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“Don’t you think it’s better to trust in God?”
Perspective of parents abandoning therapy for their child with cancer

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# Contents

Summary ............................................................................................................................................. 4  
Resumen............................................................................................................................................. 5  
Chapter One: Introduction .................................................................................................................. 6  
Statement of the problem .................................................................................................................. 7  
Literature review .............................................................................................................................. 8  
  Qualitative studies: approximation of abandonment using the concept of non-compliance.... 10  
    Non-compliance as a value-laden term ....................................................................................... 10  
    Patients as active participants during treatment ................................................................ 11  
    The social context in relation to prescribed treatment ......................................................... 12  
    Religiosity and CAM ............................................................................................................... 14  
Research question and sub-questions ............................................................................................ 15  
Chapter Two: Researching pediatric cancer patients in El Salvador .............................................. 16  
Contacting the cases ....................................................................................................................... 17  
Getting to the places ....................................................................................................................... 18  
The cases ........................................................................................................................................... 19  
Chapter Three: Revealing what is involved in living with cancer treatment .................................... 26  
Interpreting the benefit of treatment: understanding of effects .................................................... 26  
Poverty and sacrifice ....................................................................................................................... 31  
Perceptions about the institution ..................................................................................................... 34  
When emotional suffering is unbearable ....................................................................................... 39  
Religion as the main reliever, God as the main doctor ................................................................. 42  
    Immediate results and no side effects ....................................................................................... 45  
    Community support ............................................................................................................... 47
Summary

Each year 13% of the children diagnosed with cancer in El Salvador abandon the treatment prematurely and eventually die. Although there is growing interest in understanding this phenomenon from biomedical professionals, a comprehensive approach to study and analyze the patients’ family’s viewpoint is still absent. Quantifiable factors related to social conditions and patient-doctor relationships have been reported to be associated with abandonment. However, the understanding of how these factors have such influence or how parents perceive their child’s cancer and treatment has not been explored. With this study I intend to contribute to a better understanding of abandonment of treatment from the perspective of the parents of the patients.

By interviewing six parents who abandoned treatment, five interrelated topics regarding sickness and life circumstances were identified in their accounts when explaining the course of their child's illness and treatment. Since these topics are not independent from each other, how they can be linked to abandonment can’t be explained by correlating them in the same way as standardized factors, because each of these topics has a unique significance for each family, depending on the relationship among other topics and the specific life circumstances. Poverty, trust, religious convictions, emotions and effects of treatment played a role in each parent's explanation of their actions, but since each of these topics didn’t have the same status, the role they played was different; therefore, the interaction of these topics, not the topic per se, is what represents the explanatory frameworks that people used in different ways to explain stopping the child’s treatment. The implications for researching abandonment and non-adherence to treatment are that qualitative research is essential for explaining the processes and relationships that take place when such qualitative aspects are involved.
Resumen

Cada año el 13% de los niños diagnosticados con cáncer en El Salvador abandona el tratamiento prematuramente y fallece. Aunque existe un creciente interés por comprender este fenómeno por parte de los profesionales en el área biomédica, aun no se cuenta con un enfoque amplio que estudie y analice el punto de vista de las familias de estos pacientes. Se han reportado factores cuantificables relacionados con las condiciones sociales y la relación médico-paciente que se asocian con el abandono. Sin embargo, cómo estos factores influyen o cómo los padres perciben el cáncer de su hijo y el tratamiento no ha sido explorado. Con este estudio pretendo contribuir a una mejor comprensión del abandono de tratamiento desde la perspectiva de los padres de los pacientes. A través de entrevistas a seis padres que abandonaron el tratamiento, y sus explicaciones sobre el curso de la enfermedad de sus hijos y el tratamiento, se identificaron cinco aspectos interconectados entre sí referidos a la enfermedad y a sus circunstancias vida. Por el hecho de no ser independientes unos de otros, la asociación de estos aspectos con el abandono no puede ser explicada por una correlación a manera de factores estandarizados, ya que, cada uno de estos aspectos tiene un significado único para cada familia, dependiendo de la relación o presencia de otros aspectos y sus circunstancias específicas de vida. La pobreza, la confianza, las convicciones religiosas, las emociones y los efectos del tratamiento juegan un papel en la explicación de cada padre entrevistado sobre sus acciones, pero como cada uno de estos aspectos no tienen el mismo estatus, el papel que desempeñan es diferente en cada caso. Por ello, no son los aspectos en sí mismos sino la interacción entre ellos lo que constituye los marcos explicativos que las personas utilizan para razonar sobre el abandono del tratamiento del niño. Las implicaciones para la investigación del abandono y la falta de adherencia al tratamiento son que la investigación cualitativa es esencial para explicar los procesos y relaciones que tienen lugar cuando aspectos cualitativos tan complejos están involucrados.
Chapter One: Introduction

Things were pretty optimistic when I joined the team of the National Pediatric Cancer Program of El Salvador 15 years ago. We had modern treatment protocols, enough funding to have good quality chemotherapy and the basic technology for providing it. Plus, we were giving all the medical attention and treatment to the families for free. Therefore, for every child with cancer in El Salvador, no matter what his or her socioeconomic level was, we were their hope for a cure. Or weren’t we?

It was quite shocking to find out that a pretty high number of parents (around 22% at that time) used to stop their child’s treatment without any notice; many of them returning to the hospital after some weeks or months when possibilities for a cure had vanished. When talking to those who returned, most of the time their reasons explaining their conduct sounded more or less illogical to me. What could be more important than fighting, no matter what, against your child’s sickness and sticking to the treatment that offered his or her only chance of survival? Easy question, easy answer… or not?

After 15 years of struggling with this topic, I reached this point knowing only that the answer is definitely not easy, the question is probably the wrong question to be asking, and that the question departs from presumed truths that might not be true for all life circumstances.

While trying to understand these parents behavior, I learned not to judge them, I learned to listen; I could just guess that there must have been something they knew that I was unable to see sitting in that chair, in that office, with my empathetic but isolated view. Despite all my efforts, I still was too distant to them. Not knowing, not understanding was slapping me in the face, each time one of these children died, while we were just there, with open arms offering exactly what “we knew” they needed.

Now I know that there is a vast quantity of people who stop going to therapy for cancer or other diseases like tuberculosis or malaria in the world, and the implications of having a better understanding of that could reach far beyond my chair in my office in El Salvador.

Maybe the distance between me and these parents there in the hospital will change a bit after doing this study; but it will never be solved. The good thing about that is that then, we will always need to keep in touch with our patients if we want them to teach us about life, death and daily struggles regarding both.
Statement of the problem

Located in Central America, El Salvador is a small country of 21,040 square kilometers and 5,744,000 inhabitants (Ministerio de Economia 2008). Thirty percent of the population lives below the poverty line, which means that they do not have enough resources to meet their basic elementary needs (CIA 2010) Religious filiations are mainly Catholic, 57% and Protestant 21% (CIA 2010) As in most developing countries, the main health problems of childhood are related to respiratory and gastrointestinal infectious diseases (MSPAS 2010). Cancer treatment for children is not a priority for the scarce governmental resources in El Salvador, where approximately 180 children are diagnosed with cancer annually (Fundacion 2003). Contemporary treatment is provided in the only national pediatric hospital located in San Salvador, the capital city, where international and local efforts toward improving standards of care lead to an increase of 4-year survival rates from less than 5% before 1993 to 65% by 19991 (Bonilla et al. 2000). As a psychologist, I’ve been managing the psycho-social aspects of the cancer experience which in many details are different from those described in the literature produced in developed countries.

Modern treatment represents weekly visits to the hospital during periods from six months to three years according to the type of cancer. All patients are provided with no-cost treatment and housing facilities in the city as well as economic support for transportation and family basic needs when required. However, in 13% of cases parents stop their child’s treatment prematurely (Fundacion 2003), which leads to the child’s relapse and death a few months later (in almost all cases) even if they return to the hospital and restart their treatment. This behavior, known as “abandonment” in medical settings, and the resulting children’s deaths represents the first problem I am exploring.

Research looking at the causes for abandonment from the biomedical perspective, and applying mainly quantitative methods, have identified reasons such as financial and transport difficulties, distance to the hospital, parents’ illiteracy, child’s age, type of cancer and prognosis, number of house inhabitants, beliefs about cancer and treatment, aspects of the doctor-patient relationship and children’s refusal to continue treatment (Arora et al. 2007; Bonilla et al. 2009; 1

1 The Fundacion Ayudame a Vivir (FAV) is a local non-profit NGO involved in the partnership that sustains the pediatric cancer program, providing free medication, personnel and technology. It also provides financial help for some patients when needed. The medical attention is provided in the Benjamin Bloom National Pediatric Hospital.
Metzger et al. 2003; Sitaresmi et al. 2009). However, these factors are not consistent among studies and come from diverse study designs and samples.

The second problem I am addressing is that although factors such as economic resources and family and hospital dynamics may influence parents’ assessment of their child’s health situation, studies, like those mentioned above, do not attempt to explore how such influence is produced and what beliefs, reasons, or pressures might lead parents to no longer bring their children to the hospital for treatment. Therefore, in the current study I am looking at this phenomenon trying to understand the parent’s perspective regarding what leads them to stop bringing their child for chemotherapy.

Finding in depth explanations could lead to a better understanding of the factors that should be addressed with the families in the hospital and what aspects of the current medical options are not solving the real needs of the families or creating new ones. In addition, this could help the multidisciplinary team to re-define the pathway for therapeutic plans beyond the biomedical needs that would better fit the conditions of the patients.

**Literature review**

Parents who remove their sick child from treatment have been always a sensitive predicament that raises controversy in many spheres. Hospital staff, other parents, family members, civil communities, legal entities, and sometimes the mass media can be concerned and express contradictory opinions which are loaded with emotional and moral judgments toward and among the parties involved\(^2\).

Most of the literature on this subject illustrates arguments from the ethical, religious, or legal perspective, and are framed in a biomedical point of view (Asser and Swan 1998; Barnes et al. 2000; Cohen and Kemper 2005). In El Salvador, my experience in the hospital as a pediatric oncology psychologist was that judicial institutional support is absent because there is no legal framework to help to resolve this conflict as there is in the U.S.\(^3\) However, even in those

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\(^2\) One recent case provoked shock in the Australian community and the interest of the media that tracked a local family who refused chemotherapy for their 10-year-old girl and fled to El Salvador. [http://www.blip.tv/file/2707012](http://www.blip.tv/file/2707012)

\(^3\) On December 2009, a new law for protecting children and adolescents was promulgated (LEPINA), which include measures to intervene when parents refuse medical treatment for their children, but the legal and technical mechanisms for its proper application are still uncertain.
countries where legal recourse is available for the medical team to force continuation of cancer
treatment for children, the situation usually involves ambiguous details that add to controversy.
Hord et al. (2006) show how concepts like parental neglect or “minimal standards of care” are
difficult to define with comparable and equivalent meanings in the legal and the medical
perspectives (5454). On the other hand, courts who have to decide whether to force parents to
continue their child’s treatment or to involve a governmental protection agency, face the difficult
dilemma of the uncertainty of the medical results of the treatment, which in many chronic
diseases and especially in cancer, doesn’t guarantee cure or that treatment won’t cause harm
(Hord et al. 2006).

Kon (2006) addresses this controversy regarding “best interest” when courts are involved in
such conflicts, and argues that differences in education, beliefs and both a lack of understanding
and information are the main reasons for parents to refuse treatment. Cultural and religious
beliefs are factors that are usually impossible to overcome when trying to achieve agreement
among medical staff and parents (7).

Jenny (2007:1386) explains reasons of social and family situations as well as patient-doctor
relationships that can explain why parents do not give the “proper medical care” for their child,
and emphasizes the role of education in minimizing the cultural differences that underlie
decisions to “neglect” their child’s treatment.

In his study in a Dutch neonatology unit, Vermeulen (2004) explains how parents are
involved in the decision-making process with the ward staff, weighing possibilities of life for
their premature newborn according to medical terms and social decisions on quality of life.
Options are uncertain between undergoing through intensive treatment or just accept the baby to
die without intervention. The author shows that cultural aspects like the tradition of Dutch people
of inform and discuss everything may be central for parents’ participation.

Excepting Vermeulen 2004, the aforementioned are examples of publications regarding
parents’ treatment withdrawal for their child written from the perspective of a biomedical setting,
which is also the perspective in which is based the legal framework. Since I haven’t found non-
biomedical literature on abandonment or treatment refusal in children, the following sections
illustrate the literature from the perspective of adult patients who don’t comply or accept
medicines as a proxy for understanding the phenomenon of abandonment in children. All the
studies presented have been produced in the United States or Europe.
Qualitative studies: approximation of abandonment using the concept of non-compliance

Literature specifically regarding abandonment is scarce, and usually this term is associated with the concept of non-compliance or non-adherence. Some authors consider abandonment as the most extreme expression of non-compliance (Sitaresmi et al. 2009). Non-compliance refers to “patients not taking their medicine as prescribed” (Pound et al. 2005:133) or not following medical instructions (Trostle 1988), which can be intentional or accidental. In the biomedical setting this is considered as the main cause for medical ineffectiveness and waste of resources, and it is estimated that 50% of all patients are non-compliant (Conrad 1985).

In an attempt to summarize the information available from qualitative studies related to taking medicine, Pound et al. (2005) synthesized 38 qualitative papers on the topic from a 10 year period from Jan. 1992 to Dec. 2001, and concluded that non-compliance for taking medicines as prescribed is mainly because people, in general, strongly prefer to take as little medicine as possible. The categories of explanations for non-compliance include: (1) the way people weigh medicines’ effects, (both therapeutic and side effects), and the many individual criteria they use to do so, (2) the way people feel their identity is affected by medicine, and (3) the way people modify taking the medicine according to their preferences (Pound et al. 2005:137). Some of the most relevant aspects described throughout the review include: the importance of medicine side effects as disturbing both physically and socially, being dependent on medicines with a sense of losing control over their lives, the imbalance between severe adverse effects and potential benefits, fear of dependency and tolerance, fear of stigma and difficulty accepting their illness. This review argues that non-adherence stems from how medicine itself enters peoples’ lives and provokes resistance and a sense of non-passive evaluation of the consequences of taking a medicine. People, in general, tend to focus not only on the benefits of medicines but also on the potential harm and may choose to reduce their medicine intake or engage in other behaviors deemed non-compliant by the medical team. This behavior is an active response to a reality that has been overlooked by the dominant ideology that supports the idea that medicines are always beneficial.

Non-compliance as a value-laden term

Three separate studies have highlighted that non-compliance is presented by the traditional medicine system as a deviant conduct because the ideology of power and dominance of medicine is behind this value-laden term (Conrad 1985; Donovan and Blake 1992; Trostle 1998). The term
of non-compliance implies that this behavior is entirely the responsibility of the patient and that being non-compliant is a reprehensible action. The tendency in the literature is to blame the patients, presenting them as ignorant or neglectful in a context where the physician has the knowledge; therefore, alternatives to biomedicine are not possible. This perspective focuses attention on improving the doctor-patient relationship to offer a better understanding and friendlier environment for the patient’s comfort to lead to increased compliance (Donovan and Blake 1992).

Trostle (1988) argues that the concept of compliance represents an ideology, which justifies the physician’s authority. Similarly, Stevenson et al. (2002) point out that implied in the concept of non-compliance is the assumption that it’s an abnormal conduct contrary to the legitimate action of the doctor when prescribing medicines. In an attempt to create a more conciliatory position, the concept of concordance has been proposed as a way of improving the doctor-patient communication and consequently increasing compliance. Concordance refers to the establishment of a better doctor-patient relationship sharing information and beliefs in the clinical encounter, reducing the doctor-patient power imbalance, and generating the possibility for a shared decision-making process between patients and physicians (Donovan and Blake 1992:512; Pound et al. 2005:150).

The ideology of biomedicine as the dominant power possessing the ultimate truth is present not only in the daily doctor-patient encounter but also in the perspective of those who conduct research about compliance with a marked tendency to ignore the perspective of patients. Research on patients’ point of views is scarce, or when available, the findings are interpreted using a medical agenda, thus, it is implicit in research about compliance, that people should follow their doctor’s prescriptions (Donovan and Blake 1992; Pound et al. 2005).

Patients as active participants during treatment

The idea that patients are passive is implicit in the medical dominance ideology (Trostle 1988). However, Donovan and Blake (1992) state that contrary to this notion of passiveness and powerlessness, patients actively engage in decisions regarding their medical treatment. The authors found that patients will make choices according to the information they have but also based in their own beliefs and inclinations, which may often conflict with the physician’s knowledge and understanding. Moreover, what influences a patient’s choices changes according to many variables during the course of their illness (Donovan and Blake 1992:512)
According to Stevenson et al. (2002), patients will use all available information to decide and make choices. Nowadays, the increasing possibility of accessing information enhances the power of the patient in relation to the doctor and strengthens a patient’s active role in the decision-making process, which takes place in a context that involves both medical and social aspects. In other words, the decision to take medicines involves the patient’s analyzing of social and medical criteria (Stevenson 2002:100-101).

Similarly, Conrad explains that patients comply or do not comply with medical instructions depending on how these instructions are compatible with their lives’ contexts. This implies the patient’s judgment and their own interpretation about what is compatible or not, and this judgment emerges from their previous experiences and the constructed knowledge from those experiences regarding their illness and their medicines. By evaluating medicines, patients not only want to accommodate the medical regime to their living circumstances, but also want to exert some control on their own illness experience (Conrad 1985).

Conrad (1985), Stevenson et al. (2002), and Donovan and Blake (1992) explain the patient’s perspective and participation in their treatment by concluding that patients are not aware of being non-compliant, as described by doctors, and that their conduct regarding medicine is simply a way of actively participating in what they consider to be beneficial when living with a chronic medical condition in which medicine intake becomes part of their daily life.

The health belief model represents a well-organized view on how patients weigh their possibilities regarding treatment. According to Becker’s (1975) review of the literature on compliance the following are important aspects to be addressed to understand non-compliance: patient’s health beliefs regarding vulnerability, severity and trust in the treatment, perceptions of the psychological and physical costs of treatment, the quality of the doctor-patient relationship, and social demands. Despite the age of this data, the fact that the study was from the perspective of compliance as a problem to be solved for the medical system, and trying to find predictive variables for the problem, Becker’s factors continue to appear in current literature about compliance as evidenced by the more recent review of Pound et al. in 2005.

The social context in relation to prescribed treatment
Since the literature developed above is focused on patients’ options and perceptions of medical treatment, and these options are clearly shaped by aspects not necessarily biomedical, the social context in this situation acquires central relevancy.
Reynolds, van der Geest and Hardon (2002:3) explored the dynamics of medicines and “their social uses and consequences” as they consider “medicines as social and cultural phenomena” since they shape and are shaped by social relations; hence, referring to medicines implies acknowledging the social contexts where they have a role, such as healing and illness (2002:5).

Shared meanings and the social environment are what give healing practices significance. Therefore, the social framework contextualizes the use and understanding of medicines and medical practice either for indigenous or biomedical medicines, which leads to the concept of medical pluralism. Crandon-Malamud (1993) wrote extensively on this topic, arguing that people’s position within social, economic and political settings determine what is meaningful for them when evaluating and deciding about medicines and treatment (205). Therefore, as the aforementioned settings are not static, the relationship among people and these settings also changes leading to variations in what is meaningful for them and consequently in their decisions about medicines and medical systems. Moreover, the efficacy of medicines is also evaluated in these social, non-medical terms, and this attitude is often labeled by the biomedical professionals as patient’s beliefs about medicines, which often are contradictory to rational medical thinking.

Nichter, (2002) explores taking prescribed medicines in the context of poverty, institutional irregularities, and familiar, cultural and social expectations, and how social constraints determine and shape physical risk. According to the author, therapy management and patient’s decisions take place not according to medical criteria alone, since people have to weigh their family’s necessities in addition to the disease. Therefore, vulnerability to diseases corresponds to how social and family necessities are weighed in an environment with limited options. Accordingly, analyzing therapy management can help to explain patients’ decisions that from a biomedical perspective would be considered as based on irrational beliefs and ignorance. The interpretation that people give to both illness and treatment includes the context of adapting to a conflicting situation of scarce material resources s priorities.

Considering the patient as an agent who, in a social context encounters diverse treatment alternatives, means that special attention can be focused on the most frequent options described in people’s choices regarding medicines—religion or spiritual beliefs (Linnard-Palmer and Kools 2004) and complementary and alternative medicines (CAM) (Hord et al. 2006)
Religiosity and CAM

Religiosity or spirituality is a significant aspect of how patients cope with life-threatening illnesses. Particularly in cancer, White and Verhoef (2006) state that spirituality influences how patients relate to their medical condition and the medical condition also has an impact on a patient’s spiritual life. In this qualitative study of patients with prostate cancer who chose to reject biomedical treatment, spirituality was described as a strategic tool in coping with the illness by improving the perceived quality of life. However, from the field of psycho-oncology, Stefanek et al. (2004) point out that whereas spirituality can contribute to the enhancement of psychosocial health, some spiritual beliefs can also lead to rejection of medical treatment (White and Verhoef 2006). According to Montbriand (1998) (in White and Verhoef 2006) patients who refused contemporary treatment were especially involved in supportive spiritual beliefs and alternative therapies.

Recently, the use of a wide range of CAM has increased dramatically, especially for chronic conditions and life threatening illnesses (McCurdy et al. 2003). In a qualitative study conducted in the United Kingdom, Broom and Tovey (2008) explored the use of CAM among adult patients with cancer and its impact on their everyday life. CAM seemed to have a big impact on how the patients perceived their cancer and terminality and the role of a CAM therapist was essential in providing the patients with a more affectionate relationship, which was highly appreciated. The patients tended to contrast this with the impersonal and too rational experiences of the biomedical setting and scientific attitude, which, according to their perception, gave little space for hope. People expressed satisfaction with the possibility to actively participate in the healing process by training their body and mind, as well as having a significantly more personal relationship with the therapist. The same study explored how the use of CAM in daily practice is a complex activity with many constraints. In most cases, biomedical medicine can be easier to take and requires less personal effort and commitment by the patients. The authors noted an interesting aspect that the use and concomitant participation in CAM is also related to the changing feelings of patients during the illness experience or in the biomedical relationship. The whole experience of illness and treatment is full of intense and sometimes conflicting feelings that change and evolve over time. These experiences can be as simple as an inappropriate comment on the patient’s appearance or as intense as the death of a friend in the ward, or their own perception of the progress of their disease. Both extremes have the power to impact and
dramatically change the patient’s feelings and attitude towards treatment. The experience of treatment is consequently dynamic—never static—but accommodated to the individual experiences.

**Research question and sub-questions**

The main question and sub-questions to answer are:

**What circumstances, concerns and ideas influence parents to stop the biomedical treatment of their child with cancer in El Salvador?**

How do parents understand their child’s cancer and what do they expect from the biomedical treatment?

How do they value the options offered in the hospital in order to help them to adhere and avoid abandoning the treatment?

How do the parents—in their daily life circumstances—weigh the pros and cons of adhering or not to the treatment?

What alternative ways do parents use for dealing with the sickness of the child?
Chapter Two: Researching pediatric cancer patients in El Salvador

This is a qualitative exploratory study. Using a convenience-sampling method, in-depth interviews were conducted with the parents of children who had discontinued cancer treatment during the last year, from May 2009 to May 2010, according to the hospital database.

Originally, the main criteria for selecting the cases were geographic accessibility and characteristics of the case. Accessibility referred to geographic distance and terrain conditions, as well as my personal safety in the area. The country is small and the main roads are in excellent condition, however, secondary roads to little towns can be less efficient and access to some villages could take more than five hours. Because of the short time for conducting fieldwork (five weeks), I expected to interview only a few informants living far from the capital city. I also expected to get a list of 10 to 15 cases, analyze the cases’ characteristics and select some in order to have diversity among the respondents, including, for example, diagnoses that require a variety of length and frequency of treatment, various areas of origin (rural, urban), various family structures, etc.

I had also thought about only talking cases that didn’t know me from my former position as a psychologist in the hospital. My intention was to avoid the parents feeling intimidated by a hospital staff member thereby influencing them to say or not to say some things. The other cases I had not planned to include were those whose children had already died by the time of my fieldwork.

This entire well structured plan changed when I found out that the data provided by the hospital were not so accurate for my time frame, and it gave me only few cases from the time period I had planned to study mixed with older ones. Some of the cases were receiving palliative care when abandoned, meaning that the parents were aware that the child didn’t have possibilities of cure, which represents a strong aspect influencing abandonment and deserves a separate study. Another case was a Jehovah’s Witness, and another one was from Honduras. Cases with one of these conditions were excluded as possible respondents.
Contacting the cases

With regards to how to contact the families, I planned to go in person for the first contact since a phone call would be culturally strange and an in-person visit would diminish any parental misunderstandings of my intention to interview and not to attempt to convince the family to return their child to treatment. I introduced myself as a student, who had formerly worked as a psychologist with children with cancer. I explained that when I was working, I had seen parents who decided to discontinue their child’s treatment and now as a student I wanted to learn about their perspective and what they could tell me about their experience.

During my first visit, I would explain my reasons for visiting them, asking for their participation and setting an appointment for my next meeting, should they agree to participate in the interviews. In one case I proceeded with the interview because the family was willing to talk from the first moment. Written consent to participate wasn’t requested from the parents because, in my experience in previous research studies with parents of children with cancer in El Salvador, requesting “formal” permission to participate in a study and signing a form generates mistrust in the participants. Additionally, I now know that an extra reason for not calling the families in advance is that Salvadoran people are usually kind, especially to foreigners, and they would probably have difficulty saying no to my requests if I was already there at their door, as I look a bit like a foreigner, which I knew would play in my favor. It worked. However, in some cases because of the short time and long distances to reach the families, it was necessary to call them first. In one case the family agreed to meet me, in the other they didn’t, and in a third case the child had already died some months before and I discarded the case.

Maybe the most difficult thing was to explain why I was so interested in knowing something that was so seemingly useless to them, and, according to my words, also for the hospital, because if I was not doing this for a request from the hospital, then who cares? And what’s the intention? They all agreed that they had never heard about this kind of “study”. I don’t think I was always successful with my explanation, but I’m thankful that they decided to cooperate despite the fact that it was so unclear to them. I think I succeed in gaining their trust and assuring the privacy of the shared information.

In most cases I conducted the interviews in the family’s house, which was the best option for the participants. Physical conditions and space were more or less what I expected. In the urban case the three bedroom house was very small and we managed to use one of the bedrooms
for the interview, but the children and the noise from the rest of the inhabitants was always there. In rural houses with only one room, the area for the interview was the small, roofed front yard with a couple of hammocks or chairs, which is where visitors are commonly received. One of the houses had a wood stove in that area and the other one had a separate small rustic construction for that purpose. The water supply is located in the yard and the latrine is located aside in the field. In these conditions privacy is a relative concept. I taped interviews full of children’s laughs and screams mixed with barks, crows and mooing cows, while managing not to eat the mosquito clouds when talking. Regarding requesting permission for taping the interviews, I had exactly the same feeling as asking the participants to sign a consent: I felt that it could seem suspicious and I wasn’t wrong. Some of the interviewees didn’t bother to sign it at all; some said yes because they didn’t know how to say no, or what to think about the possible consequences of the taped information: and only one case tried politely saying no without actually saying it. After that, I didn’t want to risk the possibility of not being able to have the information taped and decided not to ask permission. However, I always clearly showed the tape recorder, and the reaction was the same as if I had requested permission: most cases weren’t bothered, but one asked, when the interview was finished, what I would do with the tape. When I decided not to ask permission anymore, I felt bad for taking advantage of their trust, but I was so amazed about the richness of the language and the information that I didn’t want to lose any detail.

Considering that all of the participants were from low socioeconomic conditions, and as a gesture of my thankfulness for them trusting me and taking the time to talk to me, each time I visited I gave them a basic bag of supplies like beans, rice, milk, cereal, toys and clothes for the children, etc.

Getting to the places

Unfortunately, violence and insecurity in El Salvador have frightening statistics. Hanging around, asking for directions is not a highly recommended activity for a woman, and both my relatives and my colleagues had only one question after being told about my field work: “You are not going alone, are you?” My cousin David, who is an excellent driver and knows the country very well, became my official driver and companion.

I knew from before that reaching houses in the rural areas would be difficult and unpredictable, but, in fact, I didn’t have a real clue, because reaching the “area” could be easy, but locating a family house without a house number or street name (actually without a street at
all) was like being blind in an unknown area of several square kilometers, where houses in the field were scattered without any pattern obvious to me. After Google Earth gave me at least a notion of how far the area could be from the nearest town and what road would take me there, I found out that I couldn’t do anything else by myself.

Fortunately, a friend of mine had the best solution I could think of to this problem. He works in a governmental institution that has a pretty good mapping of El Salvador and has local representatives in each municipality of the country. They are community workers, and he asked personnel in those areas that I planned to visit to guide me. That worked perfectly. After setting the day and time, we met at the main municipality and then found the villages and families together. Without those local guides, I doubt that I could have located one single house; however, contacting each local representative was time consuming and usually took three to four days in each case.

The cases

I interviewed six cases who had abandoned treatment and two cases that were adhering well to the treatment plan, despite being considered by the hospital staff as having high risk criteria for abandoning because they had very bad socioeconomic conditions and lack of family support.

I decided to start with the easiest one, meaning the nearest: Katy. Her neighborhood is located in a pretty dangerous area of San Salvador that has high gang activity, but, lucky for me, this specific neighborhood remains less conflictive and is easy to access. The strategy for this and three other cases was that David would leave me at the house, after making sure that I was safe, and would go to have a coffee and read the newspaper in a nearby place while I was interviewing. The cell phone technology was vital to the strategy because I could call David to pick me up when I finished, allowing him not to have to wait inside the car in unsafe areas.

After heading down two wrong streets and having to twice ask directions, I arrived at this little house and stood in the open doorway. The outer protective iron bar gate though closed, gave me a view of the small crowded room inside through the open inner door. In response to my friendly good morning, everybody at home turned in the direction of my voice with silent expectation. I could see the question marks on their faces and maybe a little expression of worry

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4 Protecting confidentiality, all the participant’s names have been changed.
trying to speculate who I could be. My explanation about who I was and why I was there sounded so nonsensical to me that I started to feel very uncomfortable while talking, and maybe they noticed this because, before I finished, all of them stood up at the same time, asking me to come in and take a seat. While I turned back a few steps to indicate to David that I would stay, I could see how they started to fix the cloth that was supposed to be covering the holes in the fabric of the couch, while at the time they accommodated themselves in the other two sofas. After explaining again the best that I could what I was studying, why I wanted to talk to them and, especially, assuring them that I was not a representative of the hospital or any other institution or civil authority, we started a relaxed conversation and I started to receive the information of who was who in the group. They were the nine months pregnant mother of the little Katy; the grandmother; the uncle, his wife and her mother, who was the only one who didn’t live at the house and was visiting the family. She was possibly the happiest with the arrival of a new listener to the meeting, because as soon I finished my speech, she said that wanted to show me what God says about sicknesses, and started to turn pages enthusiastically in the Bible she had been holding since I said my first good morning to them. The white veil on her head was representative of the Evangelic church. She asked me to read aloud chapter 16 of the Apocalypses and, while reading, I really was actively trying to figure out the meaning of the words, the relation with sicknesses and the anthropological explanation for my situation, sitting on the couch with this family paying attention to my words. I didn’t get a word of the entire chapter, despite having read it with genuine academic interest, or maybe that’s why. However, I must say that I really felt like an anthropologist and it felt great. After reading some more passages (Psalms, 89) Katy’s mother was willing to talk with me. We went to a tiny room with a double-bed and space for one chair, and there I started the interview with a suffocating room temperature around 33 degrees.

The second case, Javier, was the only teenager in the group. Precisely the day I had planned to look for the family in another populated low class neighborhood in the south of the capital, I went to the hospital in the early morning to pick up some papers, and I found out that he and his mother were there in a meeting with the doctor and the psychologist, who for several weeks had been insisting to them via the telephone that they needed to come to the hospital and talk. I decided not to meet them there, and I discovered that the mother works in a doctor’s office located in the upper class neighborhood of the capital, and she was there every day, so going to
her home would have been useless. Two days after, I visited her and requested their participation, to which she eagerly agreed. Javier had been admitted to the hospital a few months before I left to study in Amsterdam, and I had had a brief interview with him once. He and his mother remembered me, and it was obvious that she wanted me to talk to Javier again, hoping that he would feel understood and would agree to return to the hospital. I explained to her that I wouldn’t be in a position to try to convince him of anything, but she felt happy about having someone to whom he could talk about his treatment without pressure of any kind. I offered to invite him to eat when meeting for the interview. We set an appointment for interviewing her, and she said she would let me know then if Javier had agreed to talk to me, which he happily did with the expectation of eating at Pizza Hut, his favorite fast food restaurant.

Manuel, the third case, was hard to reach. I went to the municipality of a province an hour away from San Salvador, where I picked up two community workers to guide me. I had been warned that I’d need a sport utility vehicle (SUV), so I had loaned one from a relative. After ten minutes of driving, we hit a small stoned road, with a sharp inclination. Three hundred meters of driving upwards made me convinced to give up the vehicle and decided to continue my journey on foot with the two accompaniers. Meanwhile David managed to turn the car around and head down hill. After less than ten minutes walking and out of breath, we found a relative of the family, who told us that the couple was working in the fields and the children were not at home either. To get that information I had to explain who I was, and the woman said, trying to persuade me to suspend my search: “Oh but the child is fine anyway, and they are too poor to travel to the hospital, it is too expensive and too difficult for them.” One of my companions guessed where the couple might be and he was right. We found them on a little hill next to the one they lived on, doing field fumigation without any kind of protection. I noticed that they were suspicious of me, and the man started to talk about the many complaints they had about the hospital. I understood they were talking to quickly answer my “curiosity” and get rid of me. After 20 minutes, I managed to convince them that I wanted a longer conversation at some other moment convenient for them. They agreed to see me, but only on Sunday morning because on the other days they were busy and Sunday afternoon they go to the church. That Sunday the tropical storm Agatha was in its second day and there was heavy rain all over the country, and the flooding and landslides on the roads made it unthinkable to even try to meet them, so I waited one more week.
I faced an ethical dilemma regarding Iris, the fourth case. While I was still wondering how to reach her home, I was notified by my colleagues that she had been admitted to the hospital in bad condition, but that she might be released in one week. I decided to introduce myself to the mother in the hospital, and at least ascertain if she would be willing to talk to me. The tiny young woman was pretty wordless and shy, and this reminded me of how difficult it is to have a conversation with the “kind” of person who has such a silent attitude towards everything. In the hospital, I always felt that people like Iris’ mother usually go unnoticed, so I was really interested in getting information from her, but I wasn’t sure I’d have the skills for conducting an interview with such a non-verbal person. Finally, she said that she would talk to me, but at her home, not there in the hospital. Her directions explaining how to find her house were scarce, as well as useless. “I’ll find out”, I thought. Then I had a better idea; I could ask which day Iris would be released from the hospital and then I could take them with me in the car. However, Iris had a sudden worsening and was transferred to the ICU, where she died one week later. Immediately I discarded the case, but then, my colleague told me that the day the child died, the mother said that her father-in-law had convinced her husband to not bring the child to the hospital and now she could be blamed for her death. Then my dilemma: should I look for the mother and interview her anyway? I decided to give it a try, thinking that once I was there, if I found the situation too inappropriate, I would just give my condolences and the food supplies and leave.

Bryan was the most surprising case. He was the last case of abandonment I attended before leaving my position at the hospital. I had three reasons for not selecting this case: they already knew me as a psychologist in the hospital, who had been in the meeting of diagnosis communication with them; they lived in a pretty dangerous rural area near the city; and, since the child had not even received the first month of treatment for his leukemia, I assumed that by this time, he would have died. However, I decided to try anyway because I had too few options at that moment. The family received me, and the child was still alive and apparently healthy, one year after the abandonment of treatment.

Andres was a different kind of challenge. He lives on a little island, which is a 30 minute boat ride from the port in the East of the country, which is the hottest and remotest area of the country being a 4 hours drive from the capital city. Given the scarcity of cases by that time, I had been thinking about trying to locate this family, but the previous week we had had the tropical
storm and the weather was still a bit uncertain. Beside this, the schedules for the boats were affected by the tides and the weather, so the journey would be pretty unpredictable. Furthermore, after reaching the island I wouldn’t have had a clue of how to find the family. The island doesn’t have facilities to stay overnight and if the boat was delayed because of the bad weather, I would need to spend the night in the province in the best of the situations. Fortunately, the family of a good friend of mine live in that town and they own a well known grocery store, two blocks from the port. So, I decided to make a phone call to my case family, explaining that I wanted to interview them, and offering to pay for their boat transportation to the province port, where I could meet them at my friend’s store. They agreed, and we were able to talk in a private environment in a second floor, roofed terrace of the store.

One day, I was called by my colleague who said that they were about to have a meeting with the parents of a child who had been brought to the hospital by the police after refusing the treatment. How come? Just last December, the Government approved a new law to protect children and adolescents (LEPINA law) which Article 18th says:

Measures to safeguard the right to life.
When a child or adolescent should be treated, needing surgery or emergency hospitalization because of being in danger of imminent death or irreparable damage to their physical health, medical and surgical care will be provided in the nearest private or public health centre to stabilize the patient and then refer him/her to the appropriate center;…
If the situation is not an emergency, but may cause irreparable damage to the physical health of the child or teenager, the doctor will ask the parent or authorized representative for hospitalization or intervention of the child or adolescent, and in case of absence or opposition of them, the provider may request the intervention of the General Attorney of the Republic, who must resolve within a maximum period of twenty-four hours. (Ministerio de Gobernacion 2009: 8)

My colleague told me that the couple had been “difficult” since first arriving at the hospital when the child was diagnosed; therefore, I immediately assumed that those parents would be very angry and not wanting to talk at all. However, because this represented such a
unique case in dealing with these situations, I decided to try talking with them anyway. I knew that after their meeting with the doctors would be a bad moment to contact them, but I also knew that this would probably be my only chance to find them because the staff was planning to release the child. After that I was sure they wouldn’t even open the door in the event that I could even find them. The director of the program had always had the policy that the staff can’t force parents to accept their child’s treatment because it involves too many complex aspects, and agreement is vital. I talked briefly to them, but they didn’t agree to be interviewed or recorded.

Regarding the two cases that were undergoing treatment without abandoning, I contacted and interviewed them at the hospital. In both cases I explained that I wanted to talk with them about what the diagnosis and the treatment represented for them and their family, and what kind of situations they were facing in order to have the treatment for their children. At that moment, one of the cases, Marvin, was finishing a few days admittance due to an infection. While the mother was waiting for the papers to formalize the discharge of the child, she agreed to talk with me in the psychology office of the unit. The director of the program thought that Marvin could be an interesting case because in a couple of occasions, the mother had had a few days of delay in coming to the consultations and she was very worried about that. The seven-year-old child had been visually impaired since birth, and had been diagnosed with Leukemia five months earlier. The other case, John, was attending his weekly chemotherapy session, and the grandfather of the eight-year-old boy agreed to talk in the office while John waited for a procedure in the ward. The social worker considered this an “exemplary” case against adversity since they were extremely poor, the grandparents were the only adults responsible for John and his older sister, the grandmother was epileptic, and the only one in conditions to bring the child to the hospital was the 70 years old grandfather.

All the interviews but one lasted an average of one hour. Since presenting myself included the explanation that I wanted to know the stories of people who had had a child diagnosed with cancer in the hospital, but at some point in time had decided to stop going to the

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5 They were upset and mentioned their ideas about treatment being harmful for the child and their beliefs in miracles. I could only conclude that they were the perfect example of how a law to force parents to accept their child’s treatment won’t be helpful; instead, it will give an “official character” to the differences among parents and doctors, converting them into declared enemies forced to be together.
hospital\textsuperscript{6}, it was clear to them that my main point of interest was their reasons for abandoning; however, I always started with a very open sentence like “tell me about the time you were going to treatment” or “…about the sickness”.

The interviews had a comfortable conversation style, people were talkative and, in general, the questions I asked came from the interviewee’s discourse itself. Only in the case of Iris’ mother, where the words were scarce because both her lack of fluency and the sensitive topic, did that the interview last only about 30 minutes.

All the interviews were transcribed and analyzed, looking at the topics that were most mentioned in the discourses, but also considering the context of each case.

\textsuperscript{6} I avoided saying “stop going to the treatment” or “abandoning” because that could seem that I was saying that they were doing nothing for the child and sounded to me more judgmental.
Chapter Three: Revealing what is involved in living with cancer treatment

In this chapter I’ll address what the interviews of six parents who abandoned treatment can tell about the circumstances in which the diagnosis, treatment and its further abandonment occurred. I’ll present the information structured according to five main topics that were common to different degrees in most of the cases. According to the information examined, in their conversations interviewees included aspects related to the effects of the treatment they could see, the economic difficulties that the sickness or treatment represented, the way they perceived the institutional discourse from the hospital, the way the parents’ emotions intervened in their perceptions of the situation, and the way in which religion played a role, both in the experience of sickness and abandonment of the treatment.

Interpreting the benefit of treatment: understanding of effects

I remember some doctors, when explaining treatment side effects to the newly diagnosed parents, saying “…chemotherapy for treating cancer is the strongest medication possible among all medicines, because cancer is the strongest sickness among sicknesses...” The doctors’ intention was probably to assure parents that they would use the best resources available to save the child, and also to warn them that things wouldn’t be easy. The idea of chemotherapy as strong medicine became a common discourse among parents, and while working as a psychologist in the hospital many times I heard the worries that this idea provoked among them, as well as the actions they undertook because of that.

Listening to their stories, it was pretty clear that what started with a very common, not worrying symptom before the diagnosis had now evolved into an escalade of complex suffering for the child. From the moment of the intervention of medical knowledge and technology in each of the cases, the place and origin for the suffering changed, and it seemed to be very logical to situate it in the hospital, the doctor and the medicine instead of the sickness: their current situation was not about the sickness anymore. What was present now was the medicine, provoking many kinds of annoyances and fears; all that had to be dealt now was related to the medicines and all the risks it involved, which the doctors had warned exhaustively about. Therefore, everything that was happening in the child’s life was related to how the chemotherapy
was affecting him/her, and if those effects were secondary, non-wanted or “side effects”, it didn’t make any difference for the child’s daily life; the fact was that those effects were making the child suffer much more than what was experienced with the sickness symptoms, and that was the new reality for the parents. Katy’s mother said:

...the medicine is for curing, but sometimes inside our body, instead of aiming at the sickness, it starts to kill (the own body). Maybe the sickness is one thing, and the medicine comes to do other things that weren’t supposed to (be done)...Therefore, I saw my child doing badly because of the chemotherapy and I said to myself, she won’t tolerate it...

While working in the hospital, almost every time I talked to the parents of newly diagnosed children about their main worries, the most common fear was that the child wouldn’t tolerate the chemotherapy, and the common idea was that sometimes children die because of that.

Analyzing the way parents talked about chemotherapy, it pretty much seemed that what for doctors was “only” a non-serious “side effect”, meaning a minor annoyance, became for parents “the effect” of the treatment; it was what they saw as the most immediate result of the chemotherapy and the procedures.

Effects of treatment were constantly in the discourse of the parents I interviewed. Their child’s lack of appetite was the most common complaint, which represented a main worry because, as one of the parents said, after receiving the chemotherapy, the child would lose her appetite for two to four days, and when the child’s appetite started to increase it was near the moment of having another dose of chemotherapy and the “cycle” would start again. Consequently, the child was properly eating only few days a week, which was very worrying for the parents.

Parents also complained about weight loss. To see the child getting thinner was not a sign of improvement to them. To the contrary, if the child was getting thinner this would make him/her weak and not able to undergo the treatment; the treatment could be too strong and kill the child.
The child looking apathetic and sad was also mentioned as a bad consequence of the chemotherapy, and it made parents interpret that the child was feeling unhealthy and that his/her situation was actually becoming worse because of the treatment.

For the doctors, hair loss is such a harmless effect that it is the least worrying thing, but for the parents who referred to it, it seemed to have a wider meaning. While talking about effects of treatment, I noticed that when mentioning the hair loss, they used to apply a pity tone in their words, like feeling sorry that not even the appearance was respected, making the child look weakened, and deteriorated.

Katy and Javier’s mothers and Manuel’s father recounted the aforementioned:

...that day they didn’t give her the chemotherapy because she had a bad cold, so we came home, but she was already pretty bad. Each time we went, I would see her worsen. So I said to myself, why am I going to continue taking her (to treatment) if I know that maybe chemotherapy can heal her, but if at the end her body doesn’t tolerate it? She was not going to tolerate. You could say that now she looks plump compared to how she was: only skin and bones.

She didn’t want to eat anymore. Not even the food she likes the most, like canned juices, instant soups, chicken; nothing! She ate two bites a day, which was not really helpful for her. Neither milk...

He suffered very much first because of the hair loss, second, the weight loss; although he was already thin because of the sickness, with the chemotherapy that worsened. He stopped eating because he felt like vomiting and he didn’t like that ... then the last times he had a very aggressive temperament...

...when they (the hospital) gave me the child (after several days of hospitalization) I thought we were going to bury him, he was all swelled, without almost any hair, all white (pale), he’s not white!
From my former experience working in the hospital, I would say that the aforementioned are the “typical” effects that most of patients undergo especially during the first one or two months of treatment. In most of the cases it’s assumed by doctors that those symptoms will lessen as time goes by, but maybe is just a matter of accommodation and most of the patients and families just get adapted to the situation. The perception among the medical team is that those symptoms are the normal things to happen, and a few days after beginning treatment the child will improve, which is the goal for administering the chemotherapy, so these minor side effects shouldn’t be a main worry.

Parents also mentioned they felt worried when the child started to have difficulties walking as a side effect of the chemotherapy. They associated this with one of the scariest ideas about the chemotherapy and the procedures, which is that it may provoke inability to walk. Inability to walk is feared by the parents in general up to the level of—in some cases for example—refusing treatment when amputation surgery is required, arguing that they rather to bury their child in one piece than with an amputation. Impairment as consequence of chemotherapy or medical procedures like lumbar puncture can make parents feel really scared. The interviewees considered this procedure very dangerous, and feared also the way it is performed, what doctor was doing it (how much they knew and trusted the doctor) and how great his/her expertise was with the procedure. Parents had their particular criteria for evaluating and judging this expertise depending on their own past experiences or other patients’ stories. Manuel and Andres’ fathers said:

...The one (the doctor) who treated my child the last day did it as if he was a worthless animal, severely. When she (the mother) saw him crying he couldn’t walk because of the pain. The doctor prescribed some pills but not even that was effective. Here at home, because we did our own strategies the pain started to relieve. However, if you touch him here you can still feel the hard masses caused by that doctor.

... The child was feeling pretty bad each time they gave him the chemotherapy. Because they put an injection called ‘intrathecal’, it’s in the spine... is not that the doctors are rude, they know what are doing, but in part we also felt fear because he was already limping from one foot.... We heard rumors that because of that (the procedure)
there were children sometimes that couldn’t walk anymore, and we were very scared about that...When we came, that we had decided not to go back (to the treatment), he was limping very much, it hurt him very much. Now he walks normally.

For the parents, this was interpreted as a sign of how dangerous the treatment was and maybe just a warning of worse things to come.

Parents also talked about the pain caused by the procedures, even drawing blood for testing by venopuncture or through a permanent catheter, which were routinely done procedures each time they had to go to the hospital. But needles are synonymous for pain, no matter how routine the procedure was, and for some parents, their child’s suffering represented a big difficulty to overcome, and not a routine thing.

Manuel’s father recounted the last procedure his child had:

...the doctor said: (about the procedure) ‘This has been a success!’ For him!! (the doctor) Because he didn’t feel it!! But if the procedure would have been done on him wouldn’t have been a success!!

Although not every effect was mentioned for every case, but all the aforementioned were recounted by the interviewees as effects their child had to face while undergoing treatment. However, during the discourse, what usually started as a personal recount of effects suffered by the child, subtly became a generalization where it wasn’t clear when they were talking about things they had witnessed in other children or about things they had heard from other parents or medical staff that could happen. However, it seems that for them all these stories from others are real facts that reminded them to what extent they were risking their child. And even more important, the overall perception in most of the interviewees was that their child’s condition was worsening instead of improving, which was caused by the treatment. Interestingly, none of them recounted how the original symptoms of the sickness were relieved with the treatment, and when asked, one of the parents said that the relieving came very quick after arriving to the hospital, but a few days later bad symptoms (from the chemotherapy) started.
Poverty and sacrifice

Even though all of the interviewed were families from low socio-economic conditions -- it is extremely rare to have middle class patients who abandon therapy, money problems to accomplish going to the treatment was mentioned exclusively as the main difficulty in only one case. However, all of the cases mentioned that it was difficult to afford each visit to the hospital, which included the money for bus transportation and food.

Going to the hospital for the weekly consultation represents at least a full day visit, which means in many of the occasions that they would need money to buy some food nearby the hospital. For most of the cases, bus transportation two ways could represent from $3.00 to $20.00 once a week.

Even if small, these direct expenses for the treatment represented a considerable imbalance for these families who usually have only enough resources for daily living; spending money to get to the hospital for the child’s treatment can threaten the possibility of feeding the rest of the family, as Manuel’s father explains:

...We had to take the child to the hospital four times a week, spending $20 each time including what she needed to buy there. That is $80.00 weekly during three years...with my work I only earn $48.00 every two weeks. How to sustain my children, and have food for them? Here we are six people who eat!

The problem of losing work payment for the days that the parent goes to the hospital with the child was not mentioned because in all the cases women were in charge of taking care of the home and children, and men were the ones working for the family economy. Besides, all of the families could manage to leave the rest of the children with some relative who takes care of them while the mother was at the hospital.

Although both the medicines and the hospital services are free, parents reported that sometimes they had to buy some medicine or medical supplies that the hospital pharmacy had run out of or didn’t provide, and many times this situation was unexpected and they didn’t have the money to solve the situation. Some of the parents complained strongly about this, and they felt that much more money was necessary than they expected for continuing the therapy. While
Andres was admitted to the hospital his father explained that he used to go back home to earn some money:

...My wife stayed at the hospital and I used to come to get some clothes and to work some days for taking back some money, because sometimes they asked us to buy some medicines or injection.

Another situation that represented an economic burden for the families was that the hospital charged a fee once a month for helping with the fundraising for the chemotherapy. In most cases it was $3.00, but some of the cases interviewed didn’t have this fee assigned because they were too poor to pay. However, complaints about this were raised from two of the cases (both were complaining actively about the many institutional failures according to their opinion).

Interestingly, one of these cases didn’t have a fee assigned for collaborating with the hospital, and, according to the family, this turned out to be the explanation as to why they had a bad relationship with the staff or mistreatment of the child in the hospital. According to Manuel’s mother, they thought their difficulties originated because they didn’t pay any collaborative fee:

There was a nurse in charge of administering the treatment to the children. I asked her if the medicines for my child were ready. ‘No. Wait!’ (she said rudely). It was usually only me that they used to answer like this. I understood why: because I had not given any money to them. Other mothers asked me how much I had given. I answered, ‘Nothing. They haven’t asked me to give’. They said, ‘They have asked us to give $30.00’… It was like this-- for those who paid, there was a way of treatment, and the one who didn’t pay they treated him different.

This example shows how poverty as a concept of powerlessness became an issue in the relationship with the hospital, not only because parents couldn’t afford things, but also because it influenced how they interpret the way they were considered or treated by those with money/power and among the others in similar condition.
There was a particular situation involving money that is not related with a direct expense, but that, in one specific case, led to a much unexpected consequence: Some years ago, as a measure for preventing abandonment, a clause was introduced in the informed consent that parents have to sign when the child is starting the treatment. It states that the child will receive everything for free; however, if the parents stop the treatment, they will pay half of the expenses incurred by their child in the hospital. With this in mind, Katy’s mother was considering stopping the treatment because of fear of side effects, and decided to quit early and not wait, thinking too much, before the accumulated debt was too high.

...I said to my husband: ‘Look, it won’t be only one chemotherapy anymore, will be five (each time), so the child will not tolerate that. If I regret later, (and want to quit treatment) those five chemotherapies will accumulate, because the hospital said we have to pay 50%, (if we stop the treatment). So we will have to pay double (many folds) than what we probably owe them now.’...it will accumulate: the more treatment the more chemotherapy (debt), so, logically, we would have to pay more if I decide to quit later. So that was the moment, I told him we better stop’.

Again, money plays a role, and is an issue that parents consider when evaluating their situation.

Transportation difficulties were the most mentioned, linked with the amount of money this represented, but also with practical difficulties. Manuel’s mother had to start the journey with her seven-year-old son at three in the morning, with a battery-operated hand lamp lighting the narrow path between the bushes, to go down the hill and find transportation to the city to get the hospital at 6:00am.

Andres’ parents were always traveling together because the mother was a foreigner with no legal status. A friend of theirs, who owns a boat, used to pick them up on the island at four in the morning every Monday. Once in the port they traveled by bus and arrived at the hospital at 9:30. Since they had another appointment on Thursdays, they used to stay two days in the hospital shelter and go back home Thursday afternoon. They stayed with a relative in the port and Friday morning they took the boat to the island, where the father worked the weekend as boat driver to make money for the next trip:
We spent a lot...the boat was $2.00. We had to eat breakfast $2.00. The bus $6.00. Because I didn’t know the city I used to pay $3.00 for the taxi from the bus station to the hospital. Is not the same if you know the place and can go by bus. I used to spend like $15.00 including lunch...

In Iris’ case, money was the limitation for continuing the treatment. The mother was helpless and her personal resources were limited to the money her husband gave to her when he had it. It seems that yes, she was the poorest among the cases studied, and also was the one with the least familial support as well as her shy personality which didn’t help her to actively ask support, either from her husband or from the hospital. Her situation reminded me of what in the hospital is considered the typical case of a passive patient with high risk characteristics for abandoning:

When I stopped the treatment of my child I gave in to the thought that she would die here (at home).

Poverty has many different facets, and even though the lack of money is the direct indicator of having economic disadvantages, a broader analysis is required. When I say that only Iris’ abandonment was directly related to poverty, among the rest of the cases, I should more clearly say “lack of money” instead of poverty. Difficulties communicating and asking for help, or walking half an hour on a mountain path to the highway in order to get the hospital, or depending on the weather conditions to cross the river or the gulf and get the bus, or avoid eating to keep the money for the transportation to go back home, are also situations related and determined by poverty. And this, of course, determines how the situation of sickness and treatment will be evaluated.

Perceptions about the institution

The relationship between the interviewees and the hospital staff was also mentioned through several situations that shaped the parents’ perceptions and place themselves in relation to the institution. Parents established a relationship with the staff members of the unit, whom, to some extent, represent the institutional structure. When recounting their stories about their time
in the hospital, some interviewees gave examples of situations that influenced the way they felt or thought about undergoing treatment.

One of the complaints was regarding the way the hospital presented the help available for the patients, which in reality is not working, at least, in the way parents expect it to work. Either because the help provided is insufficient or because it is not available when it’s needed, some interviewees openly criticized this. Manuel’s father told angrily:

*The help the hospital offers is only words (not facts). Once they told her (the child’s mother) ‘you can come bringing only enough money for your transportation’ (meaning she doesn’t need anything else). She went; the staying was supposed to be about two days. First she was 19 days sleeping sitting down in a plastic chair. Then they told her she had to buy some pills: four pills 20 dollars!!... We managed to resolve...”*

“...so they say ‘come only with the money for your transportation’... No, that’s a lie! Once you are there they say ‘you have to buy some needles, you have to buy gloves, you have to buy some pills’... One is coming some times without eating and only with the money for transportation. It’s a lie, I heard them and saw that they didn’t keep (their word)...if they say they are going to help us but once we are there things are not so...

Also, in Manuel’s case, the parents were complaining about what seemed to be an unnecessarily complicated system of treatment, where apparently the hospital didn’t want to make things easier for them:

*...We thought that it would be like in the nearby hospital, where they discharged him and it was not necessary to continue going. Or like the doctor we had in the town, renowned, old fashioned and very aged that passed away already. Even if someone was very ill, he only said ‘What do you feel?’ the consultation was at that time $50.00 (ten years ago) but only with one consultation he used to solve everything. I thought it would be the same in the hospital but no! There is today an injection, tomorrow some pills... Why didn’t they give us the pills or injections to give to him here? Here even walking distance we could take him and for fifty cents they give him the injection (in the nearby clinic), but no! It was necessary to go to the hospital! And that costs $20.00.*
When asked about what kind of help they got from the hospital when facing problems in attending treatment, some of the interviewees said they didn’t feel trust enough to ask for help, and those who did, didn’t get an answer that was actually helpful. Iris’ mother remembers she told one staff member that she was having trouble with her family-in-law, who was pressing her to stop Iris’ treatment:

They advised me not to pay attention to them (the in-laws). Due to it being too far away, they weren’t able to come to explain to the family what my daughter’s diagnosis was...

A home visit would have required resources that the hospital may not have had; actually no one could have been sure that that would have been the solution for Iris’ mother’s situation, and probably the staff member she talked to had good intentions and no resources at hand, but the fact was that his/her answer was not useful in a practical way. This answer didn’t help the mother to stay far from the risk of, not only not having family support, but also being pressed to quit the treatment.

In a very different situation, Andres’ father remembers how useless the scientific explanation the doctor gave him was when he told of his intention to stop the treatment. The doctor decided to show to the father the cancer cells in a microscope, to convince him that the sickness was still there and that the treatment was necessary:

The father: ... I was seeing (in the microscope), but since one doesn’t understand anything about that...

The mother: Because the doctors understand what they see there (in the microscope), but one, who doesn’t know, what could we understand?

The father: They (the doctors) can say something to you, but since you don’t know... so he (the doctor) said:

Do you see a circle like this?

Yes I said...

Like a clock like this? By three o clock there’s a little red spot, then by four there’s another bigger.
Yes I said
Do you remember what you saw?
Yes I said
Then he showed me another in the computer and sincerely I didn’t understand anything of what he wanted to say

Andres’ father recognized the good intention of the doctor, but also understood that he didn’t know the language through which the doctor was trying to communicate with him.

Trusting staff members was a very sensitive issue especially in two of the cases interviewed, and at least two aspects were considered by them: the physical appearance of the doctor and the efficacy showed. Doctors being or appearing young didn’t have any advantage, to the contrary:

I didn’t feel trust. First, the doctors were too young, if my child would had had older doctors, then yes (he could trust), I know those doctors are good (the old ones). I know one doctor here in the town, his name is V., he is famous in the village, he is very old already, but he gives good medicine, because supposedly he studies a lot. Not nowadays, doctors nowadays even can buy the academic certificate.

One of the cases interviewed was particularly suspicious about many things in the hospital; one example was their interpretation of the request for signing a written informed consent form to participate in a basic clinical research at the hospital. Bryan’s mother remembers:

One afternoon the doctor called me; he had a lot of papers and said that he wanted me to sign something. When I asked what for? He said that it was some hospital matters, for them to do some tests...He had called several mothers for the same reason, they didn’t sign, but one of them signed and said that the doctor would test in her child to see what other sicknesses he had. I answered that I first would consult with my husband and after would sign, but I didn’t return either to answer or to sign.
The institution asking the parents for a money contribution also appeared to be suspicious for some of them because it seemed somehow contradictory with the discourse that the treatment was for free. In addition, the fact that they had been warned about being asked to pay half of the investment if they abandoned treatment, made them think that every contact from the hospital had the intention of asking for the money, instead of asking them to return to treatment. Therefore, they would probably feel more reluctant to return if they thought that once they were back in the hospital some kind of institutional or legal obligation would be imposed to make them pay. Bryan’s father says:

...I started to analyze that maybe that thing was a kind of business that they have there, because they asked a lot of questions like ‘where do you work?’ I told them the truth, that I work on the land and so…then they said I would pay a monthly fee of $3.00. Other people who said they had paid money $30.00 or more, then I said to myself ‘this is strange’...Then, (after abandoning treatment) they were calling me several times asking for the money, I told them that I wouldn’t bring the child anymore...

Conflicative situations among personnel and parents were also mentioned as reasons to feel distrust and also as a proof of not being listened to and, therefore, not belonging to the hospital system. Manuel’s mother recalled the day she tried to explain her difficulties to someone from the staff:

...I wanted to talk with someone from the personnel, but the person said: ‘No! I already know all the problems of the people here’. So we realized that there was no one with whom to have an understanding.

There can be similarities among the situations experienced by each parent in the process of learning and adapting to the hospital, but the way in which each situation impacts and is interpreted by each individually can be unique. The institutional environment can’t perceive that. From basic and obvious matters like the differences in language, to other much more complex things like the analysis of each way of reasoning, the gap among parents and medical staff in an institutional setting is definitely an important and unavoidable topic determining the actions from both sides of the relationship.
When emotional suffering is unbearable

Even though emotional suffering was not clearly recounted in all the interviews, how the mothers experienced their child’s situation seemed to be a topic that played a role when judging the convenience and benefits of the treatment. The mothers were mainly the ones in charge of taking children to the hospital and being with them all the time. Only in one case was this responsibility shared more or less equally with the father.

The mothers suffered witnessing their child going through pain and fear. In light of this suffering, they were always evaluating how painful the treatment was according to the reaction of the child, but also how the medical staff cared for the child and managed his/her fear reaction. Being there at the child’s side while he/she is undergoing painful procedures, or is vomiting, feeling sick or scared is what mothers usually had to bear, and for some of them this represented too much. Katy’s mother remembers her own suffering:

...Each time they had to puncture my child she cried so much, and I said ‘oh my God’...I couldn’t bear to see her when they had to puncture her, and that was a big suffering for her and for me...

Sometimes I used to ask my husband to tell me what we could do because I didn’t want to take the child anymore (to the hospital) because my heart was in pain seeing her being punctured. I used to say that I rather me to be punctured instead of my child...
When praying I used to say ‘Lord I can’t bear it’, there was a moment when I said (to God) that if my child was not going to live, I rather her to die a quick death, because I didn’t want to see my child suffering anymore.

Being the ones who were usually directly involved with the treatment issues, the mothers had many tasks to do without help, and some told about how they felt lonely, both physically and emotionally. At the hospital they didn’t have companionship from their community or family, and the only people they were in contact with were the medical staff or other mothers in the same situation as them. Even though sharing with other mothers helped them to find support and companionship, mothers complained about not being understood at home. Katy’s mother
explained her feelings, and Javier’s mother told about how she underwent the whole year of treatment without help:

...You want people to feel what you feel, but that will never happen. Maybe they will say ‘oh I’m sorry’ or ‘let me know if you need something’ but at that moment it is not about economic help, it’s more about feeling consoled...

...I was the only one going to the hospital, maybe if there would have been someone else, let’s say my mother, saying: ‘don’t go this Thursday, I’ll go for you’, maybe things would had been different, giving me some rest for my mind...

...The child’s aunts don’t know what it is to keep awake all night. Only the mothers of the other children (patients in the hospital), helped when he was in the hospital and I had to work and leave him alone, so they helped me when he needed to change his clothes or something else...I remember one day I woke up in the night to help him to pee, and I saw my feet so swollen that I couldn’t walk, then I realized that I needed someone to help me, but no, I finished the treatment and nobody helped me...

Iris’ mother explained that her in-laws said to her with irony that she was only “feeding the busses”, meaning she was wasting her money by going to the hospital, which made her feel that she was the only one who knew and understood what her daughter sickness was.

Conscious or unconsciously, the mothers were in the position of having most of the responsibility for all that was related to the child’s sickness and treatment. They were the ones who talked with the doctors, saw the treatment, managed the information and faced all the difficulties that being in the hospital may represent. Responsibility had many different levels and increased the mothers’ feelings of loneliness and anxiety. They were in the position of being responsible for both allowing the suffering of their children and deciding if to continue or abandon the treatment. Javier’s mother explained how she felt like she was in a blind alley with her son reactions, as he had been constantly pushing her for stop taking him to the treatment:
...He (the son) used to say to me: ‘I would like you to make them (the doctors) give you the chemotherapy for you to feel how I feel’...the day I felt overwhelmed was when he went on his knees saying: ‘Please no mom! Please don’t take me to the hospital, I beg you... I said to myself: ‘Let it be God’s will; I don’t know anymore how I lose him faster, by giving him the treatment or withdrawing?’

In this situation, her reference to God’s will doesn’t have a religious connotation per se; instead it reflects the feeling of giving up from the struggle with the dilemma of the harmful treatment and the long term possible cure.

Katy’s mother told how much she needed to share her feelings and how these were influencing what she wanted to do:

...I told my mother I didn’t want to take my child to treatment anymore, I was depressed, and she had been seeing me. She said: ’it’s your decision. I won’t inquire (further) about why you didn’t continue. I understand you, because I know how the child is and has been doing...

Iris’ mother needed money from her husband to go to the treatment each week; however, when things became more difficult and he didn’t have enough money, she remembered him saying to her: “It’s up to you. If you want, don’t take her anymore (to the hospital).” In this case, clearly the resources for going to the hospital were not in the mother’s hands, but the responsibility was placed upon her by the husband and by the hospital, since she was the only adult who showed up for Iris’ treatment.

Parents, and especially the mothers, were going through the process of treatment, managing their own feelings of fear and pain, having a role of adults strong enough to cope with everything and being responsible for the child, but at the same time, they had to deal with the feelings of the rest of the family, especially from the sick child. It seems that the dilemma of how to better support the child through the treatment was very stressful for the mothers, and feeling responsible for what the child was undergoing through the treatment in the hospital was the biggest pain.
Religion as the main reliever, God as the main doctor

The topic of religion and how it enters in the story of each case is the most flexible and bendy one. It seems that religion becomes the resource that supports the situation of the parents when stopping the treatment, and gives them emotional comfort and relief from biomedical worries.

Most of the cases interviewed didn’t hesitate when referring to God as the ultimate or even only healer for their child’s sickness. The respondents were actively participating in church congregations at least once a week most of them in the Evangelistic Church. Some were actively religious before the child was diagnosed, in other cases religiosity in the family was not so involved with the community activities, and one case started a relationship with the church as a consequence of the diagnosis. How these parents’ faith was shaped according to their own circumstances was unique, but there were also plenty of interesting shared details, which I will explain in the following.

Trust in God’s power for all the dimensions of human activity is a common expression in El Salvador. The tendency of the general population and of the interviewees is to constantly express in the common discourse their trust in God and his presence in all daily happenings. Two moments are related to both God’s presence and power: wishes for something to happen and thankfulness for something that did or didn’t happen. God’s presence is referred to in every common thing, especially among those who are more religious: simple things like being on time for an appointment or arriving home just before the rain starts, which other people would attribute to luck or chance, would be attributed to God’s presence. Expressions like “I have a job thanks to God” or “Things will be better if God wants to” are common expressions of daily life included in common conversations. Within this framework it is expected to be absolutely logical that when facing much more serious situations like cancer, the details surrounding it will be understood through God’s presence. The faith in God’s presence is constantly recalled in expressions like these from Katy and Javier’s mothers:

Thank God my child is well now, without pain and happy.

Thank God maybe the tumor is benign because doctors said it has not spread...
Another idea present constantly is a common belief that bad things happen as a consequence of misbehaving or forgetting God’s path. However, parents believe that with the child’s sickness God is not punishing the child, but is sending a message to the adults, whom God expects to return to the path and stop “misbehaving”. The task for the parents is to figure out and think deeply what God wants from them and do it, in order to gain his good favor and maybe solve the sickness. Katy’s mother explains it like this:

...An adult can say ‘I failed God in this or that, and now I got this (punishment)’, and then ask forgiveness from God and he will make the miracle for me; but is not the case with a child. God wants something from us (the adults), he wants us to see the problem and to think how we are failing him, there’s something that he wants from us... (the sickness) is not (because) something wrong that the child did, because children don’t know.

Following the previous idea, then it is expected that parents’ asking for the miracle of cure for their child usually involves some kind of promise or compromise with God, with the most common one being to attend church activities frequently. Keeping this promise is very important in order to be sure that God will also keep his part of the “deal”. Katy’s mother says:

...Sometimes I don’t want to go to church, but my uncle reminds me: ‘you know the compromise you have with God, I have it, you have it, because since we love the girl so much and God has already healed her, now we don’t have to forget that’.

Similar to the idea of the sickness as a direct message for the parents, there is another more subtle way of finding messages from God during the treatment or the sickness. I could often see how parents interpreted some specific event as a sign from God. The meaning of this sign was interpreted according to the context and the ideas that the parents had at that moment regarding what was happening with the child, as well as what they wanted to happen. These signs could be very subtle and were always completely unnoticed by the rest of the people. For example, Katy’s mother was very worried about starting a new chemotherapy plan, however, due to a little
sign of eye infection the doctor decided to suspend chemotherapy that day, which had a happy and hidden meaning for Katy’s mother:

...*For me that was a signal from God. That day I felt happy, sincerely, I was very happy of avoiding the chemotherapy.*

In the mother’s interpretation, this not only meant that the child shouldn’t have chemotherapy that day, but also that she should stop going to treatment. This was the signal she needed to confirm and justify what she had been thinking about doing.

When Steve’s parents went to the hospital to explain that they wouldn’t continue the treatment, the doctor tried to convince the father by showing him the cancer cells in the microscope and in the computer. He recounted that in both times, when he just started to see the images, first in the microscope and then on the computer, they felt a little earthquake, and both the parents and the doctor commented on it. When he was telling the story to his aunt (who is ‘gifted’), she scolded him:

*That (the earthquakes) is for you to realize that you still don’t believe what God has done in your life... I can’t believe that you still don’t see the change in your child.*

Then he realized that the earthquakes were the message from God to confirm to him that his son was already cured.

Trust in God is also expressed in the belief that God knows and will do the best thing regarding the child sickness’ outcome, which can be painful for them as parents, but God knows better anyways. They expected God to cure the child and they were sure God had already done it, but also accepted that it could also not be the case. Both situations are combined and coexist together in the discourse as Katy’s mother says:

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7 I’m using the word in English “gifted” meaning people that the parents referred to as having some special power given by God, like dreaming or seeing what God wants or having some healing power.
…Then I said to my husband: ‘if the child is going to die, I give her to God. I don’t know what will be his decision; because children are God’s angels, and he will decide what he is going to do with her.

…Children belong to God. We as parents don’t want our children to die, but if it is God’s plan to take my daughter, let his will be, I know that my child goes with him, no problem, that’s why it says that children are borrowed (the Bible)…

Immediate results and no side effects

When asked about what kind of resources they were using, if any, to help the child’s health to improve after abandoning the chemotherapy, none of the cases mentioned any complementary or alternative medicine and all referred to religion as the only and best alternative, which, indeed, they considered that had worked perfectly.

When talking about cases he saw in the hospital that have gone through the treatment and relapsed, having to start the chemotherapy again, Manuel’s father said:

Don’t you think that it is better to trust in God? Because God heals all at once, without giving treatment for years. All the money they spent and now they have to start again.

Interestingly, the father linked the fact that trusting in God was better because it gave immediate results with the fact that besides treatment lasts long and doesn’t give guarantees, also represents spending money. All these can be avoided when the chosen option is trusting in God.

Most of the respondents referred to miraculous healings that they had witnessed, had been told about, or even had gone through themselves. Four of the cases claimed that their child diagnosed with cancer had been cured by God’s power, and all of them recounted other stories upon which they supported their beliefs. In many of the miracles they were told about, the healing was preceded by a declaration of incurability by the doctors, followed by requests to God for cure and then the cure. Sometimes the sick person rejected the biomedical treatment and stayed with prayer as their only treatment, sometimes some kind of special “sacrifice” was asked for in order to probe the faith of the person, but most of the time frequent attendance at church meetings and healing prayer sessions were enough to be “benefited” with a miracle. Sometimes, parents also got some medical verification of the miracle through some blood test or other kinds
of minimum consultation, however, this verification was not for “testing God”, instead it was for the non-believers, including the doctors. Manuel’s father recounts:

Yesterday the brother in the church gave us his testimony and said: ‘I had a spoiled lung, perforated. Doctors did several tests and said that I wouldn’t tolerate the surgery. Then I went to a doctor from the Prophetic Church and he said that there was no case, I was too ill and wouldn’t tolerate the surgery, that only God could do something. For three months I could hardly breathe, couldn’t sleep or sit down… then a Christian advised him: ‘Make a sacrifice, you and your wife do five fastings, ask God and he will change everything. Have faith.’ He could hardly finish the sacrifice and then he felt better. He went to the doctor to repeat the tests… when the lung appeared in the screen it was healed, it was new! And he’s healthy now.

…what God does, doesn’t need medicines, or exams. If you believe in God, if he is going to heal you, he will do it all right, not half way. In one single time he solves everything; without treatment he will heal you. But if someone doesn’t believe in God, then they should seek for medicine; but when the doctors say ‘there’s nothing to do’, they will need to seek for God if doesn’t want to die…

For the parents the miracle had been done because they could see the child was healthy now instead of what they saw or felt when they were going to the treatment. Andres, Katy and Manuel’s parents recount:

During the first ten days in the hospital the child was feeling bad, but once I ‘reconciliated’ (turn or accept God’s path) after those ten days the child changed completely, he would play, talk, was calm with the nurses, but at the beginning he was always tired, I was worried seeing him like that…

Then I asked God if it was his will to heal the child, I had faith that she will heal. I didn’t want to have her in the hospital, because, there are so many cases of people cured of cancer without explanation. Maybe we can’t say when it happened or how, because
our mind is not enough for that. But I said: ‘God will heal the child’, because God says that we just go near him and he will come near us. So I didn’t take her anymore to the hospital. Thank God she hasn’t had pain or anything else.

...In the hospital he was always laying in the bed, all the body swollen. Then we started to give him vitamins trusting in God. Then the swelling started to decrease, the hair returned.

There were some cases when doctors expressed high levels of optimism or referred to good results of treatment with phrases that confirmed the idea among the parents that the intervention of God has been involved in the results. Andres’ parents said:

When we both accepted (God’s path) we saw how our son changed, he started to eat, at ten in the morning we had to ask for more food in the kitchen, and at lunch time he ate again...even the doctors said: ‘Andres is not sick, if the patient eats then he is not sick.’...we took him to another doctor (after quitting treatment) who believes in miracles and he said that was admirable to see how Andres’ condition had changed

Katy’s mother remembers the comments of the doctor when she first arrived at the hospital with the child in bad condition:

Your child’s kidney was not working anymore...she was living practically with only one kidney; it’s because of God’s grace that she is alive.

Community support
According to respondents, the religious community became their only or the most important source of support. Most of them explained how difficult it was to be in the hospital where the “language” was always about pessimistic and scary information; they felt that the community church could “speak their own language” and they felt supported and relieved with them. None of them said that they had been in a situation where the community asked or recommended to them that they should leave the biomedical treatment. Mainly, the community
provided supportive words to keep their faith, to do their best efforts as parents, and trust in God’s power. Katy’s mother and Manuel’s parents say:

...Then the brothers and sisters (from church) helped me a lot encouraging me in praying. I felt like something that gave me consolation, maybe not economically, but morally.

...A lot of people came, and, as you know, when Christians congregate themselves they move mountains. They have come to pray for him, and also we have taken him to several places (for praying). The last person prayed for him yesterday.

If you were in a hospital, with some serious and cruel sickness, then a Christian arrives and says to you: ‘if you have faith I’ll pray for you and you will be healed’. Then with that you feel you won’t be alone anymore. You feel that the other helped and consoled you.

It was also frequent among interviewees that a special member of the church or even a member with special hierarchy from another country, who visits local churches in special community activities, gave his/her verdict about the condition of the child. These opinions are highly valued by the parents, and are considered the final word from God about cure. This “verdict” contributes to their emotional relief, supports them in thinking that the child is not sick anymore, and they feel confident enough to call him as cured. There is no rational probe regarding this opinion and it seems to transmit a sense of absolute trust and confidence to the parents. Manuel and Katy parents told:

The last person prayed for him (the child) yesterday. It was a man who, if you hold his hand you feel an unusual thing in him. He’s very Christian; he prayed and said that God sees that the child is healthy. So the best medicine of the doctors was set aside...

I feel relieved since one brother (from church) came from Guatemala, F, a Guatemalan evangelist. He prayed for my child and told me that I didn’t need to worry
for her anymore, that when praying I had to get rid of that (the thought of the child being sick) ‘you have to think the child is healthy, because the Bible says that with our words we can talk for good or bad, words have power. If you are saying ‘the child is sick’ then you believe that because you say that. Then, if you think the child is not sick anymore, then you believe that. You have to declare your child healthy each time you pray: repeat she’s healthy, she’s healthy. If you declare so, is because it is so.’ I felt that yes, he helped me so much, and I’m not thinking that my child is sick anymore.

Also, these special or “gifted” people warned parents about how to proceed with the sickness of the child, which was something that happened several times to Andres’ parents:

...The last time we went to the hospital Andres had an injection in the leg. Then he started to feel very bad, and we had been told that if he receives again more treatment he would worsen... A sister (from church) who is gifted told us that our son would be sick more than it was before, from the same sickness or different. And it was true, he was very bad, couldn’t stop crying...

In the hospital, all the cases of parents who expressed that they were leaving the treatment because of their faith in a miraculous cure, the reaction from the staff members was to tell them about the many cases who, in the past, took that decision and after some months the child turned sick again and died. These attempts of discouraging the parents only seemed to have the contrary effect, and the immediate conclusion of the parents was that doctors were lacking faith or even worse, non-believers. For the parents, this situation seemed to prove that medical treatment was the wrong option because is based in a system with people whose beliefs are against God, which is an environment that should be avoided if they are believers. According to this logic, this situation positions doctors as clear opponents to God, and if it’s so, then doctors’ attempts can’t succeed. Manuel, Andres and Javier’s parents recall:

I asked the doctor if my child could save his life from this sickness. He said: ‘30% dies, 70% saves; and those who die is because they stop coming, they shouldn’t trust God
is going to save them. Others go to witches, and that’s how they die... That doctor doesn’t believe in God...

...The doctor was angry and said ‘if you don’t bring the child anymore, in two months you will return here in worse condition.’ Thank God we have now five months (without going to treatment).

...When I told I wanted to stop the treatment the doctor said: ‘No! If you stop the treatment he will be alive one month and after that he will die’...

These answers gave the parents exactly the opposite feeling that they found in their religious community; instead of support and hope, they received scolds and death warnings. For all those parents I interviewed these predictions from the doctors became not a scary memory, but a proof of how little faith the biomedical system has and offers to them. When watching their children looking healthy and relieved from all the pain and bad memories the treatment represented, they can only confirm that God is the only one, the almighty.

Religion came to be embedded in all the other previously explained aspects that arose in the interviews. Clearly, religion is for these parents the biggest source for getting emotional support and hope, all the life circumstances and happenings alongside the treatment experience appear to be judged through the lens of religious beliefs and explanations, which represent a supportive frame of lay knowledge and confidence.

**Trusting biomedicine**

For Marvin and Jose, life has not been easy. Their families are extremely poor; their parents fight for subsistence doing all kinds of temporary work when available in the fields according to the season. For some months they have been going to the hospital to have chemotherapy.

For the 21-year-old Marvin’s mother, having the money for traveling to the hospital is a constant agony. She sometimes does the laundry for some neighbors to help feed the small family and complement the financial help she receives from the hospital. She is very scared of missing appointments, which has happened three times, because it jeopardizes the effectiveness of the treatment. Each time she hasn’t been able to travel she calls the doctor in the hospital and
explains her situation, and she manages to get there two or three days later. If Marvin feels ill at home she calls the doctor instead of giving some medicine by herself.

Marvin’s mother says that she had trust from the beginning that God would make her son avoid bad effects from treatment, and it has been so. She doesn’t give vitamins or other alternative medicine to the child, but she goes to the Jehovah’s Witnesses church because Marvin likes it very much. When there’s no work to do in the fields, Marvin’s father traps some “garrobos” (kind of lizard whose meat is similar to poultry) for selling. Only Marvin’s grandfather, each time he sees the child ill, says that doctors are killing the child. She doesn’t think so.

Jose’s grandfather didn’t attend school, but he managed to learn to write and read, and he notes everything the doctors and nurses recommend in the hospital. He very much likes all the people who work there because they are kind and helpful. He knows with surprising clarity of mind all the details of the treatment, medicines and procedures. According to him, the treatment is “good”. He recalls the first time Jose had the lumbar puncture procedure; he asked permission and made the doctor and nurse pray with him with the boy already there in the procedures bed. He thinks God always listen, although, he doesn’t attend Catholic Church regularly, but the community is very supportive of him.

By taking care of the field where he has a room for his family, he earns $30.00 and he says he has managed to attend every consultation and treatment up to now because he asks for help from God. God sees his effort, and that’s why there is always someone in his way that helps him. He has promised that Jose will serve God when he recovers his health. Sicknesses are tests that God sends in case we don’t have enough faith. That’s why he never complains; if things are delayed in the hospital he waits. Things will resolve.

Poverty and trust in God were as much a feature of the lives of Marvin and Jose’s parents as they were of the other parents whose experiences have been discussed here. But for them, not going to the treatment is out of the question. They feel grateful to the hospital and they trust the system completely. They don’t think there is another option for healing their children. Their religious beliefs figure differently in their narratives. Like the other cases, they trust that God will help them. As all the parents use to say in the hospital: “First God, then the doctors.” But in Marvin's case, God is entrusted not with curing the child, but with ensuring that he suffers no ill-effects from the treatment. And for Jose’s grandfather sickness is a test of faith.
How all the topics discussed come together in each case to end up in abandonment of treatment, and how the process takes place is probably something unique for every family situation. I'll attempt to illustrate this in the next chapter.
Chapter Four: Abandonment of treatment as a suitable option

The topics that were discussed in the previous chapter - the topics that parents referred to in explaining the course of their child's illness and treatment - are not a set of independent factors or variables to be correlated with continuing or abandoning treatment. They are interrelated, in ways that differ from one family to another, and the significance of any or each of them may differ from family to family, depending on its particular circumstances.

The two more detailed presentations that follow show how poverty, trust, emotions, effects of treatment and religious convictions played a role in each parent's explanation of what they had done, but the roles they played were different. In the concluding sections of the chapter I return to the literature on 'abandonment of treatment', and discuss how the approach and the conclusions of this study differ from what is described there.

Katy: Emotional suffering

Katy is three years old, silent, shy, but curious enough to make some attempts at contact with me after I finished one hour of non-stop talking with her mother, Claudia.

Claudia is young, apparently 25, and despite the hot weather and the fact that she is nine months pregnant, she looks amazingly lively and unruffled. Frank, her elder child is five, and is about to leave for school looking really cute and restless.

Claudia is fluent when talking and can explain herself very well. Her study level is good for the average in the country: she finished high school. She doesn’t have a job; she takes care of the children and household while her husband spends the day in the city center selling peanuts in the streets. It seems quite impossible to sustain a family with that job, and I’m guessing that Claudia’s stepfather and her brother have jobs and some income to contribute to the house where they also live with their respective wives.

Fourteen months ago, Claudia was bathing Katy when she noticed the child’s right side of her lower abdomen bulged and she felt something solid inside which made her worry. However, that was not the first symptom of the tumor that had already started to affect her daughter. Claudia explained that some days before that, while cutting mangoes in a nearby field with her grandmother, a cow frightened Katy, and after that, she started to have some sporadic urinary incontinence. But when the girl’s urine turned red, Claudia decided to take her to the
nearby public clinic thinking that an infection was affecting her child. There, the recommendation was to do an ultrasonography (USG) and give Katy some antibiotic. Claudia gave the antibiotic, but didn’t have the USG done, which she would have to pay for in a private clinic. The child improved for a few weeks and then started to have strong pain when urinating, which alarmed Claudia, who took the child to a secondary level hospital. At the end of the day after many tests, she was informed that admittance was necessary. Claudia paid for the USG but didn’t get the information about the results. They spent five days in the hospital, the pain was relieved, and Katy was taken to the national pediatric hospital for a consultation with the nephrologists. However, they couldn’t be attended to because the hospital was on strike, so Katy was discharged from the secondary level hospital with the plan of a new admittance the following week for continuing the consultations.

Claudia felt that she had spent five days in this hospital where they couldn’t figure out what was happening with Katy and she didn’t get an explanation; since the pain was gone, and she didn’t like to see Katy undergoing so many punctures for the intravenous medication, she decided not to return.

It was at that moment that the family started to pray for Katy’s health, congregating in the Prophetic Church. Three months later, Katy’s pain returned along with difficulties urinating and defecating, and Claudia recounted: “…Then the problem was more serious and I took her to the Bloom Hospital.” (the national pediatric hospital).

Once there, she felt better informed because the doctor told her that Katy had a tumor in her right kidney and several tests would be necessary to perform, which would take a few days. The information relieved her uncertainty, but also represented a terrible shock for her: She explained, “The trauma for one to be told that your child has a tumor…I wanted to die…I knew that cancer can’t be cured.”

Then Claudia received all the information regarding the help that was available for them⁸, and was also informed that because many parents stop the treatment prematurely when they see their child improving, the informed consent she would sign included an agreement which meant that in case she abandoned the therapy, she was obliged to pay the half of the money invested in Katy’s treatment by the Foundation that would help her. Claudia recounted how, for her,

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⁸ This includes free medical attention and medicines, accommodation near the hospital when necessary and money for transportation when parents can’t afford it.
accepting or not accepting the treatment at that moment was out of the discussion: “So at that moment I signed, it wasn’t an option to say ‘I don’t want to’…” She understood that the treatment was the necessary thing to do.

Katy underwent a surgery to remove the kidney where the tumor was located and started chemotherapy once a week. When diagnosed, Claudia was told that possibilities for Katy to be cured were pretty good.

When the chemotherapy started, Katy was already very weak and thin, and sometimes even walking with an imbalanced gait. Claudia suffered the unthinkable seeing her beloved child crying while punctured and enduring all kind of annoyances. Then, when the child was apathetic and refusing to eat for several days, Claudia felt really helpless, and her main thought was that Katy wouldn’t tolerate the treatment. Katy started to lose her hair; Claudia was also very worried because the treatment was supposed to last one year, but with the first two chemotherapies, walking had become difficult for Katy due to a pain that had started in one foot. She had seen another patient with an impaired foot, whose mother had said that it was consequence of the medicine Katy was receiving.

Katy had gone just three times for chemotherapy, when new information from the tests revealed that she had a kind of tumor that meant that the child did not have very good chances for survival. Claudia was told about the change in the details of the diagnosis, which meant changes in the prognosis and the treatment, and she felt desperate. Katy would need to go for a five day admittance for chemotherapy every three weeks. Up to then, Katy’s treatment didn’t require her to spend more than one day in the hospital as admittance wasn’t necessary, which represented a big relief for Claudia, since staying in the hospital the first days was very stressful. Now she was feeling very bad, thinking of Katy staying in the hospital again for so long.

By the time this bad news impacted Claudia, she and her husband had already started to think about not taking Katy to the treatment because each week it took several days for her to recover after going to the hospital. According to Claudia, she and her husband shared the same opinion about how harmful the chemotherapy seemed to be, and that maybe it would be better to continue praying and trusting in God. She admitted that talking to someone from the staff at the hospital didn’t seem an option for reliving her suffering and worries because she didn’t feel enough trust.
Claudia was convinced that chemotherapy was having a debilitating effect on Katy, and she was very afraid because she had seen other girls in the hospital looking plump and healthy, whom she came to know that had recently died suddenly. This made her think that Katy had no opportunity for survival if even those girls who were stronger and healthier had died. She explained, “Children who are already grown up die, even when they can have more defenses, then you can imagine my child, who’s only three years old, she won’t tolerate it.”

The day the new session of chemotherapy was to start, Katy had already been admitted to the hospital when Claudia informed the doctor that Katy’s left eye was looking red. After examination, the doctor told Claudia that it would be necessary to suspend the chemotherapy to prevent an infection, and after five days of antibiotics at home he would evaluate Katy again. For Claudia this was a clear sign from God meaning that it was not convenient to give the chemotherapy to Katy, and she felt very happy and relieved. At the following appointment, the doctor said that Katy was healthy and she would have the chemotherapy after two more days.

Meanwhile, Claudia and her husband had been talking about the worries they had and also about what it could represent for them to quit the treatment, remembering the explanation they had had when Katy was diagnosed. One day they were asked to buy some pills that cost $30.00, but they couldn’t afford it, so now they were thinking that if they had had three chemotherapies for the three times they had gone to the hospital, now they would have five chemotherapies in one single visit, which would represent a bigger amount of money; so they thought that it might be better if they stopped the further treatment before starting this new session. Moreover, Katy’s mother expected that this new scheme of chemotherapy would be even worse, because if it took the child almost the whole week to recover from one day of treatment every eight days, then 22 days for five days of chemotherapy wouldn’t be enough, saying:

So I evaluated everything, and seeing how bad she was with one day (of chemotherapy) each week, she would not tolerate more than that...if she’s not going to tolerate the chemotherapy, which is the medicine for eliminating the cancer, then let it be God’s will, because if she’s going to die because of the chemotherapy, then it’s better not to put it anymore and I take on the consequences.
The day Katy had the appointment for starting the five days of chemotherapy, she didn’t show up at the hospital. Her mother explained “Then I didn’t take her that Thursday. I didn’t take her anymore. I said to myself, I know God is with me, and he will do his willing with my child.”

Since that day, five months ago, Claudia feels calm. She’s happy making the food for Katy and seeing her eating. Her tranquility comes not only from the fact of not having more chemotherapy for Katy, but also because her religious community and reputable pastors have claimed that God has healed the child. She’s not afraid of the sickness returning. She remembers the words of the staff members warning her against abandonment when she was just starting the treatment, but she says:

It is not that one doesn’t care (about the help they receive in the hospital), it is that you care a lot about seeing your child suffering, at least that was my case. It was not that I didn’t want it any more (the help?). I didn’t take her (to the hospital) any longer because I believe in God, that he healed my child. Whereas there are people that see their children well and they don’t care, they are not Christian people… but me, thank God, I didn’t take her to the hospital anymore, but we go to the church.

Claudia didn’t look for any other kind of therapy; she only needs to keep trusting in God. Trying to take care of Katy the best possible, she receives a few special considerations like less salt in the food, no chips, soda or canned juices and, when she’s misbehaving, or fighting with her brother and the father starts to scold her, Claudia intercede saying “Let her be, because thanks to God she’s now alive; remember when she was sick and you brought her the things she liked and not even that she wanted to eat.”

Claudia is convinced that children belong to God, and he loans them to us; he knows our weaknesses and knows how to help us, everything that we need is to trust him, and that is why she decided not to take Katy to the hospital and instead let God make his will. She prayed for Katy’s healing, but God decides, “Because God can test us where it hurts the most, for us to recognize that he is the only one and the almighty.”
Manuel: Conflicting logics

Things didn’t start nicely for Marta when she went to the community clinic with her youngest child Manuel in very bad condition. The first recommendation she got from the doctor was to leave her husband. The doctor even offered to send the police to put Manuel’s father in jail for taking so long to decide about going for a medical consultation for the child. The already offended Marta was then scolded for medicating Manuel by herself during numerous days with oral and injected painkillers. She was urgently sent by ambulance to the pediatric hospital in the capital. Several weeks later, when Manuel returned home, he was hairless and weak, which to Vicente, his father, didn’t represent a sign of improvement at all.

In the hospital Marta was told that Manuel had leukemia, and would need chemotherapy treatment weekly for the next three years. However, for the first month, he would need to visit the hospital much more often. To accomplish that, Marta used to leave her home at three in the morning, using a hand lamp to light the shortcut through the bushes to the main road, while carrying Manuel and the bag with his extra clothing.

Vicente was not happy at all seeing the big sacrifice of his wife, the bad shape of his weakened and hairless child, and spending $20.00 per trip. His work in the fields gave him $48.00 every two weeks. There were no mathematical operations for making this money stretch to afford two or three weekly visits to the hospital as well as feeding the rest of the children: Maria, 17, Juan, 15 and Graciela, 10. For Vicente was it absolutely nonsensical that they had to do such a complicated journey to get an injection, when the community clinic was within walking distance to his house and where it would cost a few cents to get the shot if the hospital only gave them the medicine. Marta explained that when they were in the pediatric hospital the first few days, they expected that things would be like they were in the local hospital, where usually people once were discharged; they didn’t need to keep going frequently.

The couple was displeased with the help the hospital was providing to them, which they considered insufficient. They were advised that they could pay the transportation to the hospital with some borrowed money that would be refunded once they get there. But according to Vicente, he already had enough debts from the many days Manuel spent in bad condition during his hospitalization. Besides this, the free meal the hospital provides for the mothers as an extra help is only once a day, which Vicente considered almost offensive because as he said, “A human being eats three times a day, even children!” They also didn’t feel pleased with the way
the medical matters were handled. In the unit, five specialists from the staff attend all the children, without a specific doctor in charge. For Manuel’s parents this was extremely weird; their son didn’t have a doctor. The last day they went to the consultation Marta didn’t have the $4.50 to buy the lumbar puncture needle that they requested. A doctor that they didn’t know was in charge of the procedure and Manuel struggled with strong pain. Marta thoughts that they hadn’t used enough anesthetic for her son on purpose, because she didn’t buy the needle and the hospital had to provide it. Manuel arrived home limping and they gave him natural remedies for the pain for several days, because the medicines that the doctor prescribed weren’t effective.

The couple was very thoughtful about all these happenings and Vicente’s process of thought was simple and practical:

We’re spending the money (by traveling), she is maltreating herself (by traveling and staying at the hospital), the boy may die (because of the sickness), and the doctor is killing him (with harmful and risky medicines). If he has to die, it’s better he has a good death.

They didn’t return to the hospital. Instead of that, they took Manuel to the church and the community mobilized to guarantee enough praying for him.

Vicente and Marta have taken a solution that is not unfamiliar to them; they have witnessed numerous healings through God’s intervention. For them, God resolves the situations without as many complications. In order to help God’s work, they bought vitamins and fed Manuel with the wild herbs that common food in the countryside includes that are believed to be rich in vitamins and iron. This option was pretty effective; according to Vicente, many community members from the church prayed for Manuel and declared him healed, and he was rapidly doing well, even his hair is almost normal again.

Vicente and Marta had not a single shadow of doubt about the correctness in their decision to abandon the treatment and stay with their faith. They have plenty of testimonies to recall; even his father and Vicente himself have gone through a miraculous cure. He remembers an unknown illness that affected him when was younger; the doctors didn’t know the diagnosis and said it was impossible to cure. Vicente was lying in bed feeling that he was about to die when the religious community gathered for a vigil and fast, and after few hours he was already

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9 Parents are asked to buy the needles, and when they can’t afford it, the unit has a stock for providing them in special cases.
feeling better and asking for food. He also remembers when his father fell down in the stoned road with a heavy bag of beans and broke his rib. He refused to go to the doctor because he was sure that if surgery was required he would not heal properly. The Christian community gathered for praying and sacrifice and immediately he woke up without pain. Vicente’s conclusion was that only God can operate without cutting the skin, and now probably his father would have many bothers from the long-term consequences of a surgery.

As the religious community assures the miracle, Manuel himself is also confident about his health. If his mother says that people from the hospital have been calling, he answers emphatically, “If they want to take me by force, I’ll run away! I am not sick anymore, God healed me.” She remembers that last day in the hospital when he said crying: “Don’t bring me here anymore Mom, I won’t come. I know God will heal me.” She felt these words gave her strength and felt happy.

But the couple has chosen their options not only for their religious faith; they also had examples of bad outcomes when trusting doctors. According to Vicente, his uncle’s child died of leukemia in the public hospital even after they requested many blood donors for him, and money. That’s why Vicente says, “We are going to put our faith in God (not medicines). God will do everything. I won’t spend one more penny, because (what will happen is that) I will spend, he will die, and then I won’t have for the house.”

For Vicente, many doctors know only the things that they have studied in the books, but they don’t know what living with a sickness is. Theoretical and practical aspects are different, even when talking about the same thing. He feels very offended remembering what the doctor in the community clinic said to his wife, and states that being a doctor doesn’t give anybody the right to rule the patient’s house; a doctor’s duty is to give medicines, not to get into others’ life.

Things returned to normal at Manuel’s home, life is tough for everyone and everything is in control.

Interlinked topics
For Katy’s mother, Claudia, feeling constantly overwhelmed by witnessing her daughter’s suffering represented the main topic, together with the effects that the treatment had on the child, through which she explained abandoning the treatment. In this case, the combination of these two topics resulted in a justification that was more than logical for Claudia to stop the treatment. Then, religion gets the role of giving the support, first for attempting to
bear with the situation and get some strength, and further, for assuring a safe environment when leaving the treatment; the idea that the child won’t be left unprotected against the sickness because a superior force will take care of her.

A personality trait, which is the intense sensibility of Claudia towards her daughter’s suffering, plays maybe the biggest role; her inability to cope with her own suffering made Claudia focus exclusively on the current effects of the treatment, and prevented her from thinking of the long term benefits. However, another situation came into the picture when the prognosis for Katy dropped down, taking away most of the hope that could have been placed on the biomedical option. Then, this biomedical option turned to have a change in the way it could be evaluated, because the cost-benefit evaluation gave a negative result for biomedicine when putting in the balance of how much suffering treatment was causing at the present, and how much benefit it could bring in the middle-long term.

If the answer was that the long-term benefit of treatment was saving Katy’s life, it seems that that should be a reason valuable enough to undergo every sacrifice, even if the chance is small. But in the logic of Claudia the sacrifice was not hers, it was her daughter’s, which caused an unbearable pain, especially because she felt responsible for that. Thus, Claudia’s suffering had two (sources): first, seeing the child’s suffering and being she responsible for this, and second, having a big probability of ending the journey with Katy’s death after providing her many days of suffering. With this panorama, the best answer that could rescue this equation was religion, being the best option of avoiding all the pain for Katy. Deciding withdrawal when at least having a small chance of success with the treatment can seem uncaring to the child, but through religion comes an error proof answer: undergoing the treatment gives big suffering with small chances of surviving. Instead, God gives no suffering and the chances of surviving are in God’s hands. Since God is love and almighty, he can cure Katy, but given that he knows the best and our mind can’t reach that knowledge, if Katy has to die it will be so. Therefore, in Claudia’s mind, in both cases treatment is not necessary. He will heal her because it is the way it has to be, and if it’s not, it’s his will, but the responsibility won’t be placed on Claudia and the suffering of treatment would be avoided.

Why in this equation weighing treatment or abandonment is the winner God? Because of the immediate consequence of relieving the child’s immediate suffering. Treatment and religion represent options with an unknown outcome for Katy, however, chemotherapy represents current
suffering, and religion represents current relief. If thinking about the future outcome is all about uncertainty, then it is better to pass that uncertainty to God’s hands, and the sure thing is that at, least now, her suffering will be gone.

Religion becomes the lifesaver, not only for the child who is recovering her health by praying, but also for the mother who can deposit the responsibility and the power regarding what happens with Katy in God, who always knows more and better, and always has a good further intention for us. Through this kind of reasoning, doubting or asking what if things have a non-desired outcome doesn’t make sense, because the only answer possible is that everything is in God’s hands, and he will help us to accept his will, whatever that might be. This protective and safe way of thinking protects Claudia against possible feelings of guilt or regrets about abandoning the treatment.

Moreover, religion gives, as described in the literature, the emotional support and feeling of hope that the medical relationship doesn’t provide. In this environment, hope doesn’t need to be based on any logical reasoning or scientific facts and probabilities. Hope here is a matter of faith, thus, it will resist all bad news or somber prognosis from doctors. In this environment, feelings of loneliness from the mother are also alleviated; that’s why religion works as the best option for all kind of emotional support for Claudia.

Because the outcome of the treatment is so uncertain and the course through it so devastating for Claudia, abandoning the treatment may be seen as the answer for better dealing with the feelings of not knowing what is the best thing for Katy, and at least, withdrawing her from the source of immediate pain also gives relief to Claudia. God will take care of the mid-long term results, and if the child “has” to die, then Claudia, by abandoning the treatment, could avoid feeling responsible for making Katy go through so much pain during the last days of her life.

The second case represents a different combination of topics. For Manuel’s parents their conflictive relationship with the medical system began before arriving at the pediatric hospital. Actually, it was pretty obvious that they were avoiding biomedicine as part of a kind of “belief system”. They did everything possible to heal Manuel without the intervention of doctors. They tried home medicines and pharmaceuticals, and left medical consultation as the last resource. Once in the clinic, all their possible bad ideas about doctors were confirmed. The institutional power managed to command, and Manuel’s parents managed to navigate in this situation, while
collecting a bunch of reasons to confirm their opinion that a better solution for them would be outside of that system.

In this case, the bad effects of the treatment, together with the perception of the institution as not trustable were combined as reason enough for abandoning the treatment. As in the case of Katy, Manuel’s parents returned to religion as the safe resource where their feelings of hope and their requests for healing could be accommodated. In Katy’s mother’s case, religion was saving her from the suffering of her daughter’s treatment, and in Manuel’s case religion was saving them from the conflictive situation of spending the money which would maintain the whole family on Manuel.

If Manuel’s parents wouldn’t have felt so distrustful towards the hospital, the help it provided would have given them the chance for continuing the treatment, so in this case, the combination of poverty and distrust in the system was the formula for ending up in abandonment. Religion made them feel confident of the good results of their option, which at the same time looked pretty much justified when exposing a list of complaints that made the institution look like a very bad alternative, and their abandonment as a very logical outcome. As Manuel’s father said openly, the resource of God represents the perfect way for feeling comfortable by doing something for the child without spending money (and in his view, this represents the best option because God is almighty), thus the message for themselves and for the community is that they are not passive, they are taking care of their son. At the same time, this resource provides emotional relief for the parents in two aspects: by giving support among the community and by placing the responsibility for the coming happenings on God’s will. This resource prevented them from struggling with the decision of how to spend the money among the necessities of the family. In Vicente’s logic, it was implicit that Manuel’s needs couldn’t have priority over the family needs.

While in Katy’s case poverty didn’t have an influence in abandonment, in Manuel’s case played an important role. According to his parents, they abandoned the treatment because they couldn’t afford it. Lack of money for transportation was the most concrete expression of poverty regarding getting access to the hospital, and that’s why funding for the parents is available. However, poverty also involves other kind of “lacks” or difficulties, like the limited access to transportation when living in remote areas, or making a sibling quit school in order to take care
of the home when the mother is at the hospital. These and many other situations related to poverty can’t be solved by the hospital.

The discourse of Manuel’s parents is then integrated with four different elements: the money they earn was not enough to afford the expenses of going to the treatment and maintain the family; also, they had enough complaints about the hospital to be convinced that the institution was not trustable; then, the effects of the treatment -which appeared very closely related to the institutional trust- confirmed to them that the biomedical option was harmful more than helpful. In that scenario, their religious beliefs offered a much more suitable alternative for healing Manuel, without all the trouble implied in the biomedical choice, therefore, religion seems to have a role of conciliating all the elements and offering an integrated solution.

Even though the topics are shared among most of the cases, the importance that each topic has is related to the presence or not of the other topics. For example, poverty for Vicente appears to be his concrete reason for abandoning his son’s therapy, and the offering from the hospital to pay his transportation didn’t represent a suitable answer, because it was not only about not having that money; poverty in the family is a life circumstance that permeate Vicente’s way of weighing priorities. When poverty interacts with his feeling of distrust towards the medical system, the possibilities for accepting the treatment are annulled. Looking at the complementary scenario, the mistrust influences his view about what is happening with his son, and because of that, the side effects of the treatment play the role of confirming according to his interpretation that doctors are doing the contrary thing that they should do and they are worsening the child instead of healing.

Religion seems to be a very suitable resource for all the parents when they have to conciliate their desire, or act of abandoning the treatment. Through religion and the figure of God as the protective father that will take care of their worries and will manage the responsibility for the child, the parents can deal with the situation and justify their choice through the resource of faith.

Faith or trust in God is clearly a notion that can be used to demonstrate the division between the two territories where the parents move: biomedicine and alternative therapy through religion. Parents know that when talking about faith, they are the experts, and the doctors can’t have an opinion, which shows how distant they are from each other, and why distrust is a reasonable feeling.
The outcome for Manuel, when these topics converge in his family life at the moment of being diagnosed, is treatment abandonment. It is the same for the rest of the children in the stories in this thesis, but how each one came to be in that position, and what the path was that the parents followed to end up abandoning the treatment, is only possible to understand in detail when looking at both the big picture with these topics influencing each other, and the individual circumstances where this process takes place.

In this perspective, it seems that in order to answer my research questions, I could enumerate these five topics as the constitutive elements that influence the circumstances, ideas and concerns that parents evaluate when they abandon their child’s treatment. But that also has a broader framework, since when converging, contextual situations are also intervening in how parents will assess their child’s condition and what kind of response they will have.

Religion became the only resource that parents used for handling their child’s situation after abandoning chemotherapy treatment. In fact, religion seem to be in an ambiguous position of playing sometimes a role as main motivation for changing the treatment to church meetings, and in other cases being the resource for justifying the abandoning the treatment.

**Reflections in the light of the literature**

Some of the five topics I could identify in this research have already been mentioned in the quantitative studies cited in the first chapter as “reasons” related to abandonment. Coinciding with the topics I have described, those studies found that “factors” like poverty, doctor-patient relationship and beliefs about the treatment correlate positively with abandonment. In reaction to that information, interventions like providing funding for the parents’ transportation seem logical options when trying to reduce the influence of poverty in abandonment. However, since poverty represents such a multi-dimensional living situation, much more complex than the mere lack of money, this offer will be suitable only for some of the cases.

It seems that research based on the biomedical perspective may make the assumption that parents find themselves “forced” to abandon the treatment by circumstances beyond their control like lack of money or other structural social situation, and, if these circumstances weren’t present the parents probably wouldn’t have stopped going to the treatment. Even though many of these “structural and external” situations are definitely influencing parents’ perspective, the fact that they also have their own frame of reference to judge life happenings and to face problems seem to be an absent notion in this conception.
The aforementioned complexity among the circumstances that can lead to abandonment of treatment, and how these are interlinked, can be related with the idea described in the literature of patients having to manage therapy decisions while dealing with social and familial circumstances and weigh priorities in those conditions.

From the qualitative literature, one of the subjects developed was the use of complementary or alternative therapy (CAM) among patients. The literature presented was produced in developed countries were the use of CAM is increasing noticeably. Interestingly, none of the cases studied in El Salvador were using alternative therapies after abandoning other than religion\textsuperscript{10}. Parents were very enthusiastic about attributing their good situation to God, after the experience in the hospital, and claiming him as the only alternative therapy they were using, since it was the only thing they needed. Their idea of having God as the best resource makes it senseless to look for something additional like doctors or medicines, natural remedies etc.

Nevertheless, the way in which religion and God are involved among the studied parents have interesting differences to what the literature describes: on one hand, the literature describes a kind of religiosity that is much more philosophical when helping to give meaning to the sickness, and more referred to spirituality in a broader sense, (maybe instead of belonging to a specific church). Instead, the religiosity expressed by the parents, was more referred to belonging to a collective and they were much more “magical” in their beliefs and expected outcomes from faith. On the other hand, religiosity in this study, gave the parents some of the benefits that the literature describes from alternative therapies in general, like supportive relationships and hope, which the biomedical system didn’t provide.

Conclusions

The five topics developed in this thesis represent the way in which parents account for their journey through the diagnosis, treatment and the final abandonment of therapy, and their reasoning behind it. The deeper significance of this is that these topics are not independent from each other. The way in which they interlink in each case is unique, because each of the topics means different things for different people. Therefore, the interaction of these topics, not the

\textsuperscript{10} Attending alternative therapy consultation is not very usual, but giving medicines or natural remedies is very common among patients undergoing chemotherapy. Many of these medicines are commercially sold in pharmacies and supermarkets.
topic per se, is what represents the explanatory frameworks that people used in different ways to explain stopping the child’s treatment.

Knowing how these topics and life circumstances relate to each other is essential in having a comprehensive perspective on abandonment, especially when pointing at further proposals for reducing it. However, the tendency to correlate these topics and convert them into “factors” to which to attribute causality would be a reductionist perspective that would fail in showing the richness of the dynamics the parents go through when confronted with their child situation.

Departing from the aforementioned, the implications for researching abandonment and non-adherence to treatment are that qualitative research is essential for explaining the processes and relationships that take place when such qualitative aspects are involved. Topics like the ones developed in this study can’t be reduced to measurable variables without affecting the meaning of the entire phenomenon under study, which represents an important lack, especially if the purpose is to propose further intervention alternatives.
Annexure One:

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Stevenson, F.A., N. Britten, C.A. Barry, C.P. Bradley, and N. Barber

Trostle, J.A.

Vermeulen, E.

White, M., and M. Verhoef
Annexure Two:

Topics for interviews

Open questions for recounting (including facts and feelings):

How the child got sick
How the diagnosis was given
What did they think about the diagnosis and the treatment
Hospitalization and beginnings of treatment
Reaction from the family, community, school, church etc.
Perception of the results of the treatment
Worries/ difficulties about the treatment
Consequences for the caregiver and the family
Abandonment
How do they feel after abandonment, what do they think
Worries about the sickness at the present
Family structure
How the child reacted to the diagnosis, the treatment, the hospital
How difficult was to go to the hospital
Feelings of trust or doubts regarding the treatment
What people said (family, community)
Expectations about results of the treatment
What kind of support received from the hospital/staff
Quality of communication with staff when going to the hospital