

**WHEN MEDICINE CANNOT CURE:  
DYING CHILDREN, PALLIATIVE CARE AND THE PRODUCTION OF  
COMPANIONSHIP**

by

RAFAEL WAINER

L.I.C., University of Buenos Aires, 2003

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE FACULTY OF GRADUATE STUDIES

(Anthropology)

THE UNIVERSITY OF BRITISH COLUMBIA

© Rafael Wainer, 2008

## ABSTRACT

Although the curative model of medical care is predominant it is necessary to consider the palliative strategies at the end-of-life. The inter-relation of dying children, their families and pediatric palliative care teams are seldom analyzed outside Palliative Care. However, it is important to ethnographically think about the disturbing experiences of body and subject disintegration while people are directly experiencing them, even when the person is a child or a newborn baby. A central topic in this study is how personhood, body formation and disintegration, and childhood can be understood within the context of unevenly constructed and shared palliative communication with and without words. Hence, I analyze in this study how a Palliative Care Team provides care, communicates, and ultimately produces a particular companionship to dying children and their families. This work is built on qualitative information gathered and produced during my four-month fieldwork with the Palliative Care Team. The ethnographic techniques (participant observation, non-participant observation and open-ended semi-structured interviews) I conducted show that their strategies of care and communication have as the main goal the process of companionship at the end of children's lives. It is necessary to understand how patients, parents, and other family members are situated in this field of tensions between restorative and palliative medicine, and brought into this culture of Palliative Care in a public children's hospital. My research asks, in what ways are pediatric Palliative Care practices exclusive to the social and cultural contexts of Buenos Aires? This work has three main sections: 1. care, 2. communication, and 3. companionship. In section one I focus on the clinical and non-clinical aspects of care involving the professionals' and volunteers' practices of giving care. In section two I concentrate my attention on the verbal and non-verbal aspects of the Palliative Care Team communication with children and families. In section three I consider the professional production of 'companionship'. In this thesis I will demonstrate the significance of this concept according to the Palliative Care Team members and how care and communication are the base for the 'production of companionship.'

## TABLE OF CONTENTS

ABSTRACT.....	ii
TABLE OF CONTENTS.....	iii
ACKNOWLEDGMENTS.....	iv
INTRODUCTION: WHEN MEDICINE CANNOT CURE.....	1
Death.....	4
Palliative Care.....	5
Pediatric Palliative Care.....	6
STUDY BACKGROUND.....	8
Paediatric Palliative Care: Why look at Dying Children in Buenos Aires?.....	8
The Argentinean Context.....	9
Organizational Structure of the Hospital.....	11
The Palliative Care Team.....	11
Ordinary Routines of the Palliative Care Team.....	14
Methodology.....	15
THE CONSTRUCTION OF PROFESSIONAL CARE.....	17
Strategies of Care.....	18
Practice – Pharmacological and Behavioural.....	19
Practice – Psychological.....	19
Practice – Empathy.....	19
Practice – Multidisciplinarity / Organizational.....	20
General Philosophy.....	21
Philosophy About the End of Life.....	21
Aptitude – Attitude.....	22
Practice/Philosophy of Care.....	23
Non-Pharmacologic Therapies: the Non-Organic Aspects of the Equation.....	24
Interrelationship.....	25
Two Types of Inter-relationships.....	27
Palliative Care Is a Collective Effort.....	28
THE CONSTRUCTION OF COMMUNICATION.....	30
With Words.....	30
Without Words.....	34
THE PRODUCTION OF COMPANIONSHIP.....	39
CONCLUSION.....	42
BIBLIOGRAPHY AND FILMOGRAPHY.....	44

## ACKNOWLEDGMENTS

I need to acknowledge the enormous help given by each of the members of the Palliative Care Team in which I conducted this study. I am thankful to the two doctors of the team, the residents that were rotating during my four months of fieldwork, and the two volunteers. Without their support this study would not have been conducted nor finished. I also need to say thanks to the children and parents that were indirectly studied during this research. They let me observe some of the interactions with the team members that were the source of this study.

Furthermore, I need to recognize the invaluable support given by Prof. William McKellin as my supervisor. He guided me during this process with a strong commitment and dedication. His openness and wisdom were vital for me to start, continue, and finish this project. I was highly benefited by his enjoyment for teaching and guiding grad students. Dr. McKellin is always supervising the maximum amount of students allowed by the Department and this fact says a lot about his generosity. Dr. Pat Moore, as a committee member, was also of great help. Dr Moore makes himself available at all times and is always ready to give you good words and wise advise. I am also thankful to him.

Many people were important during my two years as MA student. I will not name all my friends, colleagues, and even strangers that helped me to conclude this thesis. I will just mention some of them: thanks to Billy for helping me proof-edit my last version of this work, thanks to Natasha and Chris for our talks, thanks to Natalie and Sandra for your help with bureaucratic procedures, thanks to Tal, Emily, Marie-Eve, Susan, Larry, Chad, Julien, Oralia, Bonar, Sanjeev, Lainie, Steve, Lina, Fredy, Jan, and Solen (and the previously mentioned friends) for sharing your friendship with me. Thanks to Dan, Michele, Stella for taking care of all the small and crucial details of our lives as grad students and for creating a nice work environment.

Graduate studies usually present important financial challenges. I was able to confront the challenge of entering the Department as an unfunded MA student with the support of multiple employers: thanks to AMS Catering (Tessie), thanks to Koerner's Pub, and thanks to AMS Barbeque (Rick). I am also thankful to Prof. Leslie Roman who took me on as Research Assistant in the Department of Education in a very provocative and demanding project. I thank her for let me see and think other things on my experience at the Canadian academy. In the second semester of the first year of MA I had the chance to work as TA for Dr. Bruce Miller and Dr. Mike Blake and I thank the Department for this. In the second year of MA student I had the opportunity to be funded with a full UGF by the University, which helped me to focus on my research and to take six months off to conduct my fieldwork in Argentina.

Finally, but not less importantly, I have to say thanks to Ana. She supported me in countless ways. Her love and kindness were central for me to survive and enjoy my Canadian years (and the rest of my life too). This work is offered to her (and to Kerou). I also say thanks to my family for their unconditional love and support.

Last words, this study has the aim to highlight the diverse forms of care and accompaniment to dying children and their families; strategies of care, communication and companionship developed by a Palliative Care Team. The ultimate dedication of this research is to those children that died before and during my

fieldwork, and the ones that will die in the future. Their suffering and joy, their tears and laughter are the mirrors in which their families, the Palliative Care Team members and the anthropologist have reflected. They have taught and will teach us a lot.

## INTRODUCTION: WHEN MEDICINE CANNOT CURE

*Naomi is in a coma; she is not responding to her mother's caresses. She is twenty two years old and has been treated by the Palliative Care Team since she was four. Her brain cancer, after remissions and reoccurrences, has spread to her body. Now standing at both sides of her bed are her parents, twin sister, uncle, aunt, four members of the Palliative Care Team, and me. Yesterday we talked outside in the corridor with Naomi's parents and sister. They discussed many concerns. They believe that Naomi's body cannot resist much longer and they fear that the oximeter (which measures oxygen in the blood) has gone too high. After a short talk with the parents ensuring them that Naomi was not feeling any pain, and that she was calm, Dr. Marcos stops talking and we all pause in silence for a moment. We remain silent until Dr. Marcos reiterates to the parents and sister that Naomi is quiet and is not suffering. Dr. Marcos slowly leans forward and gives a kiss to Naomi on her left cheek.<sup>1</sup> We say goodbye and leave the room. Ms. Silva and Ms. Gómez, two volunteers of the PCT, enter the room and stay with them for some time. Ms. Silva would tell us at the end of the day that she went there and started to talk in a very soft way, more like a whisper, to Naomi saying that she loves her, that everyone loves her very much, that she has made a great effort, that everything will be just fine, and that she does not need to worry. She also caressed her and sang to her, and asked Naomi's sister to do the same. Two hours later, Naomi passed away.*

Since the revitalization of the palliative facet of medicine with the Palliative Care (hereafter PC) movement at the end of 1960's (Saunders 1984, Kübler-Ross 1975, Mauksch 1975) much discussion and debate has taken place about the merits of curative versus palliative medicine (Selwyn and Forstein 2003, Weismann 2004).

Although the curative model of medical care is prevalent (Fox 1997), there is a need for more discussion about how the whole range of medical care options (from preventive, to curative, rehabilitative, restorative, and palliative) are not discrete, but actually overlap, contradict, and struggle at the end-of-life (Sapir and Fox 1998).

While this is the situation with adults and elders, there is even less discussion and conceptual clarity in the literature in relation to children's care. The concerns of dying children and pediatric PC are rarely analyzed outside the confines of PC clinics.<sup>2</sup>

In our high-tech societies, and in western biomedicine in particular, death and dying are often considered as technical failures rather than part of a process of life that, as in Naomi's case, sometimes ends before its expected time. If the death of a child is a failure of medicine and if the objective is to prevent her death, then what are the appropriate medical possibilities to care for a dying child and her family? How can she and her family be helped? Therefore, what else is needed and what actually happens when medicine cannot cure and when we cannot avoid death (Price 2007)? Advocates of PC contend that it is not only possible but also necessary to combine curative and palliative models. Achieving accurate prognosis is usually not easy and

---

<sup>1</sup> Dr. Alex (hereafter, Alex), one of the residents at the Palliative Care Team (hereafter PCT), would write a long poem after, stating in one part: "and they bend over me to see if I am breathing."

<sup>2</sup> There is a vast non-scientific bibliography that touches issues similar to the ones that I deal with in this thesis. One popular book that focuses on the miscommunication among parents and professionals is Anne Fadiman's *The Spirit Catches You and Fall Down* (1997).

families are less disposed to accept a terminal diagnosis for their child (Meier and Beresford 2007). How does a child's life trajectory as well as family and social relations intersect with cultural values in curative and palliative pediatric healthcare?

Both physicians and families are increasingly aware that a different set of objectives and expectations are required of clinicians in PC. Although not immune from tensions and contradictions, PC professionals attempt to deal with the physical, psychological, social, and practical needs of patients and caregivers at every stage of illness. According to the World Health Organization (henceforth W.H.O.), Pediatric PC is:

[t]he active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress." (<http://www.who.int/cancer/palliative/en>).

Therefore in the context of this "total care", when patients are going through end-of-life experiences, good PC will neither hasten nor delay death (Quill et al. 2008). Its preoccupation is not death (although the specific types of death are also part of their concern) because it will eventually happen. Attention is focused on *how* it is going to happen. Therefore, the core of this study is *how* PC produces a particular type of care and communication for children who are going to die.

In the health sciences there is voluminous literature on adult PC, and more recently we have seen some studies in pediatric PC (Hurvitz et al. 2004, Salas Arrambide et al. 2004). In the social sciences however, studies of pediatric PC are rare and focus on care provided mostly in North America (Carter and Levetown 2004). There are very few studies available in other cultures about care provided for dying children, thus making it more difficult to measure the impact of a transnational medical practice in a variety of social and cultural contexts.<sup>3</sup> The fieldwork I have conducted will focus on the professional aspect of giving care in an Argentinean pediatric hospital and *acompañamiento* (companionship), the relationship established between the dying child and his/her care providers.<sup>4</sup> This concept of 'acompañamiento' offers a means of grasping the social and cultural aspects of verbal and non-verbal communication as well as the culturally appropriate understanding of agency that is afforded the child during PC. In this study I am focusing solely on the actions of the PCT.

---

<sup>3</sup> Indeed, to be fair, within Palliative Care and Pain Control disciplines there are studies showing the local differences of this transnational movement. For instance, in a special issue of *Journal of Pain and Symptom Management* 2007, 33(5), one can find articles analyzing the development of Palliative Care in places such as South Africa, Uganda, Mongolia, Nepal, Vietnam, Catalonia and Extremadura (Spain), Argentina, Hungary, Romania, India, Brazil, and several provinces of Canada.

<sup>4</sup> *Acompañamiento* is the word they use. I will discuss its particular meaning after.

Key questions in this study are: how do health care professionals provide appropriate care for suffering children during process of dying when the general biomedical orientation considers death as something to be fought against, deferred, or precluded? How do doctors and other caregivers reconcile a thorough technical knowledge of medicine with a humanistic attitude and ethical orientation at the end of a child's life (Clark 2002)? These tensions, clashes, and conflicts will be examined within a clinical setting through an ethnographic study of children's end of life 'treatment' from the standpoint of a PC Team in "Hospital Camino," a public children's hospital.<sup>5</sup> The PCT, with its aim of giving professional and familial care and relieving or alleviating children's suffering is, needless to say, at the same time trying to care for the children and family members during the dying process. As a result of these objectives in PC philosophy and practice, a series of challenges and contradictions arise. First, as in Western Europe and North America, both the family and physicians find it difficult to let a child go (House of Lords: Select Committee on the Assisted Dying for the Terminally Ill Bill 2005, Lair 1996, Bluebond-Langner 1996). Second, children feel stressed as they experience the inevitable process of physical deterioration and loss of possibilities of action (Bluebond-Langner 1978, Lawton 2000). Third, there is a sense of generational conflict between a child's limited agency and the adults' roles as decision-makers for the child (Goldman-Hain-Liben 2006). Fourth, just as friction develops between the intimacy of the family in the face of loss and the public representation and communication of death in an institutional and bureaucratic setting in Canada (Kuhl 2002, 2006), similar concerns also arise in Argentina. And finally, the socio-economic conditions in a Latin-American context limit the availability and accessibility of treatments for children (De Maio 2007).

Being labeled a "terminal" patient is extremely demanding for the person's end-of-life experience, the healthcare providers, and the family. But the problems are completely different if we compare adults with children. One of the main differences is that pediatric PC has no other possibility than to consider the family as the unit of care, whereas in adult PC this focus is not always present and the patient-doctor relationship is the principal objective. Some authors articulate these distinct difficulties in terms of the unspeakable character of pediatric PC (Ralison and Moules 2004), and the need for the parents (and very often the professionals) to use all possible means beyond standard curative forms (Bluebond-Langner et al. 2007, Weissman 2004). Indeed, according to Wolfe et al. (2000) there is an inverse relationship in the time between parents' and physician's

---

<sup>5</sup> The name of the Hospital is a pseudonym; from now on I will call it "Hospital Camino." Palliative Care professionals, volunteers, other professionals, family members and children also have pseudonyms.



recognition of children's terminal cancer prognosis and the opportunity to reduce children's suffering and have a wider integration of PC. Moreover, the definitions of child health and chronic or terminal conditions are themselves ambiguous and contextual. They mirror the genuine complexities of this phenomenon, and the various aims of policy makers and researchers (Davies and Brosco 2007). Meier and Beresford (2007) argue that even inside PC there is a need for further integration and mutual aid between adult and pediatric PC.

In terms of the anthropological significance of studying death and dying from the professional perspective it is central to highlight the double specificity of analyzing the social conditions of dying children, and the palliative professional discourses and practices that act on those conditions. This research aims to expand the anthropological knowledge of death and dying, specifically of children, by considering the experiences of suffering and dying from professionals' point of view. While most studies only focus on adult patients in the north hemisphere, I will extend this to also examine the ways in which terminally ill children, parents, and family members are being accompanied by a palliative professional team in a third world context. This study will contribute to the intense debate in relation to children and families' rights when experiencing life-threatening conditions (Davies 2004, Clark 2002), and the empowerment needed to let children (and their families) re-appropriate of their own experiences and meanings inscribed at the dying process.

## **Death**

According to Western biomedicine, death has been, and continues to be treated, as a precise moment in time. The definition of this exact moment, however, has been historically problematic. What now defines clinical death is the cessation of electrical activity in the brain or a "persistent vegetative state." This is known as "brain death" or "biological death." The clinical and legal definitions of death utilize binary notions of death, ones that distinguish life from death. But even the extreme circumstances of a "persistent vegetative state" are subject to social and cultural challenges, such as those in the cases of Terri Schiavo (Caplan et al. 2006) or in Almodovar's film "Talk to her" (2002). These are "people" that, as Kaufman (2000) has put it, live in the shadow of "death with dignity." The biomedical endeavor, however, not only focuses on death itself, it has several disciplines dealing with the dying process itself and the post-death state. However, managing chronic and terminal illnesses as well as grief and bereavement are medical actions (or processes) that are somehow situated below the hyper-visibility of the intensivists and surgeons that either fight against death or face the inevitable and inescapable death of the patient.

From an anthropological perspective, death not only includes the precise biological moment but also the preceding dying process and the bond that the survivors have with the dead (Lock 1996). Death is above all, using classical terminology, a “social fact” (Durkheim 1982): a series of events that are traversed by economic, political, religious, symbolical, material, and spiritual factors. For instance, one main feature of terminal or chronic conditions, in relation to illness trajectory, and ultimately to death in North America, is the professional and lay management of uncertainty (Becker and Kaufman 1995). In the specific case of a dying child after a long illness trajectory, parents’ notions of embodiment and transcendence (Rouse 2004) very often clash with medical or legal concepts of duty, e.g. conflicts regarding the signing of ‘do-not-resuscitate’ orders. Therefore, in the social sciences, and particularly in anthropology, we tend to emphasize the process of dying and the moment of death itself.

In this tradition, two anthropologists have produced notable studies of children’s dying processes in Latin America and in North America as well. Nancy Scheper-Hughes (1992) has analyzed the social conditions that generate high rates of infant mortality in the Northeast of Brazil. The author discusses the “old”<sup>6</sup> and “new”<sup>7</sup> reproductive strategies, the derivation of modern notions of “mother love,” and the relationships between infant mortality, poverty, social abandonment and emotional stress. One of the few studies of care provided to dying children is Bluebond-Langner’s (1978, 1996) study of the hidden experiences of dying children, and of the parents, siblings in the United States and the professionals involved in those processes. These studies were important to situate the impact of a chronic and life-threatening condition such as cystic fibrosis and cancer in the familial and social contexts of the United States.

## **Palliative Care**

Palliation has always featured in biomedicine, but in the process of modernization, professionalization, and specialization, preventive and palliative strategies have gradually lost ground in relation to the curative efforts of biomedicine (Bradshaw 1996). According to the W.H.O., palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.”<sup>8</sup>

---

<sup>6</sup> “To give birth to few infants and to ‘invest’ heavily (emotionally as well as materially) in each one from birth onward” (1992: 402).

<sup>7</sup> “To give birth to many children and, on the expectation that only a few will survive infancy, to invest selectively in those considered ‘best bets’ for survival in terms of preferred sex, birth order, appearance, health, or perceived viability” (1992: 402).

<sup>8</sup> <http://www.who.int/cancer/palliative/definition/en/>; retrieved on July 6, 2008.

However, palliative medicine is not confined to the treatment of terminally ill people. It can also aid patients with all kinds of conditions because the objectives are: to ease suffering, pain, and other stressful symptoms, to give psychological and spiritual care, to support the person in living as actively as possible, and finally to assist the family.

This relatively new concern of biomedicine with palliative care attracts the attention of the social sciences and in particular anthropology. The historical movement of PC started with the recognition that the dying patient was avoided or at least not considered in the same way that patient with restorative prognosis (Du Boulay 1984). Critics of the positivism and biologicism of biomedicine came not only from the social sciences (Freidson 1970), but also from the palliative care movement (Saunders 1984). The importance of PC was that the dying person became the primary focus of interest, and accordingly the requirement to control her symptoms was central. Another important feature that created a shift in the history of Western medicine was the inclusion of the family as an ally instead of an “other.” Biomedical knowledge tended to distrust patients’ and families’ words, but PC helped to restore the need to pay attention to what they have to say.

## **Pediatric Palliative Care**

PC for adults appeared only at the end of the 1960’s, but pediatric PC followed at least one decade later when, in 1978, the first hospice<sup>9</sup> for children was created in Virginia, United States of America,<sup>10</sup> and, in 1982, in Oxford, England.<sup>11</sup> If we compare both adult and pediatric PC the care for dying children is even more complex in terms of social problems, mainly because it directly implies more people: the child, his/her family, and professionals. In this instance, the “total care” has to focus on both the child and his/her family. From an anthropological viewpoint there is an interplay of two sources of complexity; the limitation of the medicine to cure, and the difficulties of the child, parents, siblings, and family to accept and process the end of the child’s life.

Within this general context, my research focuses on how PC professionals and volunteers participate in the end of children’s lives. I pay special attention to children and families’ experiences from the perspective of a

---

<sup>9</sup> The institution of “hospice for the very sick children” comes from the middle ages but modern hospices started only after St. Christopher’s Hospice (for adults) and the ones mentioned above for children.

<sup>10</sup> <http://www.edmarc.org/>; retrieved July 3, 2008.

<sup>11</sup> <http://www.helenanddouglas.org.uk>; retrieved July 3, 2008.

PCT. Thus, I consider it crucial to analyze the strategies of PC (relief and symptoms control, quality of life improvement, patients' and families' empowerment and autonomy) and the uniqueness of the intersection of childhood, death, PC and the Latin American context of healthcare. As a consequence, the framework of this study is how patients, parents, and other family members are situated (and situate themselves) in this field of tensions between restorative and palliative medicine, often being tagged as "problematic families," and brought into this culture of PC in a clinical setting of a public children's hospital in the city of Buenos Aires.

This work, therefore, has three main sections: 1. care, 2. communication, and 3. companionship, in order to analyze the PCT production of companionship at the end-of-life. In section one I will focus on the clinical and non-clinical aspects of care involving the professionals' and volunteers' practices of giving care. In section two I will focus attention on the verbal and non-verbal aspects of the PCT communication with children and families. In the third section I will concentrate on the professional production of 'companionship'. I consider the notion of 'companionship' as central because the PCT members have highlighted it to me; they constantly talk about their roles as 'accompanying the process' [*acompañando el proceso*] of the terminally ill child and her/his family. In this thesis I will demonstrate the significance of this concept according to the PCT members and how care and communication are the base for the 'production of companionship.' But before getting into these sections I want to present the background of this study. I will briefly discuss why it is important to study a pediatric PCT, introduce the PCT, its ordinary routines, and conclude with some methodological reflections.

## STUDY BACKGROUND

### Pediatric Palliative Care: Why Look at Dying Children in Buenos Aires?

Studies of PC reflect the North American and European contexts in which this approach to care has developed. In this thesis I will examine the extent to which professional PC practices in Argentina mirror the historical development of PC in England and North America. My research asks, in what ways are PC practices exclusive to the social and cultural contexts of Buenos Aires?

If we compare adult and pediatric PC there are certainly some convergences as well as some clear divergences. Pediatric PC emerged after adult PC mainly because there are comparatively fewer children dying than adults. For instance, in United States 55,000 children under the age of nineteen die out of 2.5 million total deaths per year (Meier and Beresford 2007). However, because of the expansion of modern medicine in United States more than one million infants and children that would have otherwise died are now living with chronic conditions and requiring PC assistance. In Argentina, in 2004, more than 290,000 people died but of those only less than 3,000 were children under the age of fourteen (INDEC 2006).

According to Meier and Beresford (2007: 285), the differences between pediatric and adult PC can be summarized in five ways

- 1) The death of a child, on the contrary to the death of an elderly person, is never tolerable or viewed as habitual or “natural,” it always represents a failure.
- 2) Because of the erratic illness trajectory medical prognosis is even more uncertain for children than for adults. The result is a need for a mixture or a dual model of curative and palliative medicine due to the difficulties for generating precise prognosis and because families are not ready to assume a terminal diagnosis for their child, even when death is close.
- 3) Critically ill children and their families often have deep-rooted relations and great emotional connections with pediatric professionals. A palliative care offer of support may be understood as external intrusion or even worse a form of disregard by the initial team.
- 4) In general parents, not the children, make treatment decisions, and the illness or the end-of-life of the child has more distinct consequences for the family than the death of an older relative.<sup>12</sup>
- 5) The children are continually shifting from one state into another and growing into new stages of personal development, regardless of his or her illness trajectory.

Children are producers and products, creators and actors of their own lives (Cohn 2005, James y Prout 1997, Toren 2004). Apart from the objective legal impediment, the social scientific literature considers children as full actors in their particular lives (Cohn 2005, Toren 2004, Coles 1986), as products and producers of “their own, collective and personal, histories” (Toren 1993: 474). Thus I think that the richness lies in the overlaps, in

---

<sup>12</sup> In a personal communication with Dr. Sharon Kaufman she told me, “I think one needs to think about uneven power relations, wherever one works (clinics, community settings, etc), when you think about choices, decisions, and how knowledge is framed etc. The politics of power relations is important for how people situate themselves, even in relation to thinking about death, and death ‘practices’” (personal communication, April 13<sup>th</sup>, 2007).

the interconnections between PCT members, children and families. What I am trying to do here is to focus on dying children, their experiences and how the PCT helps them and their families, and to examine the wide range of situations the PCT confronts on an everyday basis.

The material I present is one of the few studies of professional PC conducted outside its early ‘homeland’ in England and North America. How is PC different in the city of Buenos Aires one may ask, from England and North America? One of the core questions in this analysis is the need to consider if there are cross-cultural variations, if there is a homogeneous international palliative culture that displaces societal differences, or if there is a mixture, or both. The modern PC movement started in England at the end of the 1960s guided by Cicely Saunders (1984). At the beginning it was run through a series of hospices that were supported by social charity, and thus remained outside of the state healthcare system.

## **The Argentinean Context**

In the beginning of the 1980’s PC was introduced to Argentina. Between 1985 and 1989 Dr. Rubén Bild managed the Foundation *Prager-Bild*, an institution that helped to spread and install PC, first at this private institution, but then at public hospitals. Dr. Bild noticed that in Latin-American societies there are hardly any hospices like those in Anglo-Saxon countries, and because of this he concluded that in Latin America there is a rejection of the issue of death (personal communication, August 20, 2002). Except for the Foundation *Prager-Bild*, PC in Argentina began to expand first at the public hospitals, and then to the private sector. According to Dr. Bild this was as a result of both the pivotal weight of public healthcare and the cultural impossibility of running an institution solely as a charity in the Argentinean context.

In comparing North America and Argentina one of the differences is that obstacles to accessing a higher quality of healthcare, especially for PC, are traversed by different axes. In the United States, authors such as Stevens and Shi (2002) show how terminal children from ethnic and minority groups have low-grade patient-doctor relationships in comparison to those of “white” children. In Canada, Mio (2001) has analyzed the difficulties for PC professionals, and at times their incapacity, to deal with patients that are “ethno-cultural others.” In both the United States and Canada, geographical barriers and the lack of provision outside the few big cities strongly conditions access to pediatric PC (Connor et al. 2007, Widger 2007). In Argentina, geography is a big factor but instead of racial issues one can point to “class” as a crucial feature in the ability to

access quality pediatric PC in the public institutions or in the private health companies. But Argentina is not exempt from the social causes that in the Latin American context prevent the availability, accessibility, and affordability of PC; only 5-10% of patients in need of PC in Latin America receive it, 97% of PC is accessible in big cities, 50% or more of the patients cannot afford to pay PC service or medication (Torres et al. 2007).

In addition to the differences in the institutional histories of PC in England and North America, as opposed to Argentina, there are considerable cultural and linguistic differences that have shaped the development of PC. One important notion in this study is the verb *acompañar* (to accompany) or the noun *acompañamiento* (companionship). The PCT members constantly use those two words and because of this I have centered this notion at the core of this study. For a lack of a better word I translate *acompañar* and *acompañamiento* as ‘accompany’ and ‘companionship’, trying to keep the original meaning found in Spanish. *Acompañamiento* could have at least two meanings; the accompaniment that PCT members do with children and family at the end-of-life, and the philosophy of companionship that PCT members practice among themselves and with children and families. These concepts, as I will show, stand in contrast to “care” and “treatment” which are used to describe the activities of health care professionals acting on palliative patients in North America.<sup>13</sup>

When considering children who were experiencing the end-of-life process, two main themes appeared during the fieldwork and interviews with the PCT members, those of care and communication. The PCT members highlighted adequate care (physical, emotional, spiritual) and proper communication as equally important in their provision of PC assistance. Therefore these issues are crucial in their everyday practice.

In one interview Dr. Marcos stated that in order to perform PC one needs 50% of aptitude (excellent technical knowledge) and 50% of attitude (communication skills). Both are needed to facilitate what the PCT consider as an appropriate companionship. Therefore, one may ask, what constitutes this particular palliative companionship? This is the central question of this thesis.

---

<sup>13</sup> To be clear, “accompany” and “companionship” do not stand in complete opposition to “care” and “treatment;” the latter are also central but what struck my attention was the pivotal importance of the former in the PCT’s members discourse.

## **Organizational Structure of the Hospital**

The Hospital Camino where the PCT works operates under the Secretary of Health of the City of Buenos Aires and was established in 1875.<sup>14</sup> It was the main children's hospital in the city until 1987, when the national children's hospital was founded (conjointly supported by the national and city governments). Although each of the more than fifteen hospitals in the city has a pediatric unit, only these two hospitals are specialized in pediatrics. The Hospital Camino has approximately 500,000 consultations and 12,000 hospitalizations per year and is one of the three main options for patients with high complexity illnesses in the city and often in the country. There is another county hospital, specializing in the early ages of life, and there is supposed to be a differentiation among these three hospitals in which the latter hospital is specialized in the treatment of babies and infants. The Hospital Camino focuses on early ages (0-12 years) and young teenagers. The national hospital is dedicated to older teenagers. However, in practice this distinction is barely operative and many factors determine where children will finally be assisted. The majority of the population treated at the hospital come from the middle and lower classes within the city of Buenos Aires and the nearby Province of Buenos Aires but they also receive patients from all over the country and even from the border countries.

## **The Palliative Care Team**

Dr. Elizabeth and Dr. Marcos constitute the medical part of the PCT as head and second physician respectively (there are also a pharmacist and physical therapist associated). They are both pediatricians who specialized in PC, Elizabeth in England and Marcos in Argentina. Elizabeth started to work at the Hospital Camino in 1990 in the oncology unit and soon after a psychologist joined her. An oncologist requested she to work the management of symptoms and pain, an area that was not covered by any professional at that time. In 1992 Elizabeth went to England to study at the Bristol Royal Hospital for the Sick Children and then returned to Hospital Camino. Only in 1996 did she manage to split from oncology and create the Control Symptoms, and then the Palliative Care Team under the auspices of the Anaesthesiology Unit. In 2001, after finishing as chief-resident at the Hospital Camino, Dr Marcos started to work at the PCT as the second physician. The major activities of the PCT are to treat in-patients and ambulatory patients, participate at inter-hospital meetings, and carry out extra-hospital duties.

---

<sup>14</sup> The Health System in Argentina is public and free, but in the last 30 years, especially after the dictatorship between 1976-1983, the increasing neo-liberal policies created a major crisis in the system making it always near to collapse.



The PCT is situated in the first floor of a pavilion next to Immunology, and ironically close to the hospital's morgue. In 2000, one person came and helped to recycle two bright office spaces for the team. In comparison to the rest of the hospital these offices are more comfortable, warm, and private. As a joke other professionals called the PCT office "Medicus," which is a private medical company for middle and upper class clients. This joke is hardly understandable without knowing the context of the health system in Argentina in which public healthcare is going bankrupt and more and more people are lacking health coverage. In this neo-liberal context private companies are offering health services to middle and upper class clients, but still public health is considered as a basic right. The Hospital Camino is, in general, badly maintained. Only the units that have good contacts with the pharmaceutical companies, other companies or private foundations can afford to have nice rooms and offices. The PCT, lacking good contacts, was lucky enough to have a random person offer to paint and furnish its office.

During the last twelve years, but especially in the last five years many residents from the hospital or other institutions came to the team to be trained in PC and rotated for no less than two months. At some point throughout these years, the team had a nurse, psychologist, acupuncturist, and other physicians who eventually left the team. In spite of all the work done since 1996 the team still has a lack of official recognition from the City Government (but an informal recognition from peers). Although the PCT has a significant workload (between 120 to 150 complex consultations per month), they are not recognised as a service, unit, or section.

The team is designated as a "Palliative Care workgroup" and for the last two years they work under the administration of the Medical Clinic Department. However, there have been no official positions assigned to both Dr Elizabeth and Dr Marcos.<sup>15</sup> Indeed, they do not receive their wages from the hospital; a non-profit foundation is supporting Elizabeth's work since 1997 and Marcos' work since 2001. As far as I understand within the structure of the institution a 'workgroup' is a team that has not achieved the minimum recognition from the hospital, due to the number of patients assisted, to be considered as a 'Section', or independent unit. This recognition is needed in order to be able to ask the hospital for officially recognized and paid positions. The PCT is similar to other workgroups in that none of them have paid positions or contractual financial relationships with the hospital. However, it should be said that their situation is neither unique nor exceptional in the general context of Argentinean society where 50% of the labor force is working under the

---

<sup>15</sup> If one goes to the website of the Camino Hospital there is no reference of the PCT at all (I am not citing to keep the anonymity).

table.

The puzzling situation is that the PCT is highly appreciated within and outside the institution and has major responsibilities, but they do not have a contractual relationship with the hospital. It appears as though the institution is letting them have their space and work at the hospital. Although there is some kind of arrangement between members of the PCT and the hospital that enables them to examine and treat patients, provide access to patient information and to use resources and facilities, there is no contractual relationship. What makes this unique in terms of comparisons with North America or Europe is how precarious their jobs are (based only in scarce unpaid human resources). However, the main problem is with the city government and its lack of political will. The hospital administration recognizes the PCT effort but lacks the political power to help them become a section or service in their own right and thus qualify for official positions.

For the last three years the team has included an average of two residents per month from different hospitals in Buenos Aires and other provinces that rotate within the team.<sup>16</sup> This interest illustrates the importance of the team as a key reference point in pediatric PC within Argentina (there are less than five pediatric PCTs in the whole country). Apart from the medical professionals, the team has two main volunteers that complement the medical treatment with what they call “non-pharmacologic therapies.” Ms. Sylvia (hereafter Sylvia) and Ms. Andrea (hereafter Andrea) have impressive experience and skills in different areas: Reiki, meditation, mandala drawings, crystal-singing bowls, recitation of mantras, relaxation, visualizations, and more. They provide these techniques to both children and, very often, to family members too.

At different times during my four-month fieldwork, four residents of Pediatrics were rotating with the team, two from the Hospital Camino (both finishing the last year of residency) and two from other hospitals in Buenos Aires (one public and one private). Since January 2008, after my fieldwork had concluded, a new member was added to the team, Dr. Susan, who also rotated with the team for many months. She started to work as the third professional and thus the team is trying to address the ever-increasing demand for PC. In addition, the PCT has a monthly external supervision meeting with a professional psychologist trained in PC and Psycho-oncology.

---

<sup>16</sup> The medical hierarchy of the hospital staff is: Staff, residents from the hospital, and residents from other hospitals who are rotating at the children’s hospital. Then there are non-medical professionals such as nurses, technicians and finally there are volunteers.

## **Ordinary Routines of the Palliative Care Team**

Every Monday, to help organize the week's schedule, PCT members visit all the patients that they have been seeing in the last week plus patients that other units refer to them. Usually the request comes from the residents (they are in charge of the patients most of the time, despite the institution having more experienced staff doctors) of different units all over the hospital, but especially: Communicable Diseases, Neurosurgery, Immunology, Oncology, and Emergency. Although approximately 50% of the patients at the hospital experience different types of cancer they are treated by different specialties besides Oncology, and as a result they are admitted to distinct units within the Hospital. The PCT functions as a specialist secondary care provider so patients/families require a referral to one of these specialists for a consultation. The team needs to be asked to see a patient in order to have access to them. This happens since other units make the referrals for where patients are to be treated, and because the PCT does not have any designated beds for their patients.

The PCT members decide when they are going to see patients again throughout the week according to different criteria e.g. type of illness, how controlled the pain and symptoms are, patient and families needs, etc. Often these criteria are also influenced by the in-hospital relationships between the PCT and the other units. For instance, they have a complex and tense relation with oncology and psychopathology. They also see ambulatory patients and families at their own office (only 10-20% of the consultations are held at the PCT office). Less frequently the PCT and the other specialists discuss the patients in a formal patients 'round'. They talk about the patients informally in the corridors or in the residents and/or staff offices. Most of the time the PCT are constrained by limited time and evaluate patients themselves or with the presence of a resident of that unit. Then they have a small chat with the residents or staff in charge of the patient and discuss what they have done and what would be the appropriate next steps to take.

Every Monday, at the end of the day, the team reviews each patient's case from all the patients seen. Every member of the team adds more information about the patients that others do not know. These rich discussions allow the team to have a better idea of the patient's and family's situations, their medical and social needs and how to deal with them. This is the busiest day of the week. The rest of the week patients are seen according to the severity of their situation with some patients that have been discharged seen at the PCT office. I asked the PCT professionals why they try to see as many patients as possible on Mondays and how they decide whom to see and when? Marcos replied to me...

We try to see all patients on Monday to organize the week. Children who are at the end of their life (a few days) are seen every day. We see them or their family, even if we do not check them only to let them know that we are available. Children with pain or other symptoms, if those are not relieved; they are also seen every day, especially if we made changes in medication. If they are well controlled, and we are working more with the family, they are seen every other day or every two days. Other queries such as abstinence or management of sedation, perhaps we see them once a week.

## **Methodology**

I have known the head of the team since 2001. She was one of my first informants when I was getting into the PC world in Argentina. She suggested I see Dr. Albert and asked his permission to conduct fieldwork with his team at the National Cancer Hospital for my BA thesis (Wainer 2003), which I did. During all these years I kept in contact with her and tried, with little success, to conduct an anthropological workshop about hope at the end-of-life. Throughout my research though I never volunteered for the PCT. For this thesis I did my research with the purpose, apart from academic motives, of being of help to the team. I am willing to continue working with the PCT in the course of future research.

In terms of methods, this work is built on qualitative information gathered and produced during my four-month fieldwork with a PCT. The members of the team were recruited with a formal letter asking them to be part of the project. All members formally agreed to become participants, and when new residents came during my fieldwork they were recruited under the same process.<sup>17</sup> The main caregivers of the children were also asked for written consent allowing me to observe them while following the PCT in their everyday activities.

During this process, I employed several methods of ethnographic research; participant observation, non-participant observation and open-ended semi-structured interviews with all the members of the PCT (Lambert and McKeivitt 2002). Throughout my fieldwork I went to the hospital four times per week from 9 a.m. until 2 p.m. from August until November 2007. As a result, I produced 59 extensive daily records. During my time with the PCT I was taking brief notes, sometimes very short sentences, or even one-word comments.

Reconstruction of events, talks, and situations was made afterwards outside of the clinical setting in an attempt to be as accurate as possible in order to apprehend the complexity of those events.

In addition, I also conducted seven interviews with the members of the team and the residents at the PCT office (one interview per person). The duration of each interview was around ninety minutes. I asked the same

---

<sup>17</sup> The Behavioural Research Ethics Board at UBC and the Teaching and Ethics Committees at the Children's Hospital approved the different aspects of the study design (procedures, recruitment methods, letters, consent forms and interview questions).

open-ended questions to the members of the PCT and the residents.<sup>18</sup> The records were thoroughly analyzed and the interviews transcribed and systematically examined to identify common themes. All real names were changed to pseudonyms and any type of information that could have been used to trace the people I worked with was secured according to ethical procedures. Here my concern is not individualizing specific people but rather to scrutinize social and professional trends and the tensions between individuals, institutions, and society.

---

<sup>18</sup> They were divided in three main topics: a) past – how they became doctors and then interested in PC, b) practice – notions of illness, patients' rights, death of the other, professionals and volunteers responsibilities, professionals and volunteers experiences and knowledge, and c) specificity of PC – skills and abilities needed, capacities, communication. I also interviewed the volunteers and asked them similar questions adjusting them to these topics.

## THE CONSTRUCTION OF PROFESSIONAL CARE

In this section I will examine several diverse aspects of professional care. Three major themes emerged through the study as central to the PCT. I consider that this construction of professional care is organized through; a) strategies of care, b) the non-organic labour of the volunteers, and c) the types of inter-relationships that are built among PCT, children, and the families.

One key issue in this thesis is how the PCT produce a particular form of care. This is a process in constant flux. On the one hand the children's health status is continually changing, with some of them moving towards the 'end-of-life' and so the family is constantly adjusting to this. On the other hand, professionals/volunteers assist them with the aim of reducing their pain and symptoms and (try to) give sense to their experiences through meaningful communication. So this is the general setting in which I am focusing my approach. I will present a fieldwork note taken in a clinical unit in order to highlight the particular ways the PCT develop their forms of care.

In what follows I present one patient's case to help us explore the challenging circumstances in which the team works. Although throughout the four months I conducted fieldwork I witnessed two or three occasions when the PCT started to assist patients that would die in less than a week, usually their relation with patients/families ranges from a short period of time to years or possibly decades. This is the timeframe in which they perform their duties, and very often they cannot do much to get into the process at the early point they would prefer, because usually this option exceeds their capacities. The following passage taken from my notes indicates the patterns of interaction in which the clinicians negotiate the sharing of information with patients' families as they disclose their palliative prognosis (that it is not the same as the curative prognosis). A resident of a general clinic unit had asked for a consultation. She told the team that Gail was having a lot of pain.

*We went to see for the first time Gail, a 13-year old girl with an Ewing's sarcoma (left leg bone) and pulmonary metastasis that spilled through the pleura to one of her shoulders. The first thing Gail asked Marcos was if he would drain her lungs. Marcos explained to her that it made little sense because they would take the liquid out and soon it would return, which was not what they wanted. He added they were going to change some drugs and doses and made them more efficient so there would be no more pain and she could feel better. Gail told Marcos that she was okay; her left arm was hurting when she moved it above the shoulder, so she was not moving it at all. It was clearly noticeable that it was hard for her to breathe but she was articulately answering each of Marcos' questions. At one point Marcos asked Gail if he could take her father out for a chat, the cousin told Marcos that it was better to talk with her because the father had hearing difficulties. Then we went out to the corridor and Marcos explained to the 19-years old cousin that Gail had lack of air and problems breathing but she was completely lucid. She added that the father had already suffered all this with his wife and knew how things were going to happen, she also said the grandmother was coming to care for them, the father and the cousin were concerned that Gail was not eating much. Marcos said that he understood their worries but it was not something that they have to worry about. He added, "Now her body is under a lot of pressure and it would*

*be counterproductive to try to feed her because the body is full, she would probably vomit, all the liquid that she has in her lungs and other difficulties she is suffering can make her not hungry, you should not oblige her but when the grandmother will come you can try with very tiny pieces or just a little water or juice.” The cousin told us that daughter and mother were diagnosed with cancer at the same time, and the mother died a month ago. After chatting with Gail and her family Marcos and Alex discussed what to do, Marcos said that at some point they were going to give her buscapine (antimuscarinic) to dry her secretions and make her more comfortable, but this is only at the final stage of the terminal phase of the disease because it can lead to all kinds of infections. One day after Marcos received a call from the resident in charge of Gail who informed him that she had passed away at 6 am that day. We talked between Marcos, Alex, and me and we could not believe it because she looked bad but not so bad. Marcos said that he would try to see the father during the day but he did not have time.*

This series of events, the recognition of the condition, identifying the information that family members share about the child’s condition, and the description of the experiences the child will have during the course of events is an extreme example of the conditions of care in which the PCT is inserted. They could not do much about Gail’s life; their care came “too late.” They tried to give her some comfort, ease her pain and organize her palliative treatment but they did not have enough time to develop a strategy of care. What surprised the PCT was that they did not expect Gail to die “so fast.” However, they “came” only after someone else called them. They are dependent on others to access children and families. I asked the PCT members what they thought about it and they all agreed that it was the correct way, saying they were second level specialists and other professionals had to follow patients every day and, then, recognize in the patient’s situation the need for PC. This requirement often creates a tension, on the one hand between the specialist’s (in)capacity to cure-care and the patient’s and family’s needs for care, and, on the other hand, the impossibility of the PCT to begin treating a patient without first being asked.

## **Strategies of Care**

In talking about PC, the clinicians distinguish between the *practice* of PC and its *philosophy*. In terms of the former its goals are a precise set of techniques that focus on easing pain, symptom control, seeking comfort, and ultimately reduction of suffering for the individual. With the intention of achieving these aims the PCT utilize their extensive pharmacologic and behavioural knowledge, their non-organic techniques of the volunteers, and their psychological understandings as well. This practice/philosophy focuses on four major facets: doctor-patient relations, communication, comfort to family, and taking the family as the unit of care.

## **Practice – Pharmacological and Behavioural**

In terms of their pharmacological knowledge the PCT professionals are constantly updating their expertise. They are a primary source of education within the institution in how to properly identify the causes of certain symptoms and types of pain,<sup>19</sup> manage them with specific drugs,<sup>20</sup> and foresee the potential risks of side effects and/or drugs interactions. The PC corpus of pharmacological knowledge has been increased since the 1960s. However, the specific use and management of drugs in pediatric PC (different than adults' doses) is only recent (W.H.O. 2003). Thus, the PCT plays an important role in spreading this knowledge inside the institution. In relation to their behavioural strategies, the PCT deals with chronic and terminal symptoms as well as pain that is not sufficiently relieved by the other professionals, sometimes giving specific tips such as adjusting the positions of the bed or putting plastic gloves filled with water under the body contact zones help patients to feel better. The PC professionals try to find ways to give comfort to children and families, and to foresee potential consequences such as the side effects of drug (for example mucositis due to cancer therapies or constipation from the use of morphine) or physical effects due to long periods of rest.

## **Practice - Psychological**

Besides their recognized expertise in pain management, the PCT have developed a considerable understanding of the emotional needs of patients and families. Another crucial factor for PCT's members is their experiential and non-professionally trained psychological comprehension of children and families needs and situation. The PCT has historically had difficulty in trying to add a professional trained in psychology due to the obstacles that the "official" units (Psychopathology and Psycho-Oncology) put on their work. For this reason the PCT tends not to openly discuss psychological issues with families or other professionals because they fear that Psychopathology would complain that the PCT is "invading" their field.

## **Practice - Empathy**

For the PCT professional members it is essential to properly manage how to pharmacologically and communicatively alleviate pain and control physical and psychological symptoms (and if possible spiritual and

---

<sup>19</sup> The types of pain are mainly categorized as somatic, visceral or neuropathic according to where in the body the pain is felt. The PCTs use a wide range of drugs besides analgesics; sometimes they use antidepressants or anticonvulsants depending the typology of pain.

<sup>20</sup> The drug management is known as the analgesic ladder and is supported by the WHO.



social “symptoms”). A multidisciplinary attitude towards patients and families is another important feature in the PC practice/philosophy. Yet, something that I have found remarkable is their capacity to quickly scan and arrange the priorities when dealing with terminally ill children. The resident Alex highlighted this to me once when he remarked:

The clue-gaze, I think that my practice during this short time is related to this organized gaze. Like someone that is trained in watching a soccer game who says in three minutes, “look at that guy, he hasn’t touch the ball yet but he’s brilliant.” That type of look, this clinic eye that exists all over medicine but perhaps here has to be essential to organizing care. Because it’s like everything is messy and you can have the tendency to go to the obvious or what you think is important, “to me what is really bothering the child is the pain,” and no, perhaps what was bothering more was that he couldn’t make shit.

What Alex was trying to explain to me was this ability to scrutinize the main concerns of the PC treatment on the one hand and of the children’s and families’ needs on the other. This particular “clue-gaze” rests in an attitude that different professionals and volunteers have mentioned to me, namely a compassionate practice. Therefore, this “empathetic” role as caregiver is very important in their imagination as palliative professionals or volunteers. Elizabeth once told me in relation to the skills needed for PC,

Craft, learning, which can be reduced to knowing but to what you know you have to add a lot of creativity, and empathy with the patient. Because it also helps you not to feel omnipotent and accept that something can fail in what we propose, and give the chance to the patient to choose what they need.

## **Practice – Multidisciplinarity / Organizational**

The PCT forms of care however are intertwined with other sources of professional care and, needless to say, with other types of cures. They work as secondary providers inside the hospital, so in many ways their care has to be strategic if they want their palliative treatments to have a real effect on the children. They have to negotiate with other professionals, nurses, pharmacists and other providers inside the hospital. For instance, I remember one day when a staff from Unit 10 (Infectology) called the PCT to treat a patient that was taken into care by Oncology but the oncologist had not seen her for three days. The staff told Elizabeth, “I cannot wait for them [oncologists] to come and see her, you have to see her today and find out if you can help her ease her pain.” The PCT is often in an awkward situation with other professionals. They have to navigate the structures of power within the institution. But the residents of the different units also hold them in high esteem. Many times they teach them to do certain things, e.g. drugs management, and to help patients in ways they did not know before. The professional group of the medical residents is by far the group most open to the reception of PC knowledge and philosophy. So in relation to the latter their preoccupation for patients’ rights and types of

communication (with the importance of listening to patients and families) is somehow shared not only by all PC professionals but also by health professionals in general.

## **General Philosophy**

How do clinicians explain this relationship between the practice and philosophy of care while treating terminally ill children? Or to put it another way: is it really possible to care for and help someone else to appropriate end-of-life, even more so if it is a child? We have to look at what PC professionals say about their expectations. Marcos once told me...

The objectives and expectations we have in this speciality are very distinct from others; I mean everyone would like to cure all patients. But if one can't, although one can't modify the path, one can modify how they transit. Well, we could influence something in that last transit to make things better.

## **Philosophy About the End-of-Life**

The philosophy of PC and its ethical disposition set the PCT aside from other physicians in the hospital (Jeffrey 2005). Even while sharing similar conditions and knowledge with residents and staff of the institution, the PCT members consider what constitutes a good or a bad death in very different ways. For instance, after Rick, a four year-old child from the bordering country of Paraguay, went back to his home to die Marcos phoned the parents to ask them how everything went after they arrived in Ciudad del Este. The mother told Marcos that during the two weeks they had been at home he did not have any pain and the last day he went to sleep peacefully and quietly, without any difficulty and then died. Marcos told me

According to his mother Rick died at his home, he passed away while sleeping. He enjoyed life until the last moment, until that night that he went to sleep, he enjoyed his family, which in Paraguay are big; until his last day when he died, he did not have pain or lack of air. And the mother was sad but very calm. This gives certainty, it is a positive feedback about what one is doing. But when I went to talk with the residents [of the unit in which Rick was assisted] some of them understood what I said and others where shocked.

R: Why? What did they say?

Marcos: They felt bad, in a way although one can feel sad because a child dies, and there was a lot of involvement with the child and so on, but they could not understand that, among all the possible endings, which all were inescapable, because one cannot change the end, that was the best end. They didn't say anything but in their attitude it was clear that they didn't understand how one could take it as a good end. And to me that was a good end, and for the family, too. At least what they could communicate to me, I mean it wasn't a happy ending, it was a better, [they] were the best possible circumstances.

This different approach to the end-of-life and to what becomes important when dealing with it is perceived in the differential attitude of actors that in many cases are very similar, or very receptive to the PC philosophy. The residents, however, in their everyday experiences encounter an enormous amount of work;

suffering, dying, and death do not see a good death as desirable (Muller and Koenig 1988). Or perhaps they cannot see it.

## **Aptitude - Attitude**

It appears that the PCT's conception of their duty and how they see themselves is reflected in the idea and practice of having a dialogue with children and families. It's not an easy dialogue of course, but it's an attempt that starts from moving beyond the usual monologic forms of medicine (I know-you don't),<sup>21</sup> and seeks for a more dialogical encounter. Behind this disposition, however, there is a thorough medical and pharmacological knowledge of pain and symptom control. For instance Marcos once stated

I think that a physician has to be able to combine aptitude, the aptitude that is the knowledge needed to confront the difficulties that patients bring about. And this implies many years of study and many more of practice, and to be aware of all the things that one must know in order to make things work properly. Today this is very difficult because the knowledge not only keeps developing very fast but also the bombardment of information is huge. Diversification of information is huge; therefore, it is hard to be focused and to limit your self to what is really important to know. But on top of that, that itself is hard to achieve, the other fundamental thing is attitude, combining aptitude and attitude. I think that the key of everything is the attitude to take everything with responsibility. If one takes responsibility for trying to help the other, with all that this implies, so this will establish a different approach.

Marcos' comment on attitude seems to imply that within a context in which they have to deal with death and the failure of biomedicine, the strategies of care and biomedical knowledge are very limited. Many things are out of reach or escaping their "aptitude" and because of this they need to confront it with their "attitude."

The PCT members, especially Elizabeth and Marcos have to care for children and families in multiple and complex conditions. And they have to discover ways to care for a patient even when nothing else is working. I once asked Elizabeth what is needed in PC and how she feels when sometimes it is hard to offer something to the children and families, and she answered me,

Yes, sometimes I feel down, there's nothing, I am sad, I become sad. You know he is not going to heal, I am there, but it naturally motivates me to say, "Ok, what *can* we do?" It makes me angry sometimes; well, that is what is happening to me, how can I help? Something has to be done. I do not know how to explain it. I clearly know that it does not depend on me, that the tumor that he has is not dependent on me, on no one, no oncologist, that is not dependent. What depends on me is if I can do something to alleviate this situation. I do not know if it is a silly comfort, but you could suddenly have a disease or be born with a disease that doesn't have a cure, ok but what it matters is what we do with it.

Although these sometimes hard (but not always) situations of suffering are often considered as a burden, or something that can make PCT members angry, paradoxically it can also be seen as a "privilege" in Alex's eyes. I asked him how he felt after seeing Naomi during one of her last days, and he explained to me:

---

<sup>21</sup> PC strongly stands for the practice of listening instead of the prescriptive dialogue of the biomedicine in general.

Alex: I don't need to see another person suffering to say, "wow, it's true that suffering exists." Not because I have a deep suffering history and believe that I've lived everything, but because it's a very existential wisdom. If nothing happened to you in your life or if something impacts on you and you become sad and life's telling you "look at this" and you think on that.

R: But the bond for example is, in that liminal phase, the bond with her friend that impacted on you once, with the parents as well with the team. Every one of us is accompanying her, all of these issues. What affected you? I mean it's not like pneumonia.

Alex: No, I think that is a privileged situation, it seems to me that, this is my sensation, to say "wow, it's good to be here"!

In a way what Alex is saying is that the idea of sharing this constantly changing experience at the end-of-life is highly complex and polysemic. However, his feeling is that somehow there is an exchange, he is giving (care) but also receiving something. It is not a one but a two way street. This is precisely the definition of affect by Massumi (2002), following Spinoza. Alex is affecting and being affected in the same double-way that happens when someone who is touching something is also being touched. Although not everyone could perceive his task as one of privilege, of being in the right place at the right time (considering the social and biomedical denial of dying one would tend to think exactly the opposite!), yet Alex feels privileged for being in a situation that usually is not desired, and even avoided. The rest of the PCT's members, when interviewed regarding others' deaths, answered in a similar way stating that they feel their place is to be next to the children and families and try to help them in anything that could to make this process as comfortable as possible.

## **Practices/Philosophy of Care**

When I asked PCT professionals whether their forms of care and the PC philosophy of care were shared among professionals Marcos told me,

Marcos: There are a lot of things that are included in PC that should be included in any doctor [practice]. PC shows you, say the bad things, which are not included in other specialties and should be. When we went with Elizabeth the other day to teach a class at Luján [a city 70 kms from Buenos Aires], Elizabeth gave the first part, the generality of PC, the history and philosophy. I gave the part of symptoms, which is mostly technical. And then at the end of the talk, the coordinator that invited us told Elizabeth, "what you have told was good, but what you know is something that any doctor knows, what we do as doctor." Yes, it is true, but they do not do it. So then the second part was kind of more advanced, more technical. And in fact we are falling into the same thing that we were talking about at the beginning, whether you are talking about communication, doctor-patient relationship, giving comfort to the family, having the family as the unit of care, that's not something that I'm interesting in hearing, that's not what is important in the classroom.

Rafael: It's the obvious.

Marcos: What is relevant is to know that if [the patient] is vomiting and is not responding to the metoclopramide, haloperidol 0.2 per kilo must be given. That's what matters? But the first thing is essential because it's the philosophy that allows you to approach [the care]. I think much of this should be included in all doctors [practice], to have the chance to really contact the other, to give them space to be able to express their problem, and try to comfort them.

Therefore as I have shown, the strategy of PC care is a particular set of practices, drug management (aetiology, interactions, conflicts, etc.), physiological knowledge and methods to control symptoms and ease pain, but it is also subtended by this philosophy of care.<sup>22</sup> The clinical practices/philosophy of care can be summarized according to Marcos' last quote in: 1) doctor-patient relations, 2) communication, 3) comfort to the family, and 4) the family as the unit of care.

### **Non-Pharmacologic Therapies: the Non-Organic Aspects of the Equation**

According to the international literature terminally ill children and their families often use complementary and alternative medicine to lessen symptoms, deal with life-threatening conditions, and enhance dignity of life (Post-White 2006). Since 2000, the team has had a group of volunteers guided by Sylvia, an energetic sixty five year old woman (who often seems 10 or more years younger!). She slowly introduced non-pharmacologic therapies, henceforth NPT,<sup>23</sup> to the children, and very often to family members. These techniques do not seem to match the series of classical "occupational therapies" that hospitals may offer to their patients. When I asked Sylvia how she became interested in PC and how she approached the PCT, she replied,

Over the past 33 years I had been able to observe the effectiveness of meditation in those pupils with cancer that came to me already in the terminal stages of their illness; it helped them to alleviate their pain and to overcome their anxiety. Then in the year 2000 I had a direct experience caring for a terminally ill friend of mine in St. Oswald's Hospice in Newcastle-Upon-Tyne, where I was able to apply hands on healing [Reiki], guided visualization, and meditation on various other patients as well, with very good results. So when I came back to Argentina I contacted the head of the PC team, which I had met some years before (she had invited me to make a presentation of the benefits of meditation in the National Congress of PC), and offered my services to her unit.

Professionals and residents rotating at the PCT tend to discuss the patients' clinical, organic, physical, and familial aspects. With less intensity, however, they also talk about patients' and families' psychological, social, and spiritual conditions. Although PCT professionals set the tone of the types of treatments they provide, they have a lot of respect for the volunteers and their NPT. Over the years other volunteers have come and gone from the team, usually students of Sylvia from her meditation and Reiki classes. Andrea is one of the volunteers who work alongside Sylvia. When I asked her how she got into the team, she explained to me that...

---

<sup>22</sup> Thus, PC is a practice/philosophy that in each clinical setting would assume a different dynamic according to power relations, health policies, and tensions between cure and care.

<sup>23</sup> I wonder if calling these techniques, "therapies" is not a subtle way to reinstall facets that were left aside in medical treatment.

My first experience in the hospital in the volunteer service was with a terminal baby. It was a test. On the one hand, I realized that I was prepared to confront such a fact; on the other hand, my experience of life and my slow but incessant inner training allowed me to accompany that baby and her mother. It made me stronger.

A question that one may ask is: How does the volunteers' work relate to the physical and psychological care as well as the communication themes discussed before? I think it intertwines in a different way than the work of the professionals. It shows an epistemological and even political stand of the PC professionals in an institution very much objectivist and guided by scientific evidence. Another question is: how serious are volunteers taken as another source of care? Palliative professionals consider the volunteers as a plus for the team, something that is very rarely found in other contexts, even in PCTs all over the country. So they conceive of their jobs as complementary rather than completely different. According to the feedback from children and families and from what I have found during my fieldwork I can say that volunteer work is an important part of the PC care. If we vaguely conceive of care as a social engagement with others' suffering and their multiple sources of distress (physical, psychological, spiritual, social, and ethical), I would argue that the volunteers' job is another form of care and of companionship too.

The PCT forms of care have an intrinsic goal of holistic care. Their concern is to go beyond the physical source of suffering and pay more attention to the other aspects and complexities of PC. This is where the volunteers become involved. Marcos expresses this search for a more extensive form of care in this way, [Our] treatment implies a meticulous evaluation about which are the problematic situations, and then developing a strategy. But a strategy as holistic as possible, which has to consider these different aspects of suffering, because if we don't have it we just detect the physical suffering, we prescribe a drug if it is necessary but it is not enough for the patient.

The key element to consider when the PC professionals think about their work is the types of relationships they are able to create with, and between, patients and families. Therefore, let us now consider this relationship.

## **Interrelationship**

Just as the child is between life and death with an unclear timetable for passage between the time and experiences advances of disease and remissions, to certain extent the inter-relationship among PCT, children and families can be understood in the in-betweeness of children's end-of-life. This interpersonal gap in Kuhl's (2006) words has to do with goals, consequences, and assumptions. Depending on how close or open the gap is it can have effects on the types of bonds that professionals, children, and families are building. So it is in-

between these principal actors, in-between their bodies, in the interactions among all the actors where one can shed light into the forms of care specific to these children in this clinical setting. What is the role of the PCT members and how do they perceive, on the one hand, their responsibilities and, on the other hand, the rights/freedoms of the patients and families? How do PCT members identify patients' and families' situations and needs? We should always have in mind though that this is a particular type of relationship and thus displays unique tensions (in-between life and death, curative and palliative medicine, public and private realms), and exists under certain constraints.

There are many circumstances that generate tensions in communication at several levels. First, at the personal level, the process of caring for terminally ill children impacts children, parents, family members, and PCT members. Many authors have been paying attention to this. For instance, David Kuhl (2002, 2006) analyzes the work of professionals helping dying patients, and the reactions that the latter have according to the distinct types of interactions with patients. Kuhl confronts the usual assumptions and affirms that insensitive and cold communication from the physicians in many cases creates much more suffering than the illness itself and the patient's awareness of dying. The pioneer in dying and death studies, Kübler-Ross, (1969) has also shown in the 1960s and 1970s the worries and concerns of dying patients, and how they told her about their need for a human and warm communication with professionals. On the other side of the relation, Jamie Sork (2005) has shown the difficulties that PC professionals encounter in their everyday practice while witnessing others' suffering.

The second source of tensions lies at the family level. They are constantly looking for public and private resources, they invest materially, emotionally and symbolically, using their time and adjusting their works and lifestyle to the needs of the children (Bluebond-Langner 1996). Sometimes, if they stay at home, they have to reorganize their houses according to the needs of the terminally ill child. Some live weeks, months, and years at the hospital.

Consequently, the third level of tensions appears at the social level. How do families navigate all sorts of bureaucratic, emotional, and financial obstacles? How does care for the terminally ill child impact in multiple ways within the family? In this social level we should also locate the impositions of the healthcare system (curative and palliative). For instance, what are the children's experiences of the ways that their bodies are treated medically and socially during their care? What problems of agency, invasiveness, and objectification do

children encounter in their care? To what extent are members of the PCT aware of the margins of maneuverability that children and families exert in their everyday encounter with each of the several healthcare providers? And how much “power” has the PCT to influence and twist the institutional structure in order to mold it to the needs of children and families?

According to the PCT members the type of relations they create with families and children is now framed differently than while they were studying medicine or even outside pediatrics. Marcos remembers how in the university, and in the residency as well, there were some aspects of his training that he did not agree with, “a certain distance in relation with patients and families, little concern with other characteristics not related to the physical body.” However, even inside pediatrics the way professionals approach children and families can be very different than the palliative methodology. One explicit difference of the PCT, according to Alex, is the strategy they use to deal with tensions and difficulties in the relationship with patients and families. He comments that for him the most “problematic” families are the ones that attract his attention...

for me when there is a problematic patient in the hospital I do everything that I can to go and talk to him, also with the angry parents, it seems that there's a certain morbid pleasure but that's what motivates me. What, am I going to talk with a mother that tells me ‘Yes Doctor, you do not know how calm that I feel now’ and I do not have anything to do?

## **Two Types of Inter-relationships**

Doctor-patient/family relations must be distinguished from doctor-doctor relations because both are of a different nature. In the literature we tend to assume that what is *really* important is to figure out ways to improve the first type of inter-relationship, which is only half true. Without considering the other forms of interaction i.e. how professionals interact amongst themselves, who has the power to do what, we lose a big part of the context of action. So doctor-doctor relations can be defined in a broad sense i.e. the political dynamics of the institution, as well as in a narrow sense i.e. the types of relation that the members of the PCT create among them. Taking Alex's comment about how he wants to work with families and patients that are “problematic,” one can identify a trend with professionals in PC that puts them in a situation not overly desired by other specialists. They not only face these families but also feel passionate about doing it.



In general the medical categorization of a family as “argumentative,” as in the previous quote, is related to families that defy or reject medical opinion.<sup>24</sup> Marcos told me that they usually deal with these families that “already fought with the hematologist, fought with the traumatologist, sued the ophthalmologist” but then try to avoid those prejudices, and they usually get along well with these families. He adds,

one knows this because of the specialty or because of seeing other colleague working, or because patients and families highlight it, that here they found a different space. And I’m talking about patients and families with many years of follow-ups by professionals of this hospital or others. Patients that know a great deal about public and private healthcare, from the province or the capital city, from one specialty or other. They tell you things like ‘they never allow me to talk like this’ or ‘they never asked me these specific questions’ or ‘I don’t feel as comfortable in other places as here.’ And even the few families that we follow through the grief and bereavement process say this. That is with dead children and they’re coming to say thanks to us but they also mark these sorts of things.

A small, but important, point deserves mention here. According to the PCT members there is a difference between middle-class and lower-class families. The latter are often less inclined to confront professionals and usually the former are seen as more challenging and insistent. This is a general view and it obviously depends greatly on the situation of each family to consider how they interact and decode medical opinion and proceedings. However, at present there is no clear cut distinction between the lower middle-class with the lower class population that can only access (with difficulties) healthcare at the public institutions. Argentina, once proud of its wide middle-class, is becoming pauperized and more people have public healthcare as the only and last resource.

## **Palliative Care Is a Collective Effort**

For Elizabeth her extensive experience has taught her that the most important principle of PC is to work in a team. She remembered her time working alone and she thinks PC is impossible without a team.<sup>25</sup> She told me in an interview that it is not true that as a professional she has to treat all patients equally, because “one works with the best and also works with the worst, but the good thing is to realise, to stop and analyze ‘what I am doing?’ some sort of red light or rely on another team member because ‘I can’t stand this.’” Hence when I am referring to inter-relationships the first and obvious thing that pops up are the relations inside the team,

---

<sup>24</sup> The idea of families being argumentative is similar to wide use of the tag “dysfunctional.” Rallison and Moules (2004: 292) argue “The term *dysfunctional* trivializes and minimizes problems, setting the clinician in a privileged position to look for pathology instead of strength. Worse, it blinds one to recognize the uniqueness, capacities, and struggles of a family to make sense of a senseless event, an unspeakable event of being faced with the loss of a child.”

<sup>25</sup> This difference between Elizabeth –head of the PCT– and Alex –3<sup>rd</sup> year resident in Pediatrics and rotating for 3 months at the team– is important to highlight. Alex is “curious” about the so called “problematic” families and tries to engage with them as much as he can, but Elizabeth with all her experience conceives of PC as a collective effort very limited without a team in which support one another.

because PC is very much a collective endeavour. The second feature is the outer relation, and here we have one group (the PCT) connecting with other groups (patients and families). These two levels of inter-relationships provide the basis upon which the strategies and philosophy of care unfold in-between the personal experiences of both groups.

These inner and outer interrelationships place the PCT in a specific and unique position within the institution. Although the PCT is an outsider within the institution, paradoxically they get to know and often deeply influence some families that are experiencing their children's end-of-life. To a certain extent the PCT aims to medically and socially treat children and families with the least intrusiveness possible while always considering children's autonomy and agency. However, as an inevitable part of medical science there is always some objectification of children and families. The question is how are these tensions balanced between the PCT, children and families, and between the PCT and the Hospital Camino? This liminality, this liminal place of biomedical knowledge in which the PCT has been located is creating a broader acceptance of other forms of knowledge and practice. However, these multiple forms of care (pharmacological, behavioural, non-pharmacological and psychological) lead us to consider the flip side of the process, namely the types of communication that PCT has with children and families.

## THE CONSTRUCTION OF COMMUNICATION

The strategies of care are one pillar but what about the connections and interactions that PCT members create with children and family members? The particular kind of bond that they build will be the focus of my analysis in this section. There has been considerable work done by sociolinguists and anthropologists on doctor-patient communication (Sankar 1986, West 1993, Tannen and Wallat 1993, Cark and Mishler 1992). I begin from the assumption (or assertion) that communication has many meanings, one of which is inter-communication. This is what I have observed while working with the PCT. In relation to the types of communication that this inter-relationship between patients/families and carers creates, the members of the PCT stress the necessity for children to know what they are going through. Furthermore, communication involves the dissemination of information and the use of verbal and non-verbal means of establishing and expressing social relationships and emotions. For instance, Alex explains his idea of inter-communication in this way,

Alex: I, you know, for instance I always play in the pediatric unit<sup>26</sup> to try to detect, when I have time and the chance, *I try to make them understand the illness they have, if they can explain it to me*, and I give them all my attention. I always try to be very alert to, you know, I try to have certain confirmation that I am aligned, I loose my alignment when, for instance, I don't care that the other person understands what's he is experiencing, it is very clear for me, when I lose the interest to explain or to check how much he is understanding. It is essential in itself as a principle, and it is essential to me as a reference to check if I am connected, *if I am online*, you know, if I am on

R: It's an obligation for you too?

Alex: Yes, you know I tell the children "okay, you have pneumonia, here you have two lungs, and do you see this? blah blah blah this is like this, and like that," without falling in the playful poetry of tracing by which words they explain, that would be anecdotal, beautiful but anecdotal, it's like a tiny scientific method, because knowledge gives freedom, and it gives freedom even to a three-year old child.

In this sense, Alex seems to be focusing on two aspects of communication: the action of "explaining" (which implies a cognitive exercise to allow the child to know the process that s/he is going through, a process built from the biomedical approach of generating knowledge) and to be "connected", something that goes beyond explanations and has to do with a certain disposition, something that appears to be even more demanding i.e. to be "online."

### With Words

In order to comprehend this specific inter-communication one has to understand what is being said (Oken 1961). In this sense, narrative analysis, whether based on the patient's illness narrative (Kleinmann

---

<sup>26</sup> He works in a private general hospital that has one pediatric unit, but was rotating for three months at the PCT at the children's hospital.

1988), patients' treatment narratives (Sered and Tabory 1999), or patients' healing narratives (Small 2003), has proven a valuable instrument in helping understand people's health/illness-related experiences. Although some are more cognitive and others are more experiential, the concept of "emplotment" emerged from these different types of narrative analyses. "Emplotment" is a notion that describes the social processes whereby professionals and patients effectively engage in a narrative structure that helps them to understand treatments, therapies to illness and ways to healing (Mattingly 1989, Mattingly and Fleming 1994). But one has to keep in mind that narratives and narrativization happen between all actors. So I will pay attention to PCT members' narrativization of their companionship at the end-of-life, especially the different ways they communicate (verbally and non-verbally) with children and families. However, I recognize that this specific emplotment is intertwined through dialogue and takes the form of both the medical system and the social positioning of the actors as well. I mention this in order to point out the importance of narratives for both anthropologists and people experiencing direct or indirectly terminally ill conditions. I agree with Good (1994:133) that:

Disease occurs not only in the body—in the sense of an ontological order in the great chain of being—but in time, in place, in history, and in the context of lived experience and the social world. Its effect is on the body in the world! And for this reason, I have argued, narratives are central to the understanding of the experience of illness.

But things are said or silenced in different ways according to children's (and family's) illness trajectories and the several contexts producing the end-of-life experience. However, these emplotments not only show how people deal with disruptions but also with reconstructing their sense of self (Becker 1997). Therefore, peoples' narratives tell us about the continuous process of (de)re-construction of subjectivity. Linda Hunt (2000) expresses this idea in terms of speaking about the disruptions but also reshaping social identity. For her the performative quality of narrative "is capable of both expressing and enacting visions of reality" (Hunt 2000: 89).

Thus, in light of this the questions that need to be asked are; what is communicated and/or spoken at the end-of-life? How, where and in which situations are certain things said? How is communication proposed by the PCT? How are PC professionals actually talking to a child with cancer (Diez et al. 1997)? And most importantly, how is the "narrative vigilance" (Paley and Eva 2005) of the PCT calibrated in order to decode patients' and families' needs present in their own narratives? These issues can be addressed by looking at the first time that I saw Naomi,

*We see Naomi with her father and mother [the last visit, one week before I started fieldwork, Naomi said that she did not want to use the probe to receive her medicine], she was lying on the bed and she was almost not talking, sometimes she needed a long time to answer Marco's questions. They first talked about how she was feeling; Naomi said that she has pain and that her legs bothered her too much [they were hypertonic]. Marcos then checked her legs and talked with Monique [another PCT resident] about her symptoms. For the last two days she was not taking some of her medicine. She was eating very little and was neither taking liquids nor peeing or hardly peeing. After checking all the symptoms and measuring her pressure, between Marcos and her father they raise the bed and put it at a 45° angles. Then she could talk more. Naomi started to vehemently scratch her leg and the mother said that she could do that for her. Then Marcos asked Naomi if she wanted to have a probe to give her the medication and food she needed. Two days before she refused it, but now that it was hard for her to swallow she agreed. Marcos asked the father to go to the pharmacy and asked for the probe for Naomi, "for a cancer patient." [The father left to search for the probe]. We stayed there for a while, Marcos and the mother talked about her difficulties. Her mother told Marcos that Naomi's legs were bothering and that sometimes she lacked air. Marcos asked what she did in those cases and the mother replied that she would grab a magazine and fan her. Then Marcos talked with the father outside. He explained that they were doing this to get her better, but in this stage of her illness they don't have [curative] treatment options, however, they can do many things to help avoid her pain and suffering. Father answered that he knew that, that he was very thankful to all the professional of this hospital; he knew they did everything they could for Naomi to get better. Marcos also asked the father if he knew the illness was progressing. And the father commented they knew it, he added that the noise Naomi was making was caused by the "tiny beast" she has inside. He mentioned that he talked with other people that have been in the same situation and they all said that noise, that "arrjjj", Naomi does this because of the tiny beast she has. After a long silence he told Marcos they knew that in any moment her daughter wouldn't have any more strength... Marcos tried to comfort him and told him that her body was putting a limit that it was not she was lacking will, or them, it was her own body, which was putting the limit. The father commented he already had asked permission at his work for a leave. Marcos reassured the father that they could count on the PCT and the hospital. Naomi would have a probe and they could go home but they knew that whatever decision they would make they would follow them. Marcos added that they could take Naomi home but if they decided to bring her back they could do it whenever they decided. The father said he knew that.*

At least six important things occurred during this dialogue. First, Marcos checked the medical and palliative treatment. Second, Marcos and the father changed the bed position (from horizontal to a 45° angle). Third, Marcos talked with the father about Naomi's situation (no more curative tools but PC treatment could help ease her pain and suffering). Fourth, Marcos explained that the illness was progressing. Fifth, Marcos elucidated that it is neither Naomi's nor her parents' lack of will that "produces" her condition but rather her body is putting a limit on things. And finally, Marcos assured them that their decision (of home or hospital) could be changed at any time.

But more importantly, when Naomi sat and stood a little bit she seemed more animated, although there were moments in which it seemed that she was barely understanding what Marcos was saying and asking her. When I commented to Marcos that Naomi changed the way she talked and communicated when her front part of the bed was placed at 45° angles, Marcos said that was because she was lacking air and was uncomfortable. But the fact that everyone was paying attention to her and was concerned to try to listen to her speak at her own

pace put Naomi in a situation where her words were important. In other words, she was communicating with them. In this line, Elizabeth points out that apart from what they have been taught at the University, other things should be learnt if they want to contact patients/families,

Elizabeth: [we have to learn] basic communication, and other aspects of medicine, in the doctor-patient relation, the relation between two persons, which other things contribute to medicine to help patient, I mean we don't know how to, indeed [the patient] is underestimated...

R: a sort of de-medicalization of medicine in some aspects?

Elizabeth: yes, I would say that we need to de-medicalized [many aspects of medicine].

We should distinguish between communication as an interchange of information and communication as a social relationship. In both cases there is the requirement of finding meaning i.e. meaning defined in a more restricted or general way. Therefore, not only is it important to see communication as the basic definition of the management of information but also as the process of interaction and getting together children, family and PCT members to (try to) understand one another, their worries and fear, their expectations and desires. For instance, what things are said in which contexts and what are left silent? What is called the “management of bad information” (Krahn et al. 1993, Kuhl 2006) in the literature is strikingly similar to the skills needed to manage emotions in the doctor-patient-family relationship (Köszegei 2004, 2006). I want to highlight that the particular verbal communication at the end-of-life is traversed by discourses of managing time and the provision of comfort. Within this, one important issue is the necessity, according to the PCT members, to find meaning in what patients and families are experiencing.

In the case of these children and their families, I am thinking about these conditions as particular in the sense that people who indirectly experience them have a distinct set of social, familiar, psychological, biological, emotional and spiritual circumstances traversed by the end-of-life experience. These configurations certainly overlap with the health system, the different professional practices and the illness trajectories of the children and their families. So the focus here is on the PCT members' explanations, practice and narratives about their multiple roles as caregivers, but also about their attempts to communicate with patients and families (beyond the limitations to cure and even beyond the verbal).

I am arguing that certain configurations emerge from what I have portrayed as communication with words. Hence these other aspects of the communication, such as the attempt to carefully listen to patients and families, to check the kinds of awareness children and family have in relation to the end-of-life (Deveau and David 1995), and the possibilities to find meanings, however hard this might be, these aspects are the “said” or

“spoken” part of the equation. These are the aspects of what is explicitly assumed in the encounter between PCT, children and families. The flip side is what is communicated without being verbally said.

## **Without Words**

Here I want to understand how terminal illness, end-of-life processes, and biomedical professional discourses and practices are intertwined with social constructions and disputes over certain forms of subjectivity and experience. My point is how silence can accompany a person and structure social interactions. In order to do so I need to pay attention to “unspoken” and non-verbal communication from the PCT perspective. Marcos once told me “the majority of professionals are not used to listening”. Should we consider that only palliative professionals are capable of adjusting to these subtle influences in the non-linguistic forces that go beyond speech and verbal communication? For the PCT members, therefore, both aspects of communication (talking and listen) are equally important. Sometimes, PCT members say, listening is even more important. Then, for the PCT members how does communication without words at the end-of-life actually work? And how is this connected to other forms of communication beyond verbal meaning?

The processes of end of children’s lives, survival of parents/relatives and professionals coping with terminally ill children, *while the end of life is taking place*, is entangled with other macro and micro social configurations and dynamics. When I am referring to non-verbal communication I refer primarily but not exclusively to silent communication. Therefore I ask the following, is silence and its effects something that we need to understand in the context of terminally ill children? What types of disagreement and struggles arise in the terrain of children experiencing terminal illness in regard to the social construction of silence *within* and *while* the dying process is happening? How is the relation between context and content constantly being (re)shaped in this specific setting? Three pioneer specialists in pediatric PC in Argentina once wrote (Diez et al. 1997: 147),

Talking with the child is always a two-way process, and this is particularly true with the very ill child. Listening is the most important part. This is an obscure matter in our culture. We are used to talking all the time without listening to each other. We are very afraid of silence, of body communication. Listening involves not only hearing what the child says, but also noticing how it is said (tone of voice, body posture, eye contact and facial expression). Children choose a favorite person to talk with, and it may be a parent, a doctor, or a nurse.

Therefore, if one has to answer how content/context are being mutually affected in the hospital situation I would be inclined to say that the PCT in this socio-cultural context is letting silence function as both the background and the substance of some of the stressful interactions with children and families. There are obviously some tensions and contradictions when trying to understand these social issues. For instance, what are the ideas that cause friction when we think that a terminally ill child is usually not the owner of a healthy body and could suddenly die? S/he has been gradually deteriorating and has been experiencing this deterioration herself and so other people are implicated as well. Without being said verbally, an embodied silence is telling them that something is going wrong, that they might die. Therefore, how do we consider the spaces for terminally ill children to maneuver in relation to their own end-of-life, in-between their families and the PCT, and pay attention to what is spoken *and* silenced? To what extent are they able to appropriate their own lives and even to modestly “decide” or make suggestions for continuing or stopping treatments, to listen to what they need to listen to, to avoid hearing what they do not want to hear, to choose who may assist them or who should not?<sup>28</sup>

When the sociologists Glaser and Strauss talk about “mutual pretense”<sup>29</sup> they are highlighting an important aspect of the relationship between terminally ill patients and the people involved with them, what is called “mutual protection.” Although they are talking about adult patients, it can be applicable to children and their families too because an unevenly shared silence often covers the inter-relation as a veil. Everyone is trying to take care of the others (Bluebond-Langner 1996). Sometimes this “over-protection” can turn into therapeutic stubbornness, but usually problems arise when people directly implicated are not included in the decision-making process. In this clinical setting very often parents are taken aside (outside in the corridor) to discuss the child’s situation. Children usually know what is going on, maybe vaguely (depending on the age), but they can draw conclusions from what they see and hear. Or more importantly, from what they cannot see and hear. But I am not referring to these types of silences that are created by exclusion. What struck my attention is silence as a generative component in the communicative relationship among professionals/volunteers, children and families

---

<sup>28</sup> I asked Elizabeth once which rights and freedoms terminally ill children have and she replied to me “they have all the rights, first of all because they start from a lower place. They have to compensate what they don’t have from the physical and the social, and they also have the right to know and to be assisted, a right that for me is, the right to choose who would assist them, the right to choose who they want to take care of them.”

<sup>29</sup> “When patient and staff both know that the patient is dying but pretend otherwise—when both agree to act as if he were going to live—then a context of mutual pretense exists” (2005: 64).



as part of the context of interaction. In this sense, a principle that unifies the team is the spirit of respecting the other in her/his time and necessities, even if it is a small child. Sometimes there is an ocean of silence among children and family members in relation to the awareness and/or denial of dying. Through and with this “thick” silence the PCT manages to produce non-verbal social interactions.

It is known that the majority of the time children are accompanied and are taken care of by their family and nurses. Doctors and other professionals visit them just for short periods of time. However, despite the overload of patients that the institution manages and despite how busy the team is, the PCT members try to have time for patients and families according to their needs. They told me that they have learnt to show no haste even if they do not have time. In by different ways and with diverse intensities they show a commitment to get in contact with the bodies, emotions, minds, spirituality and social ties of children, families and friends; and at the same time to touch “the silence” what can be rarely spoken, what is silent.<sup>30</sup>

In the following event we can see one de-structuring situation and how the PCT tries to communicate beyond words with the mother, or at least to be with her and holding the silence,

*Marcos, Patricia (PCT resident) and I enter to the room in the respiratory unit. Inside there were a six-month baby, his mother and a medical resident from the unit. [The baby has a genetic condition that blocks the production of proteins that control muscles. He does not have control of his body and he cannot breathe by himself without external aid].*

*Marcos [while checking the baby] told the mother they were from the PCT and that the professionals of this unit asked them to come and see her son. He also asked how Robert was today after his crisis of lack of air? The mother replied that baby was getting better, but yesterday there were moments when he was pale and red and she did not know what to do...*

*Marcos told her that because of this problem, the professionals of that unit called them that they would try to help him and to prevent further crisis. They continue talking and getting some understanding of the baby's condition, and then Marcos added that they were thinking that it would be better if they could slowly start to give Robert morphine.*

*The mother was standing and sat rapidly after hearing the word “morphine.” Marcos explained that would be necessary to ease his sensation of breathlessness and lack of air. And to then asked the mother what did she know about morphine? The mother answered that she knew it very well, because her father had just died ten days ago due to lung cancer.*

*While Marcos and the baby's mother were talking, two physical therapists entered the room, and without any introduction started to give to the baby physical procedures in order to take out the mucus accumulated in baby's lung. The scene was really violent; they did not pay any attention to the context and the mother's feelings being exteriorized when talking with Martin. They were talking to the baby “as if” he was a normal baby with “baby language” and making jokes to the baby.*

*After the therapists left, and some talked with Marcos, the mother said that she had talked with her husband about Robert's condition, and although they did not know if it was ethical or not, but surely it was humane, and was a really hard thing to think [long pause], they had decided not to put Robert on an artificial respirator*

---

<sup>30</sup> Moules and Rallison (2004) in “The Unspeakable Nature of Pediatric Palliative Care: Unveiling Many Cloaks” talk about the indescribable condition of the pediatric palliative care at the end-of-life. This unspeakableness appears in the practice itself, in the silence regarding death, and in the silencing of children and families relative to the de-structuring situation of dying children.

*when he would [long silence] give up. After saying that the mother started to cry and we all kept next to her in silence for a long time.*

Through this story some aspects of the particular social construction of silence within the communication strategies of the PCT can be seen. For instance, how understandable is the first silence before the mother says, “Give up” and the second one when everyone is remaining silent when she was crying? Moreover, how were the mother and professionals affected by the abrupt interruption of the two physical therapists and their carelessness treatment of the baby? How intelligible was Marcos and mother silently staring at the physical therapists? We do not know it but what I suggest is that these interconnected silence-experiences are, unsurprisingly, contextual and in many ways existential.<sup>31</sup> Hence, it is important to think about the disturbing experiences of body and subject disintegration while people are directly experiencing them, even when the person is a newborn baby. Indeed, what I am trying to see here is how personhood, body formation and disintegration, and childhood or in the previous case, babyhood, can be understood within the context of unevenly constructed and shared silence.

These silences, then, are relational as well. I am saying these silences are relational in the way that they are caused and experienced. Going back to the previous note, it was a resident of the unit who called the PCT to check on Robert two weeks after he was hospitalized because he had an acute crisis of dyspnea (although he had tremendous breathing problems before due to his genetic condition). The physical experience of this child was constrained by different sources of suffering. If the crisis had not been so severe the resident probably would not have asked for the consultation with the PCT. In only one visit, Marcos had to create a rapport with the mother, support her, explain that morphine is not only for terminal patients, and talk about the strategies of care at the end-of-life. Besides, something important happened: Marcos listened to her.<sup>32</sup> The other professionals behaved as if it was a normal situation, which required regular procedures (remember how the physical therapists were making jokes and talking to the baby as if it was a common situation). By no means had they considered the possibility of trying to be as minimally invasive as possible. The staff doctor in charge was clear, he replied to Marcos’ complaint: “we know that [at this moment] kinesiology is a double-edged

---

<sup>31</sup> This idea of “existential silence” would need more explanation. I am only trying to focus on silence as affect, and to think on the limits of verbalize discourse.

<sup>32</sup> To be coherent with my analysis this part on listening should be within the section on language. But here I am focusing on what is the “content” of these silences. However, I leave it here in order to show the complex situation of this dying baby, how his suffering was unevenly shared, how he was traversing all his difficulties to breathe, and finally how he died. These events also show how difficult is to “see” or empirically consider silence-as-affect.

weapon, but it's something that we have to give him until the last moment, it is his right" (paraphrase). The next day after our visit, Robert died, and none of the people that was in that room with the baby and his mother would ever know if the mother considered that her son died because of the morphine, or if morphine was given to him because his little body needed it in order to live his last moments with dignity.<sup>33</sup>

I think communication demonstrates companionship here in a precise way; both verbal and non-verbal forms of communication were set as a strategy to "be-there" with the baby and his mother, to engage in the process or what the PCT members describe as "*acompañar el proceso*" (accompanying the process). Hence, we should explore the intense and often traumatic experience of witnessing a son's or daughter's end-of-life process while it is occurring as a means of understanding the PCT role. In order to do so, I will pay attention to the margins of maneuverability that the PCT, children and families encounter at this clinical setting.

---

<sup>33</sup> This is another example of a patient that died only one day after the first visit of the PCT.

## THE PRODUCTION OF COMPANIONSHIP

This specific bond, which the PCT members call “companionship”, can be understood as a result of the specific care and communication conducted by the PCT. Companionship sometimes can produce a certain connection, an impermanent experience of what I call “dying-among-us.” This type of experience could last from one to several encounters, but ultimately is limited in time. It is the ambiguous (un) shared witnessing and differential understanding of the end-of-life phenomenon and how it impacts on every member of that inter-relationship in unique ways.<sup>34</sup> Companionship, in the sense given in this thesis cannot be considered as something that everyone can produce. For instance, it is neither sitting beside the patient to listen to her passively nor randomly touching her. The PCT members many times told me how tired they are of hearing the clichés that to accompany a patient one needs compassion and a good heart, that PC is easy. Companionship, from their perspective, is more than adding good care and good communication, and, needless to say, it is not easy. It gives emphasis to a particular form of care and communication through which PCT members engage with children and families, in-between their experiences, to sort out this “*how is she living her dying*”, a “*how*” that is specific, contextual and situational. So in order to look at these “*hows*” I have focused on the inter-connections among the three actors.

Therefore, this particular type of human and professional connection is what matters most at the end of life. What I have showed is that care and communication equal companionship, but not just in any arbitrary way. There are certain precise and proper forms of care and communication from the perspective of the PCT. It is interesting to re-think this inter-relationship or interpersonal gap that I intend to highlight. Certain notions of childhood are built into it; through the particular historical, professional and institutional conditions and through social debates and dialogues about dying. In these complex contexts, an existential communication beneath and beyond words is what according to the PCT members helps the people implicated to process the end-of-life. But this particular management is neither unique, nor a formula to be applied to every situation. However, the idea of guiding the end-of-life reminds me of a dialogue that I had one day with two residents of the PCT, Paula one

---

<sup>34</sup> Sylvia, the head of the volunteers once told me, “Working as a volunteer in Pediatric Palliative Care, were death is a permanent feature, I have come to be more concerned not with death itself but with the way the patients die. So for us it is a success when one of our patients has a peaceful end. And it makes me unhappy when we don’t achieve this. On the other hand, being in the presence of so much tragedy has made me more conscious and appreciative of my good health and my life in general.”

of the residents told me that Mary (a 13-years old adolescent with HIV/AIDS that the team was treating) had just died and she continues,

Her final moments were impressive; she was rapidly deteriorating (she was in coma because of liver failure). All her family had seen her, her two siblings, an uncle that she loved a lot, all of them saw her at noon. And approximately at 6 pm, when she was alone with her mother and Marcia (the fourth-year resident of the unit that was in charge of her), the three alone at the room, Marcia was holding her hand, and the mother started to tell Mary that it was okay, she had made a great effort, she could go with her father where they will reunite, and Marcia told Mary that she had to listen to her stubborn mother, and in that precise moment Mary passed away while she was holding her hand. After that Marcia started to cry, and the mother comforted her and all the residents of the unit as well.

According to Paula the mother has an incredible strength, she works in a network of people with HIV-AIDS and she gives talks to the people about how to get care, and free medicines from the government and how to take them every day. The mother knew that Mary was quickly deteriorating; she told the residents that Mary will not pass a month, and Mary passed away one week after. One week or ten days after Mary's death, Paula encountered Mary's mother again and she told her she was fine, that coming to the hospital was not an easy task, but she did not feel bad because she knew that while at the hospital Mary was well taken care of, and that everyone did their best to accompany her. According to Paula, Mary told her mother to take care of herself, to be well for her other two children. Mary's mother told Paula that now she would follow her treatment and take all the antiretroviral medicines, because she knows she has to be fine in order to take care of Mary's two brothers and her partner too.

This event is interesting because it shows some of the features of care at the end-of-life, especially the ethics of companionship as a result of the PCT creation of sociability. Despite the fact that the PCT focuses on the *how*, its members are rarely present in the very last moments of the child's agony and death. But this does not mean that the PCT members are not somehow there, because Elizabeth and Marcos receive numerous phone calls and whenever they can they go to check on the patient and family outside their daily duties. This is a normal pattern, staff doctors are not habitually present beside the bed right at the moment of death, and these events are witnessed by the ones that are constantly at the hospital: nurses<sup>35</sup> and residents of the units. But at the

---

<sup>35</sup> One day when I was with Marcos and Elizabeth we found Claudia, a sixty years old nurse, and she began to tell us how she said goodbye to Stephan. She was forced to take holidays by her boss, but she did not want it. The last day (some days before his death) she went to greet him and he did not ask when she would returned (and she had not told him she was going on vacation). That surprised her because he always asked that, instead he caressed her face with his arm with the visible tumor extended and told her "I am okay, do not worry," and he also had a distinct look, his eyes were different. She was not told that Stephan had died, because of this she texted a message to Elizabeth's cell phone to find out what had happened but Elizabeth never received it. Claudia said that she should have been with him until the end because that is what she thinks should be the real accompaniment [*el verdadero acompañamiento*] and commitment, Elizabeth told her that she did a lot for Stephan and she should not feel bad for not being next to him at the end.

same time when someone dies, the PCT members always try their best to go and see the family members and to accompany them at those moments. They also call the family approximately two weeks after the child passed away to check how they are and offer (if they want) their space to talk about whatever they need and to be ready for anything they might need in their grieving process. Besides, at the end of the year they send postcards to each family with a personalized message remembering the child. Hence, as I have shown, the PCT's production of companionship is enabled by knowledge based in the practice and philosophy of care, and framed in verbal/non-verbal communication. The PC production of companionship takes time, study, and practice. Thus, it should not be associated with a loose sense of compassion or even righteousness.

It is hard to think about these situations that I have analyzed from a distance. The deaths of Mary, Naomi, and Betty (and of other children that I have witnessed) have affected (and will keep affecting) all of us, families, friends, professionals, volunteers of the PCT, and the ethnographer too. Their end-of-life experience, arduous, complex, zigzagging in seek for autonomy, dignity and meaning, have impacted us. But it is possible that the ethics of companionship unfolded by the PCT creates and influences these ideas of mutual care that Mary's mother spoke about, and acted upon with the residents. In other words, the construction of professional companionship is also an attempt to develop mutual engagement or co-companionship while living the dying.

## CONCLUSION

In this work I have analyzed the philosophy and practice of care for dying children from the perspective of a PCT in the city of Buenos Aires. The main question I have asked is how does a child's life course as well as family and social relations interconnect with cultural and professional ideals and practice in a pediatric PCT? In the hospital I studied, the doctors conceptualized palliative care for children as a process of [*acompañamiento*] "companionship" during their suffering. By companionship they mean the vast technical knowledge and the humanistic and ethical approach needed for accompanying children and families at the end of child's life. This is contextualized by a cultural understanding of the life course where children are not expected to die during the lives of their parents – children's death is an exception to the normal cultural construction of the life course. The aim of *acompañar el proceso*, the process of companionship, is also contextualized by the services available for this culturally anomalous event. On the one hand, by the usual lack of resources, the marginal positions, and the difficulties that each of the PCTs in Argentina faces with the bureaucratic institutional powers. On the other hand, by the specific forms of social interaction that PC professionals develop in this clinical setting.

This practice and philosophy of accompanying children and families and of companionship among PCT members could be compared with PC practices in "the west." It should highlight the need to address the inter-relationships of PCTs, children, and families; and the contextual ways to process the end of children's lives. This research could be helpful to other PCTs/volunteers/anthropology research on death and dying. The production of companionship in Hospital Camino in Buenos Aires is surely contextual and contrasts with North America situations, which provide technologically sophisticated care, if you have health insurance. However, it resembles other Latin American or 'Third World' countries. In this critical context of the healthcare system, children and families are experiencing the end of children's lives and a PCT is trying to help them process these critical experiences. The informants' question of how to reconcile comprehensive technical knowledge with a humanistic attitude at the end of a child's life was answered by the PCT members when referring to the need of an equal proportion of both aptitude and attitude. In the North American context Selwyn and Forstein (2003: 812) have also emphasized the need of the patients for doctor's willingness to "be there," to "accompany them through the [...] pathway [...] of (the) disease." In this study I have attempted to understand the PCT actions and knowledge, in its professional and institutional cultural contexts.

This study is also part of a current double effort, within social sciences, of turning into our own society and into direct sufferers' experiences as the key site to cross-examine the inferences of the medical knowledge with its inherent struggles and conflicts and its impact in lay people's daily life. I have privileged the PCT perspective and also highlighted the importance of the inter-relationship among the team members, and among the PCT, children, and their families. Indeed, anthropology has the strength to turn its theoretical and methodological instruments into the social sufferers to give voices to their experiences.

In my future work I will try to understand how families address PC efforts to care and accompany their dying children. I think it would be helpful to analyze the perspectives of children and/or family in comparison to the PCT. Another key feature to consider is the distribution of agency and autonomy in decision-making. For instance: What things do children and families know and not know, and how do they act upon this knowledge? How is knowledge shared and what practices of disclosure are developed in the Argentina context? The triadic inter-relationship among dying children, family, and professionals will be the focus of my next research.

In this work I have examined the diverse and complex forms of care and communication as a crucial component of both the PC practice and philosophy of companionship in a PCT, which helps children, and families who medicine cannot cure. A practice/philosophy that is culturally, institutionally, and professionally contextual to Buenos Aires, echoes other answers to the social dilemma of caring for dying children.



## BIBLIOGRAPHY AND FILMOGRAPHY

- Almodovar, Pedro. 2002. *Talk to Her*. Madrid: El Deseo S.A.
- Becker, Gay 1997. *Disrupted Lives. How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Becker, Gay and Sharon Kaufman. 1995. Managing an Uncertain Illness Trajectory in Old Age: Patients' and Physicians' Views of Stroke. *Medical Anthropology Quarterly* 9(2): 165-187.
- Bluebond-Langner, Myra. 1978. *The Private Worlds of Dying Children*. Princeton, N.Y.: Princeton University Press.
- 1996. *In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child*. Princeton, N.J.: Princeton University Press.
- Bluebond-Langner, Myra, et al. 2007 Understanding Parent's Approaches to Care and Treatment of Children With Cancer When Standard Therapy Has Failed. *Journal of Clinical Oncology* 25(17):2414-2419.
- Bradshaw, A. 1996. The Spiritual Dimension of Hospice: The Secularization of the Ideal. *Social Science and Medicine*, 43(3): 409-419.
- Caplan, A.; McCartney, J.; and Sisti, D. (eds.) 2006. *The Case of Terri Schiavo: Ethics at the End of Life*. Buffalo: Prometheus Books.
- Carter, Brian and Marcia Levetown (eds.) 2004. *Palliative Care for Infants, Children, and Adolescents: a Practical Handbook*. Baltimore: The Johns Hopkins University Press.
- Clark, David. 2002 Between Hope and Acceptance: The Medicalisation of Dying. *BMJ* 324(7342):905-907.
- Cohn, Clarice. 2005. *Antropologia da Criança*. Rio de Janeiro: Zahar, coleção Ciências Sociais passo-a-passo 57.
- Coles, Robert. 1986. *The Political Life of Children*. New York: Atlantic Monthly Press.
- Davies, Ruth. 2004. Mothers' Stories of Loss: Their Need to Be With Their Dying Child and Their Child's Body After Death. *Journal of Child Health Care* 9(4):288-300.
- Davis, Matthew M., and Jeffrey P. Brosco. 2007. Being Specific About Being Special: Defining Children's Conditions and Special Health Care Needs. *Arch Pediatr Adolesc Med* 161(10):1003-1005.
- De Maio, Fernando. 2007. Health Inequities in Argentina: Patterns, Contradictions and Implications. *Health Sociology Review*, 16(3): 279-291.
- Deveau, Eleanor and Adams David. 1995. *Beyond the Innocence of Childhood. Factors Influencing Children and Adolescents' Perceptions and Attitudes Toward Death*. New York: Baywood Publishing Company.
- Du Boulay, Shirley. 1984. *Cicely Saunders, Founder of the Modern Hospice Movement*. London: Hodder and Stoughton.
- Durkheim, Emile. 1982. *The Rules of the Sociological Method*. New York: Free Press.
- Fadiman, Anne. 1997. *The Spirit Catches You and You Fall Down*. New York: Farrar, Straus and Giroux
- Freidson, Eliot. 1970. *Professional Dominance: the Social Structure of Medical Care*. New York: Atherton Press.

- Glaser, B. and A. Strauss. 1965. *Awareness of Dying*. Chicago: Aldine.
- Goldman, Ann; Hain, Richard; Liben, Stephen (eds.). 2006. *Oxford Textbook of Palliative Care for Children*. New York: Oxford University Press.
- Good, M-J. et. al. 1994. Oncology and the Narrative Time. *Social Science & Medicine*, Vol. 38 (6): 855-862.
- House of Lords: Select Committee on the Assisted Dying for the Terminally Ill Bill. 2005. *Assisted Dying for the Terminally Ill Bill*. London: The Stationery Office Limited.
- Hunt, Linda. 2000 Strategic Suffering. Illness Narratives as Social Empowerment among Mexican Cancer Patients. In Mattingly, Cheryl, and Linda C. Garro (eds.) 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.
- INDEC. 2006. *Tasas de Mortalidad por 1000 Habitantes Según Grupos de Edad y Sexo. Total del País. Años 1980, 1990 y 2000 – 2004*. [http://www.indec.mecon.ar/principal.asp?id\\_tema=66](http://www.indec.mecon.ar/principal.asp?id_tema=66) (Retrieved, 3 June 2008).
- James, A. and A. Prout (eds.). 1997. *Constructing and Reconstructing Childhood*. Londres: Falmer Press.
- Jeffrey, David. 2005. *Patient-Centered Ethics and Communication at the End of Life*. Oxford: Radcliffe Publishing Ltd.
- Kleinmann, Arthur. 1988. *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Köszegi, Botond. 2004. Emotional Agency: The Case of the Doctor-Patient Relationship. *Unpublished*.  
----- 2006. Emotional Agency. *The Quarterly Journal of Economics*, 121(1):121-156.
- Krahn, G., A. Hallum, and C. Kime. 1993. Are There Good Ways to Give Bad News? *Am .J. Pediatrics* 91(3): 578-582.
- Kübler-Ross, Elizabeth. 1969. *On Death and Dying*. New York: Macmillan.
- Kuhl, David. 2002. *What Dying People Want: Practical Wisdom for the End of Life*. New York: Public Affairs.  
----- 2006. *Facing Death, Embracing Life: Understanding What Dying People Want*. [Toronto]: Doubleday Canada.
- Lair, George. 1996. *Counseling the Terminally Ill: Sharing the Journey*. Washington: Taylor & Francis.
- Lambert, Helen, and Christopher McKeivitt. 2002. Anthropology in Health Research: from Qualitative Methods to Multidisciplinarity. *BMJ* 325(7357):210-213.
- Lawton, Julia. 2000. *The Dying Process. Patients' Experiences of Palliative Care*. London & New York: Routledge.
- Lock, Margaret. 1996. Death in Technological Time: Locating the End of Meaningful Life. *Medical Anthropology Quarterly* 10(4): 575-600.
- Massumi, Brian. 2002. *Parables of the Virtual: Movement, Affect, Sensation*. Durham: Duke University Press.
- Mattingly, Cheryl and Maureen Hayes Fleming. 1994. *Clinical Reasoning: Forms of Inquiry in a Therapeutic Practice*. Philadelphia: FA Davies Co.
- Mattingly, Cheryl. 1998. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press.

- Mauksch, H. 1975. The organizational Context of Dying. In Kübler-Ross, Elizabeth (ed.) *Death. The Final Stage of Growth*. Englewood Cliffs: Touchstone Book.
- Meier, Diane, and Larry Beresford. 2007. Pediatric Palliative Care Offers Opportunities for Collaboration. *Journal of Palliative Medicine* 10(2): 284-289.
- Mio, Keishin. 2001. *Between Cultures, Between Life and Death: a Qualitative Study of the Experiences of Health Care Professionals Providing Hospice Palliative Care for Ethno-cultural Others*. University of British Columbia, MA thesis. *Unpublished*.
- Moules, Nancy and Lillian Rallison. 2004. The Unspeakable Nature of Pediatric Palliative Care: Unveiling Many Cloaks. *Journal of Family Nursing*, Vol. 10 (3): 287-301.
- Muller JH, and BA Koenig. 1988. On the Boundary of Life and Death: the Definition of Dying by Medical Residents. In *Biomedicine Examined*. Dordrecht/Boston: Kluwer Acad., pp. 351-74.
- Oken, D. 1961. What to Tell Cancer Patients – A Study of Medical Attitudes. *Journal of the American Medical Association* 175: 1120-28.
- Paley, J and G. Eva. 2005. Narrative Vigilance: The Analysis of Stories in Healthcare. *Nurs Philos* 6: 83-97.
- Post-White, Janice. 2006. Complementary and Alternative Medicine in Pediatric Oncology. *Journal of Pediatric Oncology Nursing* 23(5): 244-253.
- Price, Kay. 2007. Avoiding Death: The Ultimate Challenge in the Provision of Contemporary Healthcare? *Health Sociology Review* 16(5): 397-404.
- Quill, Timothy E.; Bernard Lo; and Dan W. Brock. 2008. Palliative Options of Last Resort: A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia. In Birnbacher, Dieter; Dahl, Edgar (Eds.) *Giving Death a Helping Hand*. Part I, Volume 38: 49-64.
- Rouse, Carolyn. 2004. "If She's a Vegetable, We'll Be Her Garden": Embodiment, Transcendence, and Citations of Competing Cultural Metaphors in the Case of a Dying Child. *American Ethnologist* 31(4): 514-529.
- Salas Arrambide, M. et al. 2004. Los Cuidados Paliativos: un Modelo de Atención Integral al Niño Gravemente Enfermo y su Familia. *An Pediatr (Barc)* 61(4): 330-5.
- Sapir, Marc, and Ellen Fox 1998. The Spectrum of Medical Care: Curative, Rehabilitative, and Palliative. *JAMA* 279(1):20-21.
- Saunders, Cicely. 1984. *The Management of Terminal Malignant Disease*. London: Edward Arnold.
- Scheper-Hughes, Nancy. 1992. *Death without Weeping: the Violence of Everyday Life in Brazil*. Berkeley: University of California Press.
- Sered, S. and E. Tabory. 1999. "You Are a Number, Not a Human Being": Israeli Breast Cancer Patients' Experiences with the Medical Establishment. *Medical Anthropology Quarterly*, 13(2): 223-252.
- Selwyn, Peter A., and Marshall Forstein. 2003. Overcoming the False Dichotomy of Curative vs Palliative Care for Late-Stage HIV/AIDS: "Let Me Live the Way I Want to Live, Until I Can't". *JAMA* 290(6):806-814.
- Small, Dan. 2003. *Understandings of Cancer Genetics the Case of Colon Cancer*. University of British Columbia. Dept. of Anthropology and Sociology. *PhD Thesis*.

- Sork, Jamie. 2005. *A Study of Health Care Professionals' Experiences of Witnessed Suffering*. University of British Columbia. *Thesis PhD*.
- Stevens, Gregory D., and Leiyu Shi. 2002. Effect of Managed Care on Children's Relationships With Their Primary Care Physicians: Differences by Race. *Arch Pediatr Adolesc Med* 156(4):369-377.
- Toren, Christina. 1993. Making History: The Significance of Childhood Cognition for a Comparative Anthropology of Mind. *Man*, New Series, Vol. 28, No. 3. (Sep., 1993), pp. 461-478.
- Torres Vigil, Isabel, et al. 2007 What Predicts the Quality of Advanced Cancer Care in Latin America? A Look at Five Countries: Argentina, Brazil, Cuba, Mexico, and Peru. *Journal of Pain and Symptom Management* 34(3):315-327.
- Wainer, Rafael. 2003. *To Die-Living to Live-Dying: Professional Construction of Hope, Dignity, and Here-Now in a Palliative Care Team*. Faculty of Philosophy and Literature. UBA. Honors Thesis. Unpublished.
- Weissman, David E. 2004. Decision Making at a Time of Crisis Near the End of Life. *JAMA* 292(14): 1738-1743.
- WHO. *Definition of Pediatric Palliative Care*. <http://www.who.int/cancer/palliative/en> (retrieved April 20, 2008).
- 2003. Achieving Pain Control in Pediatric Palliative Care. *Cancer Pain Release* 16(2-3).
- Widger, Kimberley, et al. 2007. Pediatric Patients Receiving Palliative Care in Canada: Results of a Multicenter Review. *Arch Pediatr Adolesc Med* 161(6):597-602.
- Wolfe, Joanne, et al. 2000. Understanding of Prognosis Among Parents of Children Who Died of Cancer: Impact on Treatment Goals and Integration of Palliative Care. *JAMA* 284(19): 2469-2475.