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“LOOKING FOR THE VOICES OF CHILDREN LIVING WITH HIV: A CASE STUDY APPROACH”

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INTRODUCTION

Despite the efforts made worldwide to address children living with HIV, no attention has been paid to the fact that children must have their own perceptions and knowledge about their health condition. In this research, I intended to find out how Chilean children construct, from their own point of view, the experience of living with HIV, which includes their perceptions, beliefs and lay knowledge. This research is inscribed in the anthropology of children, which looks at childhood as a category culturally constructed, and children as actors capable to construct their own world.

For that purpose, I developed four case studies, with girls and boys of Santiago city, who are six to nine years old. All of them acquired HIV through vertical transmission and were not aware of their disease.

Researches done by Vivo Positivo (Donoso et al. 2002, Vidal et al, 2002), among women living with HIV in Chile, have shown that they face several problems in discussing HIV with their seropositive children, since they consider the latter unable to understand and cope with the fact that they live with HIV. Although children take antiretroviral treatment several times a day and they attend medical check ups at least once a month, they are not officially told about the disease they have. This becomes more problematic when people around children, like their neighbors and teachers at school, know that they live with HIV and discriminate them: children do not know exactly what is the matter with them and why they are rejected by their social environment. As a result of this, women are unable to deal with everyday problems such as children’s compliance to medical treatment, children’s questions regarding their own health state, and discrimination.
The issue of disclosure to seropositive children is being discussed worldwide. According to the American Academy of Pediatrics (AAP) there are many obstacles which inhibit disclosure to children, including fear of negative impact on the child's will to live, parental guilt about transmitting HIV, fears about stigmatization and discrimination, beliefs about the child's difficulty with keeping a secret and parents’ denial of or difficulty in confronting their own illness. In the case of Chile these fears are increased because of the cultural reluctance to talk openly about difficult issues, and the strategy to ignore them even though each party is aware of them, in what is called "a tacit agreement".

Attempts to improve HIV positive children's quality of life have been taken, particularly through developing proper disclosure recommendations. However, no attention has been paid to the fact that even if their health status is not disclosed to them, children must have their own perceptions and knowledge about their health condition. These perceptions could have an influence on the way children cope with HIV in their everyday life. In that sense, it is important to know what children think about their own condition, in order to develop proper interventions with HIV positive children.

The main objective of this research is to find out the perceptions that HIV positive children have about living with HIV and taking antiretroviral treatments. This objective was divided into four questions: how children perceive their every day life in general and in relation to HIV, what are the perceptions children have about their health condition and antiretroviral treatment, how children perceive their bodies in relation to their illness and how they get knowledge/information about their illness.
As mentioned before, this research is based on qualitative methodology, in particular through developing four case studies, with girls and boys, who are 6 to 9 years old. The case study methodology has been defined as “a systematic inquiry into an event or a set of related events which aims to describe and explain the phenomenon of interest” (Bromley, 1990: 302; quoted by Zucker, 2001: 162). This methodological choice has to do with the search for a holistic deeper understanding of the situation of children living with HIV, stressing their own viewpoints. In that sense, its validity lays in its capacity to facilitate a greater understanding of the HIV children’s life. As a case study is meant to do, the perspective of other actors was included; in particular, the caregiver’s views were important to fully understand the world of children living with HIV. It is important to remark that I prefer using the term “caregiver” to account for the different realities that children face regarding their family structure. As will be demonstrated, two of the children involved in this research are under charge of their grandmother, which is quite common among poor families in Chile.

I carried out in-depth interviews with children themselves, through using appropriate methodology. In addition, I observed (shared with) children some moments of their every day life and I did interviews with their caregivers. Since the issue of non-disclosure was crucial to my research, several projective methodological strategies were needed to do interviews with children such as drawing, writing a letter and making a collage. Although it was not planned, during the fieldwork I decided to include a role-playing, were the children acted as the doctor and I as the child’s mother. One of the children came up with that idea, and it allowed me to get a deeper knowledge about the children’s perceptions regarding their medical treatment.

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1 See Chapter II on methodology.
Since none of the children involved in this research was aware of the disease, this research involved several ethical issues to be addressed. The methodology was designed to be ethically appropriate and to ensure that it did not involve any harm for children living with HIV and their families. The informed consent of children and their parents was asked after informing the objectives and the process of the research. Since children involved did not know their HIV status, this was done in a manner that did not reveal it to them. In addition, this research was designed taking into account the need for individual work with each child because they do not share a community and they do not recognize themselves as children living with HIV. Moreover, except for their age and sex, all the children’s personal information has been changed in order to protect their anonymity.

During the process of data collection, any hierarchical relation between the researcher –myself- and the children was avoided, children’s willingness to participate in the research was fully respected at all the stages of it.

This research proposal is the result of two years of work with women living with HIV, in which they have constantly raised the issue of disclosure to children with HIV. The two existing organizations of women living with HIV in Santiago, were involved in the research, particularly through their representatives, who discussed with me the research proposal in order to identify and solve ethical issues. They also helped me to approach children’s mothers.

This research mainly intends to contribute to the improvement of the quality of life of HIV positive children themselves, and it is expected to be a contribution for the organization of people living with HIV in Chile. I do believe that knowing the world of children living with HIV is the first step to be taken in order to help mothers and adults in charge of seropositive children improve their
Based on the existing literature about children chronically ill, I assumed that children should be able to get knowledge about their serological status and health condition, even without being officially told. This assumption led me to think that communication between HIV positive children and their caregivers could be improved if the latter get to know what children really think about their status.

At a theoretical level, this research incorporates a new perspective in anthropology such as the deconstruction of childhood as an essential category. It will address a topic that has not been fully developed in the field of medical anthropology: the relationship between children, illness and body perceptions.

At a methodological level, this research implies the development of new qualitative strategies to be used with children. In addition, it addresses the issue of the appropriateness of the methodology to be used with severely/ chronically ill children.

This research constitutes the first little effort to look for HIV positive children’s voices. In the following pages I hope I can convey, as closer as possible, the experiences of children living with HIV, how they deal with such a disease, even without knowing, how they handle the difficulties of their antiretroviral treatment, as well as other consequences of the disease.
Chapter I. The world of Chilean children living with HIV

Background information:

The devastating epidemic of HIV/AIDS is one of the biggest challenges humankind must face these days. Around 45 million people have been infected all over the world, and 14 million have already died. More than twenty years after the appearance of HIV/AIDS, the number of people affected is still increasing, due to the lack of effective preventive measures.

In Chile 9,874 people have been infected with HIV (CONASIDA, 2000), 3,012 of whom have died. About 10% of the cases refer to women. Although CONASIDA estimates that the real number of cases is 19,479, the national organization of people living with HIV "Vivo Positivo", based on UNAIDS guidelines, estimates that there are at least 40,000 people infected, since for one notified case there are at least four that remain unknown. There are around 500 registered children with HIV, which corresponds to 4% of the cases, most of them infected through vertical transmission. According to UNAIDS, 4,100 children in Chile are orphaned because of HIV. Since HIV affects the whole family, most HIV positive children have lost at least one of their parents, and some of them live in special shelters established by Catholic organizations.

According to CONASIDA, the epidemic of HIV in Chile has the following characteristics:

- Sexual transmission: 93% of the notified cases reported sexual contact as way of transmission
Feminization: A long-term analysis shows a more rapid spreading of AIDS among women. In 1993 for every 15 cases of men there was one woman notified, in 2000 this proportion was 7:1.

Predominance among homo/bisexual men: despite the process of feminization, homo/bisexual men remain the group mostly affected by HIV, with around 70% of the notified cases.

Heterosexualization: The number of transmissions through heterosexual intercourse is increasing in comparison to homosexual transmission

Pauperization: there is a shift of the epidemic toward the lower social groups. The analysis of the data available shows that those with lower educational level and less qualified jobs are most likely to be affected by HIV/AIDS.

Ruralization: there are an increasing number of cases in rural communities, and the epidemic is no longer exclusive of urban areas.

The official response to the epidemic in Chile has been weak and incapable to deal with cultural resistances to open promotion of safe sex. In 1990 the National Commission for Prevention of AIDS (CONASIDA), was created. Its mission since then is "to develop public policies oriented to make society assume prevention and diminution of the biological, psychological and social impact of HIV/AIDS and STDs through thinking, dialog, and respect to both human dignity and development of people's autonomy". Since its creation, CONASIDA has carried out several campaigns to raise social awareness about HIV/AIDS, as well as interventions at a micro level, among groups considered more vulnerable to HIV, such as young people and men who have sex with men. In addition, CONASIDA has improved the quality of health care provided to people living with HIV, particularly increasing the access to antiretroviral treatment. However, many problems remain unsolved. Most of the efforts of CONASIDA have been

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2 CONASIDA website www.minsal.cl/conasida/
devoted to cover the needs of children with HIV, whose existence seems to be less problematic in cultural terms, since they are considered "innocent victims" of the epidemic.

In 1997, the National Organization of people living with HIV "Vivo Positivo" was created, uniting seven grass-root groups existing at that moment. The main concern of this organization is to improve the quality of health care offered in the public health system, and in particular, to advocate for access to antiretroviral treatments. Since its foundation, "Vivo Positivo" has grown considerably, and nowadays unites thirty based groups from all over the country. The organization of people living with HIV has become a key social actor in the fight against HIV, and one of its biggest advocacy accomplishments was a law on prevention of HIV passed in 2002, which also includes measures against discrimination of people living with HIV.

Researches done by VIVO POSITIVO show that in general, people living with HIV face social discrimination in their workplaces, health care services, and within their own family group (Vidal et al, 2002). In the case of women living with HIV, the situation is even worse since HIV affects the whole family, affecting their husbands and sometimes their children as well. A survey conducted among women living with HIV (Donoso et al 2002) showed that around 30% of them have become widowed because of HIV and some 52% has either her husband or a child infected by HIV as well. This means that in many cases they must face suddenly the fact of being in charge of their home maintenance, which means start looking for an income as well as keeping their duties in the household. Most of the women included in this survey live in extreme poverty, and 41% of them receive a monthly income which is less than 140 US dollars. Also, 42% live
in houses that belong to other relatives ("allegadas"), which means overcrowding and unstable living conditions.

This research also pointed out the fact that women with HIV neglect their own health seeking needs in order to take care of their family. This is particularly worth worrying when they have children affected by HIV, because of their fear of the child’s death and their feeling of guilt for transmitting the disease. This hopelessness increases due to their lack of tools for communicating effectively with their children, their incapability to answer children’s questions regarding the disease and medical treatment and the anxiety they feel about the moment they will have to disclose HIV to them.

From the children’s perspective, nothing has been done in terms of social research in Chile. At an international level, the way children are being affected by HIV has been addressed in Africa, where the reality of children orphaned because of AIDS claims for action. In the developed world the discussion about children with HIV goes around children’s rights and about to what extent children should be involved in their own treatment. The issue of disclosure has deserved also a great deal of discussion, in particular about the right moment to do it. As mentioned before, the American Academy of Pediatrics has elaborated several recommendations for disclosure, but their cultural appropriateness must be reviewed.
Chapter II. Methodology

1. Type of study:

This research is exploratory - descriptive, since it is intended to grasp an issue which has not been researched in Chile. In addition, this project is problem-oriented since it is aimed at offering a response to an issue raised by the organization of women living with HIV.

2. Methodological strategy:

This research was based on qualitative methodology, which suits the main objective this research pursues: children’s perceptions about their illness. The advantage of this methodology is that allows a deeper understanding of the way the target group perceives and gives meaning to their own world. It was based upon case studies. Four case studies of children living with HIV were developed. In order to do so, I carried out in-depth interviews with children themselves, through using appropriate methodology. In addition, I observed (shared with) children some moments of their every day life and I did interviews with other informants, such as children’s parents and health care providers.

Case Studies

According to Tellis (1997) case study is an ideal methodology when a holistic, in-depth investigation is needed, since it is designed to bring out information from the viewpoint of the participants by using multiple sources of data (1997:1). This methodology is a multiperspectival analysis, since the research considers not just
the perspective of the actors but also the relevant groups of the actors and the interaction between them (Tellis, 1997:2). It also comprises a triangulated research strategy, in order to increase confidence in interpretation.

Although case study methodology does not meet the positivistic standards of representativeness, some authors (Tellis, 1997; Stake, 1995; Yin, 1994) have argued that it provides a different type of generalization, which is not statistical but analytical, since it compares a previously developed theory with the empirical results of the case study (Tellis, 1997:2). Stake argues for another approach centered in a more intuitive, empirically grounded generalization, which is called "naturalistic", according to his perspective, the validity of the information provided in case studies comes from the fact that it resonates experientially with a broad cross section of readers, thereby facilitating a greater understanding of the phenomenon (Stake, 1995 quoted by Tellis, 1997:2).

3. Sample:

Four case studies were developed. Although case study research is not sampling research, in order to maximize the information that can be grasped, the cases were selected taking into account certain characteristics:

- 2 girls, 7-10 years old, living in Santiago, HIV acquired through vertical transmission
- 2 boys, of 7-10 years old, living in Santiago. HIV acquired through vertical transmission

4. Methodological steps:
This research takes into consideration the fact that methodologies designed to study adults cannot be easily applied to children; doing research with them requires specific methodological strategies.

Three main techniques were conducted:

a) In depth Interviews with children: they were open-ended, based on a list of topics that must be covered. They were combined with appropriate techniques for children borrowed from psychology studies, such as projective ones: drawing, collage, story telling.

b) Observation and sharing: I spent as much time as possible with children and their families, in order to gain their trust and observe relevant aspect of their social interactions and behavior.

c) Interviews with other informants: mothers of children with HIV and other relatives were interviewed.

a) In depth Interviews with children:

The interviews were performed in the children’s home and they lasted about two hours each, sometimes I spent the whole morning or evening with them. The interviews were combined with other games to entertain the child and gain his/her trust.

a.1) First meeting: Getting to know each other

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“Pregunta, penitencia, dulce” (question, test, sweet)

This game was designed to help the researcher start a conversation with the child in a funny way. A board with several squares was displayed, using dices, each of us will have to advance to reach the goal. Some points of the board were marked with questions, the one who reached that place could ask the other some of the questions listed bellow. When one of the participants got the places marked as “test” she or he could ask the other to perform a difficult test such as singing, dancing, etc. When one reached the square marked as “sweet” she/he got one.

Questions Game “Getting to know each other”

1) Nickname
2) Family
3) Favorite activities
4) Activities she/he does not like
5) Closest persons
6) Places where he/she has lived
7) People with whom she/he has lived
8) Persons she/he likes the most
9) Persons she/he dislikes the most
10) Place she/he likes the most
11) Place he/she dislikes the most
12) Dreams about future

a. 2) Second meeting: Collage
The child was asked to make a collage selecting pictures of magazines, which showed how is his/her life. The materials were provided. The time given was around one hour. After finishing the collage, the child was asked to describe it and explain it. This conversation was recorded.

**a. 3) Second meeting: Showing things that matter**

In the previous session, the child was asked to bring for the next session the three things that are more important to her/him (toys, pictures etc.). The objects selected were taken as a source of information themselves, since they show the children’s personal interests. Secondly, these objects were used as starting point for an interview regarding his/her every day life.

Interview Guideline:

1) What do you every day?
   (Check if activities regarding HIV are mention, if they are, go in depth)
2) What are the activities you like the most?
3) Do you have to go hospital?
4) If yes, how often do you go?
5) Why do you go to hospital?
6) What happens there?
7) Do you like going to hospital? Why?
8) Do you take medicines?
9) If yes, how often?
10) Do you like taking medicines? Why?
11) Do you like its taste? DO you like its color?
12) Does somebody help you take medicines?
13) Is somebody else ill in your family? What does she/he have?
14) What else do you have to do regarding to your illness?
15) If she/mentions something else, ask:
    - why do you have to do that?
    - Who told you that you have to do that?

**a. 4) Third meeting: Letter to an ill child**

I read a letter with the child from another child, who is also ill. The letter presented situations that can make the child identify him/herself. The child was asked to write a letter back to the child, telling her/him things regarding to her/his own illness. During the course of this exercise, questions regarding his/her perception about her illness were asked.

Letter:
“Hi, my name is (Alicia/Marcos), I am 8 years old and I live in Cerro Navia. I go to school every day and I do not have brothers or sisters. My father died when I was three years old, so we live alone with my mum, and my grandmother. My mum works everyday, so my grandma is with me all the time. I have to go the hospital with my mum every month because we both are ill. We do not exactly what kind of disease we have, but I think is something in the heart, and we have to take medicines every day. My mum keeps them in her room. Sometimes, she goes to meet other women, I love when she takes me with her because then I get to play with other children who are also waiting for their mums. But the thing I like the most is when we have a Christmas party in that place, because there are a lot of children and we receive a lot of presents. I also like that day my mum is happy, I
love when she is smiling because sometimes she cries in her room, I don’t like when she cries. I hope we are going to get better and we can go to the beach”.

Question Guideline:

1) What kind of disease do you have?
2) If she/he says something, ask:
3) What is the cause of it?
4) Which part of the body it affects?
5) Is there any treatment for that?
6) How long have you been ill?
7) How do you know about it? (explore each of the ways he/she gets information)

a. 5) Fourth meeting: Body drawing

The child was asked to draw his/her own body, as she/he sees it. Afterwards, an interview was conducted regarding her/his drawing and disease.

Question guideline:

1) which are the things you think are the most important in your body? Why?
2) which are the things you like the most of your body? Why?
3) Is it possible to see your illness in this drawing?
4) If not, why is it so? (can you try to make it)
  If yes, where is it?
5) Does it grow when you grow up? Or is it going to disappear?
6) How does your illness work in your body?
6) Which parts of it are affected?
7) Which parts are not affected?
8) How about the blood? Is it important? Why?

b) Observation and sharing:

The observation was developed during the meetings with the child in his/her home. This technique was intended to complement and enrich the information collected from the other sources. In the case of the observation while working with the child, it was also intended to account for the nature of the relationship between the researcher and the child.

Observation guideline, while working with the child:

- child's attitude (trusting, uncomfortable, impatient etc.)
- how the child uses the space (does she move freely, does she ask for permission to do whatever etc.)
- affective expression
- attitude during the interviews (does she have problems to answer the questions, to understand them, to concentrate herself)
- best activities (which activities she likes the most during the interviews)
- rapport, interaction between the child and researcher (hierarchical, equalitarian etc.)

Observation guideline for the child's home:

- to describe the space and decor
- to look for objects that can give further information about the family (religious, political, related to HIV etc.) ask questions regarding to them.
- to describe the child's room
- to look at the interaction with other people in her family (hierarchical, is she spoiled or treated in the same way her siblings are etc).
- to pay attention to what the child does during the visit
- to pay attention to how the adults behave in front of the child (do they include her in the conversation, do they ignore her etc.)

c) Interviews with other informants

The interviews with the child's mother or other caregivers were aimed at getting more information regarding to the child's situation.

**Question Guideline for mothers or other adults in charge of the child**

a) Entrance information: name, age, number of children, main activity, and educational level.
b) How old is your child?
c) How would you define your child? how is she?
d) When did you come to know she lives with HIV?
e) How did you find it out?
f) What are the main difficulties your child has regarding HIV?
g) What are the main difficulties you have regarding to the fact that your child lives with HIV?
h) Do you have problems related to her compliance to treatment?
i) Have you talked about HIV with her?
j) Does she know she lives with HIV?
k) Have you thought about talking to her about her HIV status?
l) What are the main concerns you have about your future?
m) What are the main concerns you have about her future?
Chapter III. Children’s perceptions about their disease and treatment

1. The cases

Bianca, 6 years old

Bianca lives in one of the poorest neighborhoods in Santiago, in the area most affected by air pollution in Santiago. She lives with her grandmother, her mother, who also has HIV, and her brother, 8 months old who does not have HIV, and her uncle and aunt and their child, a 9 years old boy.

Her caregiver is her grandmother, who has looked after her since she was born. About Bianca’s mother, Ana, her grandmother says:

“She doesn’t accept that she has HIV, she doesn’t do anything about it, she doesn’t take care of herself, and neither of Bianca, I am the one who takes care of Bianca, she is like my own daughter, everyone thinks that she is my daughter, because I am the one who takes her to school everyday, who brings her to the hospital, everything (...) She (Bianca’s mother) has another child, a baby, and she just looks after him, because he doesn’t have HIV, it is like she doesn’t accept the facts as they are”

It is noteworthy that Bianca also calls her grandma “mummy” and her mother just “Andrea”. But when I asked her who is your mum she said “Ana”.
Bianca’s situation is even more complicated since in her family only her grandmother and her mother know she has HIV. The rest of the family has not been told, because of Ana’s fears of discrimination. She said “I haven’t told them, because they are going to discriminate Bianca, I don’t want Bianca to be discriminated, they are going to think ‘we live with her, we share everything with her’ and then they are going to separate their own stuff and then Bianca will feel discriminated. I know they suspect something, because they always ask why do you go that often to the hospital? What does Bianca have? She had a very serious problem in her lung when she was like three years old, so they know that she has a problem in her lung, I always tell them that that is why we go to the hospital that often, but they suspect something, they don’t believe that anymore”.

Because of this situation, Ana asked me to be very careful about the comments I made in her house, also, she asked me to go to their place in the morning, when the rest of the family was not present.

In the conversations I had with Bianca she was always concerned about her performance at school, she wants to be a better student but she cannot make it “sometimes I have to stay in classroom during the break, because I can’t finish the assignments on time, I don’t like that”. During the meetings I had with her, she asked me to help her with her homework. Since in Chile girls are usually asked to stay indoors, while boys are allowed to play outside more often, most of Bianca’s social life occurs at school, where she can play with others girls.

Bianca has had several complaints regarding HIV, and nowadays she is considerably underweight. When I did my fieldwork she had a trouble in her arm, for against the medical recommendation she had been vaccinated at school, without her grandmother’s permission. Although all children are usually
vaccinated at school, Ana had requested not to vaccine Bianca. Although she did not inform the school openly about HIV, she gave as a reason that Bianca has problems with her immunology system. Ana was very worried about the consequences the vaccine was going to have on Bianca’s health but the moment I did my interviews she had some troubles with the healing process of her scar. Bianca told me “my mum got mad about the vaccine, because she is going to be told off by the doctors, they told her that I should not be vaccinated”.

Bianca says that she does not like being to the hospital because “I get pricked and it hurts”. The only thing she likes about it is that she gets to play there and there are a lot of toys she can play with, she says “the jigsaw is my favorite”. She does not like the medicines either and she says “I take her just because my mum tells me that”. About her disease she says she does not know anything “because the doctor talks to my mummy only”.

When I asked her about her future she said that she wanted to have a lot of children and to be a doctor, to heal children and take care of them.
Jaime, 9 years

Jaime lives in Santiago, in the middle of one of the poorest neighborhoods. In order to get to his house one needs a ten minutes walk through several “pasajes” (small streets). One must walk on the car way because the pavement is in such a bad condition that it is impossible to walk on it. The poverty of the place can be measured from the large number of small stores, maybe one or two per block, which are a common survival strategy for poor people. During my fieldwork I usually would see a considerable number of men just standing in the street, which is also a clear sign of the high rate of unemployment that affects Chile these days.

The first time I saw Jaime, he was playing outside his house, waiting for me. He had been told that a “tía” was going to visit him for an interview. He said this was something exciting for him, since he is not attending school these days, so he stays home all the time and sometimes gets bored. His caregiver is his grandmother, the mother of his father. Jaime was born in May of 1994 and one month later his mother died because of AIDS. When he was just born he stayed hospitalized for several months because of health problems regarding HIV. Since then, he has lived in his grandmother’s home with his grandfather, his father and an uncle.

Irene, his grandmother says about Jaime’s mother: “she knew she had HIV but she didn’t tell my son, that was bad, she lied, she should have told him, luckily he didn’t get HIV, because you know, the transmission from woman to man is more difficult, but the child (Jaime) did. Doctors made a mistake because they knew

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3 The literal translation of “tía” is aunt. Children use to call that way any female adult who has some kind of friendship or work relation with them.
she had HIV, but they didn’t do anything, they didn’t give her the treatment to prevent the transmission, something could have been done, now Jaime has HIV as well”.

So far, he has had several physical complaints such as pneumonia, which was the cause of a three weeks hospitalization, and also he suffers from hemorrhage episodes. The last time when he had a serious hemorrhage he also went to the hospital. He does not know that he has HIV, but he thinks that the disease he has is just hemorrhage, because of these episodes.

The person who takes care of Jaime’s needs is his grandmother, she is the one who spends most time with him. Jaime’s family relations are complicated since he does not get along with his grandfather, who is in fact the authority within the family. Once I asked Jaime about the person he dislikes the most, he answered:

Jaime: it is that one, you see that picture (he points to a picture of his grandparents)
Carla: who is the person you dislike?
Jaime: that one, my grandpa, I don’t like to be with him because he hits and damages my doggy all the time.
Carla: Why does he do that?
Jaime: I don’t know, he just doesn’t like it.

Irene’s explanation regarding the bad relationship between Jaime and his grandfather is the grandfather’s jealousy about the boy: “when I brought Jaime to live here, his behavior (Jaime’s grandfather) changed completely, I think he is jealous, because all the attention I put on him before, now goes to Jaimito, he is
the thing about (whom) I worry the most, I am all the time worried about Jaimito’s needs, Jaimito’s treatment, so that’s why he doesn’t like him”

When I asked him about who is his closest person he says “my little sister Antonia”. Antonia is the three years old daughter of his father’s girlfriend. They do not live together but because of their parents’ relationship they spend much time together. One day, I asked him to do a drawing of his family, and he drew himself, his little “sister”, his father, his father’s girlfriend whom he calls “mama Daniela”, his grandfather and his grandmother. Antonia, who was also there, says “hey, she is not your mother, she is mine, I don’t lend my mum”, Jaime replies “Well, I don’t lend you my father then, there is no family then”.

Jaime seems to have a difficult relationship with the world of adults, all the time he explains that the thing he likes the most is to be with his sister and his children neighbors. When I asked him about his dreams for the future he said “I would like to live on a lonely planet with only children there, without adults”.

He is considered a naughty child by his family, they say he cannot stay sited, his grandfather often told me “he is all the time moving from one place to another, running, he cannot stay quiet”. During the time I spent with them, Jaime was continuously told off by their relatives for not staying quiet.

During my fieldwork he was suspended from school because of a fight he had with another child. According to his grandmother “he is just defending himself from discrimination”. According to her, Jaime behaves that way at school because he is being discriminated by his classmates because they know he has HIV. In

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4 It is interesting to remark that whenever I asked this question to the children they interpreted the word “future” in the way of science fiction. When I intended to correct the question to make it understood they referred to an immediate future (see Marcelo’s answer, page 17)
order to avoid discrimination, last year she subscribed the child in the hospital school which is intended for children who suffer from oncological complaints. But still Jaime is not fully integrated. She exemplifies this by telling that once he got cut in his hand at school, and everyone got scared of his bleeding. Irene also says that the child was rejected at school because he is not able to retain defecation as a result of the antiretroviral medication. In addition, she was asked to take him to a psychiatrist in order to get medication against his hyperactivity. She says that once she gets that medication for the child he is going to be accepted again at school. When I asked him about it, he said that he does not like that school because children are not nice there. He told me that he bites other children to defend himself because they make fun of him.

He is overprotected by his grandmother. Since she works as a volunteer of the organization of people with HIV in the hospital where Jaime attends school, she was able to be close to him all the time. She told me that sometimes when Jaime did not want to have lunch or when he was being too naughty in the classroom, the teachers would look for her and she had to go there and take care of Jaime. She told me several times “he is the one I love the most, sometimes I don’t care about my own health, because I have hypertension, because I want him to be fine, I care much more about his health, because he is child, he is an innocent child, he doesn’t have any blame of the disease he has”.

Despite the warnings of all Jaime’s relatives, the time I spent with him he was nice and willing to work with me. Of course he wanted me to play with him other games, and we did so. He was continuously inventing new games, and, since he had the medical paraphernalia, he spontaneously proposed me to play a role play where he was a doctor and I was the mother of an ill child. In addition, he wanted to do his own interview with me, which told me a great deal about his interests, he
asked me about my room, my family, my toys, and so on and so forth. I remember once he asked me: do you sleep with a Teddy bear? That was an important question for me, because it reminded me that, despite the great connection I had with him, I was working with a child, that is, with someone different from me, who had his own interests and concerns, someone who sees the world from a different perspective.

He likes playing “Play station” and at the time I did my fieldwork he was excitedly looking forward to receive one for his birthday. In fact he did so, and I spent a lot of time playing with him afterwards. Whenever he felt sad because of the things we were talking about, he started to talk about his play station. Once I read to him a letter of a boy who supposedly had HIV and his answer to him was “I’m going to be given a Play Station for my birthday, you can come and play with me, so you won’t be sad anymore”.

Marcelo, 8 years old

I met Marcelo for the first time in his home, located in a poor neighborhood in the north of Santiago. That time he was not in a good mood because he was asked to wake up earlier because I was going to be there for an interview. After that, we both decided to meet in the evenings after school, so we had more time to share and he did not need to wake up early in the morning.
Like other children, Marcelo got HIV because of vertical transmission. His parents both have HIV, and his father was the one who acquired it and transmitted it to Marcelo’s mother. He lives in an extended family, with his grandmother, four uncles, his parents and his twelve year old sister. His mother told me that they live this way because of the problems she has with her husband, Marcelo’s father:

“I have my own house, nearby, but I decided to move here because of the arguments I used to have with him (her husband). We fight a lot with each other, and things were getting worse. Here he cannot shout at me, he has to be careful because my mother is here, so, he cannot do that anymore (…). For me this is OK because I used to come here everyday to help my mother with the cleaning up. So for me it is easier to live here, the only thing I don’t like is that we four live all together in one room, but now we are working on building a new room, so we won’t be that crowded”.

Marcelo is fully aware of what is going on between his parents. Once he asked me to help him write a letter for his father, it was a card for father’s day, that said “Daddy, I love you and forgive me for all the things I have done which have made you angry. Thanks for forgiving me, and I’m not going to do it again. Do not drink anymore, you both do not fight again, and I love you very much. I send you a greeting if you leave, I hope you are not leaving home, and Daddy I love you very much”. Because this card was given to Marcelo’s father, Claudia, Marcelo’s mother, explained to me later on “Marcelo is too sensitive, everything affects him, he is aware of everything that happens around him, he knows the problems I face with him (her husband), that is a problem”.

Marcelo was also affected by other family issues. When I read to him the letter of a child with HIV, he wanted to write back a letter for his grandfather. It says “Hello grandpa, I send you greetings and I hope everyone feels good, and I don’t
know why you left home when we were fine all together, and I love you very much and I miss you. I hope you will come here and I want to see you. I send you greetings and I hope you will come here and you stay to sleep here. Grandpa I love you very much”. Marcelo told me he does not know why his grandpa left home. His mother told me later on that he fell in love with another woman and he went to live with her in a city in the south of Chile.

When I asked about his dreams for the future he answered “I want to be a good child, I want to obey my mum, to play, to get in when I am asked not to play outside”. He also is concerned about being good at school, he said “last year my final mark was six”\(^5\). He likes playing outside with his friends but he knows that sometimes his mother does not like those games “my mum does not like when we bite each other and when we crash with each other”.

He says that the person he likes the most is his mother, and she is the one who spends more time with him. She says “I don’t work because I prefer staying with my son, he needs me a lot, he needs someone to give his medicines to him, to be with him all the time, and I am the only one who can do that, I think it is better for him that I don’t work”.

As other HIV positive children, Marcelo does not know he has HIV. However, he knows that his disease has to do with his blood and that is why he must go every month to the hospital to get treated. Marcelo’s mother is also concerned about disclosure. She thinks Marcelo is not ready to fully understand what HIV means, and probably when he becomes older, they will talk about it with him. As an example, she mentioned the fact that her sister, who is twelve years old, was just told about the disease that affects the family, she added: “we had to tell her,

\(^5\) In the Chilean mark system seven is the highest.
because she was behaving in a wrong way, you know how children are when they are teenagers, they are rebellious, so we told her to make her more sensible, I don’t think she has accepted the situation, she is still thinking about it, but her behavior towards us has changed for better”.

Marcelo’s parents do not know exactly the moment that he will be told about HIV, they expect that when he is older he will be able to understand. Although most of the family knows about it they prefer not to talk about it. As other mothers of children affected by HIV, Claudia worries about the moment when Marcelo becomes a teenager, when he will want to start his sexual life. She says “I don’t know what is going to happen, he will want to have a girlfriend, he will fall in love with a girl and then, I don’t know, he does not know that his life is not going to be normal”.

**Esperanza, 7 years old**

When I first met Esperanza, in her home, she was waiting for me outside, she was very happy to see me and, although she did not know me before, she opened her arms to give me a big hug after jumping on me. The second nice surprise about her, was to see her nice home, painted all with nice colors and decors. Although her home is situated in one of the places with the highest rate of delinquency and social problems, her family has managed to create a nice living environment there.

Esperanza lives with her father, mother and older sister, who is fourteen years old. Esperanza’s mother has also HIV and she thinks that she acquired it because of blood transfusion, since her husband is not infected. As other cases, she did not
know her HIV positive status when she became pregnant and Esperanza was born. She came to know only a couple of years later, when the girl started to suffer from HIV related infections. The most serious one was a pulmonary infection which almost made Esperanza lose one of her lungs, her mother says “it was a miracle, the doctors were going to remove the lung because it was almost destroyed, but they couldn’t because there was no room available, so everything was postponed for the following week, then the doctor checked up Esperanza again, and he didn’t find anything, he said that it was OK, that the lung was all right, I think it was God’s intervention”.

Her sister and father know about her seropositive status and, they are very supportive to her. Her case is different from the others, in the sense that in her family everyone was involved in her treatment. I also felt how concerned they were about Esperanza’s well being, in he way they all wanted to watch the interviews I did with her and make sure that she was enjoying the time with me.

Esperanza’s mother was an important leader of the movement of people living with HIV. However, she is not longer involved in those activities because she decided that it was better to focus her energy on her daughter. This decision was influenced by the fact that when Esperanza was younger she had compliance problems, which led to resistance, and now she is taking a second-generation treatment\(^6\). According to Esperanza’s mother that was because she was not at home, and the medicines were given by a nanny, who was careless about making the girl take the pills. When they found out that Esperanza had developed resistance, her mother decided to stay with her all the time to make sure that she

\(^6\) Antiretroviral treatments are divided into three generations, the first generation medicines are supposed to be more basic and less heavy. When a patient becomes resistant to a medicine he/she must start taking a second generation treatment. The main complication appears when the patient has developed resistant to the all medicines existing so far, because that means that there is not more treatment possible anymore.
was taking her treatment in the right way. She also added “I don’t change the time I spend with my child for anything, I prefer always to be with her”.

Esperanza’s treatment is much easier than the other children’s. Her mother has decided to give her only the antiretroviral treatment, and not to give her the other treatments the health care service provides such as medicines to prevent opportunistic infections and gamma globulin. She says “She is checked by two physicians, one is from Universidad Catolica (a private clinic) and the another one is from the hospital, and they have different mentalities, dr. Valdés (private physician) has another mentality, he thinks that Esperanza produces her own enzymes, and defenses, so she doesn’t need other things. Maybe the moment when she'll need that will come, if her defenses decrease, but not now, I just give her vitamins and her drugs, and that is it. And the rest is her own capacity to defend herself, because I don’t want to feed her up with medications, that is not good for her, she can get tired of that”.

Esperanza’s mother has also disclosed her own HIV status through the media. She thinks that is a good way to help others to understand what somebody with HIV faces. She is in favor of disclosure as a way to improve people’s living with HIV quality of life, she thinks that is better when everyone knows it, so they can support the affected as well as see her as a normal person. However, she has not told Esperanza about HIV, she thinks the girl is not ready to understand what HIV means. Even though Esperanza has taken part in some of the interviews done with her mother, she is not aware of the reason of them, she says “I’m famous, I have gotten a lot of interviews”. When I asked Esperanza the reason of that she says “because my mum is great”.

33
According to Esperanza the disease she suffers from is the complaint she has in her lung. She thinks that it was healed, but she realizes that after that her health became weaker and she gets sick more easily. She also knows that the medicines she takes help her prevent other diseases. She does not like them but she adds “they are good for me”. According to the girl, her mother has diabetes and that is the reason why she goes to hospital and gets medication. Esperanza’s mother adds “she thinks that I have diabetes, I don’t know how she came up with that, she just invents her own explanations, I let her believe that because it’s better that way”.

Esperanza loves playing and spending time with her family. She is also very concerned about her performance at school. During the time I spend with her she was all the time informing me about the good marks she got and how easy it was for her to learn new things.

2. Perceptions about their disease and treatment

As it was mentioned before, none of the children I did interviews with, knows that he/she has HIV. My underlying hypothesis was that although they are not fully informed about their health condition, as a result of their own experiences of being ill and medically treated, they probably would have their own perceptions regarding their condition. The questions that guided this exploration were aimed at finding out the definition, explanation, and description that children give of their health condition.

a) The disease as the current complaint:
All children said that they did not know exactly what kind of disease they have, when asked they talked about the current or more recent complaints they have. In that sense, we can argue that their perceptions are mostly based in their immediate experience.

For instance, Bianca talks about her recent trouble in her arm:

Carla: What is the disease you have?
Bianca: the disease I have is in my arm, because I was vaccinated at school, now I have my arm like this (she shows her arm inflamed) it hurts, it is growing a scab, I’m ill of my arm, my mum got angry because in the hospital they will tell her off.
Carla: But before, I mean the disease for what you take medicines… what is that?
Bianca: I don’t know, that is because I can get sick, I am not sick but I can get sick, that is what the medicines are for.

Marcelo was not affected by complaints the moment I did my fieldwork, for him his disease was a condition of being vulnerable, which seems to be linked to the idea of weakness:

Carla: what is the disease you have?
Marcelo: I’m not ill now
Carla: but the disease you take medication for…?
Marcelo: I don’t know how it is called, I don’t know its name
Carla: But do you call it someway?
Marcelo: Yes, let’s call it “purity”
Carla: and why do you call it this way?

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7 In Spanish there are not different words to differentiate disease from illness. I think that “disease” is a more accurate translation of the Spanish word “enfermedad” which I used in my interviews.
8 he says the word “purity” in English but with Spanish pronunciation.
Marcelo: I don’t know, I just like it.

For Marcelo the disease he has is a condition of being weak more than a permanent trouble:
Carla: but the disease you have, how does it work in your body?
Marcelo: I don’t know, it is just that I can get sick, I’m not sick now, but I can get sick, that is why I take medicines, because if I take medicines I won’t get sick”

For Esperanza, the disease she has is also a condition:
Carla: What is the disease you have?
Esperanza: Well I have a cold now, I’m coughing a lot, but I don’t care I want to keep on going to school anyway
Carla: But the disease you take medicines for… what is it?
Esperanza: it is that I get sick all the time, I get colds all the time, always.
Carla: why do you take medicines for?
Esperanza: because if I take medicines I don’t get sick, and I have to get in when it is raining

Jaime calls his disease hemorrhage, because that is the main complaint he suffers from:
Carla: what is the disease you have?
Jaime: well, the disease I have is called Hemorrhage
Carla: and what does it do?
Jaime: well, because I bleed a lot, through my nose and my mouth, a lot of blood comes out…. Once I was bleeding a lot, like this, and they had to take me to the hospital
Carla: and the medicines you take are for that?
Jaime: yes, because then the blood will stop coming out.

Jaime, seems to have a deeper understanding, from his own perspective, of what his disease is, not only because his model includes causation and healing, but also because he has some knowledge about the way hemorrhage must work. For instance, when we were working on the collage with Jaime, he suddenly saw a picture of a human body, in which the blood circulation system was shown. He cut the picture and ran to his grandma and said “mum, you see, in this picture there are all the veins, is this the place where the hemorrhage is?”.

b) Causation:

For all children the disease they have does not have a clear explanation. They do not know the cause of it or the way it works inside their bodies. The only thing they know is that it is there, for some of them since they were born and for others it appeared at certain stage of their life.

Carla: why do you have this disease?
Marcelo: I don’t know, I just have it, it is here, you see, inside (he points at his abdomen)
Carla: but, were you born with it or did you get it later on?
Marcelo: I was born with it

In the case of Jaime, he can tell the moment he started to get sick continuously:
Carla: why do you have this disease?

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9 See Chapter II on methodology.
Jaime: I don’t know, it happened once and then it started, when I was younger I was never ill but once I got sick, I was in the hospital and then I started to get sick, but before I wasn’t sick
Carla: so, did you get it when you were younger or were you born with it?
Jaime: no, I got it when I was like this (he shows with his hand that he was smaller)

c) The history of the disease:

For all children there was a moment they remember or they have been told they got very ill, that is the moment when the disease started. All of them were seriously affected by respiratory infections, one of the most common opportunistic complaints among children with HIV, and because of that, all were hospitalized. Although all of them were treated since they were babies, there is a moment in their life, when they were three or four years old, that they can remember their frequent visits to hospital or the medical treatment under which they are.

For some children, the disease actually started at some point of their life, and they can remember that moment (Jaime, Esperanza). They kept memories of that moment and mentioned them in the interviews. Others think that they were born with the disease, and they do not remember the difficulties they went through, although their caregivers have told them.

d) Medication:

Since all children involved in the research take antiretroviral treatment, the medication was an important point to explore. Compliance to antiretroviral therapy is considered one of the hardest part of being a child affected by HIV
(Batles et al. 2002). In addition, children whose health is more affected, such as Jaime and Bianca, take also medicines to prevent opportunistic diseases, which increases the number of pills to be taken everyday. Therefore, it was important to inquire about what children think of their treatment and how do they feel about it.

As mentioned before, they attribute a preventive function to the treatment, which will help them to avoid getting sick. As Marcelo says “the medicines are for not getting sick and for feeling good”. This explanation comes mainly from their caregivers who say this in order to make the child take the medicine. As Esperanza says: “my mum says that if take the pills I won’t get sick again”. Jaime is the only one who has a different explanation, since for him all his medication is aimed at stopping his hemorrhage. Although this explanation comes from himself, his grandmother reinforces such explanation because it helps her to avoid talking about HIV.

Children are not clear about the name, number and schedule of their treatment. They said that their caregivers are the ones who know about it. All mentioned that sometimes they forget to give them the treatment and therefore they then would not take it.

Carla: How many pills do you have to take?
Jaime: eight
Carla: how many times per day?
Jaime: ten Ziagen and eight Videx10
Carla: and do you take them everyday?

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10 Ziagen and Videx are antiretroviral medicines. Jaime was the only child who could mention the name of his treatment.
Jaime: no, because sometimes my mum forgets it and she has to give them to me later on, and my grandpa doesn’t care about my medicines

Marcelo also mentions problems with compliance:
Carla: When do you take medicines?
Marcelo: everyday in the morning when sun comes up, everyday, but sometimes medicines are missed because my mum forgets

Children have their own perception about the antiretroviral medication they take everyday. All of them say that they do not like them but they know they are good for their health. They were very concerned about the taste of the medicines and all have their classification for them, which includes their color, shape and taste:

Carla: do you like taking medicines?
Marcelo: no! They are terribly disgusting!
Carla: how are they?
Marcelo: one is entirely orange, another one is brown, another one is bitter and the pill they give me is nice, is sweet

Carla: do you like taking the medicines?
Jaime: I don’t like the bitter ones, but there is one with strawberry taste, and one with blackberry taste, those are nice.

Carla: do you like taking the medicines?
Bianca: No, I don’t like them
Carla: and how are they?
Bianca: they have a dark color, I like the vitamins because they have a nice shape, like little animals, now they are going to buy more for me

Carla: do you know the names of the medicines you take?
Esperanza: no, I don’t, I know only their colors, white, water-colored\(^{11}\), and blue.
Carla: and how are they? Are they nice or they aren’t?
Esperanza: the blue one is the bitterest, but the water-colored one is nice, and the white one is just a little bitter.

\(^{11}\) This is the literal translation of “color de agua” this term was used for Esperanza to mean “transparent”.

Chapter IV. Body and illness

For a research focused on children’s perceptions about HIV, it is interesting to look at their perceptions regarding their own body, in particular, how they understand their disease in their body. I intended to explore children’s body perceptions by asking them to draw themselves and then requesting them to identify in which part of their body his/her disease was and how it worked within it.

It is noteworthy that for all children it was difficult to make a body drawing, they said things like “I don’t know how to draw a human body”, “I’m not good at drawing bodies”, “I don’t know how to draw feet and hands”. As can be seen in the drawings, they were much more concerned about drawing environmental elements in the drawing rather than drawing themselves. They tried to add elements, which helped them show that they were portraying their own life, adding things like “this is myself in my garden”, “here is my house”, “you can see my little cousin with me”.

I asked the children to mention the most important parts of their body, and why they think so. As a general remark I suggest that their knowledge about body functioning is very fragmentary and based on their practical experience or on things they hear which were meaningful to them. For instance Jaime says:
Carla: Do you know what are the parts of your body, do you know how they are called?
Jaime: spleen, stomach, I don’t know what else
Carla: what are the most important parts of your body?
Jaime: the spleen, there is a child who got a surgery in his spleen, and there was nothing to do.
Carla: do you know what is it for?
J: yes, it is for keeping the body equilibrium so you don’t fall, and if you fall down you can break your bones.

For Marcelo, the most important part of the body is the heart:
Carla: what are the most important parts in your body?
Marcelo: the heart is very important, because the heart helps you do everything, you can play with other children, eat, get up, everything.

In children’s answers one can identify also elements that probably have been told by adults. For instance, Esperanza’s ideas are related to what we can call a “proper” behavior regarding the own body. Although it was not an explicit issue to explore in this research, I suspect that Esperanza’s view has to do with gender norms taught in Chilean society, which stress the girls’ obligation of protecting their own body from others:

Carla: what do you think are the most important parts of your body?
Esperanza: the little cunt that one is not allowed to touch, the head, the mouth and the eyes.
Carla: and why are they that important?
Esperanza: Because if someone puts his finger into your eye that can hurt a lot, and you can get an infection because maybe his hand was dirty, the mouth is important because the girl can eat grass and swallow something she has in her mouth.
Carla: and how about the head and the “little cunt”?
Esperanza: the head is important because the brain is there, because if you don’t have it you can even almost die, the little cunt because if somebody touches it with his dirty hands\textsuperscript{12} or if somebody beats her classmate just there that is wrong, because that is a part which is not allowed to touch.

\textbf{Where is your disease?}

As mentioned before, children understand their own illness in a limited way, which is restricted to the immediate experience they have had with it so far. This is also expressed in their drawings, where they explain their illness by pointing the parts where it is supposed to be, but without providing details about the way it really works in their body.

For Marcelo his disease is in his inside, but he does not know exactly in which part. When I asked him how it works he said “I don’t know, it is just there, that’s why I can get sick at any moment”.

For Esperanza, her disease is just in her lung:

Carla: in which part of your body is your disease?
Esperanza: you have to look at the backside of the paper (where her drawing is), so you can see my lung, that is where my problem was
Carla: where is the lung?
Esperanza: in my front and back
Carla: in which lung was your problem?
Esperanza: I don’t know (she laughs)
Carla: and in which other parts of your body we can see your disease?

\textsuperscript{12}In Spanish there is no distinction between his/her to refer property. I translated arbitrarily “his hands” (sus manos) using the generally used male form. I translated “her classmate” (su companera) in a female form, because, to my thinking, she is referring to her own classmates.
Esperanza: nothing else, I don’t have more diseases

Jaime has a further explanation about the way his disease acts in his body:

Carla: where is your disease in your drawing?
Jaime: here you can see where the blood is, and then the blood comes out, everything, and then it gets out from the body
Carla: Where is the blood?
Jaime: the blood is in the whole body but it comes out through the nose and the mouth, but in the hospital they stop it, I was in the hospital once because the hemorrhage was too serious.

All children think that they are going to recover from their disease. Although they do not know exactly how that is going to happen they have been told that things will be in that way. Esperanza thinks that she is healed of her lung trouble which in fact is true, but she knows she has other health complaints:

Carla: and when you grow up what is going to happen with your lung?
Esperanza: no, but it has been healed a bit, I mean it is healed already, now I’m just sick from other things
Carla: what things?
Esperanza: yesterday I had a stomach pain, fever, cough, ear pain and vomiting

For Bianca, her arm complaint is going to disappear because that is the way things are: “it is going to heal because it always happens, Gustavo (her cousin) had the same last year and now he is all right”.

For Jaime, he will be healed when his blood stops coming out and goes back to his body:
Carla: and when you grow up, what is going to happen with your hemorrhage?
Jaime: it is going to leave, because people say that sometimes the hemorrhages leaves completely
Carla: and where does the hemorrhage go?
Jaime: it goes back to the body, to the blood and to the arms.
Chapter V. Getting knowledge about HIV

In this part of the research, my underlying hypothesis was that although children are not fully informed about their health condition they probably would be able to find it out, at least partially, by themselves, which I linked to the concept of “lay knowledge”\textsuperscript{13}.

As I explained before, children have partial information regarding HIV. For instance, they are aware of their vulnerability, and all of them know that their antiretroviral treatment is aimed at preventing them from getting other diseases and infections. However, in contradiction with what I expected to find, children are not interested in getting more information about their health condition. Whenever I asked for more specifics, they just answered “I don’t know, ask my mum, she knows everything”. This kind of answer should not be surprising in a cultural environment where children are not supposed to be knowledgeable about “adult’s businesses” and are not allowed to make decisions regarding their own good. For children, in their cultural environment, it is ‘natural’ not to know about their disease, since their caregivers are the ones who must care, even when they do not always perform this role properly, as we saw in the case of compliance with treatment.

The fact that all the medical information is given to their caregivers is not disappointing for children, since they do not show interest in understanding their

\textsuperscript{13} Lay knowledge includes the explanations that children have for their illness, which are based or related to scientific knowledge about their disease. Although this concept has not been used for childhood research, I use this working definition based on Helman’s definitions of lay theories of illness causation.
disease. At this point, it is important to remark, that although this research was
done among children living in poverty, this form of protection applies in families
which still manage to keep children functioning at school and free from issues
such as child labor or street life. In these families, despite the economic and social
problems, children are still protected as such.

Esperanza provides a good example of how children see this lack of information:
Carla: and do doctors tell you something?
E: no, they just give me toys, they explain nothing to me, just to my mummy but I
don’t know what they say to her, but I have a book where everything is written
C: what is written on it?
E: the medicines
C: do you know the names of the medicines you take?
E: no, I don’t, I know only their colors

For Esperanza, as well as the other children, this lack of information is not
something to be questioned. They like the fact that they are treated as children,
that they are allowed to play and that there are toys available for them. They
remark on the fact that toys and games are given to them while waiting for their
check ups at the hospital or while getting the gamma globulin.

Even when they do not like the taste of their medicines they make an effort to take
them. The only resistance action they have sometimes is not to remind their mums
about the pills when they forget them. They accept what they are told: the medical
treatment is good for them and must be performed.

Carla: Tell me about the hospital, how many times do you go monthly?
Marcelo: one day each month
Carla: Do you like it?

Marcelo: yes, because it is good for me, to take my blood away and to feel good, there are old ladies as well, and Bianca\textsuperscript{14} is with me as well, a little friend, she goes first, I like it because it is nice and there are good things for me there, and that ‘s it, and I can play with toys!

Children do not have information about the whole picture of HIV, which seems to be too abstract for them. On the contrary, what they have are small pieces collected from their own experience of being ill and attending health care. This became clearer while role playing about the hospital. All children were able to describe accurately what happens in the hospital from the beginning until the end of their consult, they also know the procedures they must go trough in order to get their medicines and appointments. However they lack the technical vocabulary and a deeper understanding of what those things are for. For instance, Jaime explained the whole process to me in order to help me perform my role of a child’s mother, in the role playing:

“First, you have to wait outside, you can sit if you want, and then there is a long wait. There are many people here. And then the nurse comes and shouts your name, so it's your turn, you go inside with your child (…) then you have to explain things to me, because I am the doctor, if the child is OK, things like that, and then I check the temperature, the pressure, everything with this stuff\textsuperscript{15}, but the most important thing is the blood, I get blood with the syringe and puts it into these little bottles (…) because I have to examine the blood, to check if it is all right or there is something in there (…) and then I give you a prescription, you

\textsuperscript{14}The girl who is also involved in this research.

\textsuperscript{15}He means the doctor toys for the role playing.
don’t have to ask too much because I cannot tell you everything, you just take the prescription and go to the pharmacy to get the medicines”.

All children were able to provide descriptions like this, and all of them stressed the importance of blood examination. Esperanza for instance added that “the blood exam is not done there, they take the bottles to another room and in that room there is somebody who does it, so you don’t get the results immediately, you have to wait till the next time”.

The importance of details was also shown by Bianca, who before starting the role play asked me, “and where are your papers? You must carry a lot of papers where everything is written and then you pass those papers to the nurse”.

The way children are aware of the procedures regarding their visits to hospital, is also told by Amelia, Esperanza’s mother: “I remember the first time I went with Esperanza to the hospital, it was so funny, because her father used to take her, and it was the first time I did it, I didn’t know how to do it, and Esperanza told me, hey were are you going! It is this way, you know the way she is, she told me first we have to go to the counter, and then you pass this paper, and then we go this way, it was just so funny, I was laughing all the time, and Esperanza was saying hello to everyone, because everyone knows her in the hospital, and she knows everything we have to do there”.

Another important remark regarding children’s knowledge is the fact that through role-playing they showed information about HIV that they did not mention in the interviews. For instance, when I asked Marcelo, who was acting as doctor, what kind of disease my child had, he replied “it is called “pure blood”, then I asked what is about and he said “there is something wrong in his blood, he has
something in his blood”. The same happened with Jaime, who said: “he has a very serious disease, he is going to die”. When I asked him what kind of disease “the child” had, he answered “it is a very serious one, I cannot tell you”.

This kind of comments raise important questions regarding to what extent children are really aware of their disease. In my understanding, through the role playing children felt free to put in words things about which they have certain suspicions, although they are not fully informed. Because it was a game they could mention those things without making any statement regarding their own health condition. Because of the strong ethical boundaries this research had I did not break that protection, although I tried as much as possible to get more information.

Children seem to have knowledge about their disease on two levels, one is the level of their experience, at which they construct their own disease (as explained before), including causes, history and healing. This explanation can be more or less encouraged by caregivers, who acknowledge it a good strategy to avoid giving the child the true information. A second level, is what I call the level of suspicions, where children put things they have heard or they suspect, but about which they have no certainty, as long as they have not been officially told by their caregivers. This level of suspicions seems not to be disturbing for children, because it belongs to “the adult’s world”, which means that they will have access to that when they grow up. They are aware of the fact that adults have the full information about their health condition and they do not, but that is part of what is to be child in Chilean society. However, it is important to note, that this applies to a context where children are not seriously and immediately damaged by HIV. When they were affected by AIDS-related diseases they were much younger and they can hardly remember the problems they faced. Therefore, the question of what a child affected by AIDS think of it, remains unanswered.
Chapter VI. The hardness of living with HIV

On one of the first days of my fieldwork I was invited by Marcelo’s mother to go to the hospital with them, Marcelo would have his gamma globulin injection, and it would also be an opportunity to meet Bianca, another girl who would become involved in this research. When I arrived that day in the morning, Marcelo and her mother had been waiting for their turn for more than one hour. As every day in a public hospital, the waiting room was full of people, who were there for medical attention regarding the most different matters. Bianca and her grandmother were also there, and the two children’s caregivers were complaining about the long wait they had to do, “it is always same, we are asked to be here at eight but we are not called till eleven or twelve, I don’t know why they do this”. Marcelo’s mother told me that this time they came later because they knew that had to wait anyway. She added “it is winter, it is too cold to make Marcelo wake up and get out that early, I don’t want him to get sick, that is why I prefer coming later, I know they are going to get mad (the medical staff) but he is just a child, and it is cold”. While waiting, I was introduced to Bianca’s grandmother and, since the children were playing together far away enough, I had the opportunity to explain to her the details of the research. Like other children’s caregiver she was very concerned about the fact that Bianca does not know she has HIV and she did not want me to tell the girl that. Once I explained the methodology I intended to use she agreed with collaborating with the research.

Finally, the nurse appeared, Marcelo was asked to go in, we all stayed in the waiting room, after a while Bianca was asked as well. When they came back I asked Marcelo about the examination he went trough and he said “I have to get naked and they check everything, I don’t like it”. Later on, a female doctor
appeared, because of her attitude of “authority” I knew she was doctor, but I confirmed that impression anyway. From the door she shouted at Marcelo’s mother “why did you come that late? You know you have to be early, you are asked to be early! Marcelo’s mother replied: but we have to wait anyway… The doctor then said: “but you mess up the system we have, you have to be here so we know you are coming to the check up”. Then she added “today the children had a cardiology check up, but now it is too late, it is almost twelve and people are leaving upstairs, you know that everyone leaves at twelve, just go for the gamma globulin, they are waiting for you, they also want to leave but they are waiting for you”. Marcelo’s mother asked “but how about the cardiology exam? And the doctor replied “well, we will have to do it next time”.

After that, Marcelo’s mother started to complain with me “you see the way they are, they make us wait a long time always, they did not tell me about the cardiology exam, otherwise I would have come earlier this morning, they never tell us these things”. Then, we went upstairs, where the gamma globulin procedure is performed. Because I was carrying the gamma globulin boxes I was able to get in without any questions from the medical staff, probably they assumed I was a relative of one of the children.

As soon as the children got in, they started to choose their armchair “that’s mine”, “I prefer this one”. For the gamma globulin injection they are requested to stay sited several hours with one of their arms, where the needle is put, immobilized. Once they picked up their places, the procedure started. When the nurse was about to put the needle in Marcelo’s wrist, he told me “tía, I am courageous, it hurts but I don’t cry”. However he could not help some tears coming to his eyes. The same happened to Bianca, although she felt more free to show how painful it was for her.
The quantity of gamma globulin to be injected is calculated according to the child’s weight, children know that and Marcelo told me “Bianca always finishes first, because she is lighter, I need more because I am heavier, you see the bottle, I have twice more than she”. The bottle with gamma globulin is connected to a machine, which regulates its quantity before getting into the child’s body. A nurse told me that this is a new safer system called “micro dripping”. However, Bianca’s grandmother told me that they do not like it because it takes longer, she also says “that machine does not let the child move, its alarm sounds whenever the child moves a bit”.

Marcelo described to me the procedure in this way “I go there in the morning, and then one has to wait till the bottle gets empty, and then I can go home”. This is a very accurate description, since the following hours were a long wait until the bottles were empty. The children tried to play with the toys available in the room, however it was a difficult enterprise, since whenever they move too much the process was interrupted, the alarm started to sound and a nurse came to accommodate the needle again. This happened to both children many times. Bianca was the most disappointed because she wanted to paint some story books, which was very difficult because of the needle in her left wrist.

Since the procedure takes that long, children have lunch in there meantime. They also have to go to the toilet many times. Marcelo told me that the nurses get mad when they request to remove the needle to go to the toilet, and when their mothers are not present, they are told off for that.

Marcelo’s mother and Bianca’s grandmother were talking in the mean time. However, they stayed very close to their children just in case they need
something. I had a difficult time trying to play with both children at the same time, because they could not move from their armchairs I had to pass the toys from one to another. Also, I noticed that children became more demanding in this situation, and all the adults around, seem to be more patient to them. For instance, Marcelo who is usually very sweet to his mother, started to yell at her “I am hungry, I’m hungry, I want to have lunch right now! Bring me something!”

When it was about three o’clock in the afternoon I had to leave. The children and their mothers were watching television. I asked Marcelo later on about that day and he said “We stayed there till five, at least I didn’t have to go to school”.

The difficulties children with HIV face

In this chapter I intend to describe some of the difficulties children living with HIV face in their everyday life, even when they do not know the disease they are affected by. Undoubtedly, the first one has to do with their family environment. In most of the cases some of their immediate relatives do not know that the children live with HIV. Their HIV status is not disclosed to them because the children’s caregivers are afraid that children can be discriminated or that the situation will not be understood and accepted by others. This puts children in a vulnerable situation because they live in the middle of a social crisis, which can explode at any moment.

Generally speaking, caregivers think that children are vulnerable, and they must be protected at all cost. Children must be protected from a hostile environment, where the threat of discrimination is always present. They also must be protected from the damage of the disease itself, which include its consequences in the
child’s body as well as the consequences it could have in their emotions. No disclosure is seen as a strategy to protect children from such damage. However, this strategy does not succeed in the cases when children in fact face discrimination, because it leaves them without any explanation or tool to defend themselves. That is very clear in the case of Jaime, who in reality is discriminated at school and in his neighborhood, but is unable to deal with it. The contradiction between feelings and facts, regarding to this issue is very much expressed in his case: when I asked his grandmother about disclosure she said “No, I cannot tell Jaimito, because he is a child, he can tell others and then he will be discriminated”. However, a few days later she told me “you know, here in the neighborhood people know what Jaimito has. The other day a little girl told another one, in front of Jaimito “don’t approach him because his virus has become activated’, you see, they know something, probably her parents know because those are not child’s words, those are adult’s words”. When I asked her more details she said “Jaimito told me but I did not tell him anything, I just told him not play with those children again”.

A second issue regarding the family environment is the fact that children are not actively involved in their treatment, which has negative consequences for their compliance. All children mentioned that sometimes their caregiver forgets the pills. Since they do not like taking treatment they take advantage of that to avoid it at least once. In addition, they are not clear about the number, type and schedule of the pills to be taken. Although the cultural issue of children’s dependency to adults is not going to be discussed in depth in this research, I want to highlight that, in my understanding, children’s compliance would be better if they were more involved in the process of taking their treatment. This does not necessarily mean total disclosure to children, but to explain to them how the medicines work, the schedule and the importance of compliance.
In the process of doing this research I found out that since children’s voices are neglected some problems that now occur could be avoided. For instance, the gamma globulin injection would be easier if the toys selected for the room were chosen acknowledging that children cannot move or can use only one hand. In addition, the schedule imposed by the health care service does not take into consideration children’s needs. Special attention should be given to the side effects that the antiretroviral treatment has for children, from their own perspective, which will contribute to improve its quality.

The issue of vaccination, which was mentioned in Bianca’s case, deserves a special remark. This situation was not exceptional but common among children with HIV in Chile. Despite the recommendation not to vaccine children with HIV, they are vaccinated at school because their staff is not full informed/aware of the child’s situation and of the consequences the vaccine may have for an immune depressed child. In this case, the school staff made prevail the national policy of vaccinating every child without paying attention to the exception. Bianca’s case shows how powerless a child with HIV can be in this situation: although she knew she should not be vaccinated she was not able to explain that and avoid it.

As can be seen in the case of Marcelo, it is important to note that HIV is not everything for children. Like other children in poverty they face other problems such as poor living conditions and family violence. Those issues must be addressed in the interventions with children living with HIV.

Finally, an issue that emerges in all the cases studied is the caregivers’ concern about their children’s future. This was expressed in questions regarding the best way to rear them. Sometimes caregivers spoke about children’s future, and
expressed their worry about children becoming adolescents. For them, this is the very moment when they will have to talk to their children and explain them about HIV, in order to avoid transmission and re-infection. Other times, they showed deeper fears about their possible death. For instance, Irene, Jaime’s grandmother told me once “You know, today a person went to the our group office, and she said “why do you care that much about your grandson, he is going to die anyway”. What do you think? I know he is going to die, I am aware of it, but I just don’t want to think about it, I don’t want to think that way”. This is an issue that must be addressed when working with children’s caregivers.
VII. DISCUSSION

This research was mainly framed by what Hardman calls anthropology of children, that is, an anthropology concerned with children's beliefs, values, interpretations of their viewpoints and the meanings they attribute to their world (Hardman, 1973: 86).

Although the first attempts to understand the world of children from an anthropological point of view were performed in the first half of the twentieth century by Margaret Mead, this field has not been fully developed since then. Among the reasons that explain why children have been neglected in anthropological research is the fact that they have not been considered qualified informants of their society, since it has been thought that their membership in society has not been fully accomplished until they become adults. Therefore, they are not considered social actors themselves, but a sort of "projection" of the adult world. Children have been viewed "as continuously assimilating, learning and responding to the adult, having little autonomy, contributing nothing to social values or behavior except the latent outpourings of earlier acquired experiences" (Hardman, 1973: 87).

Children living with HIV have been specially considered passive actors in relation to their disease. Because of their health condition and their character of “innocent victims” (Farmer, 1995) children have been kept ignorant of their own health condition and have been considered incapable to understand and cope with it. On the contrary, this research had as starting point, the recognition that children have agency as subjects and they must be understood as active participants in constructing information about their illness and coping with it.
Following the methodology of case study, I intended to account for the whole context in which the life of children living with HIV occurs, which meant, from an external perspective, to pay attention to their family life, performance at school and health care issues. As it was described in chapter V, even though HIV positive children are kept ignorant of their health condition, they face several problems, such as violence, discrimination and lack of access to proper health care. Their caregiver’s fears and assumptions about disclosure shape children’s life, since they are exposed to several problems without being provided with proper tools to cope with them. One example of this is the way children are vaccinated at school without taking into account their own opinion and will.

The first research question had to do with children’s perceptions regarding their every day life and the impact HIV had on it. As it was described in the first and fifth chapters, the children’s everyday life is similar to other children’s, most of their concerns and routines are the same: playing, going to school, having a good relation with their loved ones. However, HIV does have an impact on their life: vulnerable health condition, health care requirements and specially the exigencies of the antiretroviral treatment.

**Children’s perceptions about their illness and treatment**

The second question had to do with children’s perceptions about their health condition and antiretroviral treatment. For that purpose, I used the theoretical distinction between disease, as a physical state and illness, which involves the social and cultural aspects of being ill. As Helman has defined it, illness “is the subjective response of an individual and those around him to his being un-well; particularly how he and they interpret the origin and significance of this event,
how it affects his behavior, and his relationship with other people, and the various steps he takes to remedy the situation. It not only includes his experience of ill health, but also the meaning he gives to that experience” (Helman, 2000: 83).

My underlying hypothesis was that although they are not fully informed about their health condition, as a result of their own experiences of being ill and medically treated, they probably would have their own perceptions regarding their condition. The questions that guided this exploration were aimed at finding out the definition, explanation, and description that children give about it.

All children said that they did not know exactly what kind of disease they have, when asked they talked about the current or more recent complaints they have. In that sense, I argue that their perceptions are mostly based in their immediate experience. However, they are also aware of their condition of vulnerability, that is, that they can get sick easily. This is related to the function that the antiretroviral treatment has for most of them.

One exception is the case of Jaime, who has came up with his own explanatory model, based on his own experience and some pieces of knowledge he has put together. According to him, his affected by hemorrhage, and his treatment is aimed at healing him from that.

The causes of their illness are unknown for all the children involved in this research. The only thing they could distinguish is whether they were born with the disease or it started later on. This distinction is based on their personal memories regarding their illness episodes and on what they have been told by their caregivers.
Regarding the antiretroviral treatment, they have their own classification based on the characteristic of the medicines, in particular, their flavor, color and shape. None of them knows exactly their schedule and quantity of medicines to be taken. Therefore, they depended completely on their caregivers to comply with their treatment. As mentioned before, most of them attribute a preventive role to the treatment, which is related to their vulnerable health condition.

**Children’s body perceptions**

As many social scientists have pointed out in the last years (Foucault, 1995; Freund and Fisher, 1982), the body is not a biological reality but rather a social cultural construction. The physical experience of the body conforms and sustains a particular view of society. What has been called “social body” constraints the way in which the physical body has been perceived.

Children's bodies have been peculiarly "absent" in much of the adult-centered anthropological discussion of the body and culture to date. However, the development of the studies on health and children has led necessarily to the exploration of what children think of their bodies in relation to illness and health. This was one the objectives of this research. Like other researches in this field, I intended to explore children’s perceptions by asking them to draw and comment on their own body. However, I collected more information about their perceptions in this matter during the whole fieldwork.

Children were much more concerned about drawing environmental elements in the drawing rather than portraying themselves. They tried to add elements that helped them show that they were portraying their own life. In that sense, children
accounted for a holistic view, in which they are integrated to their environment, which opposes to the western adult-centered view of the body as an abstract entity divided from the self.

In addition, I asked the children to mention the most important parts of their body, and why they think so. I suggest that their knowledge about body biological functioning is very fragmentary and based on their practical experience or on things they hear which were meaningful to them. This has to do with what Christensen (2000: 56) has called “a *bricolage*” of experiences, information and biological knowledge. However, through this kind of questions children were forced to make use of a scientific adult language with which they are not familiar. In this language, their views can only be fragmented, since they are moved away from their own view in which their direct experiences and perceptions are central.

As mentioned before, children understand their own illness in a limited way, which is restricted to the immediate experience they have had with it so far. This is also expressed in their drawings, where they explain their illness by pointing the parts where it is supposed to be, but without providing details about the way it works in their body. However, Jaime was able to further explain the way his “hemorrhage” works in his body, as well as the way his healing process is going to happen.

Pia Christensen (2000) has compared the way children’s bodies are perceived by adults – as essentially vulnerable- and the way children’s talk about their own experiences of being ill or injured. She suggested that there is a distinction between an “exterior perception”, related to how adults judge children’s health and an interior perception which is related to children’s views, in particular, to the way they relate illness to personal experiences and feelings, as well as to their
own actions and others.

I suggest that the exterior / interior distinction that Christensen points out, does not fully apply to children living with HIV, since their bodies have been very medicalized and their views have been colored by their experience of being medically treated.

According to Helman (2000), medicalization is “the way in which the jurisdiction of modern medicine has expanded and now encompasses many problems that formerly were not defined as medical entities” (Gabe and Calnan, 1989 quoted by Helman, 2000). In the case of HIV positive children, medicalization has to do, on one hand, with the fact that their complexity as human beings has been reduced to their serological status, obliterating other issues that may affect them. On another hand, like in the case of other social groups seriously affected by a disease, medicine can be seen as an agent of social control, which makes them dependant on the medical profession and its links with the pharmaceutical industry. As Esperanza’s mother showed, the way children are medically treated does not necessarily lead to children’s best benefits. The way they are over-treated can involve harm for them and it can lead to children’s rejection of their medication.

Although children stress their own feelings about their disease, based on their experience, they stress at the same time external views such as the importance of medical exams and treatment. For instance, in the role-playing, all children mentioned how important is the blood exam, to check how things are going on with the child’s health. In addition, they did not put into the scene children’s feelings about being ill but rather the fact that mothers explain to the doctor how the child is doing.
The strengthen of the medical experiences children go through, can result in an internalization of these contents, since they become part of what is to be a child living with HIV. One example of this is the way they perceive themselves as vulnerable, which involves the recognition of a characteristic that makes them different from other children.

In relation to adults’ exterior perceptions, as other children, HIV positive children are told by their caregivers to avoid environmental threats, which in their case, are very much related to the threat of opportunistic diseases. One example of this is the way in which Esperanza describes a “proper” behavior regarding the protection of the own body from others and from environmental dangers. However, in the case of HIV positive children the threats to their health come from their own inside, that is, from their own vulnerability. Children are aware of that, but as long as there are no visible complaints, this is a potential situation rather than an immediate trouble, which can be prevented by taking their antiretroviral treatment.

In the chapter on knowledge about HIV, I described how accurate is the knowledge that the children have about the medical procedures they go through, although they lack explanations about what those things are for. I suggest that since children do not have complete information about HIV, what they know about their vulnerability seems to be too abstract for them. What they have are small pieces collected from their own experience of attending health care. Apart from the specific complaints they have faced, which have been taken for defining their illness in itself, their condition of vulnerability is difficult to describe. Since it cannot be seen immediately can only be measured by medical exams and check ups. In that sense, the importance children attribute to the blood and the blood exam can be linked to the fact that blood is one of the most concrete expressions
they have of their own disease.

**Getting Knowledge about HIV**

The last specific objective of this research was to find out how children get knowledge and information about their illness. In this part of the research, my underlying hypothesis was that although children are not fully informed about their health condition they probably would be able to find it out, at least partially, by themselves.

As I explained before, children have partial information regarding HIV. For instance, they are aware of their vulnerability, and all of them know what their antiretroviral treatment is aimed at. However, in contradiction with what I expected to find, children seem not to be interested in getting more information about their health condition.

The fact that all the medical information is given to their caregivers is not disappointing for children, since they do not show interest in understanding their disease, which is considered and adult’s business. In that sense, their caregivers succeed in keeping children away from the truth of their medical condition.

However, through role playing children showed information about the seriousness of their disease that they did not mention in the interviews. This raises important questions regarding to what extent children are really aware of their disease. I argue that through the role-playing children felt free to put in words things about which they have certain suspicions, although they are not fully informed. Because it was a game, they could mention those things without making any statement regarding their own health condition.
Children seem to have knowledge about their disease at two levels, one is the level of their experience, at which they construct their own disease (as explained before), including causes, history and healing. This explanation can be more or less encouraged by their caregivers, who acknowledge it a good strategy to avoid giving the child the true information. A second level is what I call the level of suspicions, where children put things they have heard or they suspect, but about which they have no certainty. This level of suspicions seems not to be disturbing for children, because it belongs to “the adult’s world”, which means that they will have access to that when they grow up. They are aware of the fact that adults have the full information about their health condition and they do not, but that is part of what is to be child in Chilean society. However, this applies to a context where children are not seriously and immediately damaged by HIV.

Bluebond-Langer (1978) in her research among children affected by leukemia, proves how contrary to what common sense says, children who face that disease are capable to get medical knowledge about their condition. Bluebond-Langer's research was performed in a context where most of children’ parents were hesitant to talk openly with their offspring about the disease. However, the author found out that children from their own experience were able to realize by themselves the different stages of their disease, which went from a more optimistic view about "getting better“ to the realization of the imminence of dying. Bluebond-Langer was able to get an insight in the way children classify their environment, medical hierarchy and different categories of adults, as well as their strategies to gain more information about their condition.

Since Bluebond-Langer’s research was very inspiring for my own research proposal, I expected to arrive to similar findings. What seems to be similar in both researches is the parent’s hesitation to talk openly about the disease and their fears
about children’s reactions to the truth. As Bluebond-Langer has pointed out, this may have to do with the fact that such a destructive disease (like cancer or HIV) challenges the protective role and that parents are supposed to fulfill and, insofar as it involves the possibility of the child’s death, disorganizes the way social life is ordered in terms of adult’s and children’s paths. In that sense, it challenges the parent’s social identity as well. In the case of HIV, the parent’s fears are also related to their guilt for transmitting the disease.

However, differences with Bluebond-Langer’s findings must be acknowledged. First, contrary to my expectations, children did not seem interested in finding out more information about their disease. This can be related to the fact that children with HIV are not permanently hospitalized and do not share their concerns with other children affected by HIV. In addition, they are not immediate and seriously damaged by HIV as children with leukemia were. In that sense, they do not fall in what Estroff calls “I am illness”, that is, in a condition that redefines the person in socially significant ways (Estroff, 1993; quoted by Reis, 2001). In the case of children with HIV, as long as they are not seriously affected and they are not aware of their condition, there is no “fusion of diagnosis with identity” (Reis; 2001: 356).

Based on the existing literature about children chronically ill, I assumed that children should be able to get knowledge about their serological status, even without being officially told. This assumption led me to think that communication between HIV positive children and their caregivers could be improved if the latter get to know what children really think about their status.

I do think that the girls I did my research with, who are also younger than the boys, were not aware at all of their disease and its consequences. Nevertheless, I
believe that in the case of boys, their level of suspicions about HIV was higher. For instance, at some point they refused to keep on talking about their disease. In addition, in the projective activity of a letter from an HIV positive child\textsuperscript{16} they related it with feeling of sadness and loneliness. Due to practical and ethical constraints\textsuperscript{17}, I was not able to get a deeper insight in that. However, I think they are aware of the taboo character their illness have and they may not want to openly raise questions about that.

In sum, I must admit that the question of to what extent children with HIV are aware of their health condition remains unanswered for me, and it is worth of a deeper research.

**The issue of disclosure**

Childhood is constituted as an essentially vulnerable stage in the western discourse, as Christensen has highlighted, vulnerability acts “almost as a master of identity for children” (Christensen, 2000: 40). This view has as counterpart the role adults must play in relation to children: children are considered vulnerable beings who can only survive and develop themselves if nurtured and protected by adults.

Children’s capabilities are constrained because of a hierarchical view, which sees them as vulnerable and unable to understand and take care of their own well being. Christensen (1998) has suggested that the hierarchical relationships of biomedicine are reproduced within the family, which places children's status as

\textsuperscript{16} See Chapter II on methodology.

\textsuperscript{17} By practical constraints, I mean the limited time for fieldwork, which does not allowed a deeper insight. The ethical constraints will be discussed at the end of the conclusions.
dependent and constrained, since children are often seen as inferior to adults in general and to health professionals in particular.

The concept of medical power (Helman, 2000: 114) highlights how medicine has been used as an agent of social control, in order to reproduce a specific social order and control deviant behavior. The position children have in the social hierarchy is reinforced by their powerlessness in their own health care. Social power in the field of health has been defined as a factor that allows people to obtain high quality, readily available medical care, and the ability to live, in a qualitative sense, a healthy long life. It affects the degree to which people can exercise control of their own care (Freund and Fisher, 1982: 10).

The issue of vulnerability is critical for the situation of children living with HIV. The main argument to support non-disclosure to children has been their incapability to understand and cope with their own situation. On behalf of their protection and own good, children have been kept away from decisions regarding their own medical treatment. As mentioned before, the decision for not disclosing HIV to children has to do not only with children’s well being but also with their caregivers’ own fears of talking about HIV.

According to Walker (2002) there is a constant tension between two different perspectives of children’s rights: the first one is what she calls “child Salvationists’ who argue for protecting children even at times against their will, and the second one is the “kiddie libbers’ , who argue for children’s right to self-determination, even when it may be against their best interests to do so. Children have the human right to be nurtured and protected from any harm, but at the same time their capacity to rule their own life must be encouraged. Undoubtedly, it is difficult to find equilibrium between both perspectives.
This controversy between Salvationism and protection has also colored the debate about whether children with HIV should be informed or not of their serological status, as well as which degree of information is good for them.

It is important to remark that this has been done in settings where there is a certain degree of child protection. In the case of more impoverished settings, like in most of Africa and other developing countries, where children are violently confronted with HIV and AIDS and forced to cope with it, not only as individuals but also at a family level, the discussion about “disclosure” seems to be inappropriate.

Researches done in North America (Batles and Lori, 2002) have come to the conclusion that social support and open communication about children’s diagnosis are essential, particularly when children become adolescents, as decisions about relationships, sexual activity, drug use, and plans for future need to be discussed. This is consistent with the caregiver’s concern about their children’s coming age, which was raised in this research. They also highlight the need to prepare children and adolescents for independent living with a serious medical condition. However, in the case of Chilean caregivers, since they do not have clear expectations about their children’s future, that has not been established as a goal. In addition, children’s dependency is reinforced and their own caring and protective attitude is considered a sign of love as well as good in itself for children.

In the North American setting, disclosure has been related to increased social support, social self-competence and decreased problem behavior. However, the

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18 Disclosure has been divided into three different levels: the immediate one has to do with the affected and his/her closer ones. The second level includes a wider environment such as school and neighbors. The third one includes disclosure through the media. The latter is considered by several researches as having a negative impact on children.
issue of discrimination remains being a serious issue in Chilean society, and it prevents caregivers from disclosing HIV to children.

In practice, many recommendations have been developed in order to promote disclosure to children with HIV and their involvement in their own treatment. Several researches point out the need to develop processes of disclosure, rather than telling “the whole truth at once”. One example of this, it is what has been called partial disclosure, in which many aspects of the disease can be told to the child but avoiding the stigmatization attached to HIV. Those recommendations also stress the need of health care integral support to council and follow up disclosure processes.

Walker (2002) suggests five steps to be taken to encourage children’s involvement in decision-making:

1) receiving medical information that is developmentally appropriate
2) having medical questions answered satisfactorily
3) expressing opinions relevant to the medical decisions to be made and the treatment processes to be employed
4) having those opinions heard and respected by adults
5) participating as completely as possible considering the child’s developmental process.

A culturally appropriate program for disclosure and support of children living with HIV must be developed in Chile, getting benefits from the experience of other countries, but taking into account cultural specificities, such as caregivers’ fears and beliefs, and specially the perceptions children themselves have about their situation. In that sense, the question about what is “developmentally appropriate” for children in Chile should be answered according to a cultural
perspective. The concepts of participation, expressing opinions and having them respected, should be also culturally defined. The role that children attribute to their caregivers and the importance of protection should not be neglected.

Finally, a disclosure intervention program cannot be developed without addressing the issue of discrimination against people living with HIV, particularly children. Because of the conceptualization of children as “innocent victims” of AIDS, scholars and policy makers tend to think that children are not discriminated. Nevertheless, the perspective is different when one looks closely to what happens in micro social settings such as school or neighborhood. The fears and wrong beliefs about the transmission of the virus, in particular to other children while playing, is a factor that increases discrimination against seropositive children. Campaigns to fight discrimination should go along with any intervention regarding disclosure of HIV.
VIII. CONCLUSIONS

This research was aimed at finding out how children construct, from their own point of view, the experience of living with HIV, which includes their perceptions, beliefs and lay knowledge.

I argue that their perceptions are mostly based in their immediate experience. However, they are also aware of their condition of vulnerability, that is, that they can get sick easily. The causes of their illness are unknown for all the children involved in this research.

Regarding the antiretroviral treatment, most of them attribute a preventive role to it, which is related to their vulnerable health condition. They have their own classification based on the characteristic of the medicines, in particular, their flavor, color and shape. Since none of them knows exactly the schedule and quantity of medicines to be taken, they depended completely on their caregivers to comply with their treatment.

In relation to the children’s body perceptions, they were much more concerned about drawing environmental elements rather than portraying themselves. They accounted for a holistic view, in which they are integrated to their environment, which opposes to the western adult-centered view of the body as an abstract entity divided from the self. However, in relation to how children perceive their disease in their body, external views, such as the importance of medical exams and treatment, seem to be more important. I argue that this has to do with the way their bodies have been medicalized. The experiences of being medically treated seem to be internalized by children, being part of what is to be a child living with HIV.
In contradiction with what I expected to find, children seem not to be interested in getting more information about their health condition. They are aware of the fact that adults have the full information about their health condition and they do not, but that is part of what is to be child in Chilean society. Nevertheless, some children have suspicions about HIV or seem to know more about it.

One of the underlying assumptions of this research was that children should be able to find out by themselves their serological status, as well as other information regarding their health condition. This assumption led me to think that communication between HIV positive children and their caregivers could be improved if the latter knew what children think about their status. Nevertheless, what I found was that the children have come up with their own explanations about their health condition, and that they seem not to be interested in finding out more information. In that sense, they caregivers succeed in keep them away from the truth.

However, even though HIV positive children are kept ignorant of their health condition, they face several problems, such as violence, discrimination and lack of access to proper health care. In that scenario, it seems appropriate to recommend disclosure processes for those children.

Disclosure does not necessarily mean that children have to be fully aware of the disease and take the whole responsibility of their own care. Rather, it is a process of gradual information in which their needs are considered and the necessary support for them and their families is provided. Disclosure recommendations should be developed taking into account cultural characteristics of Chilean society, in particular, taking into consideration what is to be child in that setting.
The issue of discrimination cannot be neglected and should be addressed as well.

More research needs to be done, in order to further account for the situation of children living with HIV. Recommendations for interventions on disclosure should also be supported by social research.

**Ethical remarks**

The environment of secrecy and social discrimination in which this research was a factor that affected this research process and its results. In addition, the fact that the informants themselves were not informed about their own health condition was an issue that was not overcome in the course of this research. In practice, during my fieldwork I had to deal constantly with this secrecy and fear for discrimination, even, among the family groups.

I have not doubts about the way the results of this research can be used for the benefit of children living with HIV and their families. However, I still wonder to what extent is ethical to involve children in research without informing them completely about the reasons for that. I hope this research will be a first step to open the discussion among children’s family, to look for ways to deal with HIV. As it is stated in the title of this research, I was looking for children’s voices about their own condition. Although I did not fully accomplished such a huge goal, I hope this case study approach will encourage more researches and interventions aimed at letting children living with HIV speak out.


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