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# Childhood cancer in El Salvador: A preliminary exploration of parental concerns in the abandonment of treatment



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## ABSTRACT

### Keywords:

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**Purpose:** 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.

**Method:** 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.

**Results:** 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.

**Conclusions:** 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.

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## 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 45–60% of cases abandon treatment in the developing world each year (Arora et al., 2007), constituting a major cause for treatment failure (Arora et al., 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,

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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; Sitaesmi 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 (Klunder-Klunder 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 affiliations are mainly Catholic, 57% and Protestant<sup>1</sup> 21% (Central Intelligence 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 rates.<sup>2</sup> For example, 5-year event free survival for children with standard risk acute lymphoblastic leukemia is now  $56.3 \pm 4.5\%$  (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; Sitaesmi 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 leads to another is still a work in progress. This study investigates abandonment of treatment in El Salvador through exploring the parents' own accounts 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 current 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 min) 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 purpose 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.<sup>3</sup> The first consideration here was that the research was not invasive, and that risks for participants were limited to possible emotional discomfort (Association, 1998; National, 2007). Second, and more importantly, the researcher recognized that the parents were in actual or

<sup>1</sup> Protestant refers mainly to charismatic and evangelical movements.

<sup>2</sup> The Fundación Ayúdame 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.

<sup>3</sup> 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. 2007: 24).

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