The Participation Of NGOs In Healthcare: The Case Of Pediatric Cancer Treatment In Argentina

by

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The Participation of NGOs in Healthcare: The Case of Pediatric Cancer Treatment in Argentina

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ABSTRACT

The deterioration of the Argentine public health system has lead to an increase in non-governmental involvement in the provision of health services. The emerging relationship between these sectors is filled with tensions, contradictions, and negotiations, reflecting the historical trajectory of non-governmental organizations (NGOs) and the transformations of the public health system. These problems are specifically evident in programs that focus on pediatric oncology treatment due to the fact that ideas about childhood, chronic disease, and mortality construct an unusual collaborative framework between governmental and non-governmental healthcare professionals. Pediatric cancer contradicts traditional notions of childhood; it points out the ambivalences associated with death; and represents a challenge to biomedical practice.

This thesis provides a historical reconstruction of pediatric medicine in Argentina with an emphasis on the involvement of non-governmental actors in treatment and policymaking. Furthermore, it presents an analysis of the discourses and practices of the staff of an NGO that collaborates with 5 public hospitals in Buenos Aires, providing medical treatment, psychotherapy, and other forms of assistance to pediatric oncology.
patients and their families. The purpose of this investigation was to determine the main difficulties experienced by the NGO’s staff members and the strategies they used to deal with problems. By carrying out thirty open-ended structured interviews and participant observation in two public hospitals in Buenos Aires, the research indicated that the main problems were the lack of training on medical procedures and hospital policies received by the staff and the fact that they were not offered counseling to cope with the emotional consequences of working with pediatric oncology patients and their families. As a consequence, many staff members experienced feelings of frustration and abandoned the organization prematurely, affecting the type of services provided to the children and their families. This information was formulated into a report with recommendations for improving the training offered to the staff and the internal communication of the organization.
Chapter One

Introduction

“The fact is that were are non-governmental; we do not have political interests”

(Carla, volunteer coordinator for the Children’s Cancer Foundation).

The quote cited above was one of the first things that Carla told me when I met her. The apolitical nature of the organization where she worked was something that she felt she needed to reiterate throughout the interview. The categorization of non-governmental organizations as something exclusive to government institutions is not something particular to the Children’s Cancer Foundation (CCF), but is common in Argentine society, even in those cases where government-non-governmental collaboration is evident.

Despite such claims, anthropologists, among other social scientists, have highlighted the political nature of NGOs and other forms of civil society organization pointing to their involvement and promotion of development programs, public policies, and international campaigns. The politicization of non-governmental organizations and

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social movements in general has been analyzed in the context of human rights struggles, and women’s, labor, and indigenous movements (Alvarez et al. 1998). However, few have undergone the task of analyzing the role played by these actors in the provision of healthcare while focusing on the relationship between NGOs and the State\(^2\). In the case of organizations focused on medical care and patient assistance, deciding who can live and who can die certainly brings with it evident ideological connotations. Therefore, one could argue that there is nothing more political than healthcare (Navarro 1976). But what happens when the individuals administering the health services (or contributing largely to the public administration of these services) are labeled as apolitical, but in reality are not? What is the reason behind the erasure of a longstanding history of government-non-government collaboration in Argentina and the depiction of unrealistic relationships between these actors in current anthropological literature?

The argument presented in this thesis is that the main reasons for the reproduction of the “apolitical nature” of NGOs in Argentina is due to the lack of historical and ethnographic studies of NGOs in the country. As a consequence, many authors have neglected the fact that the creation of the public health system that operates in Argentina today is the product of the collaboration between different types of charitable organizations, promotion societies, and communal groups with the State. These organizations made vast contributions to the creation of hospital infrastructure and implementation of campaigns, but also participated in less advertised activities like the training of physicians, the import of ideas on public health created abroad, and the

legitimating of medical specialties through specific journals, academic associations, and professional meetings.

This history of NGO involvement creates a particular terrain for contemporary organizations interested in the provision of healthcare where particular channels have been created to facilitate their participation, but at the same time the deterioration of the public health system and the increased demand of the population bring with them new obstacles and restraints. This contemporary stress on NGO resources and personnel is what is of greatest concern to many organizations, but these challenges hardly appear in academic literature. The reason for this is that most authors have carried out macro-level analyses of organizations, focusing on their expansion and absorption of the responsibilities once in the hands of the State. In doing so, they have not been able to see the particularities and complexities of NGO involvement and have failed to include the perceptions of the people that make the work of these organizations possible.

This thesis was created with the purpose of filling in these gaps in the literature on NGOs by combining historical and ethnographic research with two organizations involved in the provision of health services to children in Argentina: the Sociedad de Beneficencia (1823 to 1947) and the Children’s Cancer Foundation (CCF) (1994 to present). This study provides a historical reconstruction of the Sociedad de Beneficencia through the use of archival records. It also analyses the role played by the women that composed the organization in the professionalization and legitimating of pediatric medicine in the country by looking at their participation in the creation of public health infrastructure, promotion of medical education and practical training, and the dissemination of medical knowledge.
The role played by CCF today in the provision of healthcare to pediatric oncology patients and their family members is presented through the eyes of the organization’s staff. Their views on the organization, the public health system, and their day to day activities serve as demonstration of the particularities of working with children in this context. Furthermore, the information presented here points to the different fractures that commonly exist within NGOs, the problems in communication, and the coexistence of multiple interests and conceptions of the role of the organization.

Both components of the investigation point to the need for studying non-governmental organizations in longitudinal fashion and in smaller contexts. In other words, they demonstrate the need for a micro-analysis of the organization, its staff, and the recipient population in order to highlight the nuances of a particular context while not losing sight of its interconnectedness with larger political and economic processes.

To facilitate the presentation of the information collected through this research, the thesis is organized as follows. Chapter Two presents the theoretical framework that informed the investigation. The thesis drew from literature in the anthropological study of childhood, studies of NGOs, and critical medical anthropology in order to understand the role of healthcare provision by NGOs while taking into consideration the effects of working with children, on the one hand, and treating pediatric oncology patients on the other.

Chapter Three provides information on the methodology and the setting where the research took place. It presents the methods of data collection and analysis, as well as the ethical considerations that were taken into account before, during, and after the research.
process to ensure respect for participants, the minimization of harm, and the assurance of social justice. This chapter also contains information on Argentine history and the changes that NGOs and the public health system have experienced through time.

Chapter Four focuses on the role played by the Sociedad de Beneficencia during the creation and establishment of pediatric medicine in Argentina. It begins with a broad overview of the creation of government interest in children and the institutionalization of childhood and continues with a description of the steps that led to the professionalization of pediatric medicine and the importance of the participation of the Sociedad in this process.

Chapter Five contains the results of the ethnographic research carried out with CCF. A brief overview of the organization, its history, internal organization, and the main characteristics of the staff are included to provide the reader with an adequate background. The chapter, however, focuses mainly on the views of the staff regarding three main issues: their reasons for working at CCF, their training and supervision, and the internal communication of the organization. There are two main reasons for this. First, these topics consistently appeared in the interviews with the staff as points of disagreement and distress. Second, the administration of the organization expressed interest in obtaining an assessment of these issues, especially internal communication, because they were aware of some of the problems that the staff was experiencing.

The research for this thesis was designed with the purpose of having a direct application and providing benefit to those under study. Therefore, the interests of the administration and the staff regarding the content of the investigation were highly valued.
and integrated into the research design and discussion. Chapter Five ends with the recommendations that I made to the administration in the Summer of 2008 regarding the three issues presented and the ways in which they have transformed my comments into action.

Chapter Six contains the conclusions of the thesis where I delineate the contributions that historical and ethnographic research can make to the study of NGOs and to the analysis of their involvement in healthcare. It also highlights the importance of carrying out anthropological studies that can have a direct application and provide tangible benefits to the people who participate in research like the project described here.
Chapter 2

Theoretical Framework

Elisa: “Anthropology is the study of man in society, right?”
Cecilia: “I guess you could say that.”
Elisa: “Then, what are you doing here?”
(Field Notes, June 10th, 2008)

This conversation took place during one of the interviews that I carried out with a volunteer of the Children’s Cancer Foundation. The quotes end where they do, because at the time I had no direct response to Elisa’s question. After further thought, her comments allowed me to think about the way that anthropology is conceptualized and how we, as anthropologists, contribute to these ideas. It turned my attention to the popular topics, frameworks, and field sites we use and reminded me of the gaps in the literature that I attempted to fill with this research.

When I first read Nader’s “Up the Anthropologist- Perspectives Gained from Studying Up” (1972), I was going through a point in my anthropological training when I was feeling saturated, and quite fed up I might add, with the research that was taking place in my department and the one presented in Latin American anthropology meetings. It seemed as though if you weren’t working in an indigenous community or urban lower class population, your work had no relevance to the discipline. Nader’s (1972) article was like a breath of fresh air and it motivated me to search for my topic of interest among a different population: the middle and upper classes.
My interest was geared towards non-governmental organization, not really in terms of what they do, but of who works in them (or for them) and why. My previous consultation of Escobar’s (1995) literature had made me extremely suspicious and critical of the development industry and their role in Latin America. I mistakenly came to see all types of non-governmental organizations as “agents of colonialism” maintaining hidden agendas that would continue to reproduce the subordination of my country. Although this fact cannot be denied, different types of field experiences, a reinterpretation of Escobar (1995), and deeper literature searches, showed me that the world of NGOs is much more complex and, unfortunately, understudied.

As Pfeiffer has indicated, “Since the Seminal 1978 Alma Ata Health for All conference, medical anthropologists have worked extensively within international aid agencies, including NGOs, to help build primary health programs. But most applied research has focused on the culture and behavior of poor target populations, rather than the behavior and beliefs of providers” (2004:59). This thesis was made with the attempt to gain a better understanding of who works in these organizations, what they do, and how they relate to other actors in society in the context of the provision of health services (within the public sector) to children.

Several factors come into play when studying this topic. We have healthcare provision, which is in itself a complex terrain, but we add the fact that government and non-government actors are participating in the provision of services to the same population and in the same physical space (hospitals). Furthermore, the population that we are talking about is children, which as we will see below, demands that we take other elements into consideration; and these children are cancer patients, which adds another
layer of complexity to the analysis. In summary, this thesis looks at how biomedical services, non-governmental involvement, and ideas and practices of childhood, disease, and medical treatment intertwine within the political and economic context of Argentina.

This particular chapter presents the theoretical frameworks that informed the research questions, methodological selection, and interpretation of the data of this thesis. This discussion of previous anthropological work covers three main areas of inquiry: the Anthropology of Childhood, the Anthropology of NGOs, and Medical Anthropology (specifically the Critical Medical Approach). However, the last two themes are inserted in the larger review of the Anthropology of Childhood. The reason for this is that even though several issues are discussed in this thesis and the overall goal is improve the medical services provided to pediatric oncology patients, the concept of childhood is the lens through which medical treatment is viewed and analyzed. This is not just research on the working mechanisms of NGOs, it is research on the working mechanisms of NGOs that work with children and how this makes them different. It is not research on cancer treatment, it is research on cancer treatment in children and how ideas that prevail in our society about childhood interrelate with biomedical knowledge and procedures creating contexts for medical diagnosis and treatment that do not exist in the case of adult patients.

Elisa’s question of what I was doing, first in Argentina, and second, in this particular NGO led me to rethink my role as an applied anthropologist in this particular context. What would be the overall goal of my presence and research here? Would I be satisfied only with documenting the experiences of the volunteers and permanent staff? Would I ignore their questions about how they could improve their programs and provide better services to the children and their families? Could I develop an applied
anthropology thesis without falling into the theoretical and methodological insipidness I witnessed in previous literature? How involved in the working dynamic of the organization did I need to be in order to carry out an adequate analysis and propose solutions? What would happen to the information I delivered to the organization once I left? How would I demonstrate to the academic community that applied anthropologists can also make valuable theoretical contributions?

As the reader will see, these questions are answered in multiple ways throughout the thesis. Most of them respond to larger debates within our discipline that are themselves the product of larger political and economic processes. I ended up producing a report for the administration of CCF that contained a summary of information that they had expressed interest in. We still communicate and I know that they have decided to implement some of the suggestions I included in the report. However, I have made sure these questions were present, in some way or another, in all of the chapters of this thesis, and that some remain unanswered on purpose. The idea behind this is to draw our attention to the role that we occupy (or should occupy) in society and the goals we establish for our anthropological research and practice.

*The Anthropology of Childhood*

“The anthropology of children and childhood is still arguably in its own infancy”

(Stephens 1998:530).

In a review written in 1998, Stephens mentioned the line quoted above in order to argue in favor of the development of a dynamic anthropology of children and childhood that would be capable of illuminating the multiple contexts in which childhoods are situated and negotiated, as well as exploring the everyday worlds of children themselves.
According to her and others, the anthropology of childhood needed to step out of the margins of the discipline and occupy a more central role in both methodological and theoretical reformulations (Bluebond-Langner and Korbin 2007; Hirschfield 2002; James 2007). It needed to shed light on “the norms and values upon which this ideal of a safe, happy and protected childhood are built, are culturally and historically bound to the social preoccupations and priorities of the capitalist countries [and bourgeois classes] of Europe and the United States” (Boyden 1990:186).

Nowadays, few can say that the anthropology of childhood is marginally situated as studies about children and childhoods have incorporated a great deal of theoretical and methodological approaches, form part of anthropological study programs, and occupy significant roles during academic meetings. Medical anthropological research has played an important role in recognizing the importance of studies about children arguing that medical treatment between adults and children has been previously differentiated due to the fact that children have physical, emotional, intellectual, and legal limitations, and depend on others to advance in their development and wellbeing (Bluebond-Langner 1978). Furthermore, discourses on childhood have heavily influenced the development of pediatric medicine (Armus 2007; Colangelo 2008; Nari 1996; Rodriguez 2006); and, in addition to other categories such as gender, class and, ethnicity they determine the access and quality of healthcare available to children.

Unfortunately, even within medical studies on children, some topics attract less attention than others. Such is the case of the analysis of pediatric oncology treatment. Some anthropological work has been done with cancer survivorship in children, their adaptation and reinsertion into the school system and their relationship with their family
members and peers (Bluebond-Langner et al. 1991). However, in-depth analyses of diagnosis, chemotherapy, radiotherapy, and accompanying procedures are rare. The few studies that focus on this topic use one of the following perspectives: they explore the ways in which parents and siblings deal with the disease and treatment (Anderson and Chung 1982; Bluebond-Langner 1989, 1996; Edelstyn 1974), they analyze the perception of the disease by the children themselves (Bluebond-Langner 1978; 2005), or they focus on the difficulties health professionals face when dealing with pediatric oncology patients (Rothenberg 1974; Wainer 2005).

This literature has provided important information about the difficulties that death in children generates, the ways in which social relations are transformed, and how the disease and treatment are experienced. However, they have failed to situate the disease, treatment, and their perceptions in a political and economic context. In doing so, they have neglected other actors involved in the provision of services to patients and their families, such as non-governmental organizations (NGOs). This may be due to the fact that most of these studies take place in economically affluent countries and in private hospitals where healthcare lies solely in the hands of medical staff. Research in public hospitals in Latin America, on the other hand, shows that international agreements, national budget distributions, and the deterioration of the health system have contributed to the introduction of non-governmental actors in the provision of services, both inside and outside of the hospital.

3 The most important work on topics such as these comes from other disciplines, such as psychology and nursing. See for example: Baysinger et al. (1993), Benner and Marlow (1991), Bessel (2001), Blotcky et al. (1985), Blount et al. (1989), Chekryn (1986), Frank et al. (1997), Fritz et al. (1988), Hockenberry-Eaton and Minick (1994), Katz et al. (1988), and Suzuki (2003).
Medical thought and practice is so complex that it needs to be studied from various simultaneous angles. Therefore, in this thesis, medicine is analyzed according to three main axes. It is viewed as a part of larger processes of social formation (Navarro 1976); it is analyzed according to its governing function, especially in terms of the reproduction and regulation of the population (Foucault 1963); and it is presented as a universal human right (Castro and Singer 2004; Farmer 2003; Whiteford and Whiteford 2005).

In 1976, Navarro published *Medicine Under Capitalism* where he established that “the comprehension of our societies and their medical realities requires not an unidisciplinary or an aggregate (i.e. multidisciplinary) approach, but an altogether different approach, in which the subject of analysis-in this case, medicine- is viewed as part of the larger social formation-society-of which it is component, analyzing the relationship between the part and the whole” (1976:viii). In other words, the distribution of medical resources cannot be analyzed separately from the distribution of other types of resources in the same society, the provision of medical services cannot be studied separately from the provision of other types of services, and the exclusion of specific social classes from resources and services responds to larger political and economic arrangements (Navarro 1976, Singer 1995).

When contextualizing medical thought and practice as indicated by the previous authors, the value neutrality once attributed to medicine disappears. According to Foucault (1963), the birth of medicine must be understood within other shifts taking place in society in terms of particular ways to collect and organize knowledge. According to him, modern medicine emerges during the last years of the 18th Century when it “reflects
upon itself, identifies the origin of its positivism, beyond all theory, to the efficacy of what is observed” (Foucault 1963:5). In other words, the birth of modern medicine is marked by particular ways of seeing the patient’s body and establishing a medical gaze over them, as well as, by developing a system of observation of sickness through the collection of information (Foucault 1963, 1994). These two factors lead to the standardization of medical practice and knowledge as the recollection and interpretation of information are developed into diagnostic and therapeutic methods transmitted to students through “legitimate” training programs (Foucault 1963, 1994). This interpretation of medicine allows us to identify the different ideologies behind medical practice and the production of medical knowledge and the effect they have on the everyday life of individuals (Waitzkin 1991:19-20).

The last type of analysis of medicine presented in this thesis is complementary to the two established above. It is situated here as a response to previous analyses of medicine that present it solely in its governing or disciplining function, that is, as an instrument of the State (or dominant ideologies). However, different types of social movements have been generated throughout history demanding medical attention\(^4\). The recognition of access to healthcare as a universal human right has been the basis of political struggle. Therefore, when analyzing medicine in its universal human right quality, we can also conceptualize the provision of healthcare as a place of resistance and political transformation.

\(^4\) One of the most popular of these movements has been the social medicine (medicina social) movement in Latin America (Iriart 2002; Morgan 1998; Rosen 1985) and the establishment of socialized medicine in socialist governments (Armas Vazquez 1990; Molero Mesa 2004; Sigerist 1937, 1938).
Critical Medical Anthropology represents a useful framework through which to analyze particular medical systems by taking into consideration the three axes presented before. In essence, CMA recognizes that health is political; it acknowledges that inequalities in the distribution of health and disease are the product of class, gender, and ethnic categories; avoids separating micro-contexts from macro processes; recognizes the colonizing role of both anthropology and medicine; and seeks to change unequal and oppressive models of healthcare (Baer et al. 1986; Estroff 1988;; Navarro 1976; Pelto 1988; Scheper-Hughes 1990; Singer 1986, 1989, 1990, 1995).

This anthropological framework allows us to view biomedicine as one of many explanatory models of health and disease, therefore acknowledging the value of other types of medicine (Singer 1995). In doing so, it leads researchers to look at the different ways in which biomedical discourse became dominant throughout history and the role it has played in the constitution of modern societies, and the creation of specific subjects, like children (Colangelo 2008; Foucault 1973). CMA incorporates the anthropological holistic approach and considers all aspects of human society when analyzing particular treatments or healthcare models (Singer 1995). Finally, this framework indicates that medical knowledge and practice are neither homogeneous nor static and that “there exist ‘institutional and situational openings’ for influence and activity at many points in health care systems” (Singer 1995:87). Therefore, CMA represents a valuable mechanism through which to explain the participation of non-governmental organizations in the delivery of health services and it allows us to analyze the ways in which these actors can lead to the enactment of tangible changes in the propagation of disease and the distribution of health services. It also points to the role of anthropologists in this process.
and the need for our critical engagement in the production of literature on topics that have been previously marginalized within our discipline, like pediatric oncology treatment, and it urges us to participate in the design and implementation of actual interventions (Singer 1995).

Defining the borders of the Anthropology of Childhood

What then, is the Anthropology of Childhood, and why is it necessary? Several arguments have been made through the years that promote the development of this sub-area of anthropology. Some authors have argued that since class, race and gender were embraced by anthropologists as categories of analysis because they represented ways through which our symbolic and material worlds were organized, then age should also be included as another form of classification. Since all forms of classification entail the presence of power relations, then childhood should be analyzed as a subaltern\(^5\) category that operates within a system of inequity, disadvantage, and sustenance (Hirschfeld 2002) and is crosscut by the categories mentioned earlier creating particular, concrete realities (Helleiner 1998; Stephens 1995a).

Other anthropologists, mostly those dedicated to the study of socialization, have argued that “because so much anthropology is devoted to identifying, understanding, and conveying what people do, it seems uncontroversial that explorations of how they came to do it would be a central preoccupation of the field” (Hirschfeld 2002:612). Furthermore, if as anthropologists we strive to produce more inclusive views of the

\(^5\) Hirschfeld (2002) uses “subaltern” in this context to highlight the power differentials that exist between adults and children. According to him, these differentials are the product of social attributions of competence and maturity (Hirschfeld 2002:612).
societies we study and are a part of, then the studies of children and childhoods would be the next logical step (Bluebond-Langner and Korbin 2007:242).

The analysis of children and the ways childhoods are constructed could even point to important theoretical reformulations within the discipline because they allow us to problematize the nature, development, and construction of the individual (Bluebond-Langner and Korbin 2007:245) taking into consideration both structural constraints (Scheper-Hughes and Sargent 1998; Stephens 1995a) and the individuals’ role (James 2007) in this construction. In the case of this investigation, the relational construction of childhood is examined within the health system, but through the eyes of non-governmental actors that participate in the provision of medical and non-medical services.

In order to provide a synthetic literature review of the different lines of thought within the Anthropology of Childhood, I have divided them into the following categories: research and children, research about children, research about childhood, research with children, and research by children. This division was made according to some of the issues that generate conflict among anthropologists of childhood, such as: is any type of research that references children or childhood a part of this sub-discipline, or do anthropologists actually have to interview children and document their perspectives on the topic under study? Is childhood an entirely social category or does it have a biological and cognitive basis? Should local (cultural) forms of interpreting childhood weigh more than “Western” interpretations? Should the anthropology of childhood even be considered a sub-area of anthropology?
This brief review will situate the reader within the contemporary debates that are taking place in this area of anthropological thought and will introduce him/her to the framework that was used in this investigation.

Research and children

In a recent article, LeVine (2007) presented a historical overview of ethnographic studies of childhood. According to him, the recording and description of the lives of children did not originate within anthropology, but actually appeared in the texts of many western and non-western cultures, and were especially evident in the documents elaborated during colonial regimes as missionaries, military, and colonial administrators documented “local cultures” (LeVine 2007:247). Levine dates anthropological interest in children to the 1920s when researchers such as Mead (1928a) and Malinowski (1929) provided evidence for the cultural variations associated with child rearing and development.

According to him, the precursor of ethnographic research on childhood in U.S. anthropology was Franz Boas’s anthropometric work on child growth among European immigrants in the United States (LeVine 2007:249). Boas’s work was important because it demonstrated that human growth is not only influenced by environmental factors, but is also affected by the “social and geographical environment” (1912:217-218). These ideas were transmitted to his students and they incorporated them in the Culture and Personality movement (i.e. Sapir, Benedict, Mead) (Stocking 1992).

The Freudian theory of psychosexual stages invigorated ethnographic studies on childhood as researchers such as Malinowski (1927) and Mead (1928b) used cross-
cultural studies as a way to discredit them, while others adapted the model to the context in which they were working: Erikson (1950) among the Yurok, Spiro (1958) in an Israeli kibbutz, and Whiting and Irving Child’s (1953) famous analysis of the socialization of the oral, anal, and sexual behavior systems. Piaget’s universalist account of childhood cognitive development was scrutinized thanks to empirical evidence obtained at the time (Mead 1932; Greenfield 1966; Shweder and LeVine 1975). As can be seen, this early stage in the anthropology of childhood was characterized by the recollection of a large quantity of ethnographic data that was used to either support or reject psychological models of the time (LeVine 2007:253). These studies would mark the beginning of a bitter-sweet relationship between anthropologists of childhood and psychologists, psychiatrists, and psychoanalysts.

Research about children (and parents)

During the 1960s, a large portion of the anthropological research directed at children focused on the relationship between children and their caretakers, specifically: parental concepts and practices of infant care, different stages of socialization, language acquisition, and initial social interaction (LeVine 2007:254). Anthropologists began to focus on the household, examining the roles of different family members on the upbringing of children (Gaskins 1996, 1999; Weisner and Gallimore 1977; Weisner 1984) or the effects of adoption or “dysfunctional” family relations on socialization (Carroll 1970; Goody 1982).

The incorporation of cultural meanings through communicative participation in children became an important area of research. Some have argued that it was Sapir’s
interest on the acquisition of culture by children that influenced the sociolinguistic
movement (Ervin-Tripp and Slobin 1967; Hymes 1974) and placed children’s
incorporation of language as the main focus of research (LeVine 2007:255).
Ethnographic studies were done all over the world indicating that children acquire
important skills and information at very early stages of their development (Kernan 1969;
Contemporary sociolinguistic studies have explored communication patterns among
children and their mothers tracing how this relationship influences the child’s
construction of the self (Fung 1999; Miller et al. 2001).

Not everyone has accepted the literature presented in the previous two categories
as “valid” forms of research on children and some argue that this work has not “coalesced
into a sustained tradition of child focused research [...] nor has it succeeded in bringing
children from the margins of anthropology” (Hirschfeld 2002:611; see also Caputo 1995;
Hardman 1973; Schwarz 1981; Stephens 1998; Toren 1993). This type of research is
seen as not studying children, but adults and the way they organize the environment in
which children develop (Hirschfeld 2002:614; Toren 1993) leading them to represent
children as culturally incompetent creatures who are appendages to adult society, that is,
as adults-in-the-making (Bloch 1991; Caputo 1995; Hirschfeld 2002; James and Prout

*Research with children*

Anthropological research within this category has established itself as the “correct
form of childhood studies” as research is carried out *with* children rather than *on* children
and positions them as participating subjects rather than as the objects of adult research (Alanen 1992; James 2007). According to these authors, the greater politicization of the research process has lead to the awareness of the power differentials involved in the researcher-researched relationship responsible for muting the voices of children (Christensen and James 2000; Christensen and Prout 2002; James 2007).

Some of the research carried out in this category established as its focus the process through which children acquire knowledge as a means to describe their inherent “culture” (Corsaro 1997; Goodwin 1990; James and Prout 1990; Maltz and Borker 1986; Willis 1981). Most of the authors that carry out these types of studies have a psychological anthropology background with a great interest in cognitive research. According to these studies, “children’s cultures encompass substantial and elaborated environments that are not only distinct from, but independent of the adult environments in which they are embedded” (Hirschfeld 2002:615). This culture is seen as the product of the cognitive structure of children, and the specialized learning mechanisms that are a product of it leads children to create specific types of activities that do not appear to be linked to adult culture (Hirschfeld 1996, 1997; Opie and Opie 1960).

A strong emphasis on agency underlies this type of research as children are viewed as active participants in the socialization process and are considered capable of translating, and even transforming, “adult culture” (Hardman 1973). A large quantity of studies focus on children’s play, song development, and drawing and researchers work with children in order to illustrate the way they conceptualize their world and determine how this is similar or different to the conceptualizations made by adults. Notable examples are the studies made on “cooties” and its interpretation as a semiautonomous
cultural form maintained through children’s practices (Opie and Opie 1969; Powlishta 1995; Samuelson 1980; Thorne 1993).

Other studies apply a culturalist perspective emphasizing that “the immaturity of children is a biological fact of life, but the ways in which this immaturity is understood and made meaningful is a fact of culture” (James and Prout 1990:7). According to them, comparative work on childhood should aim at “the analysis of how different discursive practices produce different childhoods, each and all of which are ‘real’ within their own regime of truth” (James and Prout 1990:27). They have recently incorporated children’s voices to provide a critical understanding of the processes and effects of globalization on local settings and to try to connect what children say about their lives with larger political, economic, and social issues (James 2007).

Montgomery’s (2001) analysis of child prostitution in Thailand is an excellent example of this type of work. She explores the lives of children from their point of view finding out that children in Thailand do not have the same experiences as Western children and that they view their prostitution as a sense of duty to their parents. Rurevo and Bourdillion (2003) carry out a similar study in Zimbabwe, but using a gendered approach as well.

In an exploration of the professional practices of family court advisors in England, James and James (2004) examined how children’s voices provided important insight into family relations, but were also a matter of translation, mediation and interpretation as they did not go according to the interests of the court advisors. Smart and others (2001) elaborated an investigation with children on their views on parental
divorce making important contributions to the debate about the effects of divorce on the lives of children. An interesting selection here, is the investigation carried out by Finkelstein (2005) on homeless children, their interpretation of the situation in which they are living, the reasons why they got there, and the hardships they endure on an everyday basis.

In summary, anthropological research with children can provide important contributions to the anthropology of childhood in the sense that it includes children’s voices and, hence, perspectives on particular topics demonstrating that childhood is experienced and practiced differently according to specific cultural contexts or cognitive predispositions. However, if not applied carefully this approach as used by psychological anthropologists can result in an isolative characterization of children and childhood as they tend to focus on the analysis of children as something separate from the “adult world”. Culturalist analyses should also be analyzed critically as they can derive into different types of cultural relativism where exploitation and abuse are justified because they are thought to be a product of local cultural norms.

Research by children

After the “crisis of representation” reached anthropologists of childhood, the use of children as researchers and co-researchers became more common. This shift certainly mirrored larger transformations that were taking place within the discipline, especially those proposed during the 1980s by authors such as Clifford (1988), Crapanzano (1980),
and Clifford and Marcus (1986). Within this area of anthropology, the use of children as researchers helps to redress the power imbalance between adults and children during the research process (Alderson 2000; James 2007). The results of the research are more accurate in the sense that the research questions that are identified are of greater relevance to children and the research is usually geared toward a pro-child direction focusing on the respect of their rights (James 2007; Jones 2004; Roberts 2000).

Within investigations carried out by children, self-directed visual methodologies stand out as an innovative approach. They form part of visual anthropology and are based in the questioning of the practical, ethical, and technical issues of representation in social research. By allowing the children to act as the primary “data generating” agents by documenting their lives or the specific topics they want to explore through visual representation (film, photography, painting, etc.), these studies provide important information about how children represent themselves and represent others (de Block 2007; Devereaux and Hillman 1995; Buckingham and Willett 2006).

Although the use of children as researchers can generate important contributions to this area of study, it does not mean that the research directed by children will be entirely representative or work towards improving the living conditions of all children. It also does not mean that it will focus on the transformation of structures that reproduce their subordination. Furthermore, the promotion of research carried out by children does

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6 Briefly, postmodernism recognized the influence of positivism in anthropology and proposed, instead, to eliminate the idea of an objective reality that can be discovered; to deconstruct concepts otherwise uncontested; decentralize the narrative of the anthropologist to include other voices; and consider ethnography as a partial and ideological form of writing.
not mean that research about children or with children, carried out by adult researchers, is less authentic or valuable.

*Research about childhood*

Studies about childhood in anthropology emerged with the work of authors like Stephens (1995a), Scheper-Hughes (1987), and Scheper-Hughes and Sargent (1998) which strived to deconstruct the concept of childhood and locate it within both global and local contexts. These authors relied on the work carried out by the French historian Philippe Ariés (1962) who argued that the modern conception of childhood as a separate life stage emerged in Europe within the fifteenth and eighteenth centuries. Notions of children’s special nature and needs called for special attention to the child’s emotional development in the home and for formal education in the school aimed at preparing children for the transition to an adult world (Ariés 1962; Stephens 1995a).

As time passed, a vast amount of institutions contributed to the generalization of childhood (school, health, legal systems), first within Western society, and consequently, through colonialism and subsequent processes of globalization, to non-Western societies as well (Ariés 1962). Therefore, the changes in the representation of children were intimately linked to larger political and economic transformations (Stephens 1995a).

Although this investigation draws from all of the aforementioned categories, it is heavily influenced by this line of thought. The historical component of the research

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7 For historical reconstructions of childhood made within anthropology refer to: Haas (1998) which focuses on childbirth and early childhood in Florence, Italy; Rosalind and Janssen (1996) provides an excellent description of the games, rites of passage, and education experienced by children in Ancient Egypt; and Calvert (1992) uses material culture as a way to reconstruct childhood in the U.S. from the Seventeenth to the Twentieth Century.
seeks to identify the role that the health system played in the institutionalization of childhood in Argentina. By analyzing medical discourse through time, we can obtain valuable information on the construction of the meanings and representations of children. This historical reconstruction is made by consulting historical documents where children are present in the adult world. This is true of most historical descriptions of childhood. As Heywood has indicated, “it follows that if historians wish to recreate the day-to-day experiences of children in the past (what might be called the social history of children) they must in the first instance understand how adults thought and felt about the young. Childhood is of course an abstraction, referring to a particular stage of life, as opposed to the group of persons implied by the word children” (2001:10). This abstraction is found in all of the chapters of this thesis; it guides the historical reconstruction of pediatric medicine in Chapter 3 and it underlines the ethnographic research carried out on NGO staff that currently work with children.

The historical component of this research serves other purposes as well. As Armus has indicated, a historical look at medicine allows us to visualize this discipline as “an uncertain terrain, where the biomedical is penetrated by both human subjectivity and objective facts” (2005:18). It sheds light on the biological, social, cultural, political and economic characteristics of disease, enables us to interpret the initiatives originated in medicine and public health according to its disciplining, humanitarian, and assistencial dimensions (Armus 2005:18). In other words, a historical look at medicine allows us to understand the processes through which specific subjects are created in society (Foucault 1989). Furthermore, it sheds light on the multiple types of control and order exerted on

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8 See also Vann 1982, Ennew 1994 and Hoyles 1979.
specific groups by highlighting the political ideologies behind the creation of particular health systems (Foucault 1994a).

Historical reconstructions such as this one, force us to reconsider traditional representations of government, and instead assume that we will study “not the institution ‘government’, of course, but the activity that consists in governing human behavior in the framework of, and by means of, state institutions” (Foucault 1994b:74). Multiple actors participate in this process of governing in some cases, even actors we had previously labeled as “non-governmental”. The historical chapter of this thesis and the chapters that supersede it will repeatedly return to this point of tension between what we label government or non-governmental for analytical purposes and if this responds to what we actually observe.

The Anthropology of Childhood within Larger Anthropological Debates

As can be seen, research within the anthropology of childhood includes a wide range of topics and theoretical frameworks and responds to crosscutting debates within anthropology as a whole. The earliest studies included children as a marginal part of a larger investigation and were interested in applying the concepts of the Culture and Personality framework to understand the cultural differences in child rearing and socialization. Later studies acquired a more political stance, incorporating a poststructuralist approach to the study of children by deconstructing the concept of childhood altogether. They relied heavily on the historical reconstruction of childhood as a social and political category. These studies concluded that the Western concept of childhood was transmitted through the dominant international discourse heavily
promoted by multilateral organizations in order to erase the local conceptualization of childhood and ensure the reproduction of international aid or development programs. Anthropological research on children and childhood questioned the representation of childhood as a separate stage of the lifecycle and pointed to the role of professionals (anthropologists included) in its reproduction and its utilization as a form of population control and regulation\(^9\).

Anthropological research with children emerged recognizing the structural characteristics that shaped childhood, but arguing that children had the capability of reconfiguring this category in everyday practice. They stemmed from larger criticisms of more “structural analyses” that ended up, denying the role of individual actors, and depicting eternally reproducing systems of domination. Some utilized Bourdieu’s (1977) later concept of the habitus\(^10\), with its emphasis on improvisation, and described the ways in which children’s agency (capacity and willingness to act) shaped the world in which they lived. Others took these ideas even further and identified forms of resistance and subversion of the hegemonic order.

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\(^9\) Several of these studies drew from the ideas of governmentality proposed by Foucault that basically refers to a specific type of power that is exerted by obtaining knowledge about a population produced by government institutions through specific procedures, analyses, and calculations (1999:195).

\(^10\) Bourdieu defines the habitus as “the system of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them. Objectively ‘regulated’ and ‘regular’ without being in any way the product of obedience to rules, they can be collectively orchestrated without being the product of the organizing action of a conductor” (1977:72) (my emphasis). It is later on that he makes action explicit by stating that “each agent, wittingly or unwittingly, […] is a producer and reproducer of objective meaning” (Bourdieu 1977:78).
Most anthropologists within this category agreed on giving children’s voices a more important role by making them part of the research process. However, the impact of this approach on the actual improvement of their living conditions is still a matter of discussion. In a sense, research about childhood and research with children present opposing yet complementary approaches within the anthropology of childhood. Their discussion mirrors the structure vs. agency debate in anthropology.

While contemporary studies no longer adopt “an all or nothing” position and actually acknowledge the interaction between individual action and structural constraints, broad categorizations are still made. Some research is labeled as considering childhood as something external to children of which they have no control while, on the other hand, some anthropologists are blamed of depicting children as individuals with more agency than they actually have.

At first glance, it might seem as though a more structural lens has dominated this current investigation. Even though pediatric oncology is framed within the public health system, and this system is consequently situated within local and global political and economic contexts, children’s capacities to act are considered equally important. While I did not interview children and their direct voices are not heard, they are still represented as active constructors of their relationship with the medical personnel, their family members, and the NGO staff. Furthermore, their representation of the disease and its treatment occupies a significant portion of this thesis.

In the groundbreaking Small Wars: the Cultural Politics of Childhood, the authors sought to demonstrate “how the treatment and place of children are affected by global
political-economic structures and by everyday practices embedded in the micro-level interactions of local cultures” (Schepere-Hughes and Sargent 1998:2). They sought to address a general concern among contemporary anthropologists of being able to study local contexts while acknowledging the effects of global processes (Appadurai 1996).

Among anthropologists of childhood, this dilemma was brought forward with the recognition of universal children’s rights within the United Nations Convention on the Rights of the Child in 1990 (Schepere-Hughes and Sargent 1998). This Convention has generated debates within anthropology as some have argued that the rights rhetoric could serve as a screen for the transfer of Western values and economic practices dependent on a neoliberal conception of independent and right-bearing individuals (Schepere-Hughes 1998:7; see also Ennew 2002; Rosen 2008; Stephens 1995a, 1995b). Anthropologists of childhood have asked if they should promote a single universal definition of childhood or if they should defend the fact that childhood is understood and experienced differently in each society (Rosen 2008:5) While some can state that “if anthropology is worth anything at all, it must be grounded in a new ethics beyond the cultural relativisms of the past” (Schepere-Hughes 1995), others still speak in favor of privileging local discourses and practices of childhood (Rosen 2008)\(^{11}\).

\(^{11}\) Anthropologists encounter a difficult terrain when in the name of “culture” exploitative systems are reproduced. In this context they go back to the previous debate and ask whether they should act according to their own model of childhood or respect local arrangements and beliefs. This situation points to reconsiderations within anthropology of what culture is (if it exists at all), how it should be studied, and what role it should play in our research. Should we think of culture within the anthropology of childhood as Lewis and Watson-Gegeo (2004) propose by taking into consideration that cultures are variable, dynamic and in “perpetual motion” (Rosaldo 1993:104); they are ongoing sets of conversation embodying conflict, compromise, and change (Burke 1957:95-96); shaped by the dialectic of structure and agency (Giddens 1979); inherently ideological (Bakhtin 1981); and prone to manipulation through power relationships (Habermas 1979)? Or should we throw out the concept all together and “write against culture”? (Abu-Lughod 1991).
This debate is still unresolved within our discipline, but it is important to continue bringing it up because it sheds light on the moral values present in anthropological research as researchers decide what and for whom to advocate for. It also demonstrates the importance of recognizing the position the researcher occupies in terms of his/hers political ideology; the existence of problems associated with authenticity and representation; and the multiple “valid” forms of conducting anthropological research. These ideas have had a tangible effect on the anthropology of childhood as researchers have acknowledged the power differentials that exist between researchers and children, and have, therefore, strived to develop theoretical frameworks and methodological approaches that could represent the experiences of children more accurately.

In the case of studying pediatric oncology treatment in Argentina, the discourse on children’s rights is joined with a more general calling for the consideration of healthcare as a universal human right (Farmer 2003). Although this thesis acknowledges the problems that a universal depiction of childhood can generate and the importance of respecting individual representations of disease and treatment, it pronounces itself in favor of the human rights discourse by arguing that all pediatric patients should have the same access and quality of health services provided to them.

Anthropologists of childhood have not quite embarked on the task of critically examining this concept as many authors still talk about “the culture of children” (Hirschfeld 2002) or favor culturalist analyses of childhood (James 2007), but at least the problematic nature of the concept of culture has been stated (Stephens 1995a; Scheper-Hughes and Sargent 1998) and it could be the source of future transformations within this area of study.
Why Cancer?

Since this thesis is concerned with the provision of healthcare to children within the public health system in Argentina, many might wonder why the research took place in an NGO that focused only on cancer patients. Cancer generates a different context in which to study healthcare. As Bluebond-Langner (1978) has indicated, terminal diseases in pediatric patients produce complications for parents and healthcare professionals as they go against ideas about children maintained in our society where childhood is a “period of formation”; a temporal stage that will be surpassed by the other stages in our lifecycle. Young et al. in their study of the parenting of children with cancer found that “the rarity of cancer in children, the threat the illness poses to futurity, and the cultural association between cancer and death added to the sense of catastrophe that surrounded the illness.” (2002:1845).

Nowadays, cancer can acquire remission characteristics, thus not constituting a terminal disease, however, the possibility of death remains. The sole possibility of death transforms relationships among family members and with anyone in charge of caring for the child because “although, like other children, they are sensitive, intelligent, kind, willful, and young, they will not ‘become’, they have no future” (Bluebond-Langner 1978:213).

This is particularly evident in the relationship between parents and children. Many parents experience a feeling of losing control over their family, of not fulfilling their roles as caretakers in an adequate manner (Bluebond-Langer 1978; Hoffman 1971). As

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12 See also Jenks 1996; James 1998; James, Jenks and Prout 1998; Young et al. 2002.
Hoffman has indicated, “the onset of leukemia in a child represents an assault on a parent’s sense of adequacy as guardian of his child and, more generally, as a person with a meaningful control over his own and his family’s destinies” (1971:15). They respond to these feelings in different ways, but most of the time they deal with them acting as though the child were going to live, even though the medical prognosis is negative (Bluebond-Langner 1978).

Several studies have demonstrated that cancer diagnosis also leads to parents creating a new self-identity, that of the parent of the child with cancer (Young et al. 2002). All of their everyday activities are concentrated around the child, they feel a great sense of responsibility for ensuring the child’s cooperation with medical procedures, and their own needs and quality of life (as well as those of other family members) occupy a secondary role (Young et al. 2002).

Besides still representing a threat to life, cancer treatment is long, intensive, and painful (Young et al. 2002:1836). As Young et al. have indicated, cancer “is also a chronic condition: treatment may extend for several years, and it is associated with a range of adverse long-term effects, including disability and infertility, so it carries the potential to disrupt permanently parents’ and children’s biographies” (2002:1836). Cancer treatment produces serious transformations in the lives of all family members (Clarke-Steffen 1997). In the cases of heavily centralized medical systems, like in Argentina, in many cases, one of the parents must move to the capitol to accompany the
child during treatment, separating family members sometimes for years. Furthermore, in many cases, parents must abandon their jobs or are fired after requesting too many days off because they are the only caretakers of the pediatric patient and they must accompany him/her during the treatment.

The fact that cancer treatment is so demanding of the child and his/her caretakers also produces changes in the relationship between the patients and his/her well-siblings. As Bluebond-Langer has indicated, “Chronic illness sets the family and its members apart from others. […] Well siblings’ views and responses are part of a process that involves not only the parents’ responses, but also the ill child’s condition and experiences” (1996:12-13). The lives of parents and well siblings revolve around the disease and the state in which the ill child is found.

Cancer diagnosis and treatment also produces changes in the ways the children visualize themselves and their bodies. In an analysis of children’s depictions of the cancerous body, Williams and Bendelow (2000) indicated that they reproduced medical and Western notions of health and illness by representing their bodies as demonic, dys-figured, combustible, pathological and mortal. Cancer during childhood introduces notions of corporal transgression where biomedical notions of the “sick body” are internalized by the pediatric patients and shape their representation of the self and their social relations with those that surround them (Williams and Bendelow 2000).

\[13\] In her study of pediatric oncology in Japan, Saiki-Craighill (1997) found a similar phenomenon where the isolation of mothers and patients from the rest of their family was produced by the fact that medical treatment was only available in hospitals and there were no possibilities for home-care.
As Bluebond-Langner has indicated, “one dies as a member of society, linked to other individuals” (1978:235). Therefore, the child’s death not only affects family members, but also influences the healthcare professionals that contributed to their caretaking\(^{14}\). In his analysis of healthcare staff that worked with terminal pediatric patients, Rothenberg (1974) indicated that professionals experienced two emotional responses: compassion and repulsion. The former produced the need to aid and comfort the child, the latter, engendered the need to distance themselves in order to seek protection from the shock of future separation or loss (Rothenberg 1974:39).

Rothenberg goes on to say that “a patient’s failure to get well frustrates one of the primary goals and needs of the health worker” (1974:40). When healthcare professionals are not trained to deal with the emotional consequences of communicating with a dying patient, they start to feel frustration and anger (Rothenberg 1974; Stuetzer 1980), and the patient might become neglected (Truscello 1997: 73). Kleinman has explained this phenomenon in his study of chronic illness by indicating that in the case of long-term illnesses the common biomedical approaches where diseases are rapidly sorted out and magic bullets provide cures that do not work, generate difficulties for healthcare professionals that deal with these patients (1988:136).

Furthermore, as Eisenbruch and Handelman have argued “the psychosocial response of any cancer patient and his family is unique and highly complex” (1990:1298), and a great deal of these responses do not attain themselves to the rigid models used within biomedicine (Scheper-Hughes and Lock 1986), generating problems

\(^{14}\) For studies on healthcare professionals’ work with cancer patients refer to Rothenberg 1974; Stuetzer 1980
in the doctor-patient relationship and doctor-family relationship. Many anthropologists
have dedicated time to the study of the power asymmetries found within medical
discourse\textsuperscript{15}, so the only thing we will say regarding this topic is that from our discipline
we can question the quick conclusions drawn by professionals from other disciplines
when they catalogue patients as non-compliant (Farmer 2003; Hunt and Arar 2001) or
bearers of a style confronting the disease that is maladaptive (Kleinman and Kleinman
1985). We emphasize the fact that many cases that are classified as depression or other
types of psychopathologies, which are in reality the result of the questioning of the
medical authority and knowledge on behalf of the patient (Kleinman and Kleinman
1985:474).

Within the clinical literature that focuses on the study of the behavior of patients,
psychological approaches predominate. This is particularly evident in the oncology
treatment offered to pediatric patients in Argentina. Psychology has made important
contributions to the management of pain, the disease, and death by patients and families
and it is very useful during all of the phases of the treatment. However, in most cases, it
assumes that the behavior present during the medical treatment is the direct result of the
choices made by the patient, and therefore, treats clinical recommendations as goals for
which patients must “rationally” strive for (Hunt and Arar 2001:348-349). In other
words, they do not question the assumptions under which treatments are based and
evaluated, they do not take into consideration the specific context within which patients
experience their disease and treatment, and they give little importance to the different

factors that restrict and influence the decisions of patients and their families. Due to the fact that most healthcare professionals are trained within this rigid model (Good 1994), they find it extremely hard to deal with the realities of their patients and their families, and the possibility that biomedicine might fail.

As was mentioned previously, most studies have focused on the impact of cancer on these three actors: the patient, family members, and healthcare professionals. However, there are many other people that interact with pediatric oncology patients like social workers, hospital teachers, administrative personnel, and NGO staff (see Foley 1982). In the case of the NGO staff, this investigation demonstrates that they are subject to some of the same difficulties experienced by family members and healthcare professionals. However, they do not have the same type of support that many physicians and nurses have, they do not have prior training, and in many cases are not supervised by other professionals. As we will see later on in the thesis, this has negative consequences as they do not know how to work with many of these children or cannot handle emotionally distressful situations.

The last reason why this thesis focused on pediatric oncology treatment is more related to the Argentine context. In a country where one in six deaths is related to a neoplastic disease (De Simona and Tripodoro 2004: 17), 200,000 children have cancer, and 1300 new cases of pediatric oncology are diagnosed each year (ROHA 2005) one would expect large amounts of anthropological literature produced on the subject. Unfortunately, this is not the case and this misinformation produces serious consequences in the design of adequate social assistance programs to patients and families, the transformation of health policies, and the dissemination of information to the general
public. This thesis was partially created to invert the situation and generate information that can be of use to anthropologists, hospital administrators, NGO staff, healthcare professionals, public officials, patients, families, or anyone interested in pediatric oncology.

Using a Micro Perspective to Study NGOs

Anthropological research on NGOs in general has adopted a “development anthropology” perspective and has rarely included empirical, actor-oriented, ethnographic research (Nauta 2004: 43). As Nauta has indicated, “some NGO scholars that have contributed to the ‘NGO literature’, have suggested that more in-depth research is needed in order to understand NGOs” (2004: 43). Hulme and Edwards had previously brought up this point arguing that “detailed empirical research is needed to elaborate whether such approaches [participatory methods used by NGOs] lead to changed interventions and whether such changes lead to improved outcomes” (1997:10). Farrington and Bebbington have indicated that “while there are some ethnographic and actor based accounts of the work and dynamics of government institutions (…), few have been written about NGOs” (1993:57).

Anthropological research on NGOs that work with children tends to reproduce this trend as most studies take a more “transnational” look at childhood, usually using the United Nations Convention on the Rights of the Child as a base, and fail to identify the differences between foreign and local NGOs and the negotiation of their discourses on childhood16. Due to the fact that they are not able to focus on the everyday realities of

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16 For further discussion on this topic refer to: Panter-Brick (2002).
NGO workers, they miss out on the large amount of detail that makes NGO involvement so complex.

The literature on NGOs involved in the provision of healthcare tends to reproduce this same pattern. Most analyzes tend to categorize organizations depending on the type of services they provide to patients, their funding sources, or the impact they have on the development and implementation of health policy (Gilson et al. 1994). Furthermore, most of the NGOs that have been studied are international NGOs that deliver health services under emergency situations (Redfield 2005) or establish autonomous health facilities that act in opposition to government institutions (Pfeiffer 2003). Organizations that provide services to patients within public hospitals have not been properly studied.

The Literature on NGOs in Argentina

It is difficult to talk about NGOs in Argentina, or anywhere else for that matter, because it is difficult to identify them. The literature that has focused on these actors in Argentina has provided different definitions for what constitutes an NGO. This responds to a greater problem within the literature on civil society where different types of conflicting and sometimes overlapping categorizations coexist. The vague definition of civil society proposed by authors like Keane (2003) further generates problems. According to him, the concept of civil society is an ideal concept that refers to “a dynamic non-governmental system of interconnected socio-economic institutions that straddle the whole earth, and that have complex effects that are felt in its four corners”

17 The classification provided by the International Comparative Project of Johns Hopkins University (Salomon and Anheir 1997) appears useful for didactic purposes and has been used by many authors working in Argentina (Cruz and Barreiro 2006).
Some of the general characteristics that authors have attributed to civil society are that it works independently of the government (Friedman et al. 2005), it is the product of interlinked social processes (Keane 2003), has mobile and dynamic qualities (Post and Rosenblum 2002), maintains pluralism (Keane 2003), and constitutes another arena where power relationships on an international scale are negotiated (Howell and Pearce 2001). Non-governmental organizations (NGOs) are considered just one part of civil society and unfortunately, as Magazine indicates, they tend to be portrayed as either instruments of the State or romantic saviors of the people (2003:244). The actual nature and practice of NGOs is more complex than this dichotomy; it varies across time and space and involves multiple representations (Abramson 1999; Hemment 2004; Magazine 2003; Markowitz 2001). This thesis adopts a wider idea of what constitutes NGOs. The research applies Thompson’s definition of NGOs as non-profit entities that emerge from civil society (1995:12). This conceptualization of NGOs allowed me to take into consideration the multiple ways in which organized forms of civil society can participate in the provision of healthcare in Argentina. Furthermore, it made me cognizant of the fact that in order to understand what constitutes NGOs and how they work, it is necessary to analyze the perceptions and activities of their volunteers and staff members (Hemment 2004; Markowitz 2001).

Most of the literature on NGOs in Argentina tends to identify these actors as a relatively recent phenomenon (Ballon 2001; Bifarello 2006; Cruz and Barreiro 2006; Munck 2003). They usually indicate that in Argentina NGOs did not emerge until the
1980s, a relatively late time period when compared to other Latin American countries. However, in doing so, they have neglected the previous history of civil-society involvement like the case of the Sociedad de Beneficencia that we will present in Chapter Four. It is common for authors to explain the insertion of neoliberal policies in Latin America by referring to an indirect relationship between the State and civil society indicating for example that from the 1980s onward “we can visualize a certain movement, displacement of the State while at the same time witness a reacting of civil society, with a new place to occupy, a new way to appear, and new responsibilities” (Zampani 2003:4).

As a result, this literature provides a blinded version of the history of many Latin American countries and in the case of Argentina, it eliminates a past of strong charitable societies, communal groups, and beneficence societies; groups that were essential in the establishment of the contemporary health and educational systems. It is true that whenever there have been military governments, civil organizations have suffered the greatest attacks (Cruz and Barreiro 2006) and that during the Peronist governments of 1946-1952 and 1952-1955 the State absorbed most of their functions (Biernat and

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18 For example, Mayer and Iniguez (2003:2) have stated that in 2001, NGOs in Argentina reached a peak, but in no way do they provide information on what they mean by this or how the measurements of the impact of the work of NGOs on society was carried out.


20 Zampani states that previous organized forms of civil society only supported the projects that were generated by the State and that the current forms of these organizations have acquired greater forms of responsibility and autonomy (2003:4). However, this author fails to present an in-depth analysis of how the decision-making process took place between the government sector and these non-governmental actors in previous decades, forgetting to take into consideration the fact that these relationships are in constant negotiation and that even though non-governmental actors can appear to share the ideological basis of the State they also operate according to their own interests.
Ramaccioti 2005), however, when we look closely at these historical time periods we see that civil society organizations resisted in many ways and always managed to reappear when new political regimes emerged.

Cruz and Barreiro (2006) have analyzed this fact by looking at what they have called different types of ruptures in the southern cone of South America (Argentina and Uruguay). These authors have stated that during the 1960s and 1970s a new social and political model was imposed creating new ways of organizing civil society and during the 1980s, when democratic governments started to emerge, these same social actors restructured their missions and operating mechanisms (Cruz and Barreiro 2006:5). In other words, the organization of civil society has taken different forms according to its historical context and the political and social models at its disposal, but it has never completely disappeared.

Unfortunately, this heterogeneity of non-governmental organizations has not been taken into consideration in most of the local literature on NGOs, especially in the small amount produced on NGOs that provide health services. Even though Biagini (1996) carried out a study of all non-governmental organizations that work with patients that have HIV/AIDS in Buenos Aires, her analysis is superficial in the sense that it relies on a generalized typology where all organizations are categorized according to one model. Furthermore, Biagini’s (1996) review of sixteen different organizations in less than one year of fieldwork points to the macro perspective that dominated the research design and the lack of depth of the conclusions presented in her article.
As a result, Biagini’s (1996) article fails to take into consideration the meanings and practices associated with HIV-AIDS, the historical background of public policies concerning healthcare in Argentina, and the social inequalities surrounding the provision of health services. Furthermore, Biagini (1996) presents a romantic interpretation of NGOs as benefactors and opposers of the State failing to take into consideration that non-governmental organizations maintain complex relationships with the State and in many cases collaborate with government institutions and reproduce the same ideas on diseases, medical treatment, and the right to access of healthcare. Unfortunately, these same limitations are presented in the study carried out by Biagini (2005) and Sanchez (2000).

In sum, previous studies on NGOs in Argentina have failed to mention that organizations obtain their funds from a combination of sources like the government, private enterprises, donations from individuals or through fund-raising activities. Although they might not have received legal recognition, many organizations achieve complex models of internal organization and implement programs that have a direct effect on people’s lives. Organizations also change through time redirecting their mission and expanding their geographical location and staff.

These are some of the reasons why NGOs should not only be studied from a macro perspective; they need to be analyzed historically, within their particular political and economic context, and the voices of the people that work in them need to be included. As Markowitz has indicated, “ethnographic methods are well suited for assessing these interrelations and the real or potential coincidence of interests that motivate individual involvement” (2001:40). This methodological approach can point to the complexity of NGO discourses and the representation of these by the individuals that
make up its staff (Hemment 2004), as well as, the different ways in which NGOs are perceived by their users or aid recipients (Abramson 1999).

**Summary**

The anthropology of childhood is not as marginal as many researchers still like to believe. It is a prolific area of study that utilizes a wide variety of approaches and covers many topics and geographical locations. Most of its internal debates stem from disagreements on how to define children and childhood, how to study them, and what role the anthropologist and participants should play in the process. Ethnographic research will be fundamental in settling these debates as it “redefines itself as that practice of representation that illuminates the power of large-scale, imagined life possibilities over specific life trajectories” (Appadurai 1996:55).

Even though ethnographic studies of childhood and children are not new (Levine 2007), “the ethnography of childhood remains a genuine frontier” (Schwartz 1981). This is largely due to the fact that anthropologists still struggle with the definition of childhood and are not sure if it should be analyzed as a universal or local category. Ethnography will allow anthropologists of childhood to breach this distance between the local and the global, and therefore, adequately represent the structural processes and individual actions at stake (Appadurai 1996; Comaroff 1985; Moore 1999).

Hopefully, these new ethnographic studies will also shed light on the depoliticizing effects that cultural relativism is having within the anthropology of childhood as serious violations are justified in the name of “culture” (Moore 1999). The supposed boundedness and the idealization of the culture concept must be problematized
An interesting way to do this will be to incorporate into the analysis other categories of “difference” (gender and class) that interconnect with childhood and that can point to the diversity of realities and experiences among children. Furthermore, in the attempt to continue to study childhood as a category that is constructed through social relations, anthropologists need to include other actors, like NGOs, in their analysis. In doing so, authors will have to put aside macro approaches for understanding the work of non-governmental organizations, and instead favor ethnographic research.

This thesis intends to bring to the forefront many of the issues presented in this review. By using the politically and socially constructed category of childhood as the lens through which to view the provision of medical services, this investigation sheds light on the complex processes that form part of healthcare. It presents examples of how political ideology and health have been linked in the context of the Argentine past and present, transforming children into relevant social subjects and political actors, while at the same time, inserting them into a previously established model of social and biomedical hierarchies (where children occupy the lowest positions). Discourses on childhood, therefore, become a part of larger structures of social and political exclusion, as well as, processes of the medicalization of society.
Chapter 3

Methodology and Setting

“Since it is not for us to create a plan for the future that will hold for all time, all the more surely what we contemporaries have to do is the uncompromising critical evaluation of all that exists, uncompromising in the sense that our criticism fears neither its own results nor the conflict with the powers that be” (Marx 1844).

As it was mentioned in the previous chapter, this thesis draws from three different areas of anthropological literature: the Anthropology of Childhood, Critical Medical Anthropology, and the Anthropology of NGOs. These three frameworks determined the methodology used for the collection and analysis of the data and guided the elaboration of the interpretations that will be presented in the subsequent chapters. In this particular chapter, the different methods that were used in the research are presented indicating how they were informed by previous literature and the goals of the investigation. Furthermore, a brief description of Argentina, its history and its public health system are presented in order to situate the reader in the appropriate setting.

This investigation used multiple methods, as “different sources of information ensure reliability and provide a richer analysis” (Singleton et al. 1993:371). It combined archival research with ethnographic research in one of the most important NGOs
dedicated to pediatric oncology in the country for a period of three months. Archival research was chosen in order to gain a better understanding of the creation of the Argentine medical system, as well as, the context in which NGOs dedicated to healthcare operate nowadays. As it was mentioned before, one of the underlying themes of this thesis is that the provision of healthcare needs to be analyzed within the context of larger processes of social formation where categories such as gender, class, and ethnicity determine the access and quality of the medical services provided to individuals. Historical research is useful in this endeavor because it can point to the different forces present in the creation of a particular way of thinking and acting and the ways in which these have been transformed through time until acquiring their current characteristics.

The content and context of documents were analyzed, because as Ricoeur (1971) has indicated, texts are written to do something; they are produced under certain conditions embedded within social and ideological systems. Therefore, they have to be understood in the contexts of their conditions of production and reading (Hodder 2003:156).

The ethnographic research was important in the sense that it provided in-depth information on the inner dynamic of the NGO, the staff’s work and their interaction with other institutions. As other authors have indicated, “ethnography is a mode of knowing that privileges experience—often going into realms of the social that are not easily discernible within the more formal protocols used by many other disciplines” (Das and Poole 1991:14). In the case of this research, it provided insight into the everyday life of the staff, their worries, hardships, and motivations.
Part of the ethnography was used to make an assessment of the internal communication of the organization and work with volunteers and coordinators in order to determine some of the difficulties they were facing on an everyday basis. This information was then developed into recommendations for improving the organization’s situation. The idea behind the research was that it should, first of all, be useful to the people under study. CCF has undergone a considerable expansion in the last year and in-depth research that could cover these topics resulted of interest to the administration.

Archival Research Methodology

“Documents are the most despised of all ethnographic subjects”


Bruno Latour’s comment cited above sheds light on a common sentiment among anthropologists, especially applied anthropologists, towards the inclusion of historical research within ethnological studies. Many applied anthropologists justify this lack of interest by appealing to time and budget constraints or lack of interest of financial supporters or organizations that requested the investigation. The pressures and constraints within applied anthropology are, in some cases, different to those carried out in affiliation to academic institutions; however, the distaste for methods like archival research also leads applied anthropologists to not establish the importance of historical documents in their research design and to not defend this perspective to their “clients”. Furthermore, the dehistorization of applied anthropology is linked to the political economy of the discipline where, in many cases, historical analysis sheds light on issues that go against the interests of financial supporters. I do not wish to provide an in-depth examination of
this issue and why I consider it ethically challenging. At this point I will just state the problematic in the attempt to justify my inclusion of historical research in this thesis.

I do not visualize history as a perfectly constructed narrative that can explain contemporary problems and shed light on their solutions, as history is composed of many, usually contradicting, histories, muted voices, and overlapping events (Trouillot 1995, 2003). I also recognize that there are many methodological concerns when trying to interpret data outside of the original timeframe, but as Sigerist, a medical historian at Johns Hopkins, indicated in 1952, “Every historical pattern we set up is to a certain extent artificial and history never repeats itself unaltered. But patterns are useful because they help us to understand conditions” (Sigerist in Navarro 1976:38). History can help us understand the conditions that enable the reproduction of exclusionary systems of healthcare, the propagation of the same diseases for hundreds of years, and the proliferation of inevitable deaths. History can indicate how specific categories of citizens are created (women, children, foreign, criminal, etc.) and incorporated into government programs and policies.

For this portion of the thesis research, three main sources of information were consulted. First, the Archivo General de la Nacion was visited in order to analyze the records from the collection titled Instituciones de la Sociedad de Beneficencia y Asistencia Social (1823-1952). This collection contained information on the work carried out by the Sociedad de Beneficencia (Beneficence Society), an organization that played an important role in the institutionalization of childhood through its promotion of education campaigns and the administration of healthcare facilities. Original documents were consulted regarding two pediatric hospitals and three institutions that focused on
children. The goal behind this part of the research was to obtain examples of the involvement of non-governmental actors in the creation, regulation, and transformation of the Argentine health system, and specifically highlight their participation in the education and treatment of children. Table 1 indicates the specific sub-collections reviewed and the documents analyzed in each of them.

Table 1. Documents Consulted from the Collection “Instituciones de la Sociedad de Beneficencia y Asistencia Social”

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Years consulted</th>
<th>Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gov. decrees</td>
<td>Creation of the Sociedad</td>
<td>1823</td>
<td>Official government decrees establishing the creation of the Sociedad and its responsibilities.</td>
</tr>
<tr>
<td>Casa de Expositos</td>
<td>Infrastructure</td>
<td>1852-1946</td>
<td>Documents concerning the remodeling of healthcare facilities and the purchase of medical equipment.</td>
</tr>
<tr>
<td>Casa de Expositos</td>
<td>Training</td>
<td>1920-1921, 1947</td>
<td>Creation of training programs and schools for physicians and child care specialists.</td>
</tr>
<tr>
<td>Sanatorio Maritimo</td>
<td>Infrastructure</td>
<td>1915-1924, 1932-1949</td>
<td>Documents concerning the design of facilities in order to care for children with terminal diseases (especially tuberculosis).</td>
</tr>
<tr>
<td>Hospital de Ninos</td>
<td>Personnel</td>
<td>1875-1947</td>
<td>Hiring of physicians, rules of operation for the hospital, training of healthcare professionals.</td>
</tr>
<tr>
<td>Hospital de Ninos</td>
<td>Infrastructure</td>
<td>1930-1931, 1938-1939</td>
<td>Changes in the organization of the hospital, its staff, and the patients.</td>
</tr>
<tr>
<td>Institution</td>
<td>Section</td>
<td>Years</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------</td>
<td>----------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Solarium Mar del Plata</td>
<td>Infrastructure</td>
<td>1915-1947</td>
<td>Documents concerning the design of facilities in order to care for children with terminal diseases.</td>
</tr>
<tr>
<td>Asilo Saturnino Unzue</td>
<td>Infrastructure</td>
<td>1918-1949</td>
<td>Documents concerning the design of facilities in order to care for children with terminal diseases.</td>
</tr>
<tr>
<td>Asilo Saturnino Unzue</td>
<td>Normative code</td>
<td>1918-1949</td>
<td>Documents concerning the changes in rules to deal with sick children.</td>
</tr>
<tr>
<td>Consejo Medico Personnel</td>
<td>Personnel</td>
<td></td>
<td>Documents regarding the hiring of physicians.</td>
</tr>
<tr>
<td>Consejo Medico Personnel</td>
<td>Personnel</td>
<td></td>
<td>Documents regarding the traveling of physicians to European countries and the United States.</td>
</tr>
<tr>
<td>Consejo Medico Training</td>
<td>Training</td>
<td></td>
<td>Documents regarding the medical courses taught in the Sociedad’s institutions.</td>
</tr>
</tbody>
</table>

The research at the Biblioteca de la Facultad de Medicina focused on obtaining information on the origins of pediatric medicine in the country and abroad; the publications of the most important pediatricians; and the transformation of health policies over the years. Emphasis was placed on the documents produced from 1870 to 1940 as these decades are thought to have been the most important in the establishment of pediatric medicine as a legitimate medical specialty in Argentina (Colangelo 2008;
Rodriguez 2006). Table 2 indicates the categories of documents that were most important in the elaboration of the thesis.

Table 2. Documents Consulted at the Biblioteca de la Facultad de Medicina, Bs.As., Argentina

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Years consulted</th>
<th>Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidemics</td>
<td>Cholera</td>
<td>1856-1895</td>
<td>Public health measures directed at the cholera epidemics of 1867 and 1869 in Argentina</td>
</tr>
<tr>
<td>Sanitation</td>
<td>History</td>
<td>1776-1810</td>
<td>The creation of sanitation policies and infrastructure in Buenos Aires.</td>
</tr>
<tr>
<td>Medicine</td>
<td>History/Women</td>
<td>1823-1950</td>
<td>The role played by the Sociedad de Beneficencia.</td>
</tr>
<tr>
<td>Medicine</td>
<td>History/France</td>
<td>1876</td>
<td>Analyzed excerpts from medical conferences in France about pediatric institutions.</td>
</tr>
<tr>
<td>Medicine</td>
<td>History/Oncology</td>
<td>1500 B.C.-1750, 1800-1941.</td>
<td>These publications reviewed the history of cancer and its treatment.</td>
</tr>
<tr>
<td>Pediatric medicine</td>
<td>History</td>
<td>1873-1982</td>
<td>Identification of pediatricians, schools, and hospitals.</td>
</tr>
<tr>
<td>Pediatric medicine</td>
<td>History</td>
<td>1939</td>
<td>Speeches and conferences speaking in favor of pediatric medicine.</td>
</tr>
<tr>
<td>Pediatric medicine</td>
<td>Oncology</td>
<td>1959, 1960</td>
<td>Identify the history and main advances in pediatric oncology treatment in Argentina.</td>
</tr>
</tbody>
</table>
Finally, at the Biblioteca Nacional, published documents were analyzed in order to obtain information about the history of oncology and the work of non-governmental organizations in Argentina. This collection contained more recent publications from physicians, social scientists, and government officials, thus allowing me to obtain information on the current context of the provision of healthcare and non-governmental involvement.

*Ethnographic Methodology*

“[…] ethnography must redefine itself as that practice of representation which illuminates the power of large-scale imagined life possibilities over specific life trajectories” (Appadurai 1991:200).

The ethnographic portion of this thesis was designed in such a way that it could bring together all of the concepts that have been discussed so far. As Appadurai’s quote indicates, the ethnography carried out for this research tried to look at global processes from a local lens highlighting the specific textures, colors, and flavors that make the Argentine context particular. The recollection and analysis of data focused on explaining how macro political and economic processes are experienced in micro contexts, that is, in everyday life. This is useful because, as Gledhill has indicated, “the study of such micro-
political processes can, therefore, both illuminate particular local situations which might otherwise remain somewhat obscure, and contribute to an understanding of how processes at a local level not only reflect larger political processes and national-level conflicts, but may contribute to them” (2000:128).

Pediatric oncology treatment in Argentina is therefore studied in particular historical timeframes and spatial orbits, but it is always linked to previous stages and events taking place around the world. In doing so, medical thought and practice are understood as transnational political procedures that can transgress time and physical boundaries, but at the same time acquire attributes that are particular to the individuals that exert and receive medical care. The combination of archival and ethnographic research facilitated this task. The ethnographic research lasted three months and it was organized according to three main methods of data collection: structured-open ended interviews, participant observation, and social interaction diagrams.

A total of thirty staff members from different areas of the organization (administration, volunteers, coordinators, social workers, psychologists, and office personnel) were interviewed. The sample was selected in such a way that members from all of these areas could be included. Specific “representatives” of each category were selected according to their availability and desire to participate in the study. The interviews were mainly carried out in three of the organization’s sedes: Mansilla, Hospital de Elizalde, and Hospital Posadas. The first sede, is located in the central part of the city and it receives pediatric hemato-oncological patients from all hospitals. The administration and one of the largest recreational rooms are located here. By recreational room, I mean an area designated for carrying out workshops and games with the children.
These rooms are equipped with educational and recreational material for children of different ages. The second sede, is a recreational room inside the Hospital de Elizalde, the oldest children’s hospital in the country. The last sede corresponds to a small section in the pediatric oncology ward of the Hospital Posadas. During my fieldwork, I divided my time evenly between these three sedes, spending approximately one month in each. The interviews were composed of five questions that because they were designed in conjunction with the NGO administration, could provide information that would be most relevant to the organization. The interviews covered the following topics:

- Reasons why the staff members were interested in working in this organization, with children, and with oncology patients.

- Description of the range of activities they carried out on an everyday basis.

- Previous or simultaneous work in other sedes of the same organization or other organizations.

- Challenges they face when working in this particular NGO and ways in which they have overcome them.

- Recall of specific situations during the time they have worked within the organization that generated either positive or negative feelings in them (cases of specific children, relation to other staff members, encounters with parents or hospital personnel, etc.).
• Internal communication assessment: who do they interact with the most? Who do they turn to for advice? Do they frequent other staff members outside of the organization? How would they rate the measures for enhancing internal communication that the organization has?

• Demographic information: age, occupation, civil status, years within the organization.

At the end of each interview, interviewees were asked to make a diagram where they indicated how they positioned themselves within the organization. The same directions were given to each interviewee in order to compare the diagrams during the analysis phase. The work of McCarty et al. (2007) was used as a model for the elaboration of these diagrams. These authors made an analysis of personal network visualization based on the evaluation of alter pairs compared to freestyle drawings the respondents made of their personal networks (McCarty et al. 2007). In this investigation, the idea behind requesting the diagrams was for each interviewee to situate themselves graphically within the Foundation, drawing the people with which they interacted the most (closer to them) and the ones with whom they interacted the least (farthest away).

Participant observation was carried out in the three sedes where staff members were interviewed. The observations focused on obtaining information on:

• The interaction of staff members among each other, healthcare professionals, children, and their families.

• The hospital conditions under which staff members work and the difficulties they face.
• The specific cases of children and their families, the ways they experienced treatment and their perception of the services provided by the NGO.

_Data Analysis_

The documents consulted during the archival research phase were digitalized due to the fact that the archives did not allow photocopying. The jpeg files were downloaded, classified, and analyzed with Atlas ti 5.0. This software allowed me to code the documents as if they were images, identifying the fragments of the texts that were of greater use to the research. Some of the general themes that led the data analysis were:

- Identification of the role of the Sociedad de Beneficencia in: medical training, creation and administration of infrastructure geared towards the provision of pediatric medical care, and production and dissemination of medical knowledge.

- Identification of ideas about children and childhood maintained by the Sociedad and healthcare professionals.

- Determination of ideas regarding children, childhood, and medical attention used by the State.

- Description of the history of pediatric medicine in Argentina by looking particularly at the linkages with European pediatric medical schools, the role of non-governmental actors, and the role of the State.
• Selection of bibliographical information on some of the most famous pediatricians in the country, specifically the history of their medical careers in Argentina and abroad.

The structured open-ended interviews with volunteers were recorded and transcribed. The transcripts were also analyzed using Atlas ti 5.0. The coding focused on identifying excerpts of information that were related to the following points:

• Reasons why volunteers enter the organization and why they remain.

• Main activities carried out during a normal day of work.

• Difficulties faced by NGO staff members when dealing with other staff members, the NGO administration, healthcare professionals, children or their families.
  
  o Communication barriers
  
  o Inability to handle the emotional load of working in this context
  
  o Lack of training and supervision
  
  o Unequal working conditions among sedes

• Suggestions proposed by interviewees for dealing with the difficulties they face.

As it was mentioned before, each interview concluded with the elaboration of a diagram representing the place the volunteer felt he/she occupied in the organization and the interaction experienced with other staff members. The diagrams were also digitalized.
and analyzed by Atlas ti 5.0. They provided important information on the level of interaction and communication that takes place among the staff, as well as, the conceptualization of the organization made by each individual and the role they play within it. The following points were identified in each drawing and were then used to guide the comparison of all the drawings made in each sede and among sedes:

- How many sedes are identified by the interviewee?
- Which staff members within and outside the sedes are identified?
- What place do the identified individuals occupy in the drawing? (are they close, far, etc.)
- What type of organization does the NGO have in the drawing? (hierarchical, equitable, indefinable)
- Which actors or sedes are not identified in the drawing?
- Besides staff members, do other actors appear in the drawing? (i.e. children, families, doctors, etc.).

An issue that I think is important to mention refers to the translation of the names of places and quotes from interviews and historical documents. As it will be apparent in the following chapters, the names of places and organizations like the Sociedad de Beneficencia are maintained in Spanish to avoid confusions. Individuals familiar with Argentine history or its contemporary institutions would feel lost if these names were literally translated into English. The Children’s Cancer Foundation is used in English due to the fact that it is a fictitious name. The interviews and document fragments were
translated into English paying close attention to the context in order to avoid the errors that could be produced by a strict literal translation.

**Data Interpretation and Dissemination**

All of the information collected throughout the data collection process was then summarized and drafted into a report. A report had been promised to the administration of the organization after the termination of the fieldwork. Once the report was drafted, however, I met with each interviewee one last time and after obtaining their consent, I presented the report to them. I gave them a summarized oral presentation of it, showed edited versions of the diagrams, and allowed them to read through the report. Afterwards, I asked them for their feedback.

I wanted to know if my interpretation of what they had told me during the interviews and what they had drawn were adequate and accurate. My preoccupation was fueled by previous anthropological literature that has shed light on the misrepresentation and misinterpretation of the people under study. In order to deal with this situation, I followed the example of Borland (1991) and sought to broaden the dialogue with my informants on the material that I collected once my interpretations were made. As Borland has indicated, “By extending the conversation we initiate while collecting oral narratives to the later stage of interpretation, we might more sensitively negotiate issues of interpretive authority in our research” (1991:532). Therefore, I collected information

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21 By edited I mean versions where the names of the interviewees that made the drawings and any other information that could identify them was removed.

on the feedback provided during these second meetings with the interviewees and included it in the final version of the report that was turned in to the NGO administration. Thanks to this feedback I was able to resolve issues of misinterpretation and turn in a richer report. Furthermore, these second meetings with interviewees allowed me to carry out a personalized transmission of the information collected through the research to each person interviewed.

The final report was turned in to the five members of the administration and personalized meetings were held with each of them in order to answer specific questions. Afterwards, a formal presentation of the findings was held with all NGO staff members where questions and comments were presented in an open-forum format. Currently, four months after the termination of the fieldwork, I am still in contact with the NGO staff and work towards explaining and expanding the information included in the report.

**Ethical Considerations**

In order to ensure the correct application of the ethical guidelines established for anthropological research, the following measures were taken. The research proposal was analyzed by the president of CCF and authorization for the research was granted prior to the solicitation of approval from the academic committee and the Institutional Review Board (IRB) at the University of South Florida (USF). Once the final proposal was drafted and approved by the committee, an application for the IRB was submitted and the research began after the approval of the proposal by this institution. Throughout the fieldwork investigation, the guidelines proposed by the AAA, SfAA, and USF IRB were
followed carefully in order to provide the necessary protection to the research study participants (AAA 1986; IRB 2007; SfAA 2007).

Limitations of the Study

Several measures were taken through the research and writing processes to ensure that this investigation would be comprehensive and representational of the views and perceptions of the people under study. Even though this research was carried out without major complications, there are still some limitations that need to be addressed. For example, the time available for research (total of 3 months) did not allow me to interview all of the members of the organization that I would have liked to. I think that interviews with the Board of Directors and people that act as consultants for CCF could have provided useful information for understanding the internal working mechanisms of the organization.

More time for field research could have also allowed me to make a follow-up of the staff members’ perceptions and attitudes towards particular children in order to see their response to the different stages of the patients’ treatment. The shortage in time (and resources) was also felt in the archival research phase as my work within each archive had to be negotiated with time allocation for interviews and participant observation. The fact that in one of the archives I was not allowed to photocopy or photograph any of the documents and had to copy everything by hand further delayed my research. A positive aspect was that I did not experience as many labor strikes (only 3) as I had anticipated and therefore the research did not suffer in this sense.
Fieldwork Setting

In order to understand the information presented in the following chapters, I feel it is necessary to present a general background of the setting where the fieldwork took place. I have organized the section in order to provide information about Argentina and its history, specifically the areas related to the structure of its public health system and the establishment of a governmental interest in children. Due to the fact that any country’s history is actually the combination of multiple histories, where “official” accounts and muted voices intertwine to create specific configurations of public memory, this narrative of Argentine history is partial and biased. It includes a general view but focuses on the specific events and discourses that I consider most characteristic of the country and its people and that I believe are more directly related to the topic under study.

Argentina is located in the southern cone of South America. The first Spanish expeditions landed here in 1516 and encountered groups like the Diaguita, Pampas, Querandi, Huilliche, Mapuche, and Tehuelche that had populated the area for centuries (Rodriguez 2006:11). The encounters between the Spanish settlers and local groups were not peaceful; in fact this tension would remain until the government-organized genocides of the 1880s. Pedro de Elizalde founded Buenos Aires in 1536, a city that would grow considerably from the 1500s to the 1700s when the Virreinato del Rio de la Plata (Viceroyalty of the River Plate) would gain autonomy from Peru.

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Independence was obtained from Spain in 1820, but consecutive civil wars kept the country in almost permanent state of violence. Internal struggle was the product of power competition between elites and the confrontation of different ideas regarding the construction of Argentina as an independent nation headed towards “progress”. Within this idea of a “successful” country only certain types of citizens were considered. This is one of the reasons why the large amount of Afro-Argentines that populated Buenos Aires during colonial times are hardly included in depictions of the country’s history (even if they represented a third of the population at the time). It also explains why local ethnic groups were purposely erased from historical imagery, museum expositions, and historical reconstructions of Argentina (Anderman 2007). Furthermore, it explains the elites’ attitudes towards certain immigrant populations (especially Italians and Spaniards) during the migration waves of the late nineteenth century (Rodriguez 2006).

As we will see in Chapter Four, these ideas on the construction of a newly emerging country permeated the production of public institutions like the educational and health systems, creating frameworks designed for the disciplining and exclusion of particular individuals (Armus 2007; Rodriguez 2006). These processes were mainly headed by government institutions, but as we will see in the next chapter other types of civil society organizations like communal groups, charities, and beneficence societies played an important role as well.
Chapter 4

The History of Pediatric Medicine in Argentina: the Role of the Sociedad de Beneficencia

“The body is a biopolitical reality; medicine is a biopolitical strategy”

Foucault (1994:137)

NGO Involvement in the Provision of Healthcare Services

Contrary to what the contemporary literature on non-governmental organizations in Argentina stipulates, non-governmental actors have always been present in the delivery of healthcare. A quick look at charitable associations, mutual help organizations, groups based on occupation and nationality, and beneficence societies will demonstrate that these groups were actively involved in the design, creation, and administration of the infrastructure of the public health system, the implementation of campaigns and programs, the training of professionals, and the dissemination of medical knowledge.

The purpose of this chapter is to shed light on the role played by one of these actors, the Sociedad de Beneficencia, in the medical institutionalization of children. As other authors have established, “the paradigm of the Sociedad de Beneficencia has permeated the practices of many non-governmental organizations until today”
(Thompson 1995:35), so an in-depth analysis of their active involvement in the creation of an extensive medical infrastructure, participation in the establishment of pediatric medicine as a legitimate discipline, and the institutionalization of children is fundamental if we are to understand how and why contemporary NGOs oriented towards the medical treatment of children work the way they do. Furthermore, many of the institutions that were once administered by the Sociedad continue to provide medical attention to children from all over the country and part of the ethnographic portion of this investigation was carried out in one of them. Therefore, a historical review of the Sociedad and the impact of their work on society as a whole sets the tone for the following chapters.

The specific ways in which the Sociedad de Beneficencia contributed to the establishment of pediatric medicine will be explored and their actions will be linked to larger processes that were taking place nationally and internationally regarding the conceptualization and treatment of children. Special attention will be paid to the activities the organization carried out at the end of the nineteenth century and beginning of the twentieth century (approximately 1870s to 1930s) due to the fact that the largest efforts of the State to institutionalize and medicalize childhood took place around this time, and the Sociedad abandoned its more “educational” perspective and incorporated a more obvious medical orientation during this period. Furthermore, the Sociedad de Beneficencia’s work after the 1930s was heavily reduced due to different political pressures ending in its complete dissolution in 1947.  

25 The Peronist state used the centralization of social beneficence and assistance as one of its most important populist political tools. All private beneficence societies and groups were dissolved and this work was absorbed by the Fundacion Eva Peron (Biernat and Ramacciotti 2008).
The Sociedad de Beneficencia

The Sociedad has received different labels from researchers. Some have referred to it as a “quasi-governmental ladies’ charity organization” (Rodriguez 2006:105), while others have described it as “as a private entity created by the State to undergo public functions” (Thompson 1995:26). An adequate assessment of the type of organization that the Sociedad was generates problems because they had an obvious link with many government institutions in terms of funding, use of infrastructure, and decision-making, as it will be seen throughout this chapter. By shedding light on the disagreements among researchers on whether the Sociedad was geared more towards the governmental or non-governmental sector, this chapter attempts to turn the attention of the reader to the arbitrariness of making this distinction in the first place. It points to the difficulties of establishing an adequate analysis of the State and the ways in which it permeates our everyday life and leads us to question the idea that NGOs can actually represent “alternative forms of operation”.

This issue has been established within the literature on NGO involvement in the provision of healthcare. In an analysis of the potential of non-governmental participation in the health sector Gilson et al. (1994) indicated that “interaction between NGOs and government is inevitable” (1994:19). For instance, NGOs must in many cases obtain certification or licenses from government institutions, public health management teams incorporate NGO representatives for specific activities, government institutions provide funding in the form of subsidies for NGOs, and some governments devise strategies to supervise the programs implemented by non-governmental actors (Gilson et al. 1994).
The information in this chapter shows that the relationship between the Sociedad and the government was heterogeneous and suffered transformations through time. The different administrative boards of the Sociedad and the government officials in office maintained a wide range of viewpoints on the role that this organization should play in the medical treatment of children, sometimes ending in conflict and other times, in collaboration. Therefore, instead of trying to establish an adequate label for the Sociedad, I find it highly important to describe the measures that this organization took to contribute to the institutionalization of children and the legitimating of the medical profession. I wish to explain the ways in which the Sociedad both operated according to government models and utilized models that were foreign to the State.

This organization of women was created in 1823 when Bernardino Rivadavia, the President at the time, issued a governmental decree. In this document he established that: the organization titled Sociedad de Beneficencia would be legally recognized by the secretary of government; the attributions of this society would be to direct and inspect the Girls’ schools, Casa de Expósitos, birthing houses, women’s hospitals, orphanages and every other institution directed at women.; six hundred pesos a year would be provided to this society from the reserved government fund; and three thousand pesos would be destined to the girls’ schools (Archivo General de la Nación 1999:13). The first members of the Sociedad were thirteen women from the upper class who came to be called “the first thirteen”\textsuperscript{26}.

\textsuperscript{26} The first thirteen were: Mercedes de Lasala y Riglos, Maria de la Concepción Cabrera de Altolaguirre, Isabel Casamayor de Luca, Joaquina Izquierdo, Cipriana Viana de Boneo, Manuela Aguirre de García, Josefa Gabriela Ramos Mexía, Isabel Agüero de Ugalde, Maria Sánchez de Mendeville, Bernarda da
The Sociedad remained an all women’s organization during the entirety of its existence. The care of children, the elderly, other women and the sick became an important element in the role women played in society. Their involvement in this range of activities can be viewed as an important gain in their participation in the decision-making processes that took place in the public sphere, while at the same time it can be interpreted as the naturalization of their role as caretakers and benefactors, and their seclusion from other, more effective, areas of social direction and administration (Tenti Fanfani 1989). Furthermore, as Thompson has indicated, “female centrality in beneficence activities had little feminism and a lot of elitism” (1995:27) as the women allowed to participate in these organizations came from the highest social classes. This issue has been discussed elsewhere\textsuperscript{27}, so the only thing that I will say is that many other organizations in charge of providing social assistance\textsuperscript{28} adopted this same model; even CCF maintains an almost all female staff and has a difficult time incorporating male volunteers.

The creation of this Society is related to larger issues that were taking place in the country in terms of the provision of social assistance. On the one hand, restructuring was taking place since the country had not been independent for long. On the other hand, Pres. Rivadavia had passed the Law on the Reform of the Church just one year before.


\textsuperscript{28} Some of the most important ones are: Conferencias Vicentinas de San Vicente de Paul (Recalde 1991), Asociación Conservación de la Fe (Association for the Conservation of the Faith (Recalde 1991), Fundación Eva Perón, Amalia Fortabat, and even the Madres of Plaza de Mayo (Thompson 1995).
This law removed all assets and privileges from religious congregations, and consequently, terminated most of the charities that had provided healthcare and educational services to the population\(^\text{29}\). The Beneficence Society was apparently created to fill these gaps (Thompson 1995). In a report made the day that the Beneficence Society was officially installed, Rivadavia was quoted saying

“the force of the revolution [independence] in the country had corrupted the moral; due to the fact that men had been forced to move from one place to another only caring for their own ambition and partial interests; the revolution itself had not allowed them to take care of such a primordial object [women], and in reality, due to this, the country was in real chaos. […] the Society should use their work to fill this void and build the structure over which the public moral should be elevated” (Archivo General de la Nación 1999:15).

The “elevation of the public moral” would mainly entail two activities: the creation of a healthcare infrastructure and the education of the population. The infrastructure developed by the Beneficence Society was impressive considering that most of their work was done with unstable economic support\(^\text{30}\). The system elaborated by the Sociedad achieved such complexity that entire networks pertaining one disease were built. Furthermore, they developed methods for the recollection of statistical information pertinent to each institution. Detailed documentation took place at each hospital focusing mainly on the entry of patients, the number of deaths, and the number of patients that remained in care at the time.

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29 The most important religious organizations or congregations that provided social assistance to the general population at this time were: The Bethlemite Order, Hermandad de la Santa Caridad (Holy Charity Sisterhood), and the Jesuits through their Compañía de Jesús (Company of Jesus) (Thompson 1995:21-24).

30 At the archive there are several letters of the president of the organization demanding from different public officials the funds that were promised for education programs, architecture projects, and payment of salaries.
Although one cannot deny that these services were necessary at the time and they improved the living conditions of the population, it is important to mention that the government might have had different motives for the creation of the Sociedad de Beneficencia, directing their efforts to issues that were “politically required”. In other words, the period when the Sociedad had greater governmental support and when most of its larger projects were implemented, was a time when important ideas on nation-building prevailed around intellectuals and political authorities. Rodriguez (2006) explains that within a country characterized by a high level of ethnic heterogeneity, ideas regarding national identity that could unite the entire population were necessary. Government institutions and other organizations like the Sociedad played an important role in disseminating ideas about what Argentina should be like and what it meant to be Argentine.

From 1876 onwards a significant transformation occurs in the approach used by the Sociedad in working with children. In this year, a law was passed in Argentina indicating that all schools had to depend on the Consejo General de Educación (General Education Council) and, therefore, the Sociedad had to transfer all of the schools that were under their administration to this governmental institution (Ortiz 1990:37). Issues such as this one had generated conflicts between the leaders of the Sociedad and important public officials for some time. For example, when Sarmiento (General Director of the School of the Province of Buenos Aires) published the “Second Report of the Department of Schools”, Mariquita Sanchez (the Sociedad’s president) replied:

“What a bad hand my old friend has played on me this time with this dark report against this poor Sociedad […] You criticize us because we do not make innovations, and among all of your evolutions, you provide the
saddest result where in your Model School only one permanent discipline remains. Your ingenuity is precious [...] and in a land where men are always at civil war, don’t you believe that it is useful for women to care for these establishments of charity and education of their sex? [...] You are unfair, are not satisfied with politics and boys and want to fight with women; and you do not know how bad an enemy they are! [...]” (Ortiz 1990:38).

Authors like, Ortiz (1990), have indicated that after being dispossessed of their schools, the Sociedad concentrated all of their attention on social beneficence and healthcare. This so called “medical facet” of the Society began around the late 1870s. Without disproving Ortíz’s (1990) point, it is probable that the Sociedad’s decision to change approaches was also influenced by larger issues taking place in Argentina that referred to the regulation of society, its medicalization, the reproduction of the labor force, the creation of a suitable healthcare infrastructure, and changes in the conceptualization of childhood that were taking place worldwide.

The Institutionalization of Childhood

“I do not understand why the child, being the condensation of our illusions and the realization of our hopes, the live and essential motor of progress and the animator of the entire Universe; receives so little attention from Men, Peoples, and Governments” (Rueda 1937:3).

A large portion of the literature produced within the anthropology of childhood has demonstrated that the modern representation of childhood as another stage in the lifecycle emerged in Europe between the fifteenth and eighteenth century31. Notions

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31 In order to see specific historical reconstructions of childhood elaborated from an anthropological point of view, refer to Haas (1998) who carried out a study on the historical transformations of labor in Italy; Rosalind and Janssen (1996) have provided an excellent description of the games, rites of passage and
about the nature and special needs of children demanded attention to their emotional
development within the home and the instauration of a system of formal education that
could prepare them for their transition into the adult world (Aries 1962; Stephens 1995;
Scheper-Hughes 1987; and Scheper-Hughes and Sargent 1998).

Through time, a large quantity of institutions contributed to the generalization of
childhood (schools, the health system, the judicial system, etc.), first among western
societies, and consequently, through colonialism and subsequent processes of
globalization, in non-western societies as well (Aries 1962). Therefore, the changes in
the representation of childhood have always been linked to greater political and economic
transformations (Stephens 1995).

In the case of Argentina, several authors agree that the State’s concern for
children and modern ideas on childhood were introduced in the end of the nineteenth
century (Biernat and Ramacciotti 2008; Colangelo 2008; Rodriguez 2006). Even though
the country had institutions dedicated to the care of children well before this time period,
it is from the 1880s and beyond that children become a clear “project of the nation”32.
This transformation in public policy has been attributed to several factors.

According to Rodriguez (2006), the evolutionist ideas that became popular in the
work of a great deal of the professionals involved in the design and implementation of the
scientific, educational, and sanitary systems of the time played a fundamental role in the

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32 Some of the previous institutions that I am referring to here is the Casa de Expósitos created by the
Viceroy Jose de Vértiz in 1779 and the different facilities and institutions administered by the Sociedad de
Beneficencia since its creation in 1823.
institutionalization of childhood. Herbert Spencer’s *Individual Against the State* gained a lot of attention around this time as people were taken with his ideas on the care of offspring among the higher species and the importance of the reproduction of the human species for the general advancement of “the race” (Mead 2001:115; Rodriguez 2006). Jose Ingenieros, a criminologist and psychiatrist, was one of the main supporters of these ideas and was responsible for introducing them among Argentine scientists (Rodriguez 2006). These and the religious ideas that had been prevalent since the colonialization of the country made institutions like marriage and motherhood the main focus of political authorities. This approach led to a greater participation of medicine in the regulation of families by using an image of children as the future citizens of a nation and proof of “a race that was directed towards progress” (Rodriguez 2006:115).

During the last decades of the nineteenth century, the high child mortality index (Biernat and Ramacciotti 2008; Rodriguez 2006) and the low birth index (Nari 1996) became public concerns. During a time when Argentina looked incessantly towards Europe in order to obtain recognition and as a source of inspiration, the reduction of this mortality and the population of the country entered the political agenda. One of the reasons infant mortality became a serious concern was that this index was used as an international marker of the state of a country’s health (Nari 1996). Argentina needed to prove to the world that it counted with the necessary infrastructure to sanitize and educate its population, and reproduce its labor force.

The low birth index also became an interest to the State, but for other reasons. As Nari has indicated, “Quantity-quality was one of the axes that cut through the medical discourse of the time, emphasizing the controversial issue of purposely raising the
amount of births, while at the same time improving the quality of the race” (1996:155). This phenomenon was linked with the diffusion of the evolutionist ideas mentioned before and the introduction of eugenics (Rodriguez 2006). According to this school of thought, human capabilities, talents and propensity to disease are hereditary and the improvement of the “white” race must be achieved by reproducing certain individuals or groups classified as “superior” and inhibiting the reproduction of people deemed “inferior”. Argentine eugenics had a strong neolamarckian influence because it established that the morphological and functional characteristics of individuals could be modified by the social and natural environment and then be hereditarily transmitted and integrated into the genetic pool (Biernat and Ramacciotti 2008; Miranda and Vallejo 2005).

Several authors have indicated that the immediate result of production and dissemination of these ideas was the transformation of the role of women within the national imagination associating them with motherhood. “The new ideal of the mother was presented as universal, ahistorical, natural” (Nari 1996:154). A large portion of the assistance programs that were created at this time focused on making women conscious of the instinctive quality of motherhood and the mother-child binomial therefore explaining a social relationship based on biological characteristics (Biernat and Ramacciotti 2008:333). Infanticide, the abandonment of children, and adultery became penalized and the insertion of women into the labor market was seen negatively as it would drive them away from their “duties as mothers” (Biernat and Ramacciotti 2008).

In order to promote “proper” motherhood, the Argentina State relied on the schools of puericulture and, later on, pediatric medicine developed in Europe and the
United States. The ideas that revolved around childhood would gradually start to change, as it began to be represented as a unique stage in the lifecycle; a stage that had to be regulated by the State, through the health system.

The Professionalization of Pediatric Medicine

“We must save from the cradle the future of a homeland in danger” R. Gutierrez (Sociedad de Beneficencia 1910:331).

The literature that has historically explored the institutionalization of childhood in Argentina has either studied it within the educational system, the judiciary and penitentiary system or through the creation of institutions dedicated to the care of abandoned children. These authors have provided valuable information in order to understand the political uses of the category of childhood, the negotiation of its meanings and representations, and the role of the State in the regulation of individuals. However, in these narratives, the transformations that took place within the health system tend to occupy a secondary role.

As we mentioned before, at the end of the nineteenth century several factors led to the enhancement of the public interest in children, their development, and well-being. These transformations were part of larger attempts to populate a relatively “empty” country, regulate large masses of incoming immigrants, and create ideal types of citizens. The migrant population entering the country at that time was thought to contain bad habits (Rodriguez 2006). Their children were seen as “blank slates” and were therefore targeted as a way to homogenize the population and create a “civilized” country that could move towards progress, like the above quote by Ricardo Gutierrez, a famous Argentine pediatrician, indicates.
This emphasis on homogenization formed the base of both the health and educational system. In an article written in 1920, physician Eleodoro Gimenez mentioned that “education can correct the influence of the family environment in all cases; therefore it is desirable that children’s education should be controlled by the State, whose functionaries, shaped by science for life, are capable of modifying the dark shades that contemporary reality offers to children of various means.”

Immigrant parents were considered unsuitable for raising “proper citizens” and even though their children appeared most important to the nation, parents also needed to be “regulated”. Therefore, several of the institutions created by the Sociedad de Beneficencia were directed at either educating or punishing mothers. Casas de Depósito (healthcare and welfare institutions) like the Women’s Hospital (Hospital de Mujeres) or religious institutions like the Spiritual House served to contain women that had failed at their domestic roles, committed abortion, infanticide, or adultery (Rodriguez 2006:105).

This investment in infrastructure and human resources was also geared towards children as pediatric medicine began its establishment as a separate medical specialty. As Colangelo has indicated, “towards 1900, in the framework of local processes of the construction of childhood as a social problem, but at the same being part of an international movement, certain doctors began to configure their professional identity in terms of children’s doctors or pediatricians” (2008:2-3).

The consolidation of pediatric medicine in Argentina was the product of the incorporation of ideas on puericulture and pediatrics that were generated in Europe at that

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time, especially in France and Germany (Rodriguez 2006). There are a large number of publications made by doctors, among them the first Argentine pediatricians, which reference the work that was being carried out in these countries (Herrera Vegas 1876 in Bonduel 1982; Rueda 1937; Bonduel 1942). When tracing the history of the academic program on Pediatric Medicine in Argentina, Bonduel (1942) indicates that “in its rapid and ever increasing development, Argentine pediatrics received constant beneficial influence from the great spokesmen of Europe, place where the creators of this specialty in our country acquired their knowledge. Therefore, all of the problems that shook these older schools, had an immediate repercussion in our environment” (Bonduel 1942).

*Infrastructure*

This initial pediatric medicine discourse shows a transformation from studying the manifestation of diseases on children, to studying the diseases of children (Amstrong 1998). Medicine became no longer about presenting pathologies in a smaller body, but about ways of sickening and healing that concern a subject that is qualitatively different to that of adults (Colangelo 2008:5). Therefore, different procedures for diagnosis and treatment needed to be established. The medical representation of children alternated between vulnerability and plasticity, considering them to be more susceptible to disease while at the same time more resistant and prone to recover (Colangelo 2008). The malleability of children led the medical professionals’ attention to their growth and development as their bodies were represented as incomplete and in building process. Pediatric medicine, then, was created with a strong emphasis on prevention and hygiene.
This called for the creation of a hospital that would only treat pediatric patients. The first project for the creation of the Hospital de Niños de Buenos Aires (Children’s Hospital) was presented in 1867 by Maria Josefa del Pino, president of the Sociedad de Beneficencia at the time (Meroni 1982:317). It was adopted seven years later by her successor Dolores Lavalle who accepted the position on the sole condition that the hospital be built. The hospital was inaugurated in 1875. The initiative was heavily influenced by Rafael Herrera Vegas, a Venezuelan doctor exiled in Buenos Aires, and Ricardo Gutierrez, a pediatrician who carried out his training in Europe (Meroni 1982; Kohn and Aguero 1985). Gutierrez became the first director of the hospital that today carries his name. The hospital remained under the administration of the Sociedad for fifty more years representing a valuable institution for medical education and practice.

The emphasis on prophylaxis mentioned before, along with the idea of achieving a perfect race led to the establishment of a system of classification of children (i.e. weak, undisciplined, pathological, criminal, abandoned, etc.) and the elaboration of a medical infrastructure in order to deal with them. The Sociedad incorporated this system of classification into their working dynamic speaking in favor of the institutionalization of children, and creating specific institutions to deal with each type of child, apart from general pediatric hospitals. While evaluating of the idea of establishing another institution for children, Dr. Paz sent the following letter to the Sociedad identifying previous ways of child rearing and socialization as negative forms and establishing the model of institutionalization used by the Sociedad as the perfect solution.

“Many people still maintain the idea that the life of the asyled is harmful for the physical and moral health of the child; this idea was perfectly applicable in other eras, where among large infant groupings, an improper
regime was common. Today, thanks to the undeniable advances in hygiene and preventive medicine, the asylum is on its way to not be the ghost of yesterday, and doctor as well as sociologist, work in the civilized world to improve these institutes” (77).

By this time, the Sociedad held a fairly strict protocol through which children would be allocated according to these characteristics. The following diagram provides a clearer picture of their organization.

![Diagram](image-url)

Figure 1. Diagram elaborated by the Sociedad de Beneficencia to illustrate the different institutions through which boys and girls could be canalized (Archivo General de la Nacion 1999:24).

The identification of certain groups of children as delinquent and their regulation through different types of institutions has been widely discussed in the literature. What I want to focus on is the role played by the public health system in the regulation of what were called “weak children” and the use of this classification by the Sociedad in order to justify the creation of its two coastal institutes: Sanatorio Maritimo and Solarium, as well
as the Asilo Unzué. The following excerpts illustrate the spatial separation of these children from the rest. The first one comes from one of the books of reports made by the Sociedad in 1901. The second one is a fragment from the minutes of a meeting of the Sociedad’s Congress that took place in 1923.

“The registration office is found at in the main sedes, which is also the Hospital de Expósitos. From this office, the children are taken to the Observation Area, where they remain for 15 days […]. After these 15 days, if the child is considered healthy, he is assigned to a wet-nurse who is herself under the supervision of the Medical Inspectors. After the child reaches two and a half years of age, he is moved to the Casa de Expósitos, an orphanage with a capacity for 500 children.

When the child is three years he can enter the Asilo de Mercedes, and later on –from 6 to 8 years of age- to the Asilo de Huerfanos. The girls from 4 to 5 years of age enter the Colegio de la Merced. […] Some of the convalescent and weak children are sent to nearby towns and the wet-nurse has the obligation to bring them to the Hospital once a month so that their health and growth can be observed” (Leg. 21 pgs. 317. 1901).

“The President proposed that defective children should not be sent to the Institute, but should be kept in the hands of the external ladies until they have achieved the necessary age to enter the Asilo de Retardados de Torres (Torres Asylum for Retarded) or any other adequate facility. She indicated that the ladies and their families should be examined by a doctor in order to ensure that the children are in a healthy and hygienic environment. This proposal was approved by Congress.” (exp. 862. 1923).

The term “weak” could be attributed to mental retardation, debilitating diseases like tuberculosis, or unknown terminal diseases. This request, drafted by the Dr. Adolfo Rodriguez Egana, the director of the Sanatorio Marítimo\textsuperscript{34}, makes reference to these particular concepts.

“I would like to request the elimination of the summer camp that this Sanatorium usually holds at the facilities that were originally dedicated for

\textsuperscript{34} The Sanatorio Marítimo was created specifically for the treatment of tuberculosis in children (Armus 2007).
weak children and the hospitalization of those ill with chirurgic tuberculosis for the following reasons:

1. It is against the most elementary rule of hygiene and prophylaxis to mix children that have already been tuberculized and children that find themselves in physical deficit (weak children, hereditary and organic retarded, those with infectious diseases, etc.) as they are in a state of morbid opportunity that contributes to the propagation and contagion of tuberculosis in its different forms.

2. Considering that chirurgic tuberculosis is a serious lesion and difficult to cure, necessary to fight early on, and it occupies the nosological frame of infancy, in the different cities of the Republic, and seeing that the facilities of the Sociedad de Beneficencia (Sanatorio Marítimo and Solarium) are the only ones destined to house sick people of this category in all of the nation’s territory, it is imperative for me to act according to the well-being of the Administration and try to increase the capacity of both facilities as soon as possible[…].” (San Mar Leg. 98 exp. 7988 pg. 1-2. 1923)

Armus (2007) has indicated this fear of contagiousness was partially due to the large epidemics of tuberculosis that were taking place at this time. These epidemics led to the establishment of specific institutions, like the Sanatorio Marítimo mentioned earlier, but they also generated another category of “weak” children which is what Armus has called “the pretuberculosic child”, a child whose ‘delicate constitution, weakness, anemia or depression’ turned him into a potential victim of the disease” (2007:81).

In a way, any child could become infected with tuberculosis which posed a threat to the family and the nation. “The ones born prematurely, the ones with correct weight but that inhabit in humid and unclean environments, the rickety, the chlorotic, scrufulose, lymphatic, anemic, arthritic, and all those that have close relatives that had or have tuberculosis, asma, gota, and other diseases that contribute in a conscious or unconscious way to the degeneration of the race” (Guerrero in Armus 2007:85). These ideas were

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35 It is important to mention here that around this time there were other epidemics that could have also led to this fear of contagion like for example: the cholera epidemics of 1886 and 1887, and the yellow fever epidemic of 1871 (Kohn and Aguero 1985:137).
used to justify medical intervention during all levels of child growth and development.

The incessant search for children with tuberculosis reached such a point that professionals like Coni suggested “not to confuse the weak children with the needy ones […]; the paleness, thinness, and protuberance of shoulder blades, were not accompanied by positive tuberculosis tests” (Armus 2007:85).

As soon as the idea that tuberculosis was not hereditary gained general consensus among medical professionals and politicians, government and civil society efforts turned to the analysis of the environment in which children were raised (Armus 2007:86). This shift generated transformations in the organization of the Sociedad, as its members needed to be trained in order to conduct evaluations of the homes and neighborhoods of the children under their care and potential “institutionalizable” children. The ideas on puericulture that had remained inside the walls of the Sociedad’s institutions, could now be disseminated among the general population, becoming an important element in their everyday life, and a new justification for the institutionalization of children, especially those of the lowest social classes, was established. Armus has explained this phenomenon by saying that, “If, as it was thought, the predisposition to the disease had to do with the low levels of immunity resulting in inadequate life conditions, the fortification of the bodies of the children resulted in an urgency that had to be confronted by each one of the homes or through the institutions of the State and civil society” (2007:101).

While carrying out an evaluation of the institutions of the Sociedad, Dr. Madrid Paez justified the institutionalization as follows:
“Seven children from a population of twenty died, victims of the most feared complication of measles […] because we are dealing with children that came full of defects and that had until now lived in rooms lacking hygiene, exposed to repeated and multiple forms of contagion, proof, once more, of the attention that first infancy requests from us, if we aspire to have tomorrow in our facilities, robust children unharmed by any disease that could be transmitted through the environment in which they lived their first years” (Leg. 1, Letter 14/06/1923).

Although the model of inspection was highly praised in its beginning, further evaluation by physicians continued to speak in favor of direct institutionalization:

“Dr. Madrid Paez extols the system designed to remove children from the weaning nurses based on the antihygienic environment in which these ladies live and the inappropriate nourishment that they give to the children, in spite of the inspection to which they are submitted” (Leg. 1 Acta 20/06/1922).

The emphasis placed by the Sociedad on the creation of an infrastructure that could institutionalize specific categories of children has received various interpretations. Some authors have viewed this strategy as a process of obscuration, where abandoned and sick children needed to be maintained outside of the public sphere due to the risk of physical or social contagion\(^\text{36}\) of elements deemed “immoral” by the State (Tettamanti 2007:1670). The presence of weak children represented the failure of the State, and in this case, of all other groups in charge of prophylaxis and the maintenance of social order.

Other authors have relied on more utilitarian models by shedding light on the regulatory functions of institutionalization and how individuals that would be difficult to

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\(^{36}\) When I mention social contagion, I am referring to popular ideas present at this time where delinquency was seen as a “social illness” and abandoned children were represented as vectors (Rodriguez 2006; Tettamanti 2007).
integrate in the future were socialized into “good workers” (de Gonzalez 2000). Ideas such as these are evident in the various documents that refer to children as “the future moral and material capital of the nation” (Casaubon in Armus 2007:84). This approach could certainly explain why children of the lower social classes were the main focus of the Sociedad and government programs as they would represent the largest bulk of the labor force (de Gonzalez 2000).

Another less analyzed explanation for institutionalization has been that of political conversion. Some authors have explained the targeting of “poor” children because of their representation as potential criminals, but few have talked about their representation as political agitators, especially anarchists. Rodriguez (2006) provides an excellent explanation of this situation:

“Anarchism, considered by many the most explicit challenge to landed, business, and government interests, came to be seen by the Argentine elite as the biggest peril of the 1890s. State leaders found themselves in a bind: they needed immigrants for national development and to populate their country in pursuit of national greatness, but they did not like the ideas the immigrants brought with them. Suppressing such ideas and controlling rising social conflict became crucial to national goals of successful development […]” (Rodriguez 2006:24).

The institutionalization of these potential political threats would have represented a feasible solution to future problems as the children would be disciplined according to the elite’s political doctrine and moral values. Furthermore, the extensive infrastructure of the Sociedad permitted the referral of children through different types of facilities (experiencing different levels of security) and the option of reinstitutionalization after dismissal was not rare.
Medical Education and Practical Training

The Argentine State played an important role in the establishment of pediatric medicine as a separate domain of medical knowledge and practice. Through the University of Buenos Aires (UBA), it created a suitable place for academic training, discussion, and exchange of information. Dr. Rafael Herrera Vegas, in a speech pronounced during his incorporation into the National Academy of Medicine on December 3\textsuperscript{rd}, 1876 mentioned:

“In summary, due to the fact that the study of disease in children has great importance from the perspective of science, humanity, and the homeland, it is up to the College of Medicine to make an effort to establish as soon as possible the course on children that exists in its academic program. There is no cause that can be considered an insurmountable obstacle so everyone would accept as glory the inauguration of this gender of study, after competing before the law, without any other reward at this time but to do good, hoping meanwhile, that the honorable legislators become convinced, in the same way as us, of the need to save the health and life of the children that represent the excess of our mortality […]” (Herrera Vegas 1876 in Bonduel 1982).

The professionalization of pediatric medicine began with a course in the academic program of the career in Medicine offered by the UBA under the name of Cátedra de Partos, Enfermedades de Niños y Medicina Legal. In 1883, under a decree issued by the Executive Power the Cátedra de Enfermedades de los Niños y Clínica was created and Dr. Manuel Blancas was chosen as professor. It is in 1919 that the first Cátedra de Pediatría y Puericultura, an exclusive course on pediatrics, was created at the Universidad de Buenos Aires (Meroni 1982:318)\textsuperscript{37}. This last course represented an important

\textsuperscript{37} In order to see historical reconstructions of the course refer to Bonduel 1942, Meroni 1982.
transformation in the teaching of pediatric medicine as it incorporated a preventive and hygienic aspect of medical treatment that had been absent in the other courses (Colangelo 2008).

The Sociedad de Beneficencia played a fundamental role in this process by providing a suitable place where residents interested in pediatric medicine could carry out their practices. It supported the training of pediatricians abroad, the creation of new courses on pediatric medicine, and provided facilities for medical research. This was a slow process, but by the end of the Nineteenth Century, the Sociedad had a large group of physicians and nurses as permanent staff members. A Medical Council was created. These healthcare professionals worked in the Hospitals, Asylums, and Orphanages administered by the organization. On the one hand, they were important assets in the justification of measures and activities that were of interest to the Sociedad as they provided a constant medical evaluation of their programs and facilities and this could be used to strengthen the organization’s position in the eyes of the State. On the other hand, they demanded resources and attention from the administration through their requests for personnel, the improvement of the infrastructure, and the approval of courses and professional training abroad.

Some of the fragments of letters and meeting minutes illustrate these points. In 1922, Dr. Madrid Paez, director of the Casa de Expósitos, wrote an evaluation of the organization’s model of institutionalization of orphans.

“Seven deaths occurred due to the smallpox in children of parents with tuberculosis and the contaminated environment where they lived is, without a doubt, a deplorable reality that imposes the need to unite efforts in an intense and decided prophylactic campaign that can protect some
many precious existences now in danger. If these children, instead of entering the “HOME” had remained in the houses of their wet nurses, without a doubt, they would not have made it enough to occupy a bed in the hospital; they would have fallen one by one, as the others that live outside of this facility” (Leg. 1, Letter 14/06/1923).

The Sociedad relied on the professional opinion of its doctors whenever it was necessary to change norms of operation or incorporate programs. When problems arose because of an increase in infant deaths the following measures were taken:

“Name a commission composed of pediatricians from the Hospital de Niños and Casa de Expósitos with the purpose of studying this issue and all of its details and inform the Sociedad about the most convenient solution” (Leg. 1, exp. 8621, Acta 19/10/1923).

The doctors that were part of the permanent staff also used this power to their benefit. In a letter directed to the administrators of the Casa de Expósitos, Dr. Alfredo Centeno argues that:

“This Board considers, without reserves, that the institution of medical inspectors has come to fill a large void in the vigilance of the orphans distributed in the municipality, producing palpable benefits from all points of view, but it believes that the number of doctors in charge of inspection is limited, overloading their duties, and the Sociedad would be adopting a convenient measure if they increased this service with the purpose of perfecting this important branch of the establishment” (Letter 23/02/1901).

The document presented before where Dr. Madrid Paez praises the role of the Sociedad, ends as follows:

“All that is left is for me to reiterate to the distinguished Sociedad, almost as a complaint, the request that I have made many times, of the need that our old and modest building has, of the construction of a good pavilion of isolation that can contain all of the infectious patients that are present in our Hospital in all seasons of the year, due to the fact that the
new Casa de Expósitos, is unfortunately a remote fact because of the current economic conditions of our public funds” (Leg. 1 Letter 14/06/1923).

The requests that the Sociedad hardly refused were those pertaining the dictation of courses or establishment of training programs in their facilities. Their archival collection is filled with letters written by their permanent doctors soliciting permission to use the Casa de Expósitos as an academic and training facility for both students of Medicine and licensed physicians. Dr. Pedro de Elizalde\textsuperscript{38} requested permission every time he intended to teach a course:

“I have the pleasure to address the Director in order to request the authorization to dictate during the second week of January a course on the perfection of pediatric clinical training for doctors and alumni using the elements and patients of this Hospital” (Letter directed to Dr. Cranwell, director, Leg. 2, 21/11/1921).

Dr. Cranwell’s response approved the request and justified it by stating:

“It is my pleasure to inform you of the favorable response to your request, because it is a course directed at doctors, which will allow them to recognize the benefits that our institution lends, and make use of this valuable educational material that will improve our knowledge of infant pathology” (Leg. 2 3/01/1922).

The courses that were taught in facilities of the Sociedad by 1944 are included in Table 3 with the name of the doctor in charge. As can be seen, the numbers and specificity of courses imparted for pediatricians by this time had greatly increased.

\textsuperscript{38} Dr. Pedro de Elizalde worked at the Casa de Expósitos for over 40 years, serving in different positions: medical inspector, ad-honorem physician, director of the Casa de Expósitos, and honorary ad-honorem physician. In +, the Casa de Expósitos was actually named after him. As the reader will see, the ethnographic portion of this research was partially carried out in this institution that still carries his name.
Table 3. Courses imparted in the Casa de Expositos up to 1944 (Acta 12/07/1944)

<table>
<thead>
<tr>
<th>Course</th>
<th>Doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Puericulture</td>
<td>Dr. Pedro de Elizalde</td>
</tr>
<tr>
<td>Infant Tuberculosis</td>
<td>Dr. Pedro de Elizalde</td>
</tr>
<tr>
<td>Clinical Pediatrics and Puericulture</td>
<td>Dr. Pascual R. Cervini</td>
</tr>
<tr>
<td>Infant Orthopedics and Surgery</td>
<td>Dr. Marcelo Gamboa</td>
</tr>
<tr>
<td>Ear, Nose, and Throat Clinic</td>
<td>Dr. Yago Franchini</td>
</tr>
<tr>
<td>Dermatology</td>
<td>Dr. Luis Pienini</td>
</tr>
<tr>
<td>Puericulture (primary infancy)</td>
<td>Dr. Raul Beranger</td>
</tr>
<tr>
<td>Nourishment</td>
<td>Dr. Antonio Giusani</td>
</tr>
<tr>
<td>Cardiovascular Rheumatism and Electrocardiography</td>
<td>Dr. Ricardo Damorosi</td>
</tr>
</tbody>
</table>

The institutions of the Sociedad maintained whole programs like those of the School of Nurses (created in October 5\textsuperscript{th}, 1936)\textsuperscript{39} and School of Nannies which also employed physicians and represented important contributions to the training of healthcare professionals in the country. During its final years of operation, the Sociedad incorporated a large number of psychologists and in 1942, the Board of the organization authorized the creation of an organization dedicated to the “permanent synchronization of

\textsuperscript{39} Reference is made to this school in Sociedad de Beneficencia (1945).
the medical and pedagogical effort of the Sociedad” (Leg. 2 Acta 24/11/1944). This organization would dictate courses on psychological aspects of education to the teachers of the Sociedad and any other person interested in specializing in this area (Leg. 2 Acta 24/11/1944).

As it was mentioned before, Argentina has always searched for innovative ideas in other countries, especially the United States and countries in Europe. Pediatricians were not the exception and many of them carried out practices and training programs abroad (Kohn and Aguero 1985:135-136). The Sociedad realized the importance of this exchange and supported those doctors that were willing to travel abroad as long as they would return to Argentina with information relevant to the work being done at the organization’s institutions.

In 1931, Dr. Madrid Paez wrote a letter to the Board requesting for a short leave of absence from Dr. Thompson so that he could travel abroad.

“I accompany the request of a license from Dr. Alfredo S.B. Thompson, for a period of six months so that he may travel to Europe and North America. Due to the fact that in this case we are dealing with an outstanding physician of this Casa, scholar and irreproachable personal conditions, I have believed that the Sociedad could take advantage of the permanence of Dr. Thompson in the aforementioned countries and request him ad-honorem, to study the organization of the infant clinics of the states that he visits” (Leg. 1, 16/04/1931).

The meeting minutes from June 28\textsuperscript{th}, 1946 indicated that:

“Dr. Agustín A. Salvati, salaried doctor of the Casa de Expósitos, on his return from his tour of the United States of America, presented a report about the different points of medical order that are of interest to the institution” (Leg. 2, Acta 28/06/1946).
The Dissemination of Medical Knowledge

As Colangelo has indicated, the process of professionalization and institutionalization of pediatricians and pediatric medicine “implied the delimitation of a particular object of study and intervention and the legitimating of a new specialization through the creation of academic spaces, specific scientific events, professional associations, and specialized journals (2008:3). The Hospital de Niños, created by the Sociedad and administered by them for over 50 years, produced the first pediatric scientific publication in Argentina, and some even say in South America, in 1897 (Meroni 1982:317). They called it Revista del Hospital de Niños (Journal of the Children’s Hospital), and not long after its creation it became part of the Archivos Latinoamericanos de Pediatría (Latinamerican Pediatric Archives) (Puga 1982:334). An editorial in the first issue indicated:

“The specialization in the area of infant medicine is too extended over Latin America for children’s doctors to keep publishing the fruit of our observations and work in general journals of Medicine. Like in Europe, we, doctors that in these countries, are in charge of the hygiene and infant medicine, need special organizations and have thought of positive interest to gather all of the Latin-American pediatric production in one journal, that can constitute a real “Central Page” as complete as possible, not only for medicine and surgery, but also for the hygiene of infancy” (Puga 1982:334).

The creation of an academic journal pertaining only to pediatric medicine further legitimized the establishment of this discipline as an autonomous area of medical inquiry and practice and it provided the necessary framework for the dissemination of the knowledge produced in Argentina. Although many pediatricians continued to publish in European or North American journals as single authors or in collaboration with medical
groups from these countries, a new venue had been established for the communication of professionals within Argentina and among Latin American countries.

The creation of academic societies and their organization of professional meetings served this same purpose. In October of 1911, Gregorio Aráoz Alfaro, a pediatrician famous for his work on tuberculosis, created the Sociedad Argentina de Pediatría (Argentine Society of Pediatrics)\(^{40}\). His initiative followed the work that was being carried out in Europe when, in 1907, the first call for the creation of a Société Internationale de Pediatrie (International Society of Pediatrics) was published by a Russian doctor from the University of Kharkow (Colangelo 2008:4)\(^{41}\). Therefore, the creation of the first pediatric society in Argentina has been interpreted, first of all, as a turning point, and second, as the ultimate proof of the influence of European medicine on the conceptual frameworks and operating procedures of local doctors. When referring to the creation of this Society, Morano argues that

“Pediatrics is born in our country acquiring from its birth a conceptual characterization of signs that are different to those of the other specialties; and this was a European consequence, particularly French and German of the time. This is the reason why the object of this discipline is the child as a whole, with the biological attributes that confine its growth and development, and it is not directed at an organ, a system, or even a particular disease” (1982:328).

Academic societies took on the task of organizing professional meetings. The first pediatric meeting took place in Paris in 1912\(^{42}\). One year later, Argentine pediatricians

\^40\ This Society would, as of 1929, also direct the Archivos Argentinos de Pediatría mentioned before (Colángelo 2008:4).

\^41\ The creation of this society was consolidated in 1910 (Morano 1982:328).

\^42\ The meeting was called First Meeting of the International Association of Pediatrics (Colangelo 2008:4).
organized the first Congreso Americano del Nino (American Meeting on the Child) in Buenos Aires (Colangelo 2008:4). Several meetings followed as different institutions and organizations in the country supported them by providing resources in the form of money, personnel or infrastructure. In turn, they were often invited to participate in the meetings by sending physicians as representatives. Such was the case of the Sociedad de Beneficencia. In the meeting minutes of September 27th of 1940 it is stipulated that

“The President [of the Sociedad] manifested that the Organizing Committee of the First National Meeting on Puericulture had invited the Sociedad, through the Ministry of Foreign Affairs, to participate in this Meeting that will take place on October 11th […]. The President added that it had authorized, ad referendum of the Assembly, that some of the sessions that were to take place in this Meeting be carried out in the Instituto de Maternidad [Maternity Institute] and the Casa de Expósitos, and that Dr. Peralta Ramos should organize the attendance to the expositions of the Meeting” (Leg 2. exp. 1275, Acta 27/09/1940).

Physicians that belonged to the permanent staff of the Sociedad were encouraged to attend as permits were usually granted.

“It is my pleasure to inform the Inspectors [of the Casa de Expósitos] that the Presidency approves the leave that Dr. Pedro de Elizalde, director of the institution, requests for 10 days starting on the 29th of the current month with the purpose of attending the Cuarto Congreso de Pediatría (Fourth Meeting on Pediatrics) that will take place in Chile […]” (Leg. 2, Letter 13/11/1941).

The participation of the Sociedad in this process of dissemination of medical knowledge by supporting journals, societies, and meetings pertaining solely to pediatric medicine contributed to the legitimating of pediatric medicine as an important specialty of medical practice. At the same time, it was used to promote the valorization (and justification) of the Sociedad, its institutions, and personnel. This search for national and
international recognition certainly played an important role during the last years of the Sociedad’s existence when different types of political pressures were pushing towards the elimination of private beneficence and the establishment of an entirely “public” health system.

Conclusions

This chapter on the medical institutionalization of children has shed light on some of the processes behind the creation of the Argentine public health system and the establishment of pediatric medicine as a legitimate medical specialty. The underlying theme behind this chapter (and the thesis in general), is the politization of healthcare. The ideas and processes behind the creation of the public health system shed light on the larger political and economic models guiding the provision of healthcare. The creation of a concept of the Argentine nation and the legitimating of an autonomous State relied heavily on the use of “professional” knowledge and practice. Due to immigration policies, economic transformations, the literature produced in Europe and the United States, as well as, local political agitation, children became of interest to the State. Since professionals were needed to deal with this new “subject”, pediatric medicine became institutionalized and legitimised as a medical specialty.

Previous studies have only highlighted the role of the State in the institutionalization of pediatric medicine, but a more thorough analysis of the literature and historical documents, demonstrates that non-governmental actors were fundamental in this process. By examining the activities carried out by the Sociedad de Beneficencia from the end of the nineteenth century to the beginning of the twentieth century, this
chapter has demonstrated that this organization actively participated in all of the axes that led to the professionalization of pediatric medicine: the creation of infrastructure, the establishment of a particular type of medical training and practice, and the dissemination of medical knowledge through societies, journals, and professional meetings.

The analysis of the work of the Sociedad de Beneficencia allows us to question the contemporary literature on NGOs that visualizes them as relatively recent actors. By looking at NGOs historically, not only do we see the relevance of these actors, but we also acknowledge that most of the frameworks that are used by NGOs today are actually the product of a larger historical trajectory of beneficence societies, charities, community organizations, etc. As Thompson has indicated for the case of Argentina, “it was around these organizations [previous organized forms of civil society] that the different sectors of Argentine society that responded to different interests became nucleated and ideologies of social action that superposed, mixed with, and even modeled the social intervention of the State were configured” (1995:20). Therefore, the contemporary negotiation of space and resources in the context of healthcare provision between the government and non-governmental sector is the result of both the current political and economic context and the previous experiences of organizations like the Sociedad.

As we move through the other chapters in this thesis, we will see that CCF deals with a public health system that has changed in some ways, but remains intact in many others. In the strive to establish themselves as a serious provider of medical services, CCF staff members adapt many of the ideas on childhood, medicine, and the role of State that were presented in this chapter. Their experiences will appear in many ways linked to the information presented in this chapter as we think of the complexity of the provision of
medical services and the arbitrariness of considering the governmental and non-governmental sectors as dichotomous entities.
Chapter 5

Children’s Cancer Foundation

“Most of the things that we do not only have to do with families directly, but they have to do with information, dissemination, conscientization, and the transformation of health policies. The benefit is directed at children who are sick, but these networks are created to encompass all of this, to change things from the base” (Carla, volunteer coordinator).

The quote from Carla’s interview points to the overall mission of CCF and the way its goals and priorities are framed. According to the staff, the organization encompasses more than the direct provision of services, it generates networks with other organizations and government institutions, it disseminates information through popular media, and it participates in the improvement of government policies. The influence exerted by CCF on the treatment of pediatric oncology in Argentina goes beyond the number of users registered by the staff; it has multiple levels that can only be grasped when taking a closer look at their internal organization and everyday activities.

This chapter presents the information obtained through my ethnographic research with the Children’s Cancer Foundation. A brief description of the history, structure, and current organization of CCF is presented and the three main issues around which the ethnography was carried out are introduced. The main problems experienced by the NGO staff regarding each of these issues are presented, followed by my analysis of each problem and the recommendations I made to the administration of the organization.
Fragments of the interviews with volunteers and permanent staff are included to exemplify the most relevant cases.

History of the Children’s Cancer Foundation

The organization was created in 1994 by the current president in memory of her daughter, who died of cancer, in order to provide assistance to children with cancer in Argentina and their families. During the first stages of the history of the organization, emphasis was placed on the elaboration and dissemination of short books and pamphlets on pediatric cancer. These books focused on topics like the insertion of children with cancer into the school system, what to expect during chemotherapy and radiotherapy, how to tell the siblings of the child with cancer about the disease and its treatment, and how to help the child deal with pain. The books published by the organization are still an important part of the services they provide to the children and their family members. However, the organization has expanded their focus to many other activities and geographical locations, as Figure 2 indicates.
The number of children and families in its care has expanded as well as the people in its staff. From 2003 to 2006 the organization had nearly doubled its recipient population (from 1202 people to 2393). The staff of the organization is divided in three main groups: permanent staff, temporary staff, and volunteers. The former, are thirteen people that receive a salary each month and work full time at the organization. These are the president, vice-president, psychologist, social worker, general volunteer coordinator,
accountant, 3 secretaries, coordinator of Hospital Posadas, coordinator of Hospital de Elizalde, coordinator of Hospital Penna, and coordinator of Hospital de Tucuman. What I have referred to as temporary staff are all of the people that provide services to the organization but are not part of the permanent staff like the administrative council (or board of directors), medical and psychological counselors, strategic advisees, and the healthcare professionals that participate in support meetings and training seminars. Currently, the organization has approximately 100 volunteers distributed among its sedes\textsuperscript{43}. Even though this part of the staff is not remunerated for their employment, they are responsible for working during specific days and cover a specific number of hours per week.

\textit{Current Activities}

The organization provides assistance to pediatric oncology patients and their families on the following areas: emotional support, treatment support and social assistance, advocacy, recreation, education, aid networks, and diffusion through mass media. The main idea behind the provision of emotional support is to aid parents during these difficult times. When families first enter the organization, they undergo an interview. During this interview, the organization’s social worker and the psychologist talk to the parents in order to obtain information on the child’s cancer, where they are receiving treatment, the severity of the case, their need of assistance, and any other demographic information on the child or family that might be relevant. This information

\textsuperscript{43} The Spanish word sedes is used here because the English translation is headquarters and it does not have the same connotation in Spanish. Sedes in this context would mean something similar to the different branches of the organization.
is kept in a general database that can be accessed by all permanent staff members. The staff also inform the parents of all of the services provided by the organization and indicate other institutions or organizations that might be able to help them.

CCF has a parents’ support meeting once a week for those parents that have children in treatment or who have recently finished treatment. During these meetings parents talk about the things that concern them, the problems they encounter, and how they deal with them. Even though the groups are led by the organization’s psychologist, most of the talking is done by the parents and those with more experience provide advice to those whose children have recently initiated treatment.

The organization also holds grief counseling meetings for those parents whose children have died. During these meetings the parents talk about how they are dealing with their loss, how it has affected other family members and the relationships they have with them, and the strategies they are using to cope with their situation. The meetings are led by the staff psychologist, and open sharing of feelings and thoughts among all group members is encouraged. In those cases where individual therapy might be more convenient, the psychologist might recommend parents to meet with her on an individual basis and avoid group therapy meetings.

Special support meetings are held with parents that have children with retinoblastoma. There are no other support meetings for specific types of cancer expect for this one. Retinoblastoma is a malignant tumor of the retina that can be unilateral (in one eye), bilateral (in both eyes) or, in the case of children, can also be trilateral (both eyes and independent brain tumor) (Medical Encyclopedia 2008). In Western countries,
retinoblastoma is the most common form of childhood eye cancers (Oncology Encyclopedia 2008). CCF organizes special meetings for the parents of children with retinoblastoma because the administration considers it to be the cancer that most dramatically affects the daily routine of children and their family members.

During these meetings at CCF parents are informed on how to care for the children, how to stimulate their motor coordination, and change things around the house in order to suit their needs. The meetings also represent a time when parents can express doubts or concerns to a qualified physician that can guide them through the initial stages of caring for a child with this type of cancer.

sedes

The staff that has worked at the CCF since its origins recalled how at the beginning they managed with a few mats in the hallways of Hospital de Elizalde where they would play with the children while they waited for their medical consultation. Later on, they received a donation of tables and better supplies. By the year 1998, CCF had a small room where they could work with the children and then in 2007 the hospital granted them their own recreation room. The organization gradually gained space within the hospital. Figure 3 presents a timeline that better illustrates these transformations.

\[44\] There are three staff members that worked with CCF since it was created and that remain in the organization. All of them were interviewed.
Most of CCF’s achievements at Hospital de Elizalde are due in part to the support of the hospital personnel and administration as the quote from the interview with Giselle, de Elizalde’s current volunteer coordinator, indicates.

“Thanks to Dr. K from the oncology area we got this beautiful recreation room to play with the children. She fought against half of the hospital staff, architects, directors, because the authorities of the hospital considered that the recreation room was something superfluous, it was not primordial and there was no need for having this type of room in the area of hematology. So, it was thanks to her that we got everything we have now” (Giselle, de Elizalde volunteer coordinator).

The administration of CCF then moved to another location, turning the recreation room in the Hospital de Elizalde into a sede that was to be administered by a coordinator and building the second sede where they were to have their administrative offices. This new building was set up close to one of the largest children’s hospitals in the country, Hospital Gutierrez, and in proximity to another children’s hospital where most children
receive oncology care, Hospital Garrahan. This second sede was different from the first in that it was not situated inside a hospital and could provide assistance to children that were receiving ambulatory care or remained in the hospital for short periods of time during chemotherapy. It also became the administrative focal point of the organization; the place where donations were received, permanent staff worked, and meetings were held.

The third sede was established in 2004 inside the Hospital Posadas. This hospital is located in the outskirts of Buenos Aires, it has an area of influence of approximately 4 million people, and no other hospital in the country covers the same amount of medical specialties and has the same complexity (Katz 2004). The CCF sede inside this hospital is different from the one found in Hospital de Elizalde in the sense that the hospital is not a pediatric hospital (it has a policlinic model) and the NGO does not have their own recreational room. Therefore, most of their work is done alongside the beds of the patients in the ICUs or isolation rooms45.

This sede is also different from the other hospital sedes because of the particular history of the Hospital Posadas. It was created in 1957 as a hospital of respiratory diseases, but the demand of the population and the unwillingness of the Argentine government to create new hospitals led to the incorporation of multiple specialties and the increase in wards and services. This had negative consequences in the internal distribution and organization of spaces which was further complicated when the hospital was used as a clandestine spot of detention and torture during the last military

45 Isolation rooms are private rooms for the patient and close family members where oncology patients with low defense mechanisms are kept in order to avoid infections.
dictatorship in Argentina (1974-1976). As a result of these factors, the current hospital has many narrow hallways (some that do not lead to any room or exit), it is dark, and fails to meet basic security measures. This generates problems for the nearly 10,000 people that visit it every day (Katz 2004).

Another aspect to consider while analyzing the Posadas is the fact that it is highly politicized in the sense that it has been used often as form of partisan support and it contains some of the strongest unions in the country. Katz describes it as follows, “the Hospital Posadas was, finally, booty of the struggle for power in Argentina. The resources that the government provided were not few, even though many claimed their insufficiency, and its corrupt administration had allowed until my entrance to feed circuits of financial support for political parties, personal interests, and even the professional prestige […] of those deemed responsible of public health” (2004:96).

This situation severely complicates the work of CCF’s staff because throughout the years they have continuously confronted the administration in order to secure the resources necessary for diagnosing and treating the children under their care. It was not until CCF starting providing a considerable amount of money to this sede that the staff gained more autonomy, but even then the volunteers and the coordinator must always supervise how resources are spent so that money, medical supplies, and materials for the children and parents (bed sheets, soap, toys, clothes) are not deviated into activities with different purposes. Furthermore, all of the activities organized by CCF’s staff need to be previously approved by the administration. Even though, the volunteer coordinator at Posadas has been able to establish adequate relationships with the hospital personnel and administration, this was not an easy task as the quote from Laura’s interview indicates.
“In respect to this place, during the first year I struggled greatly with the order and cleanliness of this area [pediatric oncology ward]. I still struggle, but not as much as before because before I had to find out who would be willing to listen to me. Now, at least they listen to me. Another problem we had was related to maintenance. The people that are in charge of this area are a bit reticent to help us; they usually have a lot of work to do so I am permanently trying to get their attention. Now I go directly and ask them myself, before I had to go through the rest of the hospital personnel or administration and ask them to request it for me. Now I have the courage to do that, but it took some time” (Laura, Posadas volunteer coordinator).

This transformation in the relationship between CCF’s staff and the local hospital staff certainly had to do with becoming familiar with the hospital personnel and earning their space within the hospital, as Laura’s interview indicated. However, it is also linked to the financial growth of the organization and the contributions CCF has made to the hospital. For example, the fact that CCF has made an agreement with the directors of pediatric oncology to finance the construction of a separate recreation room (like the one at de Elizalde) has made the hospital administration more open and accessible to the demands of CCF’s volunteers and permanent staff members.

Another sede was created in 2003, and it is located in the northern part of the country. This sede has its own recreation room and it represents an important source of information and assistance in an area of the country that has been neglected from government services and healthcare throughout most of the history of Argentina.

The final sede is found inside Hospital Penna in Bahia Blanca, a city located in the southern part of the country. It was also created in 2003. This is the smallest sede (there is only one permanent staff member), but it is nonetheless useful to the people in the region. These last two sedes were not part of the sample analyzed in this investigation due to their geographical distance and the lack of time and resources available for this.
investigation. However, it is important to take them into consideration while reading the following sections of the chapter.

Population

The users of the services of the organization represent a heterogeneous population in the sense that they are of different social classes, gender, and geographical origin. However, the people that make more use of the wide array of services provided by the organization are from the lower social classes and come from provinces outside of Buenos Aires. The staff explained this phenomenon by indicating that people from higher social classes have other resources at their disposal like private therapy or better recreational centers for their children when compared to people from lower social classes. Furthermore, people from Buenos Aires have their social networks available to them and many of the services provided by the organization are carried out by people with close relationship to the child and his parents (i.e. counseling, emotional support, recreation, financial support, etc.).

Another reason why the services of the organization are used mostly by people from the lower social classes is that they do not have health insurance. As it was mentioned before, according to the law 23611\textsuperscript{46} every child with cancer and with no health insurance has access to free healthcare including oncology drugs for chemotherapy. Those with insurance negotiate the treatment and access to drugs with their particular companies; however, those without insurance are forced to enter a

\textsuperscript{46} Especially the modification of Article 6 in 2001 that turned the law into law number 25416 (National Senate 2008).
complicated system of bureaucratic processes in order to secure treatment and access to drugs. The legal and bureaucratic procedure includes the following steps⁴⁷:

1. Once the child is diagnosed, the doctor prepares a protocol for chemotherapy. The parents are informed that they must request those drugs from the Bank of Oncology Drugs. Chemotherapy cannot begin unless all drugs are in the patient’s possession.

2. If the child is receiving treatment in Buenos Aires, then the parents must request the drugs from the Bank of Oncology Drugs of the Nation. If the child is receiving treatment in areas outside of Buenos Aires, the family must request the drugs from the Bank located in La Plata (city found approximately 52 km from Buenos Aires). In order to obtain the drugs the parents must present a letter from the ANSES certifying that the patient does not have health insurance, a clinical history made by the child’s physician, a special form where the physician indicates the dosage of each requested drug, the child’s official documentation, and certification of address. Once all of these documents are presented, the order for the drugs is placed and the parents are informed on the date they can retrieve the drugs.

3. The drugs should be available one week after the order is placed. However, as the social worker of the organization indicated, what usually happens is that when the parents go to pick up the order, they are told that not all of the drugs have been obtained and they should come back next week. In some cases the delivery of

⁴⁷ This procedure changes depending slightly depending on the hospital where the child receives treatment and in some cases, depending on the type of cancer the child is diagnosed with.
drugs is even delayed for months which means that the child’s chemotherapy is
delayed for months, severely affecting its chances for survival.

4. The Oncology Drug Bank also has the right to reject an order. The staff indicated
that this usually happens when the requested medication is expensive and
imported from other countries. In the case of rejection of a request for medication,
the parents have to request it from Social Development, a government institution.
This request can only be made once the Oncology Drug Bank rejects the order,
delaying the entire process. Parents must turn in the following paperwork at
Social Development: letter from ANSES, clinical history, chemotherapy protocol,
child’s documentation, certification of address, a social survey (indicates their
economic situation), a handwritten letter requesting the medication and explaining
the particular situation of the child, and written documentation of the Oncology
Drug Bank’s rejection. An order is placed and parents are provided with a
specific file number. This process can take from one to three months.

5. According to the organization’s records, many children need coadjutant
medication to accompany the drugs requested for chemotherapy. In order to
obtain this medication they have to initiate a parallel procedure. Parents usually
try to obtain this medication at the hospital’s pharmacy. If the hospital does not
have it, the parents have to go to Acción Social\textsuperscript{48} in their corresponding county.
They present the same documentation as before and when the medication is not

\textsuperscript{48} This is a government office dependent of the Ministry of Health (Ministerio de Salud) that has social
assistance functions.
expensive it is usually given to them right away; however, if it is expensive or hard to find parents are asked to come back later.

This is an extremely complex process for parents that are dealing with a sick child, are not familiar with the city, and might be encountering the structure of the public health system for the first time. As a result, the guidance and support provided by CCF become instrumental in their struggle to secure the medication and best treatment available for their child. CCF not only informs them of the process, but when the Oncology Drug Bank delays the delivery of medication, the organization gives the family the missing drugs so that the child can begin with chemotherapy with the condition that when the remaining medication arrives at the Drug Bank the family donate it to CCF so that it can be used by another child. The social worker at CCF also assists parents by finding out which coadjutant medication is available in each county, saving them unnecessary trips. In extraordinary cases, CCF has also obtained medication that was missing from all healthcare facilities in the country. For example, a few months ago the president of the organization made an agreement with the Ministry of Health in order to obtain a large quantity of a drug that was only produced abroad and build a small storage in one of the organization’s sedes. Physicians all over the country could request the drug from the organization as needed. This not only reduced the amount of paperwork required from the parents in order to obtain the drug, but it also secured CCF’s position as a healthcare provider and advocate on a national level.
Staff

CCF has a hierarchical organization of its staff as is indicated in Figure 4. Decisions are usually made between the President, Operative Director and Board of Directors; however all decisions go through the President’s approval. From the outside, this model appeared to work well because it delegated responsibilities to all permanent staff members while making the decision-making process quick. However, from the inside, particularly from the point of view of the permanent staff members, this model was unfair because it did not allow everyone to work equitably in the construction and reconstruction of the NGO. The quote from Carla’s interview, the general volunteer coordinator, illustrates this point.

“I think that our teamwork has been distorted. From the upper positions of the organization to the lower ones orders are passed on, but from the bottom-up there are no responses or orders allowed. Consensus is not searched from the people in the lower ranks, however if those people want to propose something, they have to look for consensus from the ones in the higher ranks” (Carla, volunteer coordinator).

The social worker and psychologist are the two permanent staff members that have more information about the children and their family members as they conduct interviews with them, direct group meetings, and follow-up on their cases. The general volunteer coordinator is in charge of recruiting volunteers and distributing them among the sedes as well as making sure that each sede has the materials it needs to work. Each local volunteer coordinator directs its own sede, assigning time slots and responsibilities to each volunteers. The volunteers carry out most of the recreational duties and are more in contact with the children.
**Demographics**

The staff is heterogeneous in terms of age, occupation, number of years in the organization, civil status, and number of children; however, it is composed primarily of women. Of the almost 100 volunteers that make up the organization, only three are men. In the sample analyzed for this thesis, three men were interviewed and the rest of the sample (27 individuals) was composed of women. The ages of the interviewees range from the early twenties to the late fifties, however, as Figure 5 shows, most of the staff members interviewed were between 30 and 40 (the mean being 36.6).
Their occupations vary, but in order to provide a visual representation of their distribution the interviewees were grouped according to 5 groups: students, teachers, psychologists, other professionals, and those who are not employed. As Figure 6 shows, the category of other professionals is the largest group, representing 40 percent of the total sample. The staff members in this category worked as lawyers, museum specialists, occupational therapists, business administrators, and designers, among other things. The second largest group is that of students (33.33 percent) and their areas of studied were mainly centered on medicine and psychology. The third group is that of teachers (13.33 percent), which is followed by psychologists (10 percent) and staff members that were not working at the time of the interview (3.33 percent).
The number of years that the staff members had been working within the NGO, either as volunteers or permanent staff members, varied, but most of the sample (83 percent) had at least worked for an entire year at the time of the interview. Figure 7 presents the distribution of the number of years working with CCF. What is interesting to see in this graph is that most of CCF’s staff entered the organization recently reflecting not only the current expansion of the organization, but also the high volunteer turnover rate that we will discuss later on in this chapter.
In terms of civil status, 26.6 percent of the interviewees were married or cohabitating with their partners at the time of the interview, 20 percent were divorced or separated, and 53.4 percent were single.

Most of the interviewees did not have children of their own (60 percent), and the ones that did, had between 2 and 3 children (66.6 percent of the women that had children). The fact that most of the interviewees did not have children could be related to the fact that most of the interviewees are single and university students.
The volunteers and staff members that were interviewed are distributed among the organization’s sedes according to their interests as is indicated in Table 4.

Table 4. Distribution of staff members by sede

<table>
<thead>
<tr>
<th>Headquarter</th>
<th>Context</th>
<th>Type of activities</th>
<th>Permanent staff (interviewed)</th>
<th>Volunteers (interviewed)</th>
<th>Permanent staff (total)</th>
<th>Volunteers (total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mansilla</td>
<td>Non-hospital</td>
<td>Recreation, administrative</td>
<td>4</td>
<td>17</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Pedro de Elizalde</td>
<td>Hospital and non-hospital</td>
<td>Recreation, ICU visits</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Posadas</td>
<td>Hospital</td>
<td>Recreation only within ICU and isolation</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>
Most of the staff is found at Mansilla which includes the administrations and those volunteers interested in working with children outside of a hospital context. Pedro de Elizalde is the second sede in size of staff and here volunteers interested in working with children in a hospital context and those that prefer to work only within recreational rooms are found due to the fact that this sede can provide both options. The sede within Posadas is strictly for those volunteers working within a hospital context as there is no recreational room and most of the activities with the children are carried out in the ICU or isolation rooms. Tucuman maintains a similar design to that of Pedro de Elizalde but it is smaller in terms of staff. Penna is the smallest sede counting with only one permanent staff member with administrative obligations.

*Reasons for Working at CCF and the Initiation Process*

The reason why permanent staff members and volunteers decided to work within the organization varied. For most of the people interviewed the idea of contributing something to society and their interest in working with children played the most important roles in their decisions. Common ideas maintained in society about children and the need to protect them emerged in almost all interviews. The fact that these children were suffering from an aggressive disease also led several of the interviewees to state that they had chosen to work with children in these conditions because it was not fair that they were ill because they had not done anything wrong. This association between disease and culpability has been analyzed by anthropologists in different contexts. In the case of studying children within a medical context, some authors have made comparisons between adult and pediatric patients indicating that disease in adults is represented as a normal phenomenon while disease (and consequently death) in children
generates multiple contradictions for family members and the staff that cares for the child (Bluebond-Langner 1978).

When asked why they were interested in working with children with cancer, 95 percent of the staff indicated that they had not looked for this specifically, and that CCF appeared while they searched for NGOs that worked with children on the web. Even though cancer was not mentioned as a relevant factor in why they chose this NGO, 8 of the interviewees (26.6 percent) mentioned in other parts of the interview that a family member or close friend had suffered or died from cancer. This was interesting to me because the references to past experience with the disease appeared when the staff members had a hard time dealing with specific cases or the death of one of the children. The empathy of these volunteers towards the family members of the child also arose out of remembering how their own experience of accompanying someone through cancer treatment had been.

The transfer of these feelings was experienced in similar ways by staff members who had not experienced cancer or had relatives who had cancer, but that feared that their loved ones might have cancer in the future. A quote from the interview carried out with Elena, a 46 year old psychologist that had been working as volunteer for two years provides a good explanation of this.

“Sometimes I face some difficulties here. I am a mother, I have children and working with children that have an illness sometimes makes it difficult to separate things. Something happens to your children and you rush assuming that something bad happened, but you deal with it. It’s terrible; last year one of my daughters broke her foot and she had to have a resonance and the first thing that came to my mind was that 50 percent of osteosarcomas appear in the ankle. Until we opened the MRI to see the
result, you can’t imagine the stress I went through” (Elena, volunteer at Mansilla).

Ninety percent of the staff members found out about the organization through some sort of mass media (television commercial, newspaper add, or magazine article). Their next step was to look at the organization’s web page and apply online for a volunteer position. All permanent staff members except for two had previously been volunteers for several years before they became salaried workers. Therefore, the insertion of all of the people into the organization had similar characteristics. The media savvy nature of the organization and their excellent use of the media were factors that surprised me during the fieldwork. The entire application process for volunteers was carried out online, each sede had their own mailing list, the webpage was constantly updated with the organization’s most recent events, and the information of each child assisted by CCF and his family were uploaded into a general database that could be accessed by each permanent staff member online.

After the volunteers had been accepted, they received an email indicating the date and time of their interview at the Mansilla sede. This was their first contact with the staff of the organization and their first tour of CCF. During my fieldwork I was allowed to sit in on several of these group interviews and even though the information provided to the volunteers was impressive, I could not help but notice how the presentation of the organization was biased. The first impression of the new volunteers was the Mansilla sede. The people that led the interview were only from this sede, they were not properly informed on the activities and working hours of the other sedes, and since they had never worked within a hospital context, they transmitted stereotypes about this type of work to
the volunteers influencing their decisions. For example, hospital work was described as work suitable for specific “types” of people, usually described as strong. Furthermore, the volunteers did not have the option of visiting the other sedes before they chose where they wanted to work and they did not have the possibility of requesting a transfer if they changed their mind later.

As a consequence, most of the applicants chose to work in Mansilla, severely affecting the number of volunteers available in Pedro de Elizalde and Posadas. The interviews with the volunteer coordinators in these two hospitals pointed to their understaffing and work overload. These two factors generated problems between the general volunteer coordinator at Mansilla and the local coordinators in Pedro de Elizalde and Posadas because the hospital coordinators thought that the general coordinator wanted to keep all of the staff members for herself and deliberately prevented them from working outside of Mansilla.

“There are some days when there is only one volunteer in our sede or maybe two, but for the amount of work that we have you need minimum 4 volunteers each day. I always tell Carla [general volunteer coordinator] that I need more people because it makes me mad not to be able to sit down and play with the children that come to our recreational room. It is important for me to be able to talk to them and learn things from them. It also helps the families, because they know that we have time to talk to them, to listen” (Giselle, de Elizalde volunteer coordinator).

The interview with the general coordinator, however, pointed to the fact that the reason why she did not promote the insertion of volunteers into the other two sedes was that she did not understand the need for more volunteers. The general coordinator had entered the organization a few months before I started my fieldwork. She had been a volunteer for about five years at the Mansilla sede and when the previous coordinator left
she was offered the position. She had never visited any of the other sedes and had no experience working with pediatric oncology patients in a hospital context. To her, the hospitals did not need a lot of volunteers because their work was carried out in a smaller place where the children did not require a lot of supervision. Furthermore, the volunteers in the hospitals did not have the administrative obligations of those in Mansilla.

The lack of training of permanent staff members and volunteers at Mansilla on working with children in a hospital context, their permanence in only one sede, and the lack of communication that existed between sedes led to conflicts between coordinators, the under-appreciation of the hospital sedes, and the separation of the hospital sedes into isolated groups composed of the corresponding coordinator, her volunteers, and the hospital staff. These factors presented themselves over and over in the interviews representing issues of concern not only in the initial stages of the volunteers’ trajectory, but accompanying them throughout their training, supervision, and later stages of volunteer involvement.

Training and Supervision

During the fieldwork, I was told that frequent training and supervision meetings directed by the psychologist were carried out at CCF. However, during the interviews both volunteers and permanent staff members indicated that the meetings that used to be once every two weeks were now carried out once every two or three months. These meetings used to be a fundamental part of the volunteer’s work experience because most of them it was the only time they had to get to know the volunteers from other shifts or sedes and to talk about their problems and the strategies they used to deal with them.
One of the interesting things that emerged while interviewing volunteers was that there were few people with whom they could talk about their experience while working with pediatric oncology patients. Like the two quotes from the interviews with Daniela and Gina indicate, family members and friends did not feel comfortable when the volunteers referred to specific cases, discussed the children’s family situations, or expressed their feelings after finding out about negative prognoses or a child’s death.

“When we first entered the organization we were told that our family members did not have to know what happened here. If they asked us, it was O.K., but if they didn’t, we didn’t have to share our experiences with them. Later on you start to understand what they [the administration] were talking about. When you tell people what you do, they respond by saying that they could never do that, that only people without feelings can handle situations like those” (Daniela, volunteer at Mansilla).

“Sometimes when you tell another person what you do, they don’t understand that this type of work can be pleasant. They picture you as morbid; but it is pleasant because it is another reality where you can collaborate with people. Seeing a kid that just came out of chemo or a puncture and he laughed with you for five minutes fills up your soul” (Gina, volunteer at Mansilla).

Informal quick encounters with volunteers from their same shifts or the general group meetings were the only spaces available for sharing their experience and airing out their concerns. The group meetings directed by a psychologist that specializes on this type of work were not carried out frequently enough, resulting in the lack of the constant supervision and professional guidance that are needed to overcome painful situations. On the one hand, this generated stronger relationships between volunteers as they relied upon each other as important resources for sharing these experiences and seeking for advice, but on the other hand, it made many of them feel alone and doubtful when encountering distressful situations.
“We come here without tools because we do not know if we are doing things right. You don’t know if you’re benefiting the child or not. You might have them jumping up and down and then discover that it wasn’t the best thing to do at their stage of treatment. I always remember the comment made by the psychologist where she said that during social events she always ended up talking to herself. People would be like ‘Oh, how can you work with oncology patients?’ like if it were a negative thing, like a terrible thing. People around us say, ‘how can you get involved in that?’ and then they leave, they don’t want to hear about it. […] My mom, for example, doesn’t even ask me about it. She didn’t want me to come; she thought it would be bad for me” (Iliana, volunteer at Mansilla).

“I have many friends or colleagues that when you tell them that you work with children that have cancer they ask you ‘How can you work with people that are dying?’ and I respond ‘No, I am working with people that are fighting for their lives’. I think that this is what the children give me and the rest of us; because if I weren’t here there would be another crazy girl doing the same thing. That is something that Silvana [ex-volunteer coordinator] would say, that you have to be crazy to be here and we all are a little bit and that brings us together” (Valeria, volunteer at Mansilla).

Another issue related to training emerged from both of the hospital sedes. During the interviews the volunteers indicated that the training sessions they had attended at Mansilla provided them with tools for working with children solely within the setting of Mansilla and not in a hospital context. They received no training on how to develop recreational activities for children that had recently come out of surgery, that were in chemotherapy or that had returned from a lumbar punction. Volunteers were not instructed on how to sterilize materials after the children had used them to prevent infections or how to take the necessary sanitary measures before entering the isolation rooms.

“My opinion is that the organization has exceeded its capacity. According to me the dynamic at de Elizalde is totally different from the one lived at Mansilla. Here you have a kid that just came out of a punction. In Mansilla, from the Gutierrez [nearest children’s hospital] you have five blocks for the child to come down. Here they come and in two seconds we have them in the recreation room. I have never found tools to deal with
that. You play with them as much as you can put up with it, but this is terribly adrift. You don’t have information to give parents about what to do with their child after a punctum; you don’t have the tools to work with children in these conditions. […] There is a lot of change of personnel because of this; because the volunteers do not have the necessary tools to deal with what goes on here” (Alba, volunteer at de Elizalde).

Even though most staff members agree on the fact that many of their problems could be solved by having more frequent meetings, the reason why these have been distanced further apart was due to the work overload suffered by CCF’s psychologist and the difficulty of bringing together the volunteers from all sedes. The psychologist was in charge of attending to all sedes on a regular basis, she led the initial interviews with parents, and directed all group meetings at CCF. It was impossible for her to deal with all of these obligations and still be available for emergency situations.

As the map on page 100 indicates, the three sedes analyzed during this investigation were not located in close distance from each other making it hard for the volunteers to travel to Mansilla for the meetings. Furthermore, the meetings were only set in the afternoon making it difficult for volunteers with classes or family obligations to attend.

*Internal Communication*

The assessment of the internal communication of CCF was carried out by combining three methods of data collection: participant observation, interviews through which they identified the people within the organization with which they interacted the most, and social network diagrams made by each interviewee where they located themselves within the organization drawing the people they interacted with the most closer to them. According to this information a social network diagram for the entire
organization was elaborated and presented in the report as well as a sample of the staff drawings\textsuperscript{49}. The use of these visual mechanisms to represent the internal communication of the organization resulted helpful when presenting the results of the investigation to the NGO administration.

As it was mentioned before, each of the sedes of the organization appeared to have established effective networks of communication. Through private email lists they received constant updates on the activities conducted in their specific workplace, they knew when they needed to substitute a volunteer that could not make their shift, and when additional help was requested for group activities. Each sede had its own notebook where volunteers would write the most important events of the day and let the volunteers from other days know what they could expect concerning particular cases\textsuperscript{50}. Intra-sede meetings were useful for the staff because they could get to know the other volunteers, express their concerns, and look for ways to improve their work strategies. The volunteer coordinators of each sede spent a large amount of time making sure that the information got across to all of their volunteers and that no misunderstandings were generated.

The inter-sede communication and administration-sedes communication was different. As the quotes from the interviews with Carla (general volunteer coordinator) and Ana (social worker) demonstrate, the miscommunication the organization was experiencing took different shapes in the sense that information was not getting across and that things were misinterpreted and needed to be corrected, representing a waste of

\textsuperscript{49} The drawings were scanned and the names of the people identified were erased in order to protect their identities. Generic names like “volunteer from Mansilla” were inserted instead.

\textsuperscript{50} These notebooks were also used to let the staff know which children were going into palliative care and which had passed away.
time and resources. Furthermore, the problems with communication were linked to a lack of group dynamic (referred to as teamwork) where each of the permanent staff members could have an equal role to play in the decision-making process of the organization.

“The state of our internal communication is not good because the administration, which is in charge of the final decisions, are always too busy and it seems as if the issues for which we interrupt them are minor. Even though they tell us that we have to check these things with them, there are times when you are confronted with their closed office doors and you can’t check with them. Due to this, maybe you didn’t make the right decision or maybe you didn’t make any decision and that issue was kept on stand-by and things got postponed. When you try to propose them again, then they have lost importance. So, we don’t have the possibility of obtaining permanent feedback from the administration but at the same time we don’t have the possibility of making our own decisions” (Carla, volunteer coordinator).

“The communication is very vertical. It is standardized according to how the President designed the organization where everything must have her approval. For example, I can’t give out medication without letting her know first or if I have to contact another organization, then many times she prefers to do it herself because she has built these networks. This doesn’t allow us to work as a team, that is, we can’t integrate all of the staff into a working group where we could discuss each child’s case from our different perspectives. This is due to the fact that the President absorbs such a large amount of work that she does not have time” (Ana, social worker).

This was also the case for the communication between sedes where the Mansilla sede presented strong and frequent interaction with the administration, but distance was established with de Elizalde and Posadas (see Figure 9). These last two sedes hardly interacted with each other, Mansilla, and the administration with the exception of occasional emails. As a consequence, the activities that were taking place in de Elizalde and Posadas were not disseminated to the people that frequented Mansilla, their staff, and the general public as it was not included in press releases or CCF’s webpage. As it was
mentioned before, this fact was evident during the initial volunteer interviews and was probably one of the main causes of the unequal distribution of volunteers. However, its negative effect was mostly felt at the level of the parents and their children who received care in the hospitals where these two sedes were established but were not informed of the benefits they could receive from the organization as a whole.
Figure 9. Social Network Diagram of CCF indicating communication within and among sedes.
In order to improve the communication among sedes, the volunteer coordinators constantly requested more frequent face-to-face meetings and the presence of CCF’s President and Operative Director at each of their sedes at least once every two months. Since de Elizalde established its own recreational room in 2007, CCF’s administration had only visited it once. In the case of Posadas, the only person that had visited the facilities (once in four years) was the President, and most of the administration did not know how the sede operated. The following quotes from Laura’s interview (Posadas volunteer coordinator) and Giselle’s interview (de Elizalde volunteer coordinator) further illustrate this point.

“What I want is for someone [CCF administration] to come because my presence here is permanent so it’s like I’m one of the family. If someone from the Foundation comes, no matter what category they have, then people would feel like they are under some form of supervision, of control. It would give the Foundation more presence, you know? [...] A visible face of CCF every now and then is important. Important for me too, because they might see things here that I don’t see. They might have ideas and make propositions for improving what we do” (Laura, Posadas volunteer coordinator).

“CCF has become some sort of multinational company, it has grown so much. There were times when I felt bad because the administration would not come to our sede. They [CCF administration] would tell me that they would come when things were not working the way they should and because de Elizalde was working fine there was no need for them to come. It was hard for me to understand this point because I am a very emotional person and I think that human contact and relationships are very important. [...] I would also like them to see everything we have done” (Giselle, de Elizalde volunteer coordinator).

This generated resentment among the volunteer coordinators because they felt that their work was not valued by the administration. It distanced them and the volunteers under their supervision from those at Mansilla and led to the creation of volunteer typologies where those at Mansilla were represented as weak because they were not
emotionally equipped to work within a hospital context and those at de Elizalde and Posadas were seen as strong and the most important volunteers within CCF because they were the ones in direct contact with the patients.

“CCF [referring to Mansilla] and the hospitals are different. We are there with the child since the moment of diagnosis, we live everyday with them. We see when they are happy, sad, when they relapse, we are with them during punctions and medication, and we take them movies so that they don’t get bored during chemo. We are with them and their parents during the entire treatment, so our relationship is different than the one of the people at Mansilla. With the volunteers it is the same thing. The ones here see the children every day, their bonds with the children are stronger and their job is emotionally demanding” (Giselle, de Elizalde volunteer coordinator).

The lack of visits by the administration to each of these sedes also had a notable effect on the role the sedes played within each hospital. The volunteer coordinators mentioned that if the administration provided them with more visible support, then they would not have to spend so much time defending their place to the hospital administrations. In other words, the presence of CCF’s President, who was a legitimate authority on pediatric oncology treatment in the country, would grant each volunteer coordinator with more power to work with the children and would solidify the position of the sede within the hospital. However, since this was not the case, the volunteer coordinators sometimes subordinated to the orders of the hospital administrators deviating from the mission of CCF and creating ruptures in their relationship with the rest of the organization’s staff.

The direct consequence of these ruptures was the creation of islands (a term used by the volunteer coordinators) where de Elizalde and Posadas felt completely isolated from the rest of the staff. This is evident in the quote presented below and in the social
network diagrams drawn by the volunteers. A sample of these is included below (Figures 10 to 13) in order to demonstrate how volunteers from the same organization but from different sedes can present different depictions of the organization, in some cases completely erasing the other sedes.

“I think that the most important thing here is for the different sedes of the organization to get to know each other. I feel like we are three islands within CCF. Except for some people, many girls from the sede [Mansilla] do not even know that de Elizalde exists. For me it is important that besides showing what we do in pictures that they come and get to know what reality is like. That they get to know exactly how we work. We do not have to forget that CCF is what it is because of the people that work within it and all volunteers deserve greater recognition” (Giselle, de Elizalde volunteer coordinator).

Figure 10. Diagram made by Mansilla volunteer
Great distance between personnel

Individuals located in the lowest rank are more close together indicating more communication

Figure 11. Diagram made by Mansilla volunteer

Figure 12. Diagram made by de Elizalde volunteer
“The fact is that we are all a little bit disconnected. We are missing activities that can integrate the whole group; it would be good to integrate each side. I know that everyone is not always available, but like in my case I have been coming here for almost a year and recently there was a meeting and I didn’t know anybody” (Marco, Mansilla volunteer).

Diagram Analysis

The analysis of the diagrams shed light on several important issues concerning the internal communication of the organization and the ways in which the volunteers visualized themselves and their work. An element present in most of the diagrams is the lack of inclusion of other sedes. In some cases the interviewees remember to mention one sede (other than their own), but none of the interviewees identified the five sedes that make up the organization.

The distribution of personnel in the diagrams varies. However, it is possible to identify two general patterns: hierarchical and non-hierarchical (or egalitarian).
Hierarchies are expressed in different ways (ladders, levels, and figures in vertical position). The diagrams with non-hierarchical organization tend to situate the different members of the organization in the same horizontal level, even if they separate people into groups by drawing circles or other shapes.

In most cases, the people identified are the same. Most interviewees locate the volunteers that work with them on the same day and the volunteer coordinator of their sede closer to them indicating that they interact with them the most. People like the psychologist, social worker, general volunteer coordinator, and operative director appear frequently in the diagrams made by volunteers of Mansilla. This might be due to the fact that these permanent staff members work in the same sede as the volunteers from Mansilla. The only member from Mansilla that volunteers from other sedes frequently identify is the psychologist and this is due to the fact that previously she would make constant visits to all of the sedes in order to carry out volunteer supervisions.

When looking at the differences in the diagrams among sedes it is possible to see that the volunteers from de Elizalde were the ones that included the other sedes with more frequency (4 out of 5 interviewees). In the case of Mansilla only 3 out of the 17 people interviewed identified at least one sede besides the one they worked at. The Posadas volunteers failed to identify other sedes in all cases. This analysis is consistent with the interviews where the staff members at Mansilla did not have information on the other sedes (some did not even know they existed), the volunteers at de Elizalde complained that the volunteers at Mansilla had more privileges while not carrying out work as meaningful as theirs, and the volunteers at Posadas visualized themselves and their work as something separate to CCF.
Conclusions and recommendations

In essence, most of the recommendations that I made to the organization’s administration stemmed from the staff members that were interviewed. Many had similar proposals for improving the working dynamic of the organization; they had just not found the appropriate way to communicate them. Therefore, I saw my role during this project as a communicator of all of their concerns, but at the same time, of the strategies the staff thought should be implemented to deal with them. My work was centered on summarizing this information and presenting it in a way that could be easily understood by the administration and that could result in interesting and important changes for them. My recommendations were built on these ideas. The following section presents a summary of the report I delivered to the administration and the staff with the specific recommendations for dealing with the three areas of the organization under evaluation.

Reasons for Working at CCF and the Initiation Process

As part of the strategies dedicated at the recruitment of volunteers, I encouraged the administration to continue to dedicate substantial amounts of energy to update their webpage and take advantage of the contributions that technological advances could make to their everyday work\textsuperscript{51}. These sources of information had brought benefits to them in the past and would certainly continue to grant them visibility in the future. Some of the literature on NGOs has focused on this issue, indicating that “accustomed to networking in ‘physical space’ and hungry for effective means of communication and for

\textsuperscript{51} The organization is currently contemplating implementing an interdisciplinary project with social scientists and computer engineers in order to design a virtual game where children can obtain information about cancer and their particular treatment.
information, NGOs rapidly found electronic networks to be another useful and powerful milieu for their organizational and political needs” (Lins Ribeiro 1998:336).

The use of electronic networks has been essential for NGOs involved in political activism and advocacy as these networks represented channels through which information could be disseminated instantly, where global visibility could be obtained, and where pressure could be exerted on political actors (Lins Ribeiro 1998). A relatively unexplored aspect of the use of electronic networks has been the one presented here where an organization like CCF has adopted the use of electronic networks for volunteer recruitment, internal communication, and the filing of the individual cases of the children who receive the organization’s services. As the organization continues to expand geographically and in terms of staff it will depend more on these networks and will probably find new ways to adapt them to better suit the needs of the personnel and recipient population.

For the volunteer initiation process I recommended an in-depth training program (of approximately one month in duration) that included the following elements:

- Basic instruction on cancer, its diagnosis and treatment, and the ways in which the disease affects the child, the relationships between the child and his/her family members, and the relationships among family members.

- Intensive training on recreational activities that can be carried out with children in the following situations: terminated treatment, in palliative care, initial stages of chemotherapy, recovering from surgery, coming
from a punctum, later stages of chemotherapy, recovering from limb amputation, and the well-siblings of children under treatment.

- Training on working with parents referring particularly to: recommending recreational activities to carry out at home with their children, referring them to other staff (like the social worker or psychologist) concerning particular issues, or listening to their problems.

**Training and Supervision**

The initial training described before needs to be constantly reinforced and updated, especially for those volunteers working within a hospital context. Therefore, I proposed monthly internal training sessions where volunteers could be instructed on activities and strategies they could use to work with children in the particular contexts of their sedes. Their initial training would be enriched and the issues that emerged concerning the general training meetings (at Mansilla) mentioned before would be avoided.

Frequent supervision meetings were recommended where all volunteers gathered with the organization’s psychologist at Mansilla to share the difficulties that they had encountered. The psychologist’s advice and guidance could prepare the volunteers for dealing with some of the most common situations they faced when working with the children and their families. For these meetings I recommended using a group format where the interaction among volunteers from different sedes could be promoted and

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52 These activities would adhere to the specific limitations in staff, resources, time, and the condition of the children of each headquarter.
everyone could find out about the work carried out in other places. This could help reduce the separation among sedes referred to by Giselle and Laura in the previous interviews.

**Internal Communication**

I recommended that the internal communication be looked at from three different levels (see Figure 14) within sedes, between the administration and each sede, and among sedes. This separation allowed the administration to see that different types of problems were encountered at each level that required specific solutions and that while some levels were in great need of reform, the other levels were working fine.

Figure 14. Diagram indicating the levels of internal communication I identified in CCF.
As it was mentioned before, the communication within each sede did not require modification. Each volunteer coordinator had developed their own way of promoting communication with their volunteers. The communication within the administration and between the permanent staff and the volunteer coordinator of de Elizalde and Posadas, however, needed to be improved. In the report, I included two suggestions that came from the interviews with the permanent staff members: fixed regular meetings, and regular visits to the hospital sedes by the President or another member of the administration.

The regular meetings needed to be frequent (maybe once every two weeks) to ensure more direct contact among the staff and a specific time needed to be arranged for them where no distractions occurred. The lack of participation of the President and the Operative Director in meetings or their permanence for short periods of time was an issue of concern for the rest of the staff (specifically for the volunteer coordinators of the hospital sedes). These meetings could also promote the teamwork that several interviewees thought would be important for the organization because it could be a time where the discussion of the particular cases of children and their families from the points of view of all of those present could take place.

The visit to the hospital sedes by the President and other members of the organization would allow the volunteers and volunteer coordinators of each sedes to be able to show the rest of the organization what they have accomplished. It would promote the dissemination of information among the staff and would enable the recognition of all workers. These visits would also give major visibility to CCF within each hospital, solidifying their position and maybe even granting them greater autonomy. These visits
could also promote the rotation among all staff in the future allowing volunteers to visit other sedes and learn about the work of their colleagues, and consequently improving the communication among sedes.

In sum, the geographical expansion experienced by CCF and the increase in the number of services have provided benefits to the recipient population but have also contributed to the deterioration of the internal structure and working environment of the organization. The issues of concern to the staff are centered on the reduction of personal contact among the personnel and the lack of time allocated to the training of volunteers. The interviews pointed to the individual ways in which the staff members dealt with these difficulties and their ideas on how the internal working mechanism of the organization could be improved. The interviews not only got the staff thinking about these issues, but it got them talking about them and when the report was presented to the entire organization, these problems and possible solutions were discussed in an open forum. Months after this presentation, I was informed by several of the interviewees that some changes had started to take place within CCF as the administration was starting to establish more time for face-to-face meetings and a new volunteer training program was being designed.

If CCF had been viewed from a more macro perspective I would have probably only seen a strong organization in the midst of a large expansion. I would have noticed their increase in sedes, volunteers, and recipient population representing them as positive factors in the organization’s development. Even though all of these things are true, a micro perspective, obtained through ethnographic research, paints a different picture. It sheds light on the complex nature of NGOs, the messiness of its internal organization,
and the fractures in the communication among staff members. As a consequence, the
everyday problems of the people that make the existence of the organization possible can
be assessed in greater detail and more realistic and tangible solutions can be proposed.
Chapter 6

Conclusions

This thesis has examined NGO involvement in the provision of healthcare from a historical and ethnographic perspective. The historical portion of the thesis used the particular case of the Sociedad de Beneficencia to illustrate the many different ways organizations can contribute to the provision of health services, the creation of public health facilities, and the training of healthcare professionals. The ethnographic section uses the case of the Children’s Cancer Foundation to shed light on the contemporary participation of NGOs in healthcare provision, and particularly, on the experiences of the staff that work with patients.

One of the purposes of this investigation has been to demonstrate that different types of organizations have participated in the creation and maintenance of the Argentine public health system, and therefore to emphasize that NGO involvement is not a recent phenomenon, but has been present in one way or another (through community groups, mutual trust organizations, charities, beneficence societies, civil organizations, and foundations) throughout Argentine history. Another purpose of the thesis has been to highlight the various forms that NGO involvement within the health sphere can take and the particularities of working with children and cancer patients. These particularities are important as they create challenges and difficulties for the staff that might not be present in other contexts.
In sum, this thesis has demonstrated the relevance of carrying out in-depth ethnographic research with NGOs, the contributions anthropologists can make within this field, and the need for future NGO-anthropologist collaboration. In the pages that follow, I will elaborate on these two purposes drawing on the previous chapters.

Looking at NGOs within the Public Health System

When analyzing NGO involvement in the provision of healthcare, the micro perspective used in this thesis becomes useful because it allows contextualization of the work of these organizations within the structure and organization of the public health system of particular countries. Argentina was selected as the locus of study and it is not by chance that the Sociedad de Beneficencia was chosen as a representative case of the history of the involvement of organizations in health. The role played by the Sociedad in the professionalization of pediatric medicine in the country points to the specific ways in which healthcare was and continues to be visualized in Argentina: as a form of beneficence instead of as a universal human right.

I have dedicated a substantial portion of Chapter Four to explaining how the institutionalization of childhood was carried out in Argentina. The purpose of the description of this process was to shed light on the class-based notions of charity behind the creation of the nation’s public health system, and specifically, behind the medicalization of children. Health and education access were in the hands of the highest social classes and it was granted to the lower classes only as a form of beneficence, or “charity”. Healthcare was a privilege and it was awarded to the lower social classes only when particular political interests were at stake. So for example, the immigration waves that arrived to Buenos Aries between 1871 and 1914 were confronted by a young city
without enough infrastructure to provide potable water, adequate housing, and sanitation to its population (Rodriguez 2006). This led to the emergence of serious infectious disease epidemics that needed to be controlled so that they would not devastate the entire country (Armus 2007; Rodriguez 2006:179). Conceptualizations of hygiene that were imported from Europe and North America were combined with a local need to “sanitize” the population in order to create a vast public health system (Rodriguez 2006).

The State and different types of organizations usually comprised of upper class women, like the Sociedad, played a fundamental role in the creation of this infrastructure and its administration. The Sociedad fought for the elaboration of institutions that could educate and heal the children of the newly arrived immigrants (protecting themselves and their children from infection) and devised national campaigns to educate their parents. However, this institutionalization and education were usually directed at the lower social classes. The children of rich families were seldom admitted to public hospitals, orphanages, correctional facilities or asylums because they had access to private physicians and facilities. These children had private care or entered institutions suitable for their class (expensive boarding schools in Argentina or abroad, military or religious institutions, etc.).

The reasons for this interest in children and the practice of selective public institutionalization have been discussed in Chapter Four. Government interest in children was related to ideas about the immigrant population maintained by the State and individuals of the elite where this newly arrived population was seen as ignorant, backward, infected, and, in some cases, politically dangerous (Armus 2007; Rodriguez 2006). It was the role of the State and the organizations at its disposal to transform this
population into what they believed to be suitable citizens by granting them access to
education and healthcare; access for which they were not deemed worthy because they
were human beings, but because they complied with the interests of the political elite of
the time. Katz further illustrates this point by saying that “beneficence is the
foundational concept that impales the conformation and growth of the health system in
Argentina not thought of as a public service but as a conversion of its main recipients,
that is, orphans, the elderly, mothers, and the shameful poor” (2004:151).

These notions of rights and healthcare were contested throughout Argentine
recent history by a series of political and social movements that demanded a socialized
system of healthcare. However, even during periods of powerful centralized
governments, like the Peronist governments of 1946-1952 and 1952-1955, ideas of
healthcare as a universal human right were confronted with ideas of healthcare as
charity (Katz 2004). What I have discussed so far thus helps to explain contemporary
ideas on healthcare and NGO involvement in this area.

When we look at the case of CCF and its staff we are able to see that some of the
ideas on the right and access to healthcare are reproduced from earlier times in national
history. The staff is primarily composed of women, reproducing a model of social
assistance that has prevailed in Argentine history, and among other Latin American
countries, where women are represented as caretakers and benefactors (Tenti Fanfani
1989). Such women belong to middle and upper social classes and provide services to

53 The most important organization dedicated to the provision of healthcare, education, and social
assistance during these regimes was the Fundación Eva Peron, a charitable organization directed by Eva
Duarte de Peron (Peron’s wife) (Thompson 1995).
individuals from the lowest social classes. Even though the provision of healthcare was discussed with all interviewees, none attributed the problems faced by the children and family members as a violation of their human rights or the failure of the State to deal with its obligations. Instead, the staff tended to explain the situation of the users of CCF as that of experiencing “needs”. The role of the organization, according to the interviewees, was to devise strategies to deal with those needs and the organization does this by establishing sedes (branches) within public hospitals. The initial contact with the hospital personnel was full of tension, but these conflicts gradually disappeared as CCF demonstrated its efficiency, willingness to provide various forms of resources, and, most importantly, its unthreatening quality. By unthreatening, I refer to the fact that CCF does not attempt to challenge or transform the internal working mechanism of the hospital or its staff, therefore does not pose a threat to the hospital administration and high-level health officials.

In many ways the involvement of CCF in the provision of health services to pediatric oncology patients and their families appeared to work in synchrony with the structure of the Argentine public health system. A longstanding history of governmental/non-governmental collaboration within the health sphere points to this fact (Thompson 1995). However, there are three main elements that continue to produce difficulties for the staff and the organization in general: its focus on cancer patients, the fact that these patients are children, and the pressures for expansion.
"Cancer poses powerful contradictions: fighting death and accepting death, faith in medical authority and the ending of that faith" (Balshem 1999:10).

Balshem (1999) here sheds light on the particular circumstances that cancer generates. If we look at the timing of medical advances in cancer therapy we can conclude that oncology is a relatively recent medical specialty (Balshem 1999:4). The small amount of information available on the causes of cancer and the effects and side effects of the treatment when compared to other diseases is further evidence to this fact. In some cases, this lack of information and its limited dissemination have transformed cancer into a mystery, leaving room for misinterpretations.

This lack of understanding of the disease, its course, and its treatment was common among CCF’s staff members and it was one of the main causes of difficulties they experienced when dealing with patients. Many were cognizant of this fact indicating in the interviews that if they had understood the implications of particular types of cancer and the stages of its treatment they would have been better equipped to handle difficult situations because they could have anticipated future outcomes. Whether this is true or not is hard to determine, as having large amounts of information available does not guarantee being able to handle the death of a loved one. However, learning about the disease and the treatment can grant the staff members with a greater capacity to empathize with the children and family members and the ability to at least assess the direction towards which a child’s case is headed. This is the reason why a better training
program, one that could provide substantial information on these topics, was recommended to the administration.

Even though cancer survival rates have increased considerably over the last ten years (Young et al. 2002), uncertainty still remains for those undergoing treatment. This uncertainty becomes difficult to manage for patients, family members, and healthcare professionals (Bluebond-Langner 1978; Rothenberg 1974). Individuals develop different mechanisms to deal with uncertainty, including hope (Balshem 1999), aggressive biomedical treatment, use of alternative therapies (Hess 1999), the reliance on different types of beliefs (Hunt 1999), and so on. Uncertainty also affects the other people that interact with the child and the family, like CCF’s personnel. The few tools they had available for dealing with this uncertainty and the inability of people with whom to share their feelings were frequent topics of conversation during the interviews. As some of the quotes presented in Chapter Five indicated, many of the volunteers could not share their feelings with close friends or family members; they could only rely on other volunteers or the staff psychologist, in other words people who were not always available.

In order to deal with this problem, I suggested developing a constant supervision program for the staff. This supervision program would be composed of different types of face-to-face meetings led by CCF’s psychologist where these topics could be discussed. The meetings would have different characteristics depending on the position occupied by the staff member. So, for example, the volunteers from all three sedes would meet together with the psychologist to share their problems and learn from their experiences, but separate meetings for each sede would also be held in order to deal with the problems
of each particular place. This would be especially important for the sedes located within the hospitals, as they are the ones most in contact with the patients and their families.

*Working with Children*

Another unique quality of CCF’s work, one that brings another layer of complications, is the fact that it works with children—and not just any children, but children who sometimes die. Several anthropologists have undergone the task of analyzing death during childhood describing the different connotations it has when compared to death in adulthood (Bluebond-Langner 1978; Scheper-Hughes 1992, 1998). As Bluebond-Langner (1978) has indicated, the difficulty of dealing with a child’s death is linked to ideas about childhood maintained in our society where this lifestage is seen as temporary, as a period of life that will be surpassed by adolescence and adulthood. This represents children into “adults in the making,” subjects that will become (Bluebond-Langner 1978:5).

Death disrupts this notion of becoming, generating difficulties for the people who care for the child. The difficulties it poses for the family, healthcare professionals and NGO workers are different due to their relationship with the child, but most of them are centered on the belief that children (at least those of a certain age) should not die. This is linked to the fact that childhood in Western society is associated with innocence; with the need to be safeguarded by adults (Ariès 1998). As a result, some parents blame themselves for their child’s disease (Young et al. 2002) and healthcare professionals and other caretakers are faced with ambivalence in the sense that they are confronted with feelings of sadness and guilt (Rothenberg 1974).
One response to the situation described before is the establishment of channels for the expression of these feelings. This is what I recommended to CCF’s administration (see chapter five). The supervision program mentioned above and the establishment of regular face-to-face meetings among the staff might be two ways to improve communication and the possibility of identifying emotional difficulties experienced by the staff at an early stage.

*Expanding NGOs: a Look at Organizational Development*

In the previous sections of this chapter, I emphasized that the difficulties faced by CCF’s staff had less to do with working within the public health system and more to do with working with pediatric oncology patients. I have explained this situation by arguing that previous non-governmental/government collaboration in the provision of healthcare in Argentina has established the necessary frameworks for organizations like CCF to become involved in the provision of health services today with relatively few difficulties.

The only problem with this collaboration is that when the public health system starts to gradually deteriorate, its flaws and the demand of the population exert pressure on these organizations to deal with the needs of more patients and families. This is the reason why the size of CCF today is not the same as it was three years ago, nearly tripling since 2003.

The rapid expansion and the failure of the administration to adapt CCF to these changes have had serious consequences on the structure, organization, and communication channels of CCF that if not attended to promptly could generate negative effects in the future. A review of the literature on organizational design and development
points to the fact that due to the hierarchical organization of CCF, expansion without the previous internal transformation could be detrimental to CCF’s goals. In order to explain this point better, it is important to take a look at the different ways authors have categorized the internal structure of organizations.

Out of all of the forms of classifying organizations, the one I find the most helpful and suitable for this case is the open system-closed system model proposed by Katz and Kahn (1978) and later used by Mink et al. (1979). According to these authors, a closed system is more likely to have rigid hierarchical organization, view top-level decisions as final, structure itself by permanent departments, set a formalistic atmosphere, maintain one-way communication through the chain of command, and avoid external feedback (Mink et al. 1979). An open-system is more likely to have a broader and more integrated organization, view top-level decisions as subject to review, structure itself by temporary task forces, set an atmosphere that is goal oriented, communicate up, down, and across, and seek external feedback (Mink et al. 1979).

Open systems are based on the idea of functioning as an integrated whole (Mink et al. 1979) and in the case of CCF this would entail connecting all sedes with the administration in a dynamic manner. In order for this happen, two main issues need to be addressed. First, all staff members should share a common interest in working with CCF

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54 In order to understand this point, a review of the work of Peters (1988 in Reilly 1995) is useful. According to this author, contemporary business organizations dedicated to service delivery are recommended to pursue horizontal management by displacing vertical bureaucracy, thus acquiring greater flexibility (Peters in Reilly 1995:253). This recommendation has also been made by Robey where decentralization of the decision-making process is recommended for larger organizations (1991:102); and the broadening of the top positions in the hierarchy of staff members is suggested in order to obtain a more integral organization of the personnel (Mink et al. 1979).
and should express the purpose of the organization in a similar manner. As Bacidore and Thakor (2000) and Robey (1991) have indicated, the existence of a shared purpose is an intrinsic factor in the definition of an organization and, in the case of CCF, the presence of multiple ideas on the purpose of CCF across sedes contributes to their separation and if not address now could lead to their complete isolation in the future. Second, a clear definition of the role of each staff member needs to be established and communicated to the organization as a whole (Mink et al. 1979). The clarification of expectations about job tasks and performance, team roles and relationships, and work objectives allows staff members greater clarity and security in their everyday activities and fosters better communication among the personnel (Mink et al. 1979). Furthermore, as problems arise staff members can be assisted by coordinators and supervisors based on the specific characteristics of their work (Mink et al. 1999). In the case of CCF, this clarification would be most beneficial for the permanent staff members (psychologist, social worker, volunteer coordinators, President, and Operative Director) as it would allow them greater autonomy in their work. This autonomy, however, would not be completely gained as long as the verticality of the decision-making process remained the same. In other words, as long as the President and Operative Director continue to approve every decision made by the other staff members, confusion about roles and work overlap will continue to occur.

The clarification of roles between staff members could also improve the supervision program I mentioned before where each member could be provided counseling based on the particular characteristics of their position. An important point to consider here is that this clarification of roles must be accompanied by recognition of the
value of each position within the organization to avoid competition and friction among the staff. In Chapter Five we saw that both hospital sedes requested that the administration visit their sedes more often and when this did not happen they felt their work was not as important to the administration as the one carried out at Mansilla. The presence of the administration at the hospital was not interpreted as a form of supervision or control, but as an opportunity to show the highest officials of CCF the fruits of their labor.

This recognition could also be used as a form of empowerment of the staff which could in turn lead to the establishment of a better working environment. As Welch et al. have indicated, “If employees experience one or more of the empowerment dimensions, they will feel more energized and perceptions of overwork will be lessened” (2000:67). Even though their work is directed more towards a corporate sphere and they use empowerment as a way of dealing with employee overwork, the dimensions that they present for empowering the staff might be useful for the case of CCF. The four dimensions include: self-determination (choice in one’s actions), meaning (intrinsic value in one’s work), impact (making a difference), and competence (degree to which a task can be performed) (Welch et al. 2000:67-69). The empowerment of CCF’s staff members by granting them self-determination, recognizing the meaning they attribute to their own work, highlighting the many ways they can make an impact within the organization, and ensuring competence through training and supervision programs could help eliminate the major difficulties experienced by the staff and contribute to the creation of a better working environment.
Areas of Future Research

There is certainly a lot of work to be done within CCF. It would be interesting to see the results a research study focused on all five sedes generates and to analyze how the perception of sedes outside of Buenos Aires (Tucuman and Penna) differs from that of the sedes analyzed in this thesis. It would also be interesting to compare CCF to other NGOs that work with pediatric oncology patients and look at the similarities and differences in their internal organization and how this benefits or harms their staff. This comparative study could point to models that could be adapted to CCF’s needs.

A follow-up study of the relationship between CCF and government institutions in Argentina could also point to important issues as these relationships are in constant negotiation and undergo changes through time. This would be particularly interesting to do now due to the fact that the legislation in terms of public health involvement and expenditure is suffering transformations. In January of this year the Argentine government signed a treaty with Cuba for the research, development, and manufacture of oncology drugs and antiretroviral pharmaceuticals. This measure will increase the amount of available drugs in Argentina and it represents the first step in the transference of medical technology between the two countries. It would be interesting to see the position that CCF takes on this matter and how their participation in the provision of oncology drugs to patients is affected.

When I returned to Argentina for a brief period about two months after I had completed the fieldwork, I visited CCF’s staff. To my surprise, some of the recommendations that I had made (more face-to-face communication and the volunteer
training program) had already been translated into action. As a result, I became
convinced not only that anthropologists can make important contributions to the internal
working mechanisms of NGOs, but also that long-term collaboration between
anthropologists and NGOs is possible. In the end, I think that the contributions that I
made to CCF are nothing compared to all of the things that the staff interviewed for this
thesis taught me, and, for that, I am forever grateful.
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