Curing children, caring for families

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

Rossell Curco, N.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)
Choosing a Miracle: Impoverishment, Mistrust, and Discordant Views in Abandonment of Treatment of Children with Cancer in El Salvador

In El Salvador, at the only hospital offering pediatric oncology care, the number of children abandoning treatment for cancer has decreased in recent years (13%-3%). An investigation of caregivers’ motives for abandonment was performed over 15 months from 2012-2014. Caregiver and health team perspectives on abandonment are reported using the Explanatory Model (EM) framework. Semi-structured in-depth interviews and in hospital participant observations were conducted with caregivers of children diagnosed with cancer, who abandoned their child’s treatment or were considering abandoning, and with members of the medical team.

Of the 41 caregivers interviewed, 26 caregivers (of 19 children) abandoned their child’s treatment, returned from a series of missed appointments, or showed a risk of abandoning. Caregivers of eight children stated that a miraculous cure was the main reason for abandoning; increasing impoverishment and misgivings towards treatment and outcomes were also mentioned. The responses of the medical team demonstrated a discordant EM for the child’s cancer and treatment effects and that only biomedical treatment was effective for cure. The caregivers’ increasing impoverishment (not only financial) and misgivings about the child’s treatment caused them to reconsider their therapeutic choices, and rely on their belief in a miraculous cure, thus abandoning. The caregivers and medical team’s discordant EM about the child’s cancer and treatment must be acknowledged and shared decision-making considered to decrease abandonment.

**Keywords:** abandonment of treatment, miracles, beliefs, childhood cancer, pediatric oncology

BACKGROUND

As in most low- and middle-income countries (LMIC), abandonment of treatment has been an obstacle for improved cure rates for childhood cancer in El Salvador. We define abandonment according to the SIOP PODC Working Group: “…failure either to begin (conventionally termed refusal) or to continue the planned course (abandonment)… [or] a hiatus of 4 or more weeks in the scheduled treatment” (Mostert et al., 2011). Concordant with research from multiple countries (Li & Jin, 2012; Meremikwu et al., 2005; Mostert et al., 2006; Ramzan et al., 2013; Wang et al., 2011) poverty, low family income and illiteracy (or low education level) have been documented as associated with abandonment in El Salvador (Bonilla et al., 2009). Distance to the hospital may be a factor in abandonment (in Honduras, (Metzger et al., 2003), but not in El Salvador. Families’ cultural views, e.g., religious or spiritual beliefs and alternative therapies have been linked to abandonment (Arora et al., 2007; Bonilla et al., 2009; Metzger et al., 2003; Sitaresmi, 2009), and this is true in El Salvador. Doctor-parent relationship issues have been mentioned as a factor in the decision to abandon (Sitaresmi et al., 2010; Wang et al., 2011), but have not been investigated in El Salvador.

The economic burden of cancer treatment has been studied in high-income countries (Tsimicalis et al., 2013) and LMIC (Hopkins, Burns, & Eden, 2013), and shows a toll on families from all social strata. The impact of a childhood cancer diagnosis on a family with unstable employment, existing debt, expenses for additional children, transportation, and medications continues long after treatment is completed due to additional debt. For families living in chronic poverty with a child with cancer, this has an even greater impact. “The long-term disability and ongoing costs of cancer impoverish families and health systems while worsening social exclusion and diminishing overall well-being.” (Knaul, Frenk, & Shulman, 2011). For the purposes of this article, impoverishment is defined as a situation in which out-of-pocket health care expenses drive a family already living below the poverty line, into further financial difficulty (Shi et al., 2011).

Theoretical Framework

Clinical encounters are shaped by what Kleinman calls Explanatory Models (EMs): how those involved in a sickness, either as practitioner or as patient or relative, define and understand the sickness, its etiology, treatment process and outcome (Helman, 1984a). Clinicians and patients have their own EMs originating from distinct systems of knowledge and values. Differences in social class, education, cultural beliefs, past experiences, among other issues, shape how people make sense of their suffering and make decisions
Practitioners and patients construct their own EMs for the same condition, and in the clinical encounter these EMs are transacted, frequently leading to some level of discordance, tension or conflict that may affect clinical care (Kleinman, 1978; Kleinman, Eisenberg, & Good, 1978).

We explore how caregivers’ belief in miracles influenced clinical interactions in childhood cancer care in El Salvador and ultimately led to abandoning treatment. We present narratives from caregivers who considered abandoning or who abandoned their child’s treatment arguing that a miraculous healing had occurred and we illustrate the caregivers and medical team’s (MT) discordant views.

**METHODS**

**Setting**
Just over one-third of the Salvadoran population (6.1 million) lives in poverty (Central Intelligence Agency, May, 2018; World Bank, 2015), half are Catholic (50%), and the rest Evangelical (38%) or other religions (12%). Approximately 200 children (<12 years old) who are diagnosed annually with cancer receive free treatment at the only pediatric oncology unit located in the national pediatric hospital, Benjamin Bloom Children’s Hospital (BBCH) in the capital. Survival rates are approximately 60% overall (Bonilla et al., 2010). Families with significant economic difficulties receive financial and psychosocial support from two local foundations. Abandonment-tracking and follow-up have shown a drop in abandonment from 13% in recent years (Bonilla et al., 2000; Bonilla et al., 2010) to 3% today (Salaverria et al., 2015).

**Design**
This was an ethnographic, qualitative study using convenience sampling. Participant observation and semi-structured in-depth interviews were conducted during 15 months of fieldwork on multiple visits between November 2012 and June 2014 with selected caregivers of children with cancer treated at BBCH. Caregivers, as well as the MT (one pediatric oncologist, two pediatricians, two nurses, two social workers and one psychologist) were interviewed at the hospital. In addition to private interviews, conversations and observations of hospital daily activity were conducted, including provider-caregiver-patient interactions, and providers’ case discussions.

**Participants**
Caregivers of children undergoing first line treatment without relapse were eligible to participate if they met the SIOP PODC criteria for abandonment, or were deemed to be at risk of abandoning according to the MT. The MT’s
criteria for “risk of abandonment” included: a significant lack of family or social support (e.g., single pregnant mother with children and no extended family), apparent lack of treatment adherence (e.g., regularly missing appointments), uncertain and limited economic means (e.g., peasant families with only sporadic employment), or clear notice from the caregivers that they did not want to continue treatment (e.g., a verbal statement to the MT).

A total of 41 caretakers (40 parents and one grandparent) of 34 children were approached for interviews and all consented. A subset of 26 caregivers (of 19 children) abandoned their child’s treatment, had a series of missed appointments, or expressed an inability or unwillingness to continue treatment. In this subset, 13 caregivers (of eight children) stated that a miracle was their reason for abandonment.

**Procedure**

During fieldwork, the MT directed the researcher (first author NR) to identified caregivers who met the inclusion criteria described above. The Ethics Committee for Clinical Research approved the study and participants were approached at the hospital. NR informed the caregivers (who were unknown to her) that she had formerly been a psychologist in the pediatric oncology unit, but now worked as a medical anthropology researcher and was not involved in patient or family care. The purpose of the study, and the voluntary and confidential nature of participation were also explained. Respondents received no remuneration.

Caregivers were interviewed during their child’s outpatient appointments or hospitalizations. Interviews were recorded (except for two caregivers who did not agree, so notes were written). All caregivers who were approached agreed to participate during the first meeting; all interviews were held on that occasion or during a second encounter.

**Interviews**

A semi-structured interview guide designed by NR included open-ended questions about the family’s circumstances at the start of treatment, the treatment process and the child’s treatment experience (e.g., side effects and emotional state), the extended family and community’ opinions regarding the family’s situation in general (e.g., finances, religion, transportation, home environment, family and friends’ advice, and use of alternative therapies), and sources of help and support. The interviews were conducted in El Salvadoran Spanish, NR’s native language, and lasted approximately 45-60

---

5 The remaining 16 parents showed no indication for abandoning their child’s treatment, although initially the MT had identified risk factors.
minutes. The quotations presented here are NR’s translations only.

Analysis
Conventional content analysis (Hsieh & Shannon, 2005) by NR identified themes emerging from the caregiver interview data. (Weber, 1990) Themes were then reviewed with the last author and checked against relevant interviews. Finally, themes were categorized (also known as “inductive category development” (Hsieh & Shannon, 2005)) by NR.

The MT’s complementary interview data were analyzed to determine the child’s treatment plan, reasons for referral for economic help or social services. Inconsistencies in interview data from caregivers and the MT did not invalidate the data, but rather were considered additional data.

RESULTS

Two categories of caregiver suffering emerged from the data: 1) increasing impoverishment and 2) misgivings about medical treatment effects and cure. A third category included a miracle as an alternative therapeutic option for the caregivers.

For 19/34 children, the caregivers intended to discontinue their child’s cancer treatment or had already done so. The caregivers (13) of 8/19 children stated that a miraculous healing had occurred or would soon occur, or that they trusted that God would care for their child. These caregivers framed their faith-based accounts in living circumstances of increased impoverishment (material scarcity and vulnerability), and misgivings about their child’s treatment and/or medical procedures. These respondents believed that a reliance on God’s power to perform a miracle was a better therapeutic option than chemotherapy.

To illustrate the results of the caregiver interviews, we present the story of one fictitious child, Elisa, who represents an amalgamation of caregiver responses. Elisa’s mother’s story reflects the findings of suffering and miracles experienced by these caregivers. Elisa is a four year-old-girl with two older sisters cared for by her mother in a small rural town (population 23,000) one hour outside the capital. Families’ incomes are daily wage agricultural work, or informal commerce. Elisa’s father left El Salvador to find work and the family relies on his remittances. The family attends a charismatic Christian church where the majority of their community worships. Elisa was about to end her induction phase (in the second month of treatment for acute lymphoblastic leukemia [ALL]) when her mother abandoned treatment. They returned three months later when national social services for children’s welfare protection located Elisa.
CHAPTER FIVE

Increasing impoverishment
Most families who were interviewed and considered abandonment or had abandoned their child’s treatment in favor of a miracle were living at the limit of their resources and suffered from financial limitations that made it impossible to continue their child’s long-term treatment (up to 2.5 years for ALL, a common diagnosis). They were unable to pay for transportation to frequent hospital appointments or had other challenges (e.g., lack childcare for siblings, unable to take time off from work, or need to purchase basic personal hygiene products for use in the hospital since these are not provided to caregivers) that conflicted with attending treatment. Elisa’s mother was not able to cover her family’s basic needs and her financial limitations were a concern increased by Elisa’s cancer diagnosis.

*If there is someone that I feel close to, I ask for the favor of lending me five dollars…sometimes other mothers give me one or two dollars so I can eat, because the food here [in the hospital] is only for the children…For the children at home…sometimes the brothers from the church where I worship bring me little supply of food, not much because we all are poor in the church; a little beans, rice, corn…*

The family’s continuing impoverishment was not only financial. Rather, Elisa’s mother’s impoverishment included an overall life of hardship and stress, and the sense that daily responsibilities of caring for her other children, and her own suffering watching her daughter’s side effects of treatment were becoming more challenging (discussed next).

Misgivings
All caregivers who abandoned or were considering abandoning in favor of a miracle were afraid of the possible health complications resulting from their child’s treatment based on what they had already observed, heard, or experienced. Elisa’s mother said, “I was doubtful about the chemotherapy, that it would be too strong for my child, with three [courses] that she had received she could barely walk…the chemotherapy might cure, but we don’t know what other complications it can cause in her body.” Cancer procedures and medicines were painful and scary, leaving Elisa emotionally labile and weak. Finally, Elisa’s mother removed her from the hospital and abandoned treatment.

Miracles
All caregivers who mentioned that a miraculous healing had a role in their decision to abandon or consider abandoning were convinced that whatever
happened to their child would ultimately be God’s will. The caregivers referred to the improvements in their children’s condition as miracles, or the result of God’s intervention. The miracles came as result of collective or individual praying, personal sacrifice, fasting, or promises. Elisa’s mother said,

...in a vigil the child [Elisa] received healing, because she was very pale and did not want to play, and at the next day she woke up with color in her cheeks and played like never before. The brothers [church leaders] said that next time I go to the hospital I should ask the doctors to perform tests to show them that the child received healing, [and] they will find nothing wrong with the child and consequently the medicines will no longer be necessary.

All caregivers had heard stories of or experienced other miraculous healing, which greatly reinforced their trust in a miracle for their child’s cancer. After abandoning treatment, the caregivers considered their child’s improving appetite, play, and resolution of pain or other health issues as miraculous. They contrasted the child’s poor condition during treatment (weakness or loss of appetite periods, and predisposition to other illnesses) as a proof of the miracle, and not the chemotherapy.

Just before Elisa finished induction therapy, her mother was certain that God had cured her. The signs of the miracle were that Elisa ate, appeared healthy, and was happy again, which was in striking contrast to the worrisome loss of appetite, weakness, bad mood, and pain during multiple procedures of her treatment in the hospital.

One day, in a prayer, I felt that God had healed my daughter. She started to recover the ability to walk in previous days, but after that prayer, from one day to the next, her leg pain disappeared and she walked normally again. When I told I wanted to stop the treatment the doctor said: ‘No! If you stop the treatment she will live one month and after that she will die’.

Elisa’s mother did not return to the hospital for three months. When the hospital’s psychologist called her, she explained that Elisa had been cured by God and no longer needed treatment. She continued taking good care of Elisa at home and felt at peace, with no pending conflicts with the hospital.

Eventually Elisa had to return to the hospital because she was located by the government’s social services for children welfare, who would have removed her from her mother’s custody if she had not resumed treatment.
I keep coming to the treatment in order to not lose custody. I am sure that my child is cured. She does not have any side effects from the chemotherapy, and that is because she is healed.

Although Elisa’s mother continued her child’s treatment, she was not happy about returning to the situation that worried her and made her daughter suffer. Since the doctors had warned Elisa’s mother about treatment side effects, and her daughter had been experiencing fewer side effects at home, this served to reinforce the confirmation of the miracle cure for her mother.

For me the only doctor is God. He has the last word, whatever the doctors at the hospital say. The man from the governmental social services asked me, “where is the paper that states that God has healed your child?” I replied that Elisa could barely walk when I took her away from the hospital, and now she even gained weight and her hair started to grow again. They think that because they are doctors they are everything. I said these things to the doctor and he did not say anything, but I know he is mad at me.

With her characteristic serious expression, Elisa’s mother attended every appointment, but she was sure that she had higher knowledge beyond what the doctors saw—the knowledge of those who have faith in God.

MT Perspective
When facing caregivers who wanted to abandon treatment due to a miracle, the MT’ reactions varied from predicting a certain deadly outcome for the child, to attempts to show respect for the caregivers’ beliefs and negotiate the possibility of continuing treatment alongside religious practices. The MT considered beliefs in miracles to be contrary to scientific knowledge, and most had seen during their professional practice that it was unproductive to try to change caregivers’ mind. The MT also considered that in some cases the caregiver’s search for a miracle was the result of desperation, anguish, lack of education, or community pressure.

In an interview with a father, one doctor said “I respect your faith, but why not try both strategies? The help from God and the treatment from the hospital together… I can tell you that to my knowledge, your child needs the [medical] treatment to be cured”. According to the psychologists and social workers (who shared the doctors’ opinions), some caregivers used a religious-based reason as just an excuse to not continue their child’s treatment, but were not comfortable confronting the caregivers with this idea.
CHAPTER FIVE

CONCLUSIONS

This research shows that caregivers who had abandoned their child’s cancer treatment in El Salvador and relied on their belief in a miraculous cure, had experienced increasing impoverishment, and misgivings about the biomedical treatment. The caregivers’ experiences with their child’s improved health after abandoning treatment (in part due to the lack of chemotherapy side effects) affirmed that their religious beliefs and practices superseded medical advice. This occurred despite initial teaching about chemotherapy side effects when the child was diagnosed and weekly teaching during hospitalization and outpatient treatment. It appears that education alone is not adequate to bridge the gap in EMs of the caregivers and MT.

A survey in 2009 revealed that almost 95% of the Salvadorans surveyed believed in miracles, that God answered their prayers (73%) and that at some point they had been healed from an illness by God (64%) (Instituto Universitario de Opinión Pública (IUDOP) Universidad Centroamericana José Simeón Cañas, 2009). In a study in Iran, Taleghani et al. (2012, p.334) reported, “Faith and religious beliefs brought comfort to some caregivers. While expressing frustration with science, they did not cease to hope that a divine miracle might cure their child”. Njuguna et al. (2015, p.1254) in Kenya noted that 27% of caregivers of children with cancer believed that their child’s health “was beyond doctor’s control and determined by luck, fate, or God...”. Usoulet and Schauder (2012) documented that Salvadoran mothers of children with cancer had a strong sense that God controlled their children’s health and felt comforted. These findings are in line with the findings of this study regarding caregiver beliefs in a miracle cure for their child and comfort in their belief in God’s power. Unfortunately, in BBCH, there is no priest or Christian clergy available for counselling. Therefore, spiritual support is provided only by their religious community and these community members are generally unaware of the biomedical aspects of childhood cancer.

Although families of children with cancer are given transportation money if needed in El Salvador, logistics are complex and include challenges of finding a driver, intermittent bus schedules, poor weather conditions, and inconsistent support from institutions. Moreover, poverty is more complex than a lack of financial means; these families have an overall increasing impoverishment (Reeve, 2012; Sen, 1987). For example, Israëls et al. (2008) noted that parents of children with cancer in Malawi were concerned about transportation costs, lack of money for food while their child was hospitalized and problems with children left at home. The abovementioned literature from multiple LMIC shows caregiver impoverishment due to the child’s
cancer, suffering and reliance on God for a miraculous cure, which supports this study’s findings.

EMs served as a framework to understand the caregivers’ experiences, health-seeking behaviors, and decision-making. Despite following a common trajectory and goal for the child’s cure, the MT and caregivers’ EMs diverged when the caregivers made the clinical decision to reject the child’s medical plan and abandon treatment. The main components of the caregivers’ EM intertwined their misgivings about the medical treatment, increasing impoverishment and beliefs in a miraculous solution. The MT may not see religion and miracles as a remedy for childhood cancer, but rather hold biomedical treatment as the only option for cure—their EM. With disparate EMs, both the MT and caregivers will require effective communication to come to a “shared treatment decision-making model” and compromise during clinical encounters (Pirbhai, 2003).

Limitations
This study was based on a small number of caregivers of children with cancer in El Salvador. The findings are particularly relevant for El Salvadoran culture and religious beliefs and may not translate to other settings. However, there are LMIC where religion has a similar presence and so the findings here may prove illuminating for pediatric oncology teams elsewhere.

Recommendations
There is a wide difference between the caregivers and the MT’s EMs for childhood cancer and treatment in El Salvador and this distance must be bridged. The caregivers who say they believe that God has cured or will shortly cure their child with a miracle and thus abandon medical care must not be condemned. Their experience and beliefs should be explored in open communication to achieve shared decision-making. Comprehensive interventions should combine addressing the child’s wellbeing, treatment efficacy and decreasing family stress while recognizing that impoverishment is not limited to finances.

Approaches should consider the current El Salvadoran law for treatment enforcement, “Ley Protección Integral de la Niñez y Adolescencia” [Law for the Comprehensive Protection of Children and Adolescents], which includes wording to ensure that children with life-threatening illnesses receive adequate health care. Thus, families who abandon their child’s cancer treatment are forced by governmental authorities to return to the hospital despite their belief that God has cured their child. How the caregivers experience this forced return is yet to be explored, but warrants investigation to address their quality of life during on-going treatment.
CHAPTER FIVE

Current financial support must be more consistently applied for families in fragile circumstances. Spiritual counseling in the hospital could serve to mitigate the caregivers’ distress while negotiating the foreign biomedical environment. There are two social workers and two psychologists available to families on the pediatric oncology unit. However, strategies for earliest identification of families with complex psychological distress that goes beyond the universal coping challenges of families of children with cancer need to be enhanced if abandonment is to be further reduced. Current psychosocial and financial support might solve most families’ immediate pressing needs, but do not appear to be a long-term solution for a minority of caregivers. The possible unintended consequences of the disparate EMs of the MT and caregivers are continuing to make a miracle appear to be a suitable caregiver solution to their child’s cancer and subsequent decision to abandon treatment. The law addresses treatment abandonment for children with cancer, but it does not diminish their caregiver’s strong belief in miracles as opposed to biomedicine, or their distress at what they see as their child’s continuing suffering throughout their return for cancer treatment.

ACKNOWLEDGEMENTS

NR’s work was supported by the Brocher Foundation.