Curing children, caring for families

The path to personalized care in childhood cancer treatment in El Salvador

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Childhood Cancer in El Salvador: A Preliminary Exploration of Parental Concerns in the Abandonment of Treatment

In El Salvador, children under 12 diagnosed with cancer have access to free treatment at a specialized national facility. Until recently, 13 percent of patients annually abandoned therapy—a serious loss of lives and scarce resources. This qualitative study explores how some parents perceived their child’s cancer and treatment, and what led them to stop bringing their child for chemotherapy. In in-depth interviews, parents of six children who abandoned their child’s cancer treatment discussed sickness and life circumstances during the course of treatment. Poverty, effects of treatment, mistrust, emotions and religious convictions all figured in the parents’ explanation of their actions. However, each family weighed these concerns differently. It was the interaction of the concerns, and not the concern per se, that represented the explanatory frameworks the families used to explain stopping their child’s treatment. This finding illustrates the parents’ navigation among a collection of variable concerns, rather than exposing one fixed cause for their behavior. For example, poverty affects a parent’s worldview as well as concrete living conditions, and therefore has a complex relationship with abandonment of treatment. Thus, it follows that strategies to reduce treatment abandonment (and increase a child’s chance for survival) must be multidimensional. Qualitative studies of how families perceive childhood cancer and treatment can illuminate the processes and relationships involved in abandonment of treatment. This approach can also show how families’ living circumstances frame their perceptions and inform strategies to improve how medical services are provided, thus reducing abandonment of treatment.

**Keywords:** childhood cancer, abandonment of treatment, parents’ perspectives, low-income countries, qualitative research.
CHAPTER TWO

INTRODUCTION

Treating childhood cancer in developing countries involves challenges regarding availability of human and technical resources as well as provision of chemotherapy and supportive drugs. In many countries, partnerships and collaborative efforts have been devoted to alleviating this situation and improving treatment outcomes (Ribeiro and Pui, 2005): a strategy that has been particularly successful in the Central America region (Howard et al., 2007). However, extra challenges regarding sociocultural aspects that affect treatment outcomes in low income countries also have to be faced. One instance of this is the phenomenon called abandonment of treatment (AT), almost unknown in the developed world.

Abandonment of treatment refers to cases in which parents either prematurely stop or do not start their child’s therapy after diagnosis (Mostert et al., 2011). It is estimated that up to 45 to 60% of cases abandon treatment in the developing world each year (Arora et al., 2007), constituting a major cause for treatment failure (Arora, Pizer, & Eden, 2010). Sitaresmi et al. (2009) considered AT to be an extreme form of non-adherence: a long-standing and well-known problem affecting the treatment of chronic diseases worldwide. Non-adherence to medications is similarly multi-causal and also involves sociocultural factors. Both phenomena involve patients, health care providers, and the societies and cultures in which they live and work. Research has focused on trying to determine causality and risk profiles. The vast literature on non-adherence may teach us that sufficient accuracy, even for single predictive factors or profiles of non-adherent patients, has not been achieved (Bosworth et al., 2006).

Research on AT across the globe, most of it using quantitative methods, correlates abandonment of treatment with factors such as financial and transportation difficulties, beliefs about cancer and treatment, and poor doctor-patient relationships (Arora et al., 2007, Bonilla et al., 2009, Kulkarni et al., 2009, Li and Jin, 2012, Metzger et al., 2003, Sitaresmi et al., 2010, Wang et al., 2011). The importance of addressing social factors (Lam et al., 2012), and the need for qualitative studies to understand how, and under what circumstances, these lead to abandonment has been acknowledged (Bonilla et al., 2009).

Reports from Latin America tend to show similar factors associated with abandonment. In Mexico the differences in abandonment rates before (21.4%) and after (13.3%) the introduction of national health insurance indicates the relevance of economic factors as a trigger for the problem (Klünder-Klünder et al., 2012). In Honduras, long distances to the hospital proved to have an important impact on abandonment rates, which lead to the
establishment of satellite clinics outside the capital city to reduce the problem (Metzger et al., 2003). In Colombia, in addition to factors found elsewhere, difficulties regarding the health system organization appear to be associated with abandonment, and a 3.9 higher chance to relapse and die for children who abandoned was reported (Suárez et al., 2011). In Paraguay, a strategy identifying social and economic risk factors, and a close follow up of patients, was reported to reduce abandonment dramatically (Samudio et al., 2013). In El Salvador, abandonment of treatment was similarly associated with socioeconomic variables including parents’ illiteracy, crowded homes and low household income (Bonilla et al., 2009).

El Salvador is a Central American country of about 21,000 square kilometers and 6,000,000 inhabitants. Thirty percent of the population lives below the poverty line, which means that they lack the resources to meet their basic needs; religious filiations are mainly Catholic, 57% and Protestant2 21% (Central Inteligence Agency, 2013). Approximately 180 children are diagnosed with cancer annually, and treatment is available at no cost at the only national pediatric hospital, located in the capital San Salvador. Improved standards of care involving collaboration with international partners, have led to significantly increased survival rates3. For example, 5-year event free survival for children with standard risk acute lymphoblastic leukemia is now 56.3 ± 4.5% (Bonilla et al., 2010) compared to less than 5% before 1993 (Pedrosa et al., 2000).

Patients generally have weekly visits to the hospital for six months to three years depending on the type of cancer. Housing facilities in the city as well as economic support for transportation and family basic needs are provided if necessary. Despite this support, AT had a steady rate of 13% until recently. In almost all cases, the child dies a few months later, even if he or she returns to the hospital and restarts treatment.

Studies and recommended strategies on AT focus mainly on both prevention by detecting risk factors, and strengthening education for parents about diagnosis and treatment (Spinetta et al., 2002). However, few studies have investigated the perspective of the families regarding treatment or its abandonment (Israëls et al., 2008; Sitaresmi et al., 2010). Although conditions such as economic resources and family and hospital dynamics may influence parents’ assessment of their child’s health situation and decisions about therapy, the understanding of how precisely one thing

2 Protestant refers mainly to charismatic and evangelical movements.
3 The Fundación 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 Children's Hospital.
leads to another is still a work in progress. This study investigates abandon-
ment of treatment in El Salvador through exploring the parents’ own ac-
counts of why they stopped bringing their child for chemotherapy.

Understanding parents’ reasoning should lead to a better understanding
of the questions that hospitals need to address, and point to aspects of cur-
rent practice that do not meet the families’ real needs or may even create
new problems. In addition, new information could help the multidisciplinary
team to re-define the pathway for therapeutic plans that would better fit the
patients’ conditions.

METHOD

This qualitative exploratory study used a convenience-sampling method and
included in-depth interviews, conducted during five weeks, with parents
of six children who had discontinued cancer treatment. The topic guide of
the interviews included questions regarding the parents’ feelings, thoughts
and experiences about the diagnosis, therapy, and hospital; practicalities of
undergoing treatment; perception of their child’s health condition; use of
alternative therapies; and the community and extended family’s role in their
management of the illness. Nine interviews (lasting between 60 and 90
minutes) were conducted with one or both parents at their home or work
place, and one child (15-year-old) was also interviewed, previous permission
having been obtained from his parents and from the child himself.

The medical and scientific director of the Oncology Department
reviewed and approved the study, as did a committee of the Social Science
Faculty at the University of Amsterdam. The process of domiciliary search
and interviews was considered as an extended service for the patients which
normally the hospital does not provide. In this context, the hospital ethics
committee waived the requirement of formal ethical review, and approved
the subsequent in-depth project currently under way, conceived to permit
deeper exploration of the results presented here. To ask their participation,
families were visited at home or phoned. They were informed about the pur-
pose of the study, and the voluntary and confidential nature of participation.
The researcher-interviewer (NR) explained to the parents that she was not a
member of the hospital personnel, although she had been previously; that
agreement or refusal to participate in the study would have no consequence
for their relationship with the hospital or their child’s right to receive medical
attention, and that parents were free to withdraw from the interview at any
point and without consequence.
Weighing up possible risks and benefits to participants, the researcher-interviewer decided to ask oral consent only.\(^4\) The first consideration here was that the research was not invasive, and that risks for participants were limited to possible emotional discomfort (American Anthropological Association, 1998; National Health and Medical Research Council, 2007). Second, and more importantly, the researcher recognized that the parents were in actual or potential conflict with the hospital. Signing a document of consent could represent surrender to bureaucratic power, and increase rather than alleviate feelings of vulnerability.

The interviews were held in Spanish, recorded and transcribed by the researcher-interviewer, and kept confidential from hospital staff. The quotations presented here are NR’s translations and all names are fictitious. Emerging themes were identified on each interview based on frequency and significance along the parents’ accounts. No analysis software was used. The themes that emerged were grouped according to similarities of the participants’ descriptions, and the relevancy of one or more topics on each case was also identified. The process of building the analysis was discussed among the authors.

**RESULTS**

The hospital data base provided contact information for 14 children who had abandoned treatment within the previous one-year period. Four children were deceased and these families were excluded from the research; three could not be located; and one family refused to participate. When the study took place, the children appeared healthy in five of the six families who agreed to participate. Their last round of chemotherapy had taken place between two and ten months previously.

In five of the six families interviewed, the father was the income provider and the mother took care of the household. In one family, the child with cancer was an only child. Four of the families lived in rural areas and worked in the fields, barely meeting their basic needs. Two families lived in San Salvador, in one of which the father worked as a peanuts street vendor, and in the other the mother was an employee in a small cafeteria. Four of the six children were male; four were diagnosed with acute lymphoblastic leukemia and two children had solid tumors. The youngest was one year old, the oldest 15. Four families were Evangelical and two Catholic.

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\(^4\) The Code of Ethics of the American Anthropological Association (1998) considers the quality and not the format of informed consent to be relevant. The possibility that written consent may not be culturally appropriate is increasingly recognized in health and medical research (e.g. National Health and Medical Research Council of Australia et al. 2013: 24).
CHAPTER TWO

The main themes the parents expressed in their narratives about treatment abandonment were: a) treatment side effects and procedures, b) poverty, both financial sacrifice and ancillary issues such as risky transportation, c) perceptions about the misdirected/unavailable financial support from the hospital and hospital jargon and regulations, d) emotional distress related to their child’s suffering and parental isolation and loneliness, and e) support from their religious community and belief, in God as well as in miraculous cures for their child (whether witnessed or hoped for).

Side effects and procedures

*He suffered very much because of the hair and weight loss; although he was already thin because of the sickness, thinness worsened with the chemotherapy. He stopped eating because he felt always like vomiting... then the last times he had a very aggressive temperament... (Javier’s mother)*

Parents found the effects of treatment tormenting. For the six families their child’s lack of appetite was the most common complaint, and a major worry. As one of the parents said, after receiving the chemotherapy, their child lost her appetite for 2-4 days, and when her appetite returned it was time for another dose of chemotherapy and the cycle of not eating began again. Consequently, the child was eating properly only few days a week, which for her parents was difficult to reconcile with the idea that she was getting better.

Parents also worried about their children’s weight loss and saw it as a sign that their child was not improving. According to their interpretation, if the child was getting thinner this would make him/her weak and unable to undergo the treatment; the treatment might be ‘too strong’ for the debilitated child and kill him/her. In general, the idea of treatment being “too strong” and dangerous was predominant among the parents.

Another source of parental distress was medical procedures like routine venipunctures and especially intrathecal, lumbar and/or bone marrow punctures. These are painful treatments, but pain was not the parents’ main worry; rather it was the idea that the procedure was dangerous and could lead to the child’s losing the ability to walk.

Poverty

*...We had to take the child to the hospital four times a week, spending $20 each time including what we needed to buy there. ... I only earn $48.00 every two weeks. How to sustain my children, and have food for*
Although all parents mentioned that it was difficult to pay for hospital visits, which included paying for bus transportation and food during the child’s hospitalization or outpatient treatment, only one parent mentioned money as their main difficulty. Still, the hospital weekly consultation and treatment represented at least a full day visit, and bus transportation ranged from $3.00 to $20.00. Even if this cost was small, these direct treatment expenses represented a considerable challenge for families with barely enough resources for daily living. The economy of the four families living in rural areas was not based on cash, but on stored crops; thus obtaining cash to go to the hospital was a major difficulty and they incurred constant debts with neighbors and relatives.

One parent reported risking a one-hour walk in the dark on a mountain path to the bus stop; another one mentioned risky weather conditions when crossing the river to catch the bus. They also avoided buying food while in the hospital to save money for transportation back home. To save money, the parents also eschewed buying medicines or consulting a doctor when their other children were sick. These parents worried that meeting the costs of their child’s cancer treatment meant fewer resources for the whole family’s daily needs and that this threatened the health and well-being of their other children.

**Perceptions about the hospital support and regulations**

…I wanted to explain our situation to 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 who could understand us.  
*(Manuel’s mother)*

Many encounters of the parents with the hospital staff were progressively permeated by a sense of distrust resulting from the parents’ experiences with misdirected/unavailable financial support from the hospital and hospital jargon and regulations. These experiences shaped how parents perceived their child’s treatment. Five of the six families felt disturbed by ineffective administrative or medical procedures, or changes within the therapeutic plan or prognosis. One complaint was that the support of the hospital failed to match parents’ expectations, either because help was insufficient or was not available when needed.
CHAPTER TWO

Three of the interviewees said they knew that support from the hospital for accessing treatment was available, but asking for support meant explaining their situation to hospital personnel, and they did not trust them enough or felt embarrassed to do so. One of the mothers said that when she told the staff that her in-laws were pushing her to stop bringing her child to the hospital, she didn’t get a helpful answer or concrete staff action to help her. Subsequently, she ran out of money and support to continue her child’s treatment.

Two parents mentioned conflictual situations with personnel as reasons for their distrust, such as disagreements about signing consent for medical tests, or unsympathetic attitudes when wanting to explain a mistake they had made when caring for the child. These situations made them feel that they were not being listened to, and that they did not have a say.

**Emotional suffering**

...Each time they had to puncture my child, she cried so much... I couldn’t bear to see that. That was a big suffering for her and for me... I used to say that it’d rather me to be punctured instead of my child... I told my mother I didn’t want to take my child to treatment anymore, I was depressed... (Katy’s mother)

Mothers were generally in charge of taking the children to the hospital and staying with them. In one family, the father shared shifts with the mother. Being at the child’s side while undergoing painful procedures, vomiting, feeling sick or scared is what mothers usually had to bear. In light of their child’s suffering, they continually evaluated how painful a treatment was according to their child’s reaction and how the medical staff managed the child’s fear. The mothers suffered as they witnessed their child’s pain and fear.

Directly involved with the treatment, mothers had many tasks to perform without help. Some narrated how they felt both physically and emotionally lonely as a consequence. At the hospital, they didn’t have the companionship of their community or family. The only people they were in contact with were the medical staff or other mothers in the same situation. Although sharing with other mothers helped them to find support and companionship, the mothers interviewed felt they were not being understood at home and that they could hardly talk about their feelings.

**Religious beliefs**

...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
CHAPTER TWO

one single time he solves everything; without treatment he will heal you. (Manuel’s father)

Most of the parents referred to God as the ultimate or only healer of their child’s sickness. The respondents actively participated in church congregations at least once a week, most of them in the Evangelical Church. Some had been actively religious before their child was diagnosed, but one family became involved with the church as a consequence of their child’s diagnosis.

Three parents reported that religion was where they found support and hope either while undergoing treatment or after abandonment. The religious community and its leaders were their main source of support and positive thoughts, stressing the importance of keeping their faith in God’s power to secure healing for their child. Four families stated that the healing prayers or their constant church attendance led to or confirmed a miraculous cure of their child. In some cases, such events took place while the child was still going to the hospital for treatment and reinforced the parents’ idea to abandon. In other cases, according to the parents, the confirmation of a miracle occurred after they had abandoned treatment. All the parents said that their religious beliefs and practices were the only alternative therapies they used after abandoning.

DISCUSSION

The five themes identified in the parents’ narratives are concordant with findings of previous quantitative studies. Parents framed their treatment abandonment in a collection of interrelated circumstances, a situation also reported by Sitaresmi et al. (2010) in their study in Indonesia. These concerns speak to the complexity of abandonment, and suggest that fixed or single cause-effect explanations are inadequate.

Side effects (e.g. infection or long-term dysfunction) and medical procedures were extremely worrying for the parents. The importance of proper management of side effects and procedures that could be related to abandonment, especially those involving health risks and pain, has been pointed out (Arora et al., 2010, Sitaresmi et al., 2010, Yeh et al., 1999). However, treatment effects which doctors consider of minor importance, such as hair loss, lack of appetite, or mood changes, were of major significance for parents. Such changes in their children seemed to have a big impact on family life, and on the parents’ sense of normality. Health-threatening conditions are the realm of medical intervention, whereas the parents understood mood changes, feeding and physical appearance as their responsibility. Therefore, it is important that hospital staff not dismiss these concerns, since what may
CHAPTER TWO

seem to be minor parental worries may affect parents’ trust in hospital personnel and turn into major sources of anxiety over treatment.

Previous studies show abandonment being related to poverty (Bonilla et al., 2009; Meremikwu et al., 2005; Mostert et al., 2012; Mostert, Sitaresmi, Gundy, & Veerman, 2006; Sitaresmi et al., 2010). Poverty is however a multifaceted phenomenon, involving much more than lack of financial resources (Sen, 1987). Practical constraints and difficulties described by the parents show how poverty entails disadvantages going beyond the lack of money in a setting where treatment is free of charge as it is in El Salvador. Moreover, disadvantage influences the constitution of a worldview. Thus, the family’s daily living circumstances, the challenges that attending treatment represented, and the family’s sacrifices and their consequences, influenced how the sickness and treatment were evaluated. The common attribution of abandonment to the purely monetary aspect of poverty needs to be rethought, bringing in the linkage between chronic material scarcity and human capabilities and constraints.

The relationship between the parents and the hospital staff was also an aspect that shaped the parents’ perceptions and connection with the institution. The staff members represent the institutional structure of the hospital with whom the parents have to build a relationship from the start of their child’s diagnosis. In this process, each family interprets the pathway of diagnosis and treatment in its own way. Issues like unclear medical terminology or institutional rules, or what are perceived as dangerous medical procedures, highlighted the differences between parents’ and medical staff’s position, knowledge, and interpretations. These differences are shaped by the structure and culture of the hospital and reflect the parents’ vulnerability and dependence on the doctors’ knowledge. This power imbalance, normalized and perhaps inevitable, may remain unperceived. Differences in perspectives may lead parents and medical personnel to engage in incompatible practices, despite the fact that both intend the best for the child.

Parents’ religious beliefs were so fundamentally implicated in the experience of their child’s cancer that it is impossible to establish their beliefs as either cause or consequence of treatment abandonment. Rather, religious beliefs seemed to operate in both ways. Taking religious beliefs as a direct cause of abandonment would imply a reductionist explanation for a complex issue that deserves deeper research. However, in this study, it was clear that the notion of an almighty God who takes care of all those who are weak or helpless in the face of adversity (and especially of those who are less privileged), was part of the parents’ worldview, and provided a sense of hope and relief. The most tangible expression of God almighty in their circumstances was the miracles that they experienced in their children as soon as they
abandoned treatment. Apart from the joy of seeing their children healed, the miracle evidenced the rightness of their decision to rely on God’s faith and abandon treatment.

The multiple parental motives for treatment abandonment show that the encounter with their child’s cancer and its treatment was an ongoing experience: a social process that encompassed more than just the doctor-patient interaction. The perception of treatments as harmful, and the uncertainty in therapy plans or outcomes, often resulted in a justification for abandoning treatment, and reinforced parents’ beliefs in a miraculous cure without the burden of medical treatment. Religion gave some parents the support and strength to bear with their child’s treatment; however, when parents’ doubts regarding the benefits of therapy increased, religion provided a safe haven. Having abandoned the treatment, religion provided both a reassurance that God would not leave their child unprotected, and a way to avoid feelings of guilt or responsibility for the possibility of a bad outcome for their child, which would be God’s will.

The concerns parents referred to in explaining the course of their child’s illness and treatment are not a set of independent variables to be correlated with continuing or abandoning treatment. They are interrelated with meanings that differ from one family to another, depending on their particular circumstances. Therefore, the interaction of these concerns in the narrative and experience of the families, not the concern per se, is what represents the explanatory framework that the parents used in various ways to explain stopping their child’s treatment.

Moreover, such interactions are a changing and dynamic process influenced by circumstances related to social situations, as well as the course of the child’s disease. Therefore, parents’ motives to abandon treatment may vary if the child looks healthy, is deteriorating, or has just returned to the hospital. More work needs to be done to analyze how the evolution of a child’s health status impacts on the parents’ reasoning and actions. The very fact that children included in this study were alive and apparently healthy, may have had an influence on the parents’ positive views on abandonment as a correct decision for their children. Knowing how these various aspects and life circumstances relate is essential for a comprehensive perspective on abandonment when designing measures for addressing the phenomenon.

RECOMMENDATIONS

Initiatives to decrease treatment abandonment should be multi-focused with an individualized staff approach for each family. Providing material resources to poor families can have a major positive impact in helping the parents
continue their child’s treatment, especially if the process of providing this help is smooth and well organized. However, it is more important that this leads to the detection of families for whom material help is not sufficient, i.e., families who face more complex emotional and domestic situations. On the other hand, the failures or lack of empathy in the provision of this help may produce the contrary effect, widening a gap between hospital staff and families, and increasing mistrust.

Since extended family, neighbors, and church members represent the main source of support for many families such as those in this study, it could be beneficial for the hospital staff to pay attention to the family’s local circumstances and develop stronger links with local resources. Such local resources could be municipality offices, public clinics, schools, police stations, NGOs etc. Developing links of communication and information directed to the local community may help improve the quality of support that the families receive, thus encouraging them to maintain their child’s treatment.

The implications for researching abandonment and non-adherence to treatment are that qualitative research is essential for elucidating the processes and relationships that take place in the clinical encounter and beyond. A qualitative perspective illuminates the complex dynamics the parents experience when confronted with their child’s cancer, dependent on their family’s situation. Aspects like the ones discussed in this study cannot be reduced to measurable variables without affecting the meaning of the entire phenomenon under study. This is a lacuna for those who are researching treatment abandonment for childhood cancer in countries with low and middle incomes. More suitable intervention measures will depend on further qualitative investigation concurrent with existing quantitative inquiry.

Limitations
This study was performed in one small low-income country in Central America. The results cannot be generalized; rather the intention was to explore in depth the reasons for which families stop bringing their child to cancer treatment in this setting. The fieldwork time was short and therefore, it was not possible to conduct a more thorough ethnographic description of the parents’ experiences. All parents were interviewed once the treatment had already been abandoned. It is possible that parents who were considering abandoning their child’s therapy but had not yet done so may have perceived their child’s treatment experience differently. In all cases but one, the children were alive and appeared healthy at the moment of the interview. The exact influence of such a significant fact on participants’ answers can’t be determined; however, other parents who had abandoned their child’s treatment and whose children subsequently died may have responded differently.