Curing children, caring for families

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Introduction

On arrival at the Oncology ward, Patricia’s eyes showed obvious pain as her inflated belly rose with each heavy breath. Speechless, her mother wondered how her lively 5-year-old’s illness that seemingly started just a few days ago had turned into this frightening scene. Doctors explained that Patricia had acute lymphoblastic leukemia (ALL), meaning, “blood cancer”. After she was stabilized, treatment would include chemotherapy and day clinic visits, typically once a week, for more than two years. During the next month, as Patricia received rounds of antibiotics, chemotherapy, and various tests, her mother grew familiar with the ward routines, medical visits, hygiene precautions, and steps needed to look after her daughter. A team of health care professionals would provide what was needed and treatment would be available for free. She never expressed doubts about the treatment plan. When asked whether she was aware how near death Patricia had been and how important it was to follow the treatment plan, she always answered, “Yes”.

It was a different child with sparkling eyes who left the ward to go home to her family in a small province, one hour away from the hospital. But Patricia did not come back for her appointment the next week, nor even the next month.

Ten months later, Patricia and her mother returned. Just as before, her daughter’s condition was deplorable, with bleeding and vomiting. Her smile was gone; her eyes were again unlit. Tireless efforts were initiated in the small intensive care unit, with the oncology team fighting to make resources available. Her mother was, again, speechless. Because Patricia had not completed treatment, doctors thought she could still benefit from starting protocol treatment and possibly be cured if she survived this crisis and actually received all of her treatments this time.

Patricia did recover again. Multiple plans were set before her discharge to facilitate her to continue treatment; her mother would have help from her sister to return, by moving to her sister’s house in a nearby small town with better transportation.

But Patricia never returned. Months later, the team heard back from the village that Patricia had died at home a few weeks earlier.
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Patricia’s story is one of countless I witnessed when I started working in the multidisciplinary team of the nascent childhood cancer program in El Salvador as a recently graduated psychologist. These children’s stories were all similar and equally tragic. Each was an enigma for me to address, and a source of immense frustration. “What do we do with abandonment?” the medical director asked just a few days after I started my job. Seeing the questioning expression on my face, he added as clarification: “The parents who stop bringing the child to the treatment. We need to solve that”. This brief, initial bewildering moment started my journey with abandonment of treatment that culminates with this thesis 20 years later.

ARGUMENT

The Salvadoran pediatric cancer program embraces the values of modern medicine and scientific progress. Unfortunately, treatment abandonment, a non-biomedical response to a child’s cancer treatment experience, challenges the efficacy of the program’s care and success. Abandonment of treatment is the term used in pediatric oncology to refer to the event of a child not beginning or continuing their planned course of treatment. International recommendations state a time frame to qualify for having abandoned treatment as minimum of four weeks of absence from scheduled treatment (Mostert et al., 2011). The Salvadoran childhood cancer program subscribes to this definition and this serves as the inclusion criterion for children in this study who abandoned treatment.

In El Salvador, a minority of children with cancer abandon their treatment, yet this action has an important impact on the cancer program. In this thesis, I argue that in the process of searching for a solution for abandonment of treatment, the health team increased standardization of follow up practices and control, which paradoxically led to increased personalization and quality of care for all children receiving treatment for cancer.

This research follows the accounts of parents of children with cancer in El Salvador who stopped or intended to stop taking their child to the hospital for treatment. It also includes the perspectives of the medical and psychosocial team by exposing and analyzing their strategies to solve or diminish abandonment of treatment. By exploring the distinct views and experiences on treatment abandonment from parents and healthcare providers, this study provides new perspectives for scholarly research on abandonment, as well as recommendations for practical interventions.
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OBJECTIVE

The objective of this research was to explore how parents of children with cancer who abandon their child’s treatment explain their actions, and how the medical and psychosocial staff’s understanding of and response to abandonment of treatment have influenced how care is provided in the only childhood cancer program in El Salvador.

CHILDHOOD CANCER TREATMENT IN EL SALVADOR

El Salvador covers 21,000 km² in Central America. A total of 6.3 million inhabitants include more than 1.6 million children under 15 years old (Central Intelligence Agency, May, 2018). Classified as a lower-middle-income country according to the World Bank (April 16, 2018), a third of Salvadoran households receive remittances from the more than two million migrant nationals in the U.S. (Calvo-González & López, 2015). Crime and violence are the main problems hindering progress and economic growth and 41% of the population in 2012 lived in poverty (World Bank, April 16, 2018).

The Salvadoran pediatric cancer program

Treatment for children suffering from cancer is not a priority within the Salvadoran health system, since the government is occupied with a higher incidence of acute infectious diseases requiring significant budget resources. This is generally true across low- and middle-income countries (L&MIC). The Benjamin Bloom National Children’s Hospital (HBB) is the country’s only tertiary national pediatric hospital and is located in the capital city, San Salvador. In 1993, a partnership was established between HBB, a local non-profit foundation (Fundación Ayúdame a Vivir [FAV] Help me to live Foundation), and St. Jude Children’s Research Hospital (SJCRH) of Memphis, Tennessee. This became known as the childhood cancer program, which offers care in the HBB oncology ward and the FAV medical center for ambulatory treatment. Both institutions share personnel, resources and physical space (the FAV medical center is located inside HBB). Throughout this dissertation, the place where the research interactions took place is referred to as ‘the hospital’.

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1 The sections in this chapter that relate to the background on pediatric cancer care in El Salvador and abandonment of treatment are partly based on my previously written work in 2014: “Parents abandoning treatment for their child with cancer in El Salvador: Parents and doctors’ diverse perspectives and mutual consequences”, in Beyond Diagnosis. Relating person to patient, patient to person. Eds. Peter Bray and Teresa Casal. Oxford: Inter-Disciplinary Press.
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All children under 12 diagnosed with cancer (approximately 200/year) receive free medical treatment at HBB. It is estimated that before 1994, when the cancer program began, overall survival was about 10% (Bonilla et al., 2000). By 2004, cure rates for children with leukemia had climbed to 65% (Valsecchi et al., 2004). Unfortunately, abandonment of treatment was soon identified as an important challenge. The frequency of abandonment was not accurately quantified due to a lack of systematized data gathering processes and the ambiguity of the definition of abandonment. Internationally, acknowledgment of abandonment of treatment in childhood cancer was just beginning and research on the topic was nascent. Multidisciplinary interventions in El Salvador included providing treatment information and financial help for transportation, which reduced abandonment rates from an initial overall estimate of 23% to 13% from 1994 – 2002 (Valsecchi et al., 2004). Following 2002, progress remained stagnant as about 25 children (13%) continued to leaving treatment each year (Bonilla et al., 2009). However, in the past six years of this research, abandonment of treatment has decreased substantially, and I elaborate on these changes in the coming chapters.

The socio-demographic characteristics of the population receiving care in the cancer program reflect the characteristics of the general population of the country. However, internal hospital calculations are used to assign families to categories of need for potential support. These calculations do not match the classification of human development reports at a country level. According to hospital social worker’s data from 2015, approximately 70% of the families coming to the oncology unit live in extreme poverty without a fixed income; they survive on informal, temporary work and have a monthly income below US$ 50. Sixteen percent have a monthly income less than US$ 250, and only 14% live above the poverty level.

Although El Salvador is small and cities are well connected by main roads, in less developed areas, roads and public transport are deficient, which means lengthy and uncomfortable travel to reach the capital city. Trips to HBB can last one to four hours, and require changing public transportation vehicles (buses, mini-vans, or pick-up trucks) two or three times.

Facing abandonment of treatment
The initial years of the cancer program were full of hope. The multidisciplinary team was enthusiastic and discovered the incredible feeling of seeing a child with cancer recovering their life thanks to a collective effort that was as exhausting as rewarding. Professionals working on the oncology ward before the cancer program was established had only seen cancer as equivalent to suffering and death. They were sure that cancer could not be cured since they had rarely seen this happen. Now, there was good reason for optimism
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since promising results were starting to be achieved. The team learned that evidence-based medicine and dedicated teamwork could indeed change the dismal fate of children with cancer. They saw children recovering and entering back to their healthy lives after surviving a diagnosis that a few years earlier had been a death sentence.

From time to time, someone on the team would realize they had not seen a specific child back for their hospital appointments for several weeks. Thus, it was shocking to find that same child at the hospital emergency unit a few months later, usually very ill, severely infected and with visible signs of having had a relapse of their cancer. The shock would turn into helpless frustration and anger when eventually the child relapsed again and died, despite having restarted treatment and achieved temporary remission of their disease. While these stories repeated over and over, the team learnt that cancer was a one-chance disease and abandonment was an open door to the easiest way to miss that chance.

After diagnosis, the child is expected to achieve initial remission of their disease within a few weeks of intensive chemotherapy. The child then receives long-term treatment directed at cure, (unless cure is not possible, in which case they are treated with palliative care). In general, chemotherapy protocols are the best chance children have to survive cancer since bone marrow transplant (an elective therapy for certain types of cancer and recurrent disease) is not available in El Salvador. A bone marrow transplant can be the only option for most children whose cancer has returned if chemotherapy fails to keep the disease in remission. Most children in El Salvador whose disease has relapsed have a grim prognosis. Remission can be achieved a second and even third time with chemotherapy, but since cancer cells develop resistance to chemotherapy drugs, sooner or later most will have another relapse and eventually die. Children who returned after a period of abandonment of treatment, often had relapsed cancer. The team knew, based on science, that each child restarting treatment for a second time after abandonment would most likely not survive, despite their best efforts and wishes. Still, additional chemotherapy was administered as the team thought that maybe this time the child might survive. However, after a few months of remission, the child would inevitably die.

It is understandable that parents are overwhelmed with the burden of their child’s cancer treatment. In addition to the emotional aspects of cancer treatment, the family’s whole life is deeply disrupted in practical ways. Modern treatment entails weekly visits to the hospital for periods of six months to three years depending on the type of cancer the child has. Acute lymphoblastic leukemia, the most common childhood cancer in Central America, requires treatment for 2-3 years. This entails a complex mix of one-day-a-week
treatments, periods of short admissions (3-5 days), several hours of intravenous infusions, intramuscular injections, intrathecal punctures, lumbar punctures and daily oral medications. The treatment for solid tumors, e.g., central nervous system tumors, Ewing sarcomas, osteosarcomas, Wilms tumors, and retinoblastomas, may include surgery for biopsy and/or mass removal, and a sequence of short admissions (3-7 days) for treatment every three weeks, daily visits for one week of injections, weekly visits for medical check-ups, and oral medication at home. Children’s treatment can last about six months, or up to one or two years for the majority of cases. Daily radiotherapy over approximately 28-35 days is required for some tumors.

The treatment schemes provided are based on protocols. This means that each disease has established drugs to be administered at specific times, doses and days. The child must meet required clinical guidelines for recovered physical status before and immediately after each treatment round to continue to the next treatment. If they do not achieve these markers, their next treatment is delayed. This requires frequent clinical laboratory and physical exams at the hospital. Treatment-related complications, such as life-threatening infections, are unfortunate consequences of cancer therapy that oblige the child to pause treatment while the complication is resolved. These pauses (sometimes for days or weeks), and particularly severe infections and added complications can be highly traumatic for parents and children, since they put the child at the limit of losing their life. Many medical specialists are required for successful cancer treatment, including tests, procedures, and medicines. Children who do not adhere to their medication regimen and have frequent and/or prolonged interruptions in their treatment protocols, due to infections, absences, treatment abandonment, etc. have higher risk for treatment failure (Suarez et al., 2015)(Bhatia et al. 2012, Suarez et al. 2015).

Psychosocial care
When a child is diagnosed with cancer in El Salvador, the family’s financial resources have no impact on the medical treatment the child receives. All patients are provided with no-cost treatment. The only paperwork involved in the child’s admittance to the hospital relates to his/her proper identification and clinical history. HBB is the only facility that offers childhood cancer treatment in El Salvador. From the beginning, the program contributed socioeconomic support for patients in greatest need. The FAV provides most of this help, although for many years it was limited and irregular. An association of parents of children with cancer grew slowly (Asociación Salvadoreña de Padres y Amigos de Niños con Cáncer, ASAPAC), and has joined the support efforts by contributing resources for families, especially financial help.

After a child is diagnosed with cancer, temporary housing in the city,
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financial support for transportation or other basic family needs are available following a hospital social worker’s evaluation. Recently there has been an increase in funding with the growing participation of small local donors and volunteer groups other than FAV and ASAPAC. Support includes regular subsidies for parents’ breakfast and lunch when their children are hospitalized (and parent breakfasts when a child is in the day hospital), increased funds for transportation subsidies, and better and closer parental housing for times when their child is hospitalized.

Beyond the socioeconomic impact, cancer treatment has a harsh physical and emotional toll on the children. It requires taking numerous pills at home daily, painful needle punctures for blood tests, intravenous infusions, intramuscular injections, and more. Children receiving treatment for cancer also suffer expected side effects including nausea, loss of appetite, general weakness and apathy, hair loss, irritability, and labile moods. There is disruption in families’ routines as the children must leave school or normal daily activities and go to the hospital in the capital city on a regular basis thus creating sibling care challenges and new financial and family burdens due to parental work interruptions.

Thus, psychosocial care of the children and parents is part of the cancer treatment protocol as much as medical therapy. A multidisciplinary meeting with parents to communicate the child’s diagnosis includes information about the type of cancer and planned treatment, its duration, expected side effects, and sources of additional help if needed (e.g. psychosocial, economic, and/or schooling). The importance of following the treatment without interruption is strongly emphasized with a warning that not doing so will likely result in the child’s death. One key element in the information provided is that after a few days or weeks of treatment, the signs of the cancer will disappear to a large extent, but that this will not mean that the child is cured and treatment is no longer necessary.

Psychosocial follow-up estimates the family’s material and emotional status in regard to their ability to adhere to the treatment. The psychologists and social workers evaluate the family’s precarity and material, social, and emotional resources. The team also looks at the parents’ comprehension of the diagnosis and medical treatment, family dynamics, personality traits that might impede adjustment to the new reality, willingness to adhere to the treatment, pre-existing conditions that increase their vulnerability for emotional or economic burden, religious and health beliefs, and any situation or obstacle that could become a trigger for abandonment.

The psychologists, social workers, nurse educator and day clinic head nurse who form the psychosocial team engage in all activities to help parents and children emotionally adjust to the diagnosis and treatment. Examples
include group sessions and educational meetings on treatment-related topics, private individual sessions about specific family emotional worries, crisis interventions, palliative care follow up, school re-entry and adaptation, hospital school, and sibling and family dynamics.

My initial questions
In 1994, the childhood cancer program was conceived to guarantee treatment to children without financial cost. Therefore, the pediatric oncology team was assumed to be playing a winning card without impediment to treatment access since it was free. The multidisciplinary team at HBB had been trained in state-of-the-art, modern pediatric cancer treatment, had confidence and enthusiasm, and was committed to providing the best care for children with cancer and their families. In less than ten years results had been rewarding as the team saw cure rates dramatically improve, fewer fatalities caused by preventable complications, and a growing sense of bonding among parents, patients and staff members. However, despite all the positive results, abandonment of treatment was still not solved. After years of interventions improving communication with parents, and investing time and effort supporting families in major need, abandonment of treatment decreased, but to the oncology team’s growing frustration, it was still a problem; this was unacceptable.

In 2009, having witnessed families continuing to abandon treatment and still failing to understand the reasons and solve the problems, I wondered what I was missing. I realized that for too long I had seen this problem from the program psychologist’s perspective, which was a partial or insufficient view. As a member of the pediatric oncology team, I quickly learned that you can’t treat a child with cancer if their parents are not engaged in the process. This became essential in the team’s handling of our relationship with parents. The treatment is too long and complex not to involve parents completely; it requires the participation of a long list of medical and health professionals, and parents. The treatment does not take place only in the hospital. It happens in (or invades) the child’s home as well, and their home is embedded in a community of extended family members, neighbors, and church members. Childhood cancer treatment affects all aspects of family life. Therefore, we had to better understand social, economic, and cultural conditions and gain the parents’ trust to address abandonment of treatment.

Cancer is a disease surrounded by myths and fear and is generally seen as synonymous with death. Most parents have many relatives and neighbors offering opinions, advice and remedies for their child. Gaining the parents’ trust was fundamental, and provision of clear information was the key strategy for building this relationship from the first day. That is why I needed to
understand where we had failed to prevent abandonment. It seemed to me that we were offering good care. We were a unique model of attention in HBB. We had a strong health team who provided comprehensive parental education and support. The head of the department used to say to the parents: “We (parents and medical team) are on the same side, we are on the same team, we are not enemies, we fight together against our common enemy that is the cancer of your child. You are part of the team and we need your help”. His approach showed the team’s beliefs about the valuable role of the parents in the treatment trajectory. Therefore, we felt deeply disappointed, even betrayed, when parents abandoned their child’s treatment. Yet, despite all good intentions and justification for the medical director’s words, the very fact that he had to emphasize the parents’ role showed that the medical team and parents were in two distinct (if not opposed) positions in a shared situation. That is why a call for unity for the sake of the child’s recovery was necessary. The two-sided trajectory remained visible throughout my fieldwork, as I describe in the chapters of this dissertation.

During the years in which I was facing abandonment of treatment as a hospital psychologist, my thoughts were focused on why the parents abandoned treatment despite the real chance of cure for their child. Why did this happen if we were facilitating so much support for them during their child’s treatment? Why was all that we were doing to stop treatment abandonment not enough, or ineffective? I assumed that part of the answer would be found in the parents’ experiences at the hospital, and another part would probably lie in actions that the team was failing to do. Or perhaps, one part was related to events and experiences, and the other related to less tangible aspects like processes and relationships in the hospital and treatment trajectory. Answers might be found by analyzing the actors as well as the processes and relationships. Although I had had many conversations with parents who returned to the hospital after abandoning their child’s treatment, I still had all those questions.

In search of new analytical and methodological tools, in 2009 I started a medical anthropology master’s program and then PhD at the University of Amsterdam to gain new insights into childhood cancer treatment abandonment. It seemed to me that anthropology would provide a new lens to broaden my perspective on the parents’ perceptions and interpretations of their experience of having a child with cancer, and allow me to examine the care system of the cancer program from a new position and methodological view. Then, I could take a holistic approach using a qualitative methodology to explore explanations of a collective problem through personalized cases.
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OVERVIEW ON ABANDONMENT OF TREATMENT

The gap in childhood cancer survival
This research is based on advances in pediatric oncology in the last 40 years. In the 1950s, childhood cancer was synonymous with death, and doctors could only manage the care of children as they were dying (Holland, 1998). In the 1970s, however, combination therapy began to cure children with some cancers. Today, in high-income countries (HIC), more than 80% of children diagnosed with cancer survive and are expected to live a long life (Wagner & Antic, 1997). However, those statistics only apply to resource-rich countries (Yaris, Mandiracioglu, & Bykpamukcu, 2004). Medical advances that have made this success possible are a combination of treatment strategies and multiple modern drugs, together with excellent supportive care and adherence to therapeutic plans. Good quality treatment for childhood cancer is not possible without a multidisciplinary team providing all aspects of care – not only biological aspects – in the cancer experience of a child and family.

Approximately 80% of the estimated 250,000 children diagnosed with cancer every year worldwide live in L&MIC where effective treatment is often not available (Garcia et al., 2007; Kellie & Howard, 2008). This implies that most will face a certain death even if a cure is medically possible. The enormous difference in pediatric cancer outcomes between HIC and L&MIC is an issue of inequality for access to cancer treatment that has been well documented and inspires a call to action (Masera et al., 1993). A document introduced at the International Society of Pediatric Oncology (SIOP), in 1995, brought the aforementioned situation to light, and stated the need for a steady commitment of medical and research centers in HIC to collaborate in changing global outcomes for childhood cancer (Masera & Biondi, 2003). Various partnerships and twinning programs between HIC and L&MIC have worked to bridge the gap between the two scenarios (Antillon et al., 2005; Masera et al., 1998; Ribeiro & Pui, 2005). By transferring knowledge and technology through partnerships, care and cure rates have improved substantially in economically disadvantaged nations around the globe, including El Salvador (Bonilla et al., 2000; Ribeiro & Pui, 2005).

Since the early 1980s, multiple partnerships and collaborations have been realized. For example, the U.S. National Cancer Institute has had a long-established collaboration with the National Cancer Institute in Cairo and three hospitals in India, for the study and treatment of acute lymphoblastic leukemia (ALL), which improved ALL survival rates from less than 20% to up to 60% (Pui & Ribeiro, 2003). In Yogyakarta, Indonesia, a collaboration with the Vrije Universiteit in Amsterdam over two decades has helped with
training doctors, nurses, and other personnel, as well as guided the intro-
duction and adaptation of modern treatment protocols for childhood cancer
(Veerman, Sutaryo, & Sumadiono, 2005).

Among the first and most extensively reported partnerships in Central
America is the pediatric oncology twinning program in Nicaragua, estab-
lished in 1986 between La Mascota Children’s Hospital of Managua, the
University of Milan, Italy, and the Hospital of Bellinzona in Switzerland (Masera
et al., 1993). Seven years later, in 1993, the pediatric cancer program of El
Salvador initiated as the result of the collaborative partnership between the
national pediatric hospital HBB, the local non-profit foundation FAV, and
SJCRH (US). This successful collaboration expanded the scope of SJCRH’s
international work, which has established partnerships in more than 20 cen-
ters in Latin America, Asia and Africa through their International Outreach
Program. Partnership strategies were directed mainly to training pediatric on-
cologists and nurses, starting adapted protocols for diagnosis and treatment,
and providing some financial support (Ribeiro & Bonilla, 2000).

Across L&MIC, as access to treatment improved and protocols and can-
cer registries were established, abandonment of treatment became evident
(Navarrete et al., 2014). Despite the initial lack of a standard definition and
criteria for measuring and reporting abandonment, many countries started
to pay attention to its high incidence and dreadful consequences. A literatu-
re search in 2007 showed a wide range of abandonment incidence in Asia,
Latin America and the Middle East with many centers reporting rates higher
than 40% (Arora, Eden, & Pizer, 2007). More recent meta-analysis (Gupta et
al., 2013) and global survey reports (Friedrich et al., 2016) still note very high
abandonment rates, and calculate that it probably accounts ‘for at least one
third of the survival gap between HIC and L&MIC’ (Friedrich et al., 2015).

Abandonment of treatment is a phenomenon of L&MIC countries. Alt-
ough this issue had been described in HIC, such as Taiwan in the late 90s,
cases in HIC are rare and therefore receive wide media scrutiny and legal
intervention (Lam, Rossell, & Ribeiro, 2012). Laengler et al. (2011) reported
an annual abandonment incidence of 0.5% in a two-year study of 70 pedi-
atriac oncology clinics in Germany. Although various social and cultural fac-
tors are related to abandonment of treatment both in resource-rich and -poor
settings, the differences in incidence and procedures to address it are more
obvious than similarities. Thus, research to develop strategies to fight the
problem are a priority almost exclusively in L&MIC (Lam et al., 2012). Efforts to
find strategies to solve the survival gaps and sociocultural challenges of fami-
lies of children with cancer in L&MIC, make this study’s findings relevant for
L&MIC outside El Salvador.
**Abandonment of treatment**

The term ‘abandonment’ has not been without controversy or criticism in pediatric oncology. In fact, one of the problems in researching and measuring abandonment of treatment has been the variety of terms used in multiple studies: treatment default, treatment drop-out, interrupted treatment, discharge against medical advice, etc. All these terms have limitations due to inaccuracy and specificity (Weaver, Howard, & Lam, 2015; Weaver et al., 2015). Thus, the definition and label for the situation has been addressed in scientific literature on this topic. As an attempt to remedy this situation, the Abandonment of Treatment Working Group of the Pediatric Oncology in Developing Countries (PODC) Committee – of the International Society of Paediatric Oncology (SIOP) – released a statement proposing five recommendations to adopt terminology and standards for biomedical research about abandonment of treatment in pediatric cancer worldwide, which includes a general definition for this phenomenon as being the failure to start treatment upfront, or treatment interruption during four weeks or more (Mostert et al., 2011). These recommendations have been increasingly incorporated by the international community reporting and studying pediatric cancer treatment outcomes, and most countries use the term abandonment both for reporting scholarly research, as well as for registering outcomes and patient follow-up.

Beyond the implications for scientific research production, the main criticism is often related to the sense of implicit blame, surrender, or passivity that the term ‘abandonment’ places on the parents’ action. Aware of this interpretation, the pediatric oncology community has acknowledged that the term ‘abandonment’ is not intended to place responsibility or blame on the parents (Mostert et al., 2011; Weaver et al., 2015). In my study, it will become apparent that parents view the term ‘abandonment’ from another perspective. The stories and accounts included in the coming chapters illustrate how parents who stop bringing their child to the hospital do not in fact see themselves as abandoning their child’s treatment. I will elaborate on these diverging views in the concluding chapter.

The vast majority of the literature does not advance the parents or patients’ perspectives, but instead takes a biomedical view in searching for an understanding of abandonment of treatment. The very radical outcomes and consequences of abandonment make the phenomenon particularly worrisome to biomedical professionals. Abandonment of treatment generally leads to disease relapse and eventual death (Mostert et al., 2011) and represents a substantial obstacle for curing cancer in children in L&MIC (Friedrich et al., 2016; Kumar, Moulik, Mishra, & Kumar, 2013; Suarez, Guzman, Villa, & Gamboa, 2011).

It is estimated that 50-60% of families worldwide abandon their child’s
therapy (Arora et al., 2007). As international collaboration projects increased in past years, the impact of abandonment of treatment has become a burden and unavoidable concern when starting collaborative programs and partnerships. Thus, practical interventions and scholarly research on this topic have been encouraged. Biomedical studies began by searching for contributing factors in medical records retrospectively. Early findings from authors Sweet-Cordero et al. (1999) and Yeh et al. (1999) identified multiple factors contributing to treatment abandonment. This effort illuminated main lines of work to move forward, and more qualitative research was recognized as essential to do so.

In the positivistic approach of biomedical childhood cancer treatment, substantial focus has been put on establishing standards for definitions and measures of abandonment and finding risk indicators and predictors. Research in several L&MIC correlate abandonment of treatment with factors such as financial and transportation difficulties, parents’ illiteracy, distance to the hospital, crowded homes, beliefs about cancer and treatment, and poor doctor-patient relationships (Bonilla et al., 2009; Kumar et al., 2013; Meremikwu et al., 2005; Metzger et al., 2003; Ramzan, Yadav, & Sachdeva, 2013; Sitaresmi, Mostert, Schook, & Veerman, 2010; Slone et al., 2014; Wang, Jin, Xu, & Zhang, 2011). This study supports such correlations, but also brings to the forefront the insider perspective of the families and emphasizes the relational character of the identified indicators along the experience of cancer and abandonment of treatment.

The consequences of abandonment have an impact on families, health professionals, and cancer programs. A number of parents who abandon their child’s treatment eventually come back to the hospital and re-start therapy. Some parents return when the child shows obvious symptoms of the illness and the relapse of the cancer is evident, and others return when the child is already in very bad health. As already described, in many of these cases, remission can be re-achieved, only to have the child experience another relapse and die several months later. The consequences of treatment abandonment are not only the devastating loss of a child’s life, but also the impact on the hospital staff’s morale, and other parents of children undergoing treatment, which may add to confusion and myths about cancer’s (in)curability.

Abandonment of treatment also has a financial cost, making programs more expensive in two ways: 1) medicines and the human and technical resources initially invested seem wasted when a child abandons treatment and dies, and 2) increased costs required to stabilize a child when he/she is brought back into hospital after a period of abandonment, particularly if the child has relapsed or has an infection requiring prolonged antibiotics and intensive care, as is usually the case. The more complicated the child’s
clinical condition is, the longer it takes to recover and more medicines and hospital resources are required. This makes their treatment more expensive. Even if recovery and remission are regained, it is the most likely prognosis that the child will eventually relapse and die of their disease. This creates an economic and moral predicament since abandonment of treatment occurs in settings with scant capital; the pediatric cancer programs suffer from scarce or limited resources that initially are utilized to cure the child but are wasted through abandonment.

At project level, treatment abandonment is a factor that damages the image and plans for progress of a childhood cancer program in low-resource settings. Success and program improvement depend on survival rates and other related statistics since these programs rely on international and local donor support. Successful outcomes encourage existing collaboration with international partners and improve the chances that local ministries of health will look favorably on supporting childhood cancer care. Thus, treatment abandonment not only negatively affects the survival rates of a cancer program, and increases costs, but also indicates the lack of success of the health teams’ interventions directed to reduce the problem.

RESEARCH QUESTION

Biomedical literature provides valuable information regarding some identified factors related to abandonment of treatment. However, it does not provide sufficient explanations to encompass the complexity of abandonment or its solution. The ethnographic method used in the present study aims to unravel the complexities of the cancer experience of the families and their stories of abandonment of treatment to advance the quality of care in El Salvador and other L&MIC. Analyzing the health team’s position, understanding, and experiences was an essential part of the study to achieve a comprehensive view of the phenomenon of abandonment of treatment and its consequences in the Salvadoran childhood cancer program. For this study, I formulated the following question:

How has the response from the pediatric cancer program to solve abandonment of treatment in El Salvador shaped the provision of treatment for the patients?
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METHODOLOGY

The participants
Fieldwork was conducted over 15 months between November 2012 and June 2014. Parents who abandoned treatment, returned from having abandoned, or were close to abandoning (defined as showing signs of being at risk of abandoning according to the psychosocial team), at some point during the fieldwork period were approached for inclusion on the study. A total of 41 families (mothers, fathers, grandparents) were included in the study. In all cases, the actual or intended discontinuation happened while the child was undergoing first-line treatment - defined as treatment intended to be curative, not palliative - and the child had not had a previous relapse. The study also includes interviews with six families (part of the 41 total) meeting the same criteria conducted during six weeks of fieldwork in May and June 2010.

I discontinued working as a member of the HBB team when I started my masters and PhD studies, but I had access to the pediatric oncology unit and the patients. The cases presented here were selected by the psychosocial team as appropriate for referral to me as the researcher, according to criteria presented below. The psychologists and social workers referred children who fit the profile of having parents who were at risk of abandoning their child’s treatment. There is no standardized scientific instrument to measure risk of treatment abandonment. The team relied on their own experience to detect what they considered as signs for possible abandonment and how to prevent it. There was no way of knowing if the families would actually abandon treatment. Therefore, all families that seemed to meet the criteria for a risk of abandoning were included in my research.

Parents meeting the following criteria were interviewed:
(1) Parents of children recently diagnosed (one to two months) undergoing or finishing their initial phase of treatment (induction), after being discharged to their home after their first hospitalization.
(2) Parents of children who had missed a treatment but were back in the hospital before four weeks of absence and continued treatment normally.
(3) Parents who at any point during their child’s treatment expressed to one or more members of the medical team an intention to not continue their child’s treatment.
(4) Parents who had abandoned their child’s treatment and eventually returned to the hospital.
(5) Parents who at any point during their child’s treatment had abandoned their child’s treatment and did not return to the hospital.
(6) Patients who had high-risk characteristics to abandon their child’s treatment due to complicated living conditions, and required substantial economic support and close follow-up, according to the psychosocial team’s assessment.

Interviews and observations

Health team interviews
I conducted semi-structured interviews with a total of seven team members among doctors, nurses, social workers and psychologists. I also had conversations with them about case developments, joined case discussions and conversations among themselves, and learned the team’s perspective on many families. Since the team was constantly attending to parents and or interacting in multiple health care-related activities, these discussions took place in an informal manner, by appointment or by random encounters as they consulted with each other about specific or general information on the child and family.

Parent or caregiver interviews
I interviewed the parents of 34 children during my fieldwork period of 15 months. In some cases, I interviewed both parents. Including parents and caregivers interviewed in 2010 whose data is included here, a total of 41 parents were interviewed. In this group of 41, the parents of 19 children abandoned their child’s treatment, had a series of missed appointments, or expressed an inability or unwillingness to continue treatment. A total of 35 parents or caregivers in both interview cohorts were interviewed at the hospital. Five parents who abandoned treatment and did not return to the hospital were interviewed at their homes, and one at her work place. Home visits for interviews were eventually discontinued due to general safety reasons since crime and violence have turned El Salvador into a very unsafe place to travel.

The interviews and conversations were framed mainly within the circumstances that the parents were facing while undergoing treatment. The content focused on either their circumstances at home or the hospital, and how their experience was during that period. The topic guide of the interviews included questions regarding the parents’ feelings, thoughts and experiences about their child’s diagnosis, therapy, the hospital, practicalities of their child’s treatment, perception of their child’s health condition and treatment effectiveness, reasons for not wanting or suspending medical treatment, use of alternative therapies and support systems, and the community and extended family’s role in their management of their child’s illness.
CHAPTER ONE

Informal conversations and observations
In addition to formal private interviews, informal conversations and observations of daily activities at the hospital were done. For example, I observed the process of the early morning arrival of the children for their regular appointment for a medical check and/or treatment, and the scheduling of appointments by the nursing and reception staff; interactions in the waiting area; clinical visits with the doctors; chemotherapy administration and treatment procedures; and parent interviews, meetings and consultations with the social workers, psychologists, nurse educator, clinical nurses, receptionists and clinical secretary.

I also participated in multidisciplinary team meetings and medical ward rounds for some patients. Children were visited while undergoing routine chemotherapy sessions and when they were hospitalized due to medical complications, either in the pediatric oncology ward or other hospital wards. Participant observation did not only focus on the children participating in the study or being interviewed. The dynamic of the pediatric oncology department was observed in general, and in this context, informal conversations took place, or private encounters were scheduled in agreement with the parents if convenient in the time frame of the clinical appointment their child was attending.

Informed consent
The parents were approached directly at the hospital, usually in the waiting area or in the chemotherapy area when accompanying their child while undergoing treatment. In explaining the purpose of the research, I informed the parents about my former position as psychologist in the pediatric oncology unit, the study purpose, and voluntary and confidential nature of their participation. I emphasized that I had no responsibility with the medical team and their information would not be shared. Interviews were recorded if parents agreed and were kept confidential. I encouraged the parents to ask questions about the project, to give feedback on their understanding of my explanations about the research, or any issue that worried them about the study, and to consult with their spouses about participating, if appropriate. Parents were told to feel free to change their opinion about participating in the study or refuse to talk in coming encounters and that their agreement or refusal to participate in the study would have no consequence for their relationship with the hospital or their child’s treatment, emphasizing that all participants were free to withdraw from any interview at any point and without consequence. Before interviews and/or encounters, I asked parents if the moment was appropriate considering their child’s programmed activities and treatment and their responsibilities in that regard. It was my priority to respect the child’s
treatment schedule so as to make my research convenient for parents and not delay their return home. The parents were seen on multiple occasions, so informal sporadic encounters and conversations took place throughout their child’s treatment in addition to private interviews.

OVERVIEW OF CHAPTERS IN THIS THESIS

Chapter 1 is an introduction to my research and presents the background of the problem of abandonment of treatment in general, and specifically in El Salvador. I present a description of the general setting of the Salvadoran pediatric cancer program, and my origins in the field of pediatric oncology as a psychologist and later as a researcher in medical anthropology that lead to the present thesis.

Chapter 2 explores parental explanations for their child’s treatment abandonment. The main reasons for abandonment in the parents’ narratives are an interrelated collection of situations framed in poverty, anguish and fear about therapy side effects, conflicting interpretations regarding hospital rules, and religious beliefs. The parents’ experiences demonstrate that poverty evidently involves more than just a lack of money, which has been frequently overlooked in initial interventions of the Salvadoran cancer program. Despite the provision of material resources as an essential first step to help families not to abandon treatment, other dimensions have to be considered to create a more comprehensive strategy and obtain improved results. What poverty means to the families and how they cope with it differ from one family to another. Interventions such as providing funding for transportation or food seem to be logical options when trying to reduce the influence of poverty on abandonment of treatment. However, since poverty is such a multi-dimensional situation, this financial support will only help some families. The multiple dimensions of abandonment expose the trajectory of cancer treatment as both a relational and an experiential situation that occur among two groups of actors: the medical team and the parents.

Chapter 3 explains in detail the oncology team’s latest intervention strategy for addressing treatment abandonment occurring mainly in a preventive stage. It demonstrates the value of coordinated efforts in the efficient use of communication and technological resources, the empowerment that the psychosocial team can achieve regarding its value within the medical team, and the possibility of gaining a closer relationship with the parents in need of extra help. This chapter focuses on the health professionals’ quest to guarantee that the children stay on treatment and prioritize a protocol-based follow up of families to detect and solve challenges (factors) that might impede the continuation of cancer treatment. This standardized approach appears to be
appropriate in terms of effectively keeping children on treatment. The team appears to be closer to the parents and their circumstances and engages in closer relationships as they try to discern the factors motivating abandonment. The strategy involves navigating care, control, and power depending on the actors in the relationship, and the moments or circumstances in which the relationship is being evaluated. The parents perceived the team’s attention mainly as caring and saw themselves as standing out from the crowd and being special to the medical team.

Chapter 4 shows the value of incorporating external resources from institutions in the patient’s community that can help locate children who have abandoned (or been absent from treatment) and provide resources for resumption of their treatment. It also details the effort that this kind of initiative entails, and the risks of misunderstandings and unintended complications for the children’s families. This chapter develops dimensions of care and control by introducing professionals and institutions outside the hospital, and building a network that combines professional experience, personal interest and basic communication and computer technologies. Again, a paradox can be seen in this well-intentioned strategy since it can bring unintended conflicts or upsetting experiences that contradict the child’s care and thus demand extra resources and efforts from the team to fix or to continue the positive aspects of the network while diminishing the negative aspects.

Chapter 5 offers a perspective on how a belief in a miraculous cure becomes a suitable resource for some parents to solve their child’s disease, financial struggles worsened by the treatment, and anxiety and misgivings over the harmful effects and uncertain treatment results. This chapter brings the parent’s experience in the treatment trajectory back to the forefront and explores the basic elements of the mistrust that lies underneath the parent-doctor clinical encounter. The parents cannot put their experience with their child’s illness in line with the information they receive at the hospital, as well as from other sources of experiential, vicarious, and lay knowledge. Additionally, the increasing impact of attending treatment on the family’s precarious living conditions increases the sense of urgency for a solution that cures the child without leaving the family financially extenuated.

Chapter 6 explores the application of a legal resource (a law requiring a parent to return their child to treatment of any life-threatening disease or face state removal of the child from the home) to force the continuation of treatment by the parents who abandon treatment. Parents’ experiences and the medical team’s responses reveal the importance of a careful and individualized management of children’s care that enables the continuation of treatment and a non-conflictive relationship between parents and medical team. The new paradox is how an external instrument in the form of third-party
legal intervention connects parents and doctors and creates mutual obligations, in the sense of parents attending to their child’s treatment, and the medical team providing and facilitating resources. The law appears to mediate the opposing views of some parents and doctors. While the law creates a social bond in the form of mutual obligation, it does not have an impact on the provision of care. This approach contributes to a path towards personalized care.

In the concluding Chapter 7, I discuss the value of standardized yet personalized care as the apex of the doctor-parent clinical encounter and relationship that is particularly meaningful in a long-term doctor-parent relationship with uncertain results and a high risk of psychosocial tension under the difficult circumstances of caring for children with cancer.