In fact, one could argue that children during cancer treatment are indeed engulfed under several medical gazes, at least under the hematological, communicable diseases, and palliative gazes.

101 For reasons of space I cannot provide further detail here about the wide range of therapeutic options families undertake precisely because they are under the biomedical gaze.
The instance itself of permeation and fluid exchange has a key role in producing bodies that have to be visible to the hematological gaze. As children’s bodies are constantly folded and unfolded (Deleuze 2010), pulled out and pushed in (Grosz 1994), and through the process of introducing objects and extracting/inserting fluids, children are turned into “leukemia patients.”

There is a process marked with distinguishable hiatus, as I showed in Chapters 4 and 5: often children felt bad and ill, then they were taken to doctors to find what they “have”, then they have “something strange in the blood” and so they became “children with an illness.” Along this process, children are turned into patients through procedures that put into question their capacity to have control over their bodies. The focal points of the children’s corporeal experience, the different spots on the body’s surface (boundaries / holes / check points) are located in a continuum of practices that transgress the inside and outside of their bodies. Bodily interiors are forced outwards (Nancy 2006).

Hematologists are very aware of their capacity to intensely affect these children and families, and are trying to change practices that are stressful for children and family members. Certainly, everyone is affected, though in very different ways, and on different sides of the ‘permeable bodies’ spectrum. As an example of professionals’ perception of children’s (im)permeability, hematologists often explicitly call the Procedure Room where they perform the lumbar punctures and bone marrow examinations a “terrible room.” This place is associated with torturing children and inflicting suffering. Mariana, a fellow at the HU once described to me the Procedure Room in this way:

That room is terrible, *almost* like a torture room, but on the other hand, this is what we have. We would be happy to do it in a different way, anaesthetize them, […] take the child asleep from his mother, when he awakes he is again with his mother and father, but we are not able to do it [there are institutional constraints], so we bring the child with one or both parents and sedate them and do our best.
Mariana is thus critical of the procedure itself and that they should better in handling it. She recognizes the transgressions in the integrity of the child’s body, but as part of her profession she learns to objectify child’s body in order to make it legible. As I mentioned before, this seems an irresolvable paradox: to create present suffering to avoid future (potentially lethal) suffering. Frequently this recursive process of having to permeate these bodies more and more occurs when children are getting worse not better. In fact, hematologists get to know those children who have the most difficulties and who are not doing well since they see them more often. Mariana told me in an interview:

…the [hematological] pathology is terrible, how children go through it is dreadful, but the connection you have with the family, the doctor-patient relationship is what helps you to keep on going until the end. Because although it is true that not all of them are going bad, you connect more with those who are not doing well, because you are most of the time with them, and share things like, hard times, and I think we end up influencing hundred percent what they live through.

Back in 2010 she told me that in the last two years the Hematology team had started to provide sedation to children for particularly painful procedures (lumbar punctures or bone marrow examinations), even though these procedures, according to the hematologists, should be done with anesthetics at the Intermediate Intensive Care Unit to prevent any pain from the procedure itself. Given the institutional constraints, the Intermediate Intensive Care Unit is always full and cannot take these patients for these ‘minor procedures.’ They instead perform those procedures at the HU themselves. Thus, given the circumstances, there is a clear commitment to minimize pain. In fact, Lisandro the head of the HU also in an interview told me they chose to

…optimize the pricks and if the [Chemotherapy] protocol says there is a lumbar puncture [LP] on day 29 [of treatment] and day 33 the bone marrow [aspiration], I put the LP with the bone marrow together, because if it doesn’t affect the prognosis or the progression of the disease, I just schedule them at the same time [to avoid pain].
This is one aspect and effect of the corporeal inter-relationship between all parties concerned in this context. Children and family members also play a central role in these corporeal relationships. Children put their bodies forward to countless medical interventions and family members (not without endless frictions) sustain, adhere, negotiate, and comply with the medical treatment, as well as mobilize the resources to pursue treatment (though in many instances throughout treatment they also resist it).

In all these particular instances, there is an evident process of (im)permeability in which children’s bodies are opening and closing at the same time, simultaneously being objectified as medical knowledge and subjectified as an aching body in need. Children’s bodies may be permeated daily but they also resist it daily. Medical technology becomes a site of constant conflict: it is an extension of the human body’s capacities, an intermediary, and an intromission, something distant and intimate at the same time (Nancy 2006). There is a battle between bodies that resist pricking or being pricked. The needle, as an extension of the hand, is a body-needle that is introduced in the body of the Other in order to extract cerebrospinal fluid, bone marrow, or blood. The bodies of the health professionals are constantly breaking into children’s bodies, and possibly the best example is the port-a-cath: an outside of the inside. Clinicians introduce and remove ‘information’ from them in the form of blood, bone marrow, urine, and so on. Simultaneously, children’s bodies resist these intrusions, close up, and affect professionals in myriad ways while children’s parents and other family members witness and legitimize these painful interactions.

Children negotiate the transgression of their body limits in everyday interactions. Let us take for instance the dual action of taking blood from a child’s body and introducing medicine into the body (as previously described in several chapters). The child may, after some time,
develop the skills to negotiate with the doctors and nurses and ask to be pricked only in one arm and leave the other free of pricks, or to be pricked by only one specific doctor or nurse whom she trusts (and who may cause her less pain). But in spite of all the negotiation, there is an external bending of forces that are being folded in, an exteriority (medical bodies, objects, equipment, even spatial arrangements) internalized. Although this is a very common experience for subjects immobilized at any clinical institution, my fieldwork indicated to me the fact that because these subjects are children, it creates a certain compulsion for professionals and family members to produce (manage and heal) even more permeable bodies. This is precisely the idea that children are “even more permeable than adults,” as one hematologist told me. As a consequence, this mediation is created via manifold sources of (im)permeability. Children’s (im)permeability becomes both a channel and an end to ensure the free and (relatively) unobstructed access to the body either for diagnostic and/or therapeutic reasons.

**Inter-subjectivity and extroversion**

Another source of (im)permeability is related to the inter-subjective relations between health professionals, children, and families. Young (1997) highlighted how the medical history-taking process provokes patients (and, in this case, family members) to look at their bodies from the outside rather than from inside, and to see their bodies in parts rather than as a whole. What does this process imply? It implies multiple observers looking at the body from the outside (and here I also include all medical image-making such as X-Ray, CT scan, and MRI, which are maps of a hidden territory), and one of them experiencing and *being* that body. This is why, following Nancy (2006), I call it a “forced extroversion”: an outwardly disposition. From the children’s and family members’ points of view, this disposition can very easily become one of their main forms
of life and a source of both endless fear and expectations. It produces a sort of schizophrenic division between the corporal/subjective experience and what doctors and other professionals say (often not so explicitly) about those experiences.

However, this is true for any person in contact with the biomedical system: there is a tendency to objectify, de-contextualize, and fragment the body for particular biomedical proposes. Specifically, then, how do children living with leukemia consider themselves in light of the daily request for their fluids to be taken out, measured, and described? Staff doctors, medical residents at CDU, fellows at HU, and nurses check every day, many times per day, all over the child’s body (including all orifices) for wounds that may open the space for infections.102 Children’s bodies are constantly pricked, moved, X-rayed, cut, immobilized, biopsied, isolated, ultra-sounded, MRIed, and probed. What impact must all these actions exert on children’s bodies and minds, that is, on their corporeal subjectivity?

Additionally, and very importantly, such (im)permeabilizing processes need to be considered hand in hand with what happens at the family level. My approach here is to try to approximate how children view their concrete circumstances at the Hospital Infantil, as well as their negotiations to endure those same circumstances. Indeed, even small children can act in very specific ways to try to modify their own circumstances. During my fieldwork at the CDU I met Rosana, a two-year old girl living with leukemia who, every time a medical resident or nurse would enter her room, she would sit and grab all the things that were on her bed, her father’s cell phone, some blankets and dolls, and put them around her in a circle. I interpreted this as a

102 I should highlight that the permeability of the body not only happens at medically orchestrated locations but also at patients’ homes. Families are trained and pedagogically educated to look for signals of potential infections all over their children’s bodies. Of course, the intensity of this permeability is very different when compared with clinical sites and the biomedical technologies of permeability.
protection circle. As soon as we enter Rosana would start waving her hands as in “bye bye” to tell us (without words) “leave me alone, don’t bother me.” I saw her act out this ritual every time that I entered the room with one of the resident doctors, and it appears she did it every day, all the time, the residents told me. Although she was not impermeable at all–she was receiving chemotherapy drugs and had been hospitalized several times for different conditions–she was trying to influence others to shield herself from the constant invasion by residents, staff doctors, nurses, and other professionals. It is possible that she was trying to ‘thicken’ her limits and create some distance from the health professionals who were trying to invade her world.

Mila, the head of residents at the CDU once told me:

…for the children, it is very important that you are accompanying them, and that you are changing something of their lives and being useful. It is not only important that you extracted blood, that you did the blood count and you found he has anemia, that’s good, but the fact that the child said ‘thanks’ and he grabbed your hand and he felt better, that’s what I feel is more important…

This also represents what I refer to as ‘permeable bodies’, which go beyond the mere physical. It is precisely the connection between this particular child and this particular medical resident, and conversely how corporeal exteriority meets interior psyche for both individuals, what links different experiences of (im)permeability and what constitutes permeable-interconnected-bodies. This is what counts most towards dignifying these lives. In a way, it is a sort of reversal of the normalizing biomedical process, where instead of objectifying, de-contextualizing, and fragmenting the body, the experiences are of subjectification, re-contextualization and defragmentation of particularly permeable bodies.

Children’s bodies and dignity, although always forced and under external pressures through the management of their (im)permeability by the health professionals and parents, still show unexpected margins of maneuver, in spite of the array of experiences to which children are
subject. Children would often be very attentive to everything that surrounds them; they would try to hear everything related to them or their parents and try to make sense of their world. One mother told me that her 7-year-old daughter “pays attention to everything that is said to her or to me. The other day some doctors mentioned the word ‘tumors’ and then she was asking me a lot of questions.” Of course, the word “tumor” is not any word, and children would often be more attentive to every piece of information that may affect them or their parents and families (Bluebond-Langner 1978, Bluebond-Langner et al. 1990).

However, there are many other instances in which children’s bodies are passively treated. For example, when I was conducting fieldwork at the CDU, medical residents often heard that a very busy fellow at the HU came, colgó la quimo (“hung the chemo”) without any preparation, and return to their unit. A pre-medication (antiemetic, anti-histamine, anti-acid, anti-inflammatory and sedative) that prepares the body to receive very aggressive chemotherapy drugs (and reduce its side effects) should always be administered to help the body navigate the intense chemical implosion (often the day before) and, in such cases, this did not occur. At the same time, certainly, children and family members need to know, and be prepared to, the IV bag hanging on the IV pole contains chemotherapy (although after a couple of times, they will know it). In instances such as this, neither the child nor the medical residents assisting the child at the CDU would be prepared for this, and this often caused tensions among the different health professionals and the different units. Cases like this not only highlight instances of disregard, but also show that children’s bodies are indeed more permeable than other bodies (at least in their lack of capacity to take decisions for their own lives).
Professionals’ (im)permeability

In contrast, professionals’ (im)permeability is different than that of children’s. Professionals generally fear permeability. For instance, when children’s bodies are enhanced in their capacities to be breached, professionals’ bodies create a separation from the objectified and aching bodies. Professionals fear pricking themselves with a needle, or ‘catching’ a virus or anything else that children and family members might be experiencing. While this fear is based on the possibility of contagion, it is striking how much being pricked becomes a serious issue to doctors. As I already showed in Chapter 5, in Argentina, medical residents (under the supervision of staff doctors) are the ones that are constantly assisting children, extracting blood, diagnosing them, prescribing medicine, and doing tests. Nurses, on the other hand, have a marginal role and are usually understaffed in every unit, they prepare and provide the medication for each child but often residents are the ones closer to children in the everyday experience of being hospitalized.103

I observed three cases in which medical residents pricked themselves when trying to work with a child, and they experienced these as very tragic events. Once I was at the medical residents’ office at the CDU and the head of the fellows at the HU entered the residents’ room crying. She looked absolutely devastated, and we wondered what had happened, if a child had just died. But it was not that: she had pricked herself with a needle while trying to take blood from a child. These children with hematological conditions very often need (lots of) blood transfusions,104 which bring risks of hepatitis, HIV, or other conditions (a rare but potential risk). In the three cases I observed, the doctors had to take anti-retroviral drugs for weeks and check

103 The professional-patient ratio is also different. When I was conducting fieldwork at the CDU second-year residents were in charge of two or three patients at a time and one or two nurses per shift were in charge of the whole unit with sixteen or eighteen patients.
104 Just to give an example, while I was conducting fieldwork, a 13-year old girl with a rare and undiagnosed bone marrow aplasia had 210 units of blood transfusions in a couple of months.
often whether they had contracted any infection or complication. They had not, but these experiences of ‘becoming a patient’ were very intense for the professionals: their bodies became a medical object, a corporeality that was just prior seen as Other – that of the children’s, not their own. This potential permeability (in one second you are a medical subject, in the next a medical object) is very much avoided (something that children deal on a daily basis). It is clear then that professionals are influenced by their relationships amongst themselves and with children and families to construct particular forms of (im)permeability.

Needless to say, it is neither possible nor feasible to be in a state of full impermeability or full permeability. In fact, all of the actors fell somewhere in between these two extremes. But there are still remarkable differences between how children and health professionals live their (im)permeability. As already noted, according to some professionals, children are “more permeable” than adults. Mariana, fellow from the HU told me:

Look, I think children are extremely permeable, way more permeable than adults, no doubt about it. If we did the things we do to children to adults, it would be like taking an axe to the back of their head. Children, pediatric patients, are super permeable to this, and you know that after a certain time they can adapt, they can adapt emotionally much better. They quickly incorporate this. That is, you tell a child that he has leukemia and he doesn’t take it like an adult would. The same with an adolescent, that is, a small child you tell him that he has leukemia and he incorporates that and he can even use it as part of a game.

Mariana’s notion of children’s permeability is not the same as the one I am working with here. This idea that children are ‘extremely permeable’ compared to adult patients can perhaps be understood in the context of a self-organized professional hematological narrative: it is a notion influenced partly by what she has experienced as a hematologist and partly by the professional self-convincing fact that children are more permeable. I have no room to expand on this distinction here but it may relate to the notion, common among the hematologists with whom I worked with, that children with solid tumours often cannot accept their condition and relate to
oncologists with a lot of friction, whereas children with ‘liquid’ tumours (hematological conditions)—which are ‘invisible’—often can accept the diagnosis and relate better to hematologists. Still, it is remarkable how hematologists and other professionals conceive children’s bodies as being “extremely permeable.” In-between them though are family members dealing with these intense treatments.

**Family members’ (im)permeability**

As we saw throughout the dissertation parents and family members are situated in-between health professionals and children, and thus they function as intermediaries in manifold ways in these interventions on children’s bodies. In the long vignette about a bone marrow examination I described in Chapter 5, Ulysses’ mother played a dual role: on the one hand, she was supporting Ulysses, she was touching him, holding his hand, making eye contact, reassuring him that the procedure was going to be fast. On the other hand, she was telling the nurse to hurry up, she was witnessing her son suffering, and she was helping the resident and nurse to permeate Ulysses’ body. This mother, and all the parents and family members I observed, are immersed in medical processes that objectify children’s bodies. Legally, medically, and socio-culturally, the boundaries of children’s bodies cannot be controlled by children and therefore are under their parents’ control. Parents and other family members become the guardians of children’s (im)permeability; they are constantly facilitating and witnessing the interventions enacted upon their children’s bodies. The task is not pleasant. Indeed, parents live with the constant pressure to succeed in their role as double agents (caregivers and care-seekers; see Bluebond-Langner et al. 2010): to protect their children, they (indirectly) have to inflict a lot of pain.
Once, I was in a corridor of the Hospital Infantil taking notes, and overheard a mother (who I had not seen at the CDU) talking on the public phone. She was saying something along these lines:

…they [resident doctors] are continually checking her butt, her mouth, between her toes, and not once per day, but many, many times, endlessly. Every time they enter the room, I keep staring through the window because I want to kill myself. It is not nice this, you know, to constantly look at them checking on my daughter, but what else can I do, one has to undergo this…

This is a key aspect of the process I have analyzed in this study: parents and other family members endlessly witness children’s (im)permeability and forced extroversion, and are in-between this objectification of children’s bodies as patients (and subjectification as children in pain). They also “have to undergo” these processes as subjects that have to understand and comply to medical treatment, decide for the best interests of their children, and have to respect what their children think is good for them. This is also an important part of parents’ relational dignity of life: how to keep certain control over your own child’s body, ease pain, and minimize suffering.

**How can we talk about dignity?**

There is often a lot of talk among professionals (both hematologists and communicable diseases specialists) and parents about the capacity of the immune system to defend the child’s body during treatment (especially when compromised or depressed). Parents usually relate it with children’s estado de ánimo (“mood”) as if they do not want to “depress” children with bad news because it would directly affect children’s mood (and, therefore, their immune systems).¹⁰⁵

Parents see a close connection between the child’s emotional well-being and dignity, though it is

¹⁰⁵ For a classic look at how discourses about the body (and its defensive system) are embedded in cultural common sense, see Martin (1994).
often overlooked. According to Street and Kissane (2001), dignity of life, although central to the discussion about end-of-life care strategies, in most cases, has been taken for granted in scientific research and clinical work. For these authors, dignity includes autonomy and self-determination, and is an intrinsic part of personhood. For instance, a wide range of professionals, policy-makers, legislators, patients’ movements, and international and national health organizations, among others, regularly use the expression “to die with dignity” without specifying what this entails, or what dying people conceive of as the end of life with dignity. The motivations behind the use of this term range from seeking better care services for patients and expanding patients’ autonomy, to supporting medically assisted suicide to dignify the dying process. Anthropologists such as Lawton (2000) and Kaufman (2000) have shown the hidden agenda and contradictions in relation to the advocacy of “death with dignity.” In this wide range of voices and possibilities, the “silenced discourse of dignity as relational and embodied” (Street and Kissane 2001:94) has been given less attention, and the personal, historical and cultural understandings of dignity of life have been widely suppressed. Yet, these factors elucidate the contextual and changing experiential comprehension of what is good for one’s self and for others (Taylor 1989). The silence to which Street and Kissane refer reflects the lack of detailed attention to the concrete processes, simultaneously individual and collective, that give (or strip) dignity to life. As I illustrated in Chapter 5, these particular relational bodies are turned into medical objects.

Children’s, families’ and professionals’ daily lives are saturated with instances of high and low levels of (im)permeable intensity. Indeed, these instances fill their inter-personal relationships and their personal space. If, according to several kinds of doctors, “everything goes well,” every child, depending on the type of leukemia and a series of medical and social parameters, will undergo at least a dozen lumbar punctures and half a dozen bone marrow
examinations during the one or two year course of treatment. On top of these extremely painful procedures, every month there will be countless blood extractions, and other tests, and – depending on the child’s condition and her immune system – several hospitalizations caused by infections, mucositis, pain, and so on. Consequently, these interventions will require blood transfusions (usually red blood cells and/or platelets), more tests, medical imaging, biopsies, etc. In addition, certainly, children undergo a stressful and painful treatment with chemotherapy. Which frequently it involves some sort of surgery (biopsies, insertion of implantable portacath, etc.), and seldom radiotherapy (which is only prescribed for some types of leukemia and under certain circumstances) with the inherent chances of countless side effects and the likelihood of more hospitalizations. In some cases, the last option is to undergo bone marrow transplantation. Thus, the child’s body, its vulnerability and permeability, and life’s dignity are painfully crisscrossed. We have a clear paradox here in relation to child’s dignity of life: to hurt today to prevent future hurt.

**Conclusion: Dignity of life**

In this chapter, I have discussed ‘permeable bodies’ and the need to analyze the body in terms of its capabilities, which must be understood in the context of both the intimate relation between subjectivity and corporeality, and the social relationships that are built between the different actors who participate in the everyday lives of children with hematological conditions. In considering permeability of their bodies, I have also attempted to confront, from different angles, the question of dignity of life during treatment: How can we talk about dignity of life in these particular contexts? As I have argued, children’s bodies, children’s (im)permeability, and children’s dignity cannot be understood separately. They have to be considered together, and in
relation to the triad of children, health professionals, and families. This triple relationship is very much present in pediatrics, since unlike other medical specialists, pediatricians have to deal with the family as a unit. Yet, when considering children’s dignity, it is not so common both in North America and in Argentina to connect it to children’s bodies and children’s (im)permeability. In many instances professionals act as if children lack the capacities to evaluate their own (im)permeability. Certainly, we need regulations and clear definitions of what a good medical practice should be, and what rights children have as medical subjects (what I called as “prescriptive forms”). However, my point is that we also need to pay attention to non-prescriptive forms of embodying dignity, and ultimately, living life under the clinical gazes during cancer treatment. In different ways children, family members, and professionals were all thinking about these issues while treating children.

A key aspect of the phenomenon that I have examined is the role of children’s bodies in mediating the social relationships among children, their physician, and family members. In these circumstances, health professionals, while intensely permeating children’s bodies, are also trying to understand, affect, and, ultimately, communicate an essential message to children and their families: “there is nothing wrong with you” (what is wrong is your blood, your bone marrow). However, all the people involved in this process – sick children, healthy siblings, parents, and professionals – are entangled in a web that medicalizes and objectifies experiences, feelings, and thoughts. Children like Alex, who kept his portacath as a reminder of what he had gone through and as something to display and to tell to his own children, show how children not only are dramatically changed by the flow of procedures but also can intensely influence others. Alex’s portacath epitomizes the core tension of this dissertation between the medicalization and objectification of children’s bodies through an endless flow of procedures and the corporeal and
subjective experience of children like Alex who felt, thought, and experienced his cancer treatment in a very particular way.

The “profound invalidation,” as Wendell (1996:125) has called it, is a component of the wide “epistemic invalidation” embodied by people with all kinds of disabilities (Wendell 1996:127). In the case of children with life-limiting conditions like leukemia, it is clear that adults (professional and parents) are thinking and deciding in the children’s best interests (or, at least with their own best intentions) because of their uncertainty of the ability of children to think and decide for themselves. But can children (depending their age and condition) have a say in what’s happening to their bodies? Can their needs, at least, be heard by the family and health professionals? These are central questions when thinking about children’s dignity of life and their therapeutic trajectories. Bluebond-Langner et al. (2010) have argued that it is important to listen to children in what they have to say about their own bodies and the proposed treatments, even if it implies talking about failure of treatment and end of life decisions. Children should be implicated on their medical treatments and medical research without assuming “how children wish to be involved or what they may know or have the capacity to understand” (Bluebond-Langner et al. 2010:337).

Indeed, the social shadows that cover the lives of people with disabilities (or, of women, children, old people) and that are intersected with sociological dimensions such as class, ethnicity, or sexual orientation are ultimately political; and the response, critics, struggles, oppositions, and steps to resituate them are also political. Therefore, the critical path is to collectivize and socialize seemingly individual problems. When five-year old Leonardo says “Prick me here; please don’t prick me in this other arm. I know my body,” or when the hematologist Mariana says “…children are extremely permeable, way more permeable than
adults, no doubt about it,” or when a mother says “It is not nice (…) to constantly look at them checking on my daughter’s butt” they were all talking in different ways about children’s dignity of life. These were not individual issues but rather children, families, and professionals were all implicated on these “permeable bodies.”

As Young (1997) argues, the body of the Other, in this case of a child, always reveals a self. In the context of this chapter, I focused on the permeable body and its role in creating a situated sense of dignity, not one that is taken for granted or imposed from the top down but one that materializes in the interactions and emerging social relationships among the child, parents and family, the physicians, and other clinical staff, all mediated by the child’s body. It is perhaps with the heightened awareness of (im)permeability that one can start to comprehend these children’s dignity of life. To do so, it is necessary to examine the social and medical processes that start from, and interact with, the body on all levels of its complexity, and to consider the social relationships that sustain those bodies.

There are extensive discussions on the quality of life within the social sciences (Rapley 2003). In this chapter, I have reflected on the relation between children’s medicalized bodies and its impact on broader social landscapes. I have examined the experiences of children with hematological conditions in this clinical context, to focus in particular on the relationship among children’s bodies, experiences and capacities, and their overall well-being, without tying my analysis to specific ‘objective’ and/or ‘subjective’ indicators. I have also examined the social relationships that are mediated by their bodies. I have found that life’s dignity – one step beyond quality of life – is connected with the kinds of relations each body is able to create and the experiences that emerge from the body itself. We cannot assume a priori what kinds of experiences any person, in a given context, will consider as enhancing or eroding their dignity of
life. We can try to approximate those experiences, however, provided we acknowledge that any condensation of people’s experiences into a codified concept (in this case, of quality of life) will always fall short, and that this approximation codified into a ‘quality of life guide’ is an endless process of questioning and fine-tuning what people actually think and feel. What is good for one person or group is more than any checklist. It is crucial to attempt to understand this from their perspectives. Quality and dignity of life cannot be deduced.
Chapter 11: Conclusions

No longer deemed an inescapably incurable and terminal condition, childhood cancer nevertheless still represents myriad challenges for children, families, and professionals. Widening our understanding of the life-long impact that childhood cancer has on the lives of children, their families, and professionals treating children is critical to understand and being able to offer wide-ranging and sensitive care to them. For all the ubiquitous and ambiguous presence of cancer in our modern lives and in our bodies (Jain 2013), we have examined how pediatric cancer treatments are produced, how they work in particular clinical settings, and how they affect not only on children, but also on those accompanying and treating children. Therefore, my research focused on the impacts of cancer treatments on children’s corporeal experience and their bodies as mediating clinical social relationships. This dissertation reveals how understanding the production of these biomedical interventions is critical to grasp the corporeal and subjective experiences of children going through years of omnipresent treatment and how it also affects families, and key health professionals.

I looked at the contradictory and frictional ways several key units within the Hospital Infantil assist children living with hematological cancers. I focused on three crucial places with overlapping spheres of practice to see their unique ways of affecting children. I showed how children living with hematological cancers undergo chemotherapy and are assisted by the HU. But, when hospitalized they come under the care of the CDU, prompting multiple frictions between these two units. In addition, when children experience pain, which happens frequently, palliativists are responsible for controlling their pain and other symptoms. Thus children triangulate among these three specialties.
From my research with parents participating in the CCF, I learned how parents and other caregivers comprehended, were affected by, and reacted to while they submitted themselves to the cancer treatments. These multi-family meetings were critical for grasping the caregivers’ point of view.

I took the theoretical and methodological decision to focus on children’s bodies to place children in the middle of these clinical encounters. This places the study in the tradition initiated by Marcel Mauss (1973), of looking at the body’s reorganization by external forces. The result was to discover that children’s “permeable bodies” were not only subject to medical treatments, they were also instrumental in establishing and maintaining the relationships of treatment. By placing children’s bodies at the center of my analysis, I was able to observe and analyze how they became hubs in-between myriad medical forces injected into and extracted from children’s bodies while attempting to wipe out the “bad cells” through a flow of procedures. I also uncovered how bodies became extroverted (turn inside out) by the medical procedures in the pursuit of a life without illness.

To overcome illness, children’s bodies were objectified, although as I have argued throughout this study, they escaped total medical objectification. There was always a corporeal subject with an aching body, comforted by the vicariously experiencing body of parents, and observed and manipulated by the empathetic and technologically proficient bodies of doctors. As I discussed in Chapters 5, 6, and 7, one of the consequences of this is the inherent invasiveness of hematological and communicable diseases treatments, which are critically needed to cure these children. Indeed, I have also showed in Chapter 8 how the invasiveness of treatment is related to children’s inter-corporeal pain, which for many children, caregivers, and included professionals is perhaps the most difficult aspect of the hematological treatment even
more than the cancer itself. Indeed, I have shown how pain can be conceived as an affect that
shatters meaning and as a social relationship, something that happens between people. By doing
so, I have considered how pain is not only a blurry experience between illness and treatment, but
also a force that fuses corporeality with subjectivity. In fact, as I have illustrated in Chapter 7,
children’s corporeality and subjectivity is affected throughout the lengthy cancer treatment.

In Chapters 7, 8, and 9 I showed how bodies are open and dynamic systems even under
excruciating pain or when the whole family is reconfigured. When children experience cancer
treatment their corporealities and subjectivities become restructured during the lengthy,
emotionally strenuous, and painful therapeutic journeys. Particular invasive practices produce
what Taylor (2005) described as “surfacing the body interior,” producing the interiority /
exteriority of the permeable, Mobius like body during treatment.

I looked carefully at three types of bodies involved in these children’s care: the child, the
caregiver, and the professional. They are all simultaneously affected and were affected by
children’s permeable bodies. In addition, as I have showed in Chapter 10, permeability of bodies,
and dignity of life are all part of the same social, medical, and inter-personal processes. As Grosz
argues (1994) people’s bodies’ surfaces are incessantly being colonized by medicine, as is the
case of children’s bodies in this study. Following Grosz (1994) I have shown how we can focus
on children’s corporeality to illuminate their subjectivity and how they grow in spite and because
of their intense medicalization. I have also demonstrated how children learn to live in a
medicalized body and how they need to bancarsela (“endure”) their painful cancer treatment as
well.

There is a fundamental inter-relatedness and entanglement between the social, familiar,
inter-subjective, and medical worlds of children with hematological and other life-limiting
conditions and those that surround them. It is precisely the in-betweenness that traverses these bodies the focus of this dissertation. Brennan (2004) calls this process as “transmission of affect.” My emphasis on biomedical interventions, the flow of procedures, and the production of permeable bodies shows the process of mutual affectations among children, parents, and clinicians.

Children, professionals, and family members all moved through a series of affective, spatial-temporal, and corporeal, medical, and social thresholds. Initially, children and caregivers found themselves in an almost surreal world surrounded by machines’ beeps, tubes, unpleasant drugs, syringes, IV bags filled with fluids, doctors, medical residents, nurses, and other kinds of professionals. Radical transformations and major displacements occurred on a daily basis, not only to children’s bodies-emotions-minds but also to their families, and their social worlds. Children and parents also discovered other families in similar situations. They tried hard to not compare their circumstances with others, though they also found it hard to resist the temptation. Families were isolated in hospital rooms for weeks and months trying to fight children’s infections and enduring painful procedures and treatments, while surrounded by odd noises, smells, and medical apparatuses that was transformed over time from a bizarre choreography of the flow of procedures into familiar routines. They were frequently far from their siblings, other families, and friends. On these journeys, as they crisscrossed different therapeutic thresholds that overlap with several clinical units staffed by different health specialists, they encountered physical, emotional, and psychological challenges as they shifted from the liminality of one threshold to the next.

The physicians who treated these children with hematological conditions were drawn from three specialties, which represented different perspectives and patterns of practice:
hematology, communicable disease, and palliative care. Physicians from the Hematology Unit and the Communicable Diseases Unit were largely responsible for children’s care in the hospital. These two sets of professionals interacted with them in different ways and try to anchor the long-term worries and expectations into a narrative of the here-now focused on “little steps” through “restitution narratives” (Frank 1995). Argentinian physicians’ practices were similar to those of American oncologists described by Del Vecchio Good et al. (1990, 1994) as trying to create “narratives of immediacy,” short-term temporal narratives that focus on the next necessary therapeutic steps for both children and families avoiding as much as possible talk about prognosis and long-term possibilities. Similarly, Argentinian parents, as I showed in Chapter 9, like American parents, tried to support their children and “keep the spirit alive” (Woodgate & Degner 2003) or, as they said, they “keep on fighting.”

Yet, it was clear to me from the beginning of my research that overcoming hematological diseases, is a dynamic struggle that children, with the help of others, actively face every day. Moreover, I was also able to observe how every day children would, for the lack of a better word, “grew” while being treated. Parents like Valeria told me how her seven-year old son crece rápido (“grow fast”), or Juliana told me how her three-year old boy got más vivo (“smarter”) and despierto (“more aware”) because of their cancer treatments. While there was a difference between children who are healthy and have a “normal development,” and the ones who during the course of treatment undergo corporeal and subjective changes, those in the hospital were constantly adapting, resisting, and developing. Children also paid attention to how others look at (and reacted towards) them. Thus, under these different kinds of developments, over long-term clinical processes, I have shown how children and those involved in treating and caring for
children not only conceive and represent children and their always-changing bodies, but also act in relation to this knowledge.

Several conclusions are drawn from this study. First, children living with hematological cancers and their families are at the center of, and need to navigate, a complex entanglement of medical and social institutions, various professionals and their systems of knowledge, all designed to provide services and potentially a cure for their children. Inevitably parents encounter frictions both between and within these systems.

The initial systemic friction that parents face is the organization of health services distributed across the provinces of Argentina and the internal limitations in the funding systems. Then, families encountered the temporary isolation of children and caregivers from the rest of the family. When looking at this particular clinical site it is important to consider the dialectic entanglements of key spaces within and outside the Hospital Infantil, since particular spaces are often created in their inter-relationships (Gordillo 2004). Children and caregivers repeatedly told me about the difficulties of living far from their families. Even children and families from the City of Buenos Aires felt somewhat alienated from their families and friends when secluded at the Hospital Infantil for long periods of the treatment. In addition, families experienced great peer-support and encouragement at the multi-family meetings at the CCF. This organization proved very useful to help caregivers and family members understand the double role that they are forced to play when they provide comfort for their children, while also support clinicians’ expectations for adherence and compliance with invasive and painful procedures. As I discussed in Chapter 9, families are faced by ethical and financial dilemmas when mobilizing resources and reconsidering their different forms of “therapeutic relatedness.”
One recommendation from this study is to expand and support the work of NGOs like CCF, which indeed is growing, and reaching families at far away provinces with the support of other NGOs. From the time when I began this study and conducted my research until 2015, CCF has expanded exponentially and has enlarged its facility to meet the growing demand from families.

The second major finding, and perhaps the most significant friction encountered after families entered the hospital for treatment was that between the Hematology Unit and its hematologists, and the Communicable Diseases Unit and the communicable disease specialists regarding the aggressiveness of their hematological treatments. Each had a different interpretation of what it means to “run in front or behind the disease.” Hematologists were worried about their cancer treatment and potential delay in chemotherapy phases whereas communicable diseases specialists were worried about children quemándose (“burning”) because of their infections and depressed and compromised immune-systems. As an example of tensions between these two units, I remember one day when hematologists discussed a patient with leukemia treated at the Communicable Diseases Unit and the discrepancies they had in terms of their use of antibiotics, Fiona from the Hematology Unit said,

> In cases like this one we have to do anti-pediatrics. We cannot sit on our chairs and wait to see if a particular symptom gets well by itself. In these cases, we need to actively and forcefully intervene and look for symptoms (even pre-symptoms) because we know that if we wait we would run behind the disease.

> These kinds of frictions—doing “pediatrics” Vs. “anti-pediatrics”—are part of the tensions within the different specialties at the Hospital Infantil and become critical in the everyday lived experiences of children throughout their lengthy treatments. One recommendation that this study can offer is the need for a better communication among the different medical specialties that assist children living with cancer. In both cases hematologists and communicable diseases
specialists are committed to their patients and attempting to solve their medical problems. Yet, they use different models of knowledge, temporalities, rhythms, and ways of interacting with patients and their families during the therapeutic process. In this case it seems a cross-breeding between the two specialties could help each team, their cancer patients, and families.

Also, within each unit there were also frictions among physicians with different levels of training: between the often overworked, sleep-deprived, and stressed out medical residents and clinical staff at the Communicable Diseases Unit and between fellows and staff hematologists at the Hematology Unit. This reflects not only the status of the hospital within the healthcare system as a tertiary care, teaching hospital but also the actual labor conditions for medical residents and staff physicians. Children and families were consequently exposed to physicians with varying degrees of technical expertise and clinical acumen.

The second conclusion of this study is theoretical and is related with Grosz’s (1994) notion that bodies are never static but rather they are fluid and work interactively in their encounters with other bodies. Relationships among children, parents, and physicians are constantly changing as they are mediated by interaction with children’s bodies. Their bodies are constantly traversed by, and constituted in, hematological treatments. Also, the constant testing and imaging create vectors of biomedical and psychological pain. Children’s bodies can be understood using the image of a Möbius strip with its psychical interior and corporeal exterior endlessly folding in/out. I claim that these biomedically orchestrated interventions into children’s bodies constitute children’s medicalized permeable bodies. This is most clearly expressed by the symbolism of Alex’s Port-a-Cath. The port was the point of articulation between the inside and outside of his body during his treatments. The fluids moving through it changed over the course of his care, until it was no longer a necessary device in his treatment. Then, once doctors
removed it, Alex kept his port, because to him it remained part of his corporeality and subjectivity.

One problem with the Möbius-strip model of corporeal experience proposed by Grosz (1994), that she recognizes is that it cannot grasp the temporal process of becoming and transformation. Becoming a cancer patient, a child transformed by cancer treatment, is also a process of (un)doing and (un)learning. As I have shown in Chapter 7, children experience cancer and its treatment as the moment across thresholds during which they experienced both constrictions and expansions of life.

I have attempted to grasp the material, constitutive aspects of becoming an intensely medicalized child’s body colonized by biomedical practices aiming for a “life without illness” and discourses about the outcomes of treatment. In North America, the professional discourse of hope usually emerges contemplating treatment goals. Good et al. (1990) have noted that oncologists in U.S. have developed a discourse in which there is a great emphasis on the “will” (affecting mind/body relationships), personhood (individual, autonomous, with the power of thought), and in which “hope” becomes the catalyst for change. In the North American context there is a technological, ethical, and legal understanding of personhood that places prominence on individualism and control.

Similarly, in Argentina hematologists also stress the importance of developing trust in the treatment and in the knowledge built up by countless professionals dealing with pediatric cancers. Very often hematologists would tell children and caregivers “this is the most up-to date available treatment you could get in this country, which is similar to what other oncologists and hematologists are doing worldwide.” Oncologists and hematologists feel an obligation to be optimistic about children’s futures.
However, as I have shown in Chapters 8 and 9, children and those around them live in the painful here-now. Rather than a discourse of hope, Argentinian parents express a discourse of struggle. This is, in the first instance, a struggle to obtain care within the Argentinian health services. Second, instead of describing personhood with tropes of individualism and control, especially children’s, I have shown that children and parents also confront frictions around issues of dependency and control over children’s bodies, expressed in the different perspectives and practices of hematologists, communicable disease specialists, and palliativists. Each discipline has its own conception of the dynamics of children’s bodies, which are experienced by children and parents as struggles between autonomy and dependency, differing approaches to invasive treatment and pain management, and among differing expectations.

I began this study by describing four main arguments for this dissertation. The first argument pointed to the theoretical and methodological need to focus simultaneously on the diverse worldviews of children, professionals, and family members in order to comprehend not only the range of key actors that are part of these medical journeys but also how they are differentially affecting one another. The second argument made the case that children’s therapeutic processes encompassed broad social landscapes of homes, neighbourhoods, schools, and workplaces of parents and siblings that both sustain and surround children’s experiences in this pediatric hospital. I have argued that it was crucial to look at the series of medically orchestrated spatial, affective, and temporal “thresholds” managed by key sets of professional teams but differently experienced by children, professionals, and family members. The third argument of this study focused on the inter-relationships among children, parents, and professionals, and emerge through interactions centered on children’s bodies. Their bodies become both the source from which, and the target to, bio-technologies, knowledge and expertise
that are applied during the course of treatments. Not only do children’s bodies become mediators among these actors, they also became the sites of frictions since differences remain despite mediation. Their differences most commonly emerge during invasive procedures during which parents must decide the ultimate value of the treatment against their child’s immediate suffering.

The fourth argument centered specifically on children’s pain, and how it indeed affects everyone around children. Children are socialized throughout the lengthy treatment by living, dealing, and struggling with pain. I have showed how children themselves legitimate and resignify their experiences of pain, for instance, by keeping their portacath as souvenirs. Children’s pain through cancer treatment is a potentially temporary, urgently needed, but nevertheless liminal experience that comes as a by-product of cancer treatment. Yet, as I have shown, it is also a lived experience caused by treatment itself and its countless invasive procedures. This dissertation has shown how constitutive and destabilizing is pain for children living with cancer and those around them. Indeed, this study has also indicated how closely linked are children’s experience of chronic pain and liminality during the lengthy cancer treatment (Honkasalo 2001).

These four arguments informed this ethnography and helped to foreground an anthropological reflection particularly on the promises and risks of pediatric cancer treatment and more generally on the role of the body, especially children’s bodies, in cancer treatment. By focusing on the production of children’s permeable bodies I wanted to locate children at the center of these intense relationships to understand who children living with cancer “are” and how they should be cared for.

I began this Dissertation with a vignette with Valeria and her mother while waiting for the following chemotherapy cycle and the mother attempting to share some of Valeria’s pain and
suffering. I hope I was able to capture the lived experiences and struggles of countless children like Valeria, their caregivers, families, and professionals. Valeria is an example of the power of medicine to help children overcome cancer; she had been free of cancer now for more than two decades.

This dissertation sheds lights to a particular clinical site in the City of Buenos Aires. There are similarities and differences between Argentina and North America in the ways children living with hematological cancers are assisted and treated. The Argentine case is fascinating due to its unique combination of historical, political, and social factors. In Argentina, the great majority of children with hematological cancers are treated in the public sector, in the few specialized sites like the one in which I conducted research. The public hospitals are central players within the Argentina health care system. Most of the families who seek care at the Hospital Infantil come from other places outside the City of Buenos Aires and are lower-middle or working class families. These families receive the best possible treatment at these public hospitals and many of them receive it free. Thus, access to care is somewhat similar to access in Canada with its universal health care system, but is different from the largely private health care system in the U.S. These systems of access have repercussions for our understanding of how places like a hospital function and how actors within these places interact. The encounters between children, parents, and clinicians I described here can be understood against the background of both the Argentine health care system and its long history of public hospitals and the role of these public hospitals as social and medical central hubs in the expansion of medical knowledge and practice. Additionally, as in Canada access to cancer care is considered a political right, a social right of citizenship. This is very similar when compared with Canada. Yet, one difference, as I showed in Chapter 9, is the overall social context of social struggle in which
families are embedded. Families have to “keep on fighting” in order to pursue their children’s treatments and this is often one among many challenges they face.

I must recognize and address some limitations in this dissertation. First, this study was limited to one central institution within the broader social and medical landscape of pediatric cancer in Argentina, and may not reflect practices at other centres. Second, middle and upper-class children and families who were assisted in private institutions were not part of this study. Although the great majority of children living with cancer are treated in public institutions, it is worth exploring the social class differences in relation the provision and experience of cancer care in public Vs. private hospitals in the Argentine context of care.

Second, the focus on children’s bodies limited this study in several ways. As explained in Chapter 3, for methodological and ethical reasons I decided not to interview children or to use other useful means such as drawings to understand their point of view, and thus obtain their own direct accounts of their experiences although I did talk a lot with children. In addition, the limitation of focusing on children’s bodies and on looking at children, parents, and several clinicians at the same time is that I had to juggle data gathering from the three perspectives.

Third, although as the study was conducted in a medical institution is likely the medical perspective would often predominate over children’s and parents.’ Certainly, if this study would have focused on children’s houses and the cheap hotels relocated families live during the one to two-year treatment it would have shed light to the family challenges and hardships that I analyzed in Chapter 9 from a different angle. This is also a study worth conducting in the future to understand how this “therapeutic relatedness” is transformed at home or at the cheap hotels when children and the main caregiver(s) pursue cancer treatment.
Fourth, I limited this study to children living with leukemia primarily for methodological reasons to enable me to focus on children who experience intense forms of medicalization and where in hospital for long stretches of their treatments. Yet, other children in this institution also experience different treatments and are also transformed into “permeable bodies.” For instance, children living with solid tumors have experiences that are in many ways similar, but the specific modes of treatment made it difficult to include them in this study. More specifically, children living with blood cancers and enduring cancer treatments provide a great example of the struggles families, physicians, and societies face when attempting to cure children with “invisible illnesses.” The flow of procedures is all the more difficult to understand for children living with leukemia and parents precisely because they are not evident as with solid tumors.

Fifth, this study has focused more on the treatment process than the outcomes. I began this study with the aim of analyzing children’s end of life experiences but then my focus shifted to look at the intricacies of the social and medical relationships among children, parents, and clinicians during the chemotherapy treatment. This means that the rich data I collected in relation to treatment outcomes, children’s end of life or children’s survival, was less developed to leave space for the main focus of this study. Another ethnographic study worth pursuing is to focus on cancer treatment outcomes and to investigate what it means to children, families, and clinicians to survive a pediatric cancer or to die of it.

In the future, I would first like to conduct ethnographic research with few families with children with cancer following families in their everyday lives. That is, placing less emphasis on the Hospital and professional knowledge and practices, and more on families, their houses, their travels to/from the hospital, and their everyday struggles. In addition, I would like to document and analyze in more depth the life-altering consequences of surviving a pediatric cancer in
Argentina. The new field of cancer survivorship is getting momentum and we need to understand the socio-anthropological dimensions of how cancer survivors live and make sense of their past medical experiences. I would like to investigate their experiences as chronic patients, with new imagined futures.

As a final reflection I want to say that I felt honored and fortunate to be able to work with all the children, caregivers, and professionals that were part of this study. By talking to and observing them, they helped me uncover social worlds that were strange to me. I hope I was able to illuminate at least some aspects of these social worlds showing their complexities and richness. I also want to acknowledge my respect for both the children that endured and survived cancer and for those that could not overcome it and died during my research. This respect is extended also to their parents and other family members who did their best to take care of them under difficult circumstances. In addition, I also want to thank the hematologists, communicable diseases specialists, and palliativists who every day did their best to assist these children to overcome cancer and reach the land of survival. In countless ways, they have taught me about permeability, vulnerability, and trust.
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