



*Curing Children, Caring for Families. The Path to Personalized Care in
Childhood Cancer Treatment in El Salvador*

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Summary

This dissertation follows the trajectory of the childhood cancer program of El Salvador in its quest to eliminate abandonment of treatment. Abandonment of treatment is the term used in pediatric oncology to refer to those cases in which the parents do not start their child's cancer treatment or do not continue after starting. Abandonment of treatment costs children's lives and is an obstacle to the improvement of cure rates of cancer programs in developing countries. This thesis shows how over the course of its trajectory, the Salvadoran childhood cancer program succeeded not only in reducing abandonment of treatment, but also in improving the quality of care for all its patients. In the process, the hospital team's professional expertise was also boosted.

The research on which the thesis is based addressed the centrality of the problem of abandonment to the paediatric oncology program. It starts with the 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?* To answer this question, institutional processes and personal experiences were analysed from the perspectives of both the hospital team as well as the parents.

As an initial approach, the parents' reasons for and perspectives on abandonment of treatment were explored (Chapter 2). Common elements present in the accounts of the parents when they talked about their treatment experiences and abandonment were chronic poverty, anguish and fear about the therapy effects, conflicting interpretations regarding hospital rules, and alternative perspectives framed in religious beliefs. Despite the provision of material resources as an essential first step to help families not to abandon treatment, the non-material dimension of poverty and the coping strategies of each family were frequently overlooked by the oncology health care team. Poverty showed to be a powerful multi-dimensional component of the parents' worldview, while abandonment of treatment made evident the relational and experiential character of cancer treatment and that its trajectory is constituted in the encounter between two groups of actors: the medical team and the parents.

The hospital health-team initiatives to reduce or prevent abandonment of treatment were also analysed (Chapters 3 and 4). First, Chapter 3 explains in detail the oncology health team's strategy of a close follow-up of patients to address treatment abandonment in its very early stages. This attempt of the health professionals to guarantee that the children stay on treatment prioritizes a protocol-based follow-up of families that helps to detect and solve the challenges that might impede their continuation of the treatment. This standardized approach seems to be appropriate for effectively keeping children on treatment. Moreover, the health team gains better knowledge of the patients' life circumstances, and engages in closer relationships with the families as they try to discern the factors motivating abandonment. Second, the qualitative and personalized essence of this protocolled follow-up strategy is highlighted in Chapter 4, which shows the added value of incorporating resources external to the hospital realm. Local institutions that operate in the patient's community were asked to team up with the hospital's staff and help locate children who have abandoned (or have been absent from treatment) and provide resources for resumption of their treatment. This kind of initiative requires careful team work, but also entails risks of misunderstandings and unintended complications for the parents, who have to deal with personnel from

diverse institutions, with diverse levels of knowledge and understanding of the personal circumstances they as a family have to go through while attending treatment.

To bring the parents' experiences to the forefront, Chapters 5 and 6 offer examples of particular strategies parents deploy to cope with their difficult situation. Chapter 5 zooms in on cases of parents who believe a miraculous healing has invalidated the need for medical treatment of their child. The role of poor living conditions in such view is made evident. A miraculous cure becomes an alternative resource for some parents to solve the problem of their child's disease as well as the financial struggles worsened by the treatment. The 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 overextended. However, anxiety and misgivings over the harmful effects and uncertain treatment results play an equal role in making alternatives to treatment acceptable. Correspondingly, this chapter explores the basic elements of the mistrust in the clinical encounter of parent and doctor.

Chapter 6 analyses the specific experiences of families approached through a legal intervention to return to treatment. This final-resort strategy consists of the application of a legal resource to force the continuation of treatment by the parents who abandon treatment. According to the law, the parents may face state removal of their parental rights and the child being taken under state custody. 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 concluding discussion dwells on the positive results for the quality of care that followed the introduction of the aforementioned protocols. Those protocols systematized information and standardized actions aimed at preventing abandonment of treatment. They increased control over patients' adherence to treatment and schedules, but they also became a tool for a more accurate assessment of the families' needs, leading to a more personalized and engaged care provision. Thus, this thesis presents the argument that in the process of searching for a solution for abandonment of treatment, the standardization of follow-up practices paradoxically led to increased personalization and quality of care for all children receiving treatment for cancer. However, as the Salvadoran case showed, such standardization of care can only result in increased quality of care if paired with the allocation of sufficient resources to support families' needs as well as the provision of tools to qualified and dedicated staff, enabling them to pay the systematic attention necessary to improve healthcare for the poorest.