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Edelmira Castillo

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INTERPRETIVE STUDY OF PARENTS' CONCERNS, SKILLS, AND PRACTICES IN CARING FOR THEIR CHILD WITH CANCER IN COLOMBIA

Edelmira Castillo

Dedicated to the memory of my beloved parents Blanca and José

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INTERPRETIVE STUDY OF PARENTS' CONCENS, SKILLS, AND PRACTICES IN CARING FOR THEIR CHILD WITH CANCER IN COLOMBIA

ABSTRACT

Edelmira Castillo E.

Increased survival for children with cancer and the parents' central role in their care suggest the need for further research on the parents' experience in different cultures. This interpretive study was conducted in Cali, Colombia to understand the meaning of the illness for the parents, their concerns, and practices in caring for their child. Participants were the father or mother of a child 3 to 12 year old, diagnosed with leukemia for 3 to 18 months and under treatment. Twenty parents representing 11 families participated in multiple interpretive interviews conducted at home.

Parents' trajectory in learning to live with the illness began with the loss of the parents' world at the time of diagnosis. Beginning recovery of this lost world became possible when the disease went into remission. Parents recovered some sense of normalcy in their lives and turned their attention to other children, themselves, and needs beyond the illness during the maintenance phase. This normality was disrupted by hospitalizations due to other illnesses or very low blood counts and by changes in treatment protocol and follow-up tests. Religion and faith allowed parents to find a meaning that helped them to accept the illness.

Cultural expectations shaped the parents' possibilities in being with and caring for the child. Mothers more than fathers perceived their involvement with the child's care as taxing and rewarding. Fathers were more distant due to their work but equally concerned about the child. The illness had both positive and negative impacts on couple and family relations. Most parents experienced increased closeness and love but parents with previously disrupted relationships had heightened difficulties once the illness remitted.

Parents' caring practices evolved from the practical advice of other parents, relatives, friends, health professionals, and by trial and error. The caring practices were directed toward protecting the child from infection and other illnesses, bleeding, exposure to the sun and chemicals. Other practices were aimed to boost the child's immune system and decrease the child's discomfort and suffering from the side effects of chemotherapy, the pain and fear from having a deadly disease and the treatment procedures.

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1: SIGNIFICANCE AND BACKGROUND OF PARENTS AND CHILDHOOD CANCER

Cancer is not only a life-threatening and chronic disease but it stands as a symbol for the unknown and dangerous, for suffering and pain, for guilt and shame, for chaos and anxiety (Bolund, 1990). When the person suffering the disease is a child, these emotional reactions could be stronger for the child, parents, siblings, extended family, and health care providers. Recent advances in the treatment of childhood cancer have changed its prognosis. In developed countries, childhood cancer formerly seen as an acute, almost invariably fatal disease is now seen as a life-threatening and chronic illness (Heath, 1996). Lengthening the course of the disease has had a profound effect on the children and the families and merits more research. However, in the majority of the developing countries, cancer is still considered as a fatal illness. The mortality rates are still high perhaps because of the lack of access to early diagnosis and treatment. Regardless of the prognosis of the disease, the diagnosis of cancer in a child is devastating for the whole family and the child.

Cancer affects all family members and the child in every aspect of their lives. They have to live under a permanent “Damocles sword” (Koocher & O’Malley, 1981). Uncertainty, stress and anxiety abound during the whole illness trajectory even when the disease is under control. Families must effectively cope with the situation in order to battle the disease and keep the family’s life going for all its members. The physical and emotional demands of the cancer experience change according to the developmental stage of the family, the family structure, and the degree of the family’s and community support (Chesler, 1993). The parents of children with cancer are usually learning their parenting role, which itself is a strain, but they also have to face the reality that they, alone, no longer can protect and provide for their child. Regardless of the parents' capabilities to provide for the child, they are held responsible for the child's well being and care in any situation.

The diagnosis of cancer creates a crisis for the family and the child (Heath, 1996). This crisis can be seen as the process that marks the transition from the life of being healthy to the life of having an illness and constant threat. It also is the process of learning to integrate new realities, and finding new ways of coping with them within a tolerable mental, social, and physical suffering (Bolund, 1990).

Knowing and understanding the parents' experience with childhood cancer is essential for the care of the children and their families. Nurses, as health care professionals concerned for the health and well-being of the child and her/his family, are pivotal in supporting the child and the family, and the parents in particular through the cancer experience. Nurses need also to be empathic with the family and supportive of its efforts to cope with the child's illness. To do so, nurses need to be knowledgeable about the child and family's experiences. The experience of caring for and raising a child with cancer has not been extensively studied. Most of the studies about the family of children with cancer has been done using research methodologies which do not allow the researchers to understand and describe the everyday concerns, practices, habits, difficulties the parents encounter in this situation. Parents of children with cancer face a completely new situation which requires new capabilities to meet the demands of the ill child, other family members and the parents themselves. The outcome of the parents' coping with the situation varies with the illness trajectory, the parents' resources, and the context in which they live (Michael & Copeland, 1987). In this dissertation, I will begin by presenting information on cancer incidence and survival rates in developed and developing countries. Next, I will briefly review four theoretical perspectives through which I might view the family of the child with cancer. I will also review the existing knowledge about parents and childhood cancer at the time of diagnosis and during treatment.

Incidence, Mortality, and Survival Rates of Childhood Cancer

Over the last three decades, cancer incidence, survival, and mortality rates have changed in developed countries and some developing countries. Parker, Tong, Bolden, and Wingo (1997) reported cancer as the second leading cause of death in all age groups under 15 in 1993 for the USA population. Leukemia was the first cancer cause of death in children under 15 and brain tumor the second. The data used to calculate the mortality rates is incomplete and not very reliable for many countries. Mortality rates have declined in developed countries but not in developing countries (Levi, La Vecchia, Licchini, Negri, & Boyle, 1995). The mortality rate is still very high in Latin American (Cuba, Uruguay, Argentina, Costa Rica) as well as Kuwait, New Zealand, and Singapore. The pattern is similar for leukemia, which accounts for about 50% of all childhood cancer mortality. In Latin American countries some recent declines in mortality rates due to leukemia have been observed in Argentina, Chile, Costa Rica, Cuba, and Uruguay but the rates are substantially higher than the rates in North America. No evidence of decline was apparent in Colombia, Panama, and Venezuela. The declines in mortality from cancer were essentially attributable to improved management of the disease, including newer multidrug chemotherapy, improved radiotherapy and diagnostic techniques, and the introduction of supportive care (Parkin, Stiller, Draper, & Bieber, 1988).

However, even in the United States of America (USA), cancer incidence and survival rates are related to socioeconomic status, both being higher in persons with low socioeconomic status (Wilkes, Freeman, & Prout, 1994). Late diagnosis related to lack of access to health care, increased risk factors such as diet, smoking, and environmental contamination, and fatalism among the poor are some of the possible causes of the differences in incidence and survival rates between the socioeconomically disadvantaged persons and persons with higher socioeconomic status (Wilkes, Freeman, & Prout, 1994). The lack of noticeable declines in mortality rates among developing countries emphasizes the role of socioeconomic status in cancer incidence and survival as well as the need to provide resources for adequate treatment of childhood cancer in these countries. It also shows the need for developing interventions to support the families of the children in facing and meeting the demands of the illness situation.

The incidence of childhood cancer in Cali follows some of the mentioned patterns. Carrascal (1992) reported, for the 1982-1986 period, leukemia as the most common type of cancer, with ALL being the most common for children from 1-9 years of age. There were differences in incidence of ALL between boys and girls, being higher for girls in all age groups. Wilm's tumor was the second most common type of cancer for boys (incidence of 1.5-2.1/100,000) and brain tumors for girls (incidence 0.9-2.8/100,0000). Hodgkin's and Non-Hodgkin's lymphomas were more frequent among boys than girls with Hodgkin's lymphoma having a higher incidence.

The findings about cancer mortality and survival could mean that childhood cancer is not curable as some researchers and clinicians have concluded. It seems that we are very far from achieving the cure of childhood cancer, even in developed countries, where the risk of dying from recurrence of the cancer or from a second cancer is still high. Besides, survival from childhood cancer has been based only on 5 years-survival time from the diagnosis of the initial cancer. Survival rates for children under age 15 in USA has increased for all types of cancer (Parker et al., 1997) from 1986 to 1992. Wilm's tumor has the highest survival rate followed by Hodgkin's disease, ALL leukemia, soft tissue tumors, Non-Hodgkin's lymphoma, cancer of the bones and joints, neuroblastoma, brain and other nervous system tumors, and AML leukemia. Survival data for other countries is not available. The number of observed deaths among survivors of childhood cancer was four times higher than the expected deaths. Infections, respiratory, and cardiovascular deaths were especially high (Robertson, Hawkins,& Kingston, 1994). These authors also reported that 74% of the survivors'death was caused by recurrent cancers, 15% treatment related effects, and 7% secondary cancer. The risk of dying of recurrent cancer in the next 10 years after surviving 5 years from diagnosis has decreased from 12% in 1940-1970 to 8% in 1971-1985 while the risk of dying from a treatment related effect has increased from 1% to 2%. Robison and Mertens (1993) stated that with the introduction of a more intensive multiagent therapy for childhood cancer not only are a greater number of children surviving their initial cancer but also they may be at greater risk for developing a second malignancy. According to them, the most consistent finding of the larger studies about this issue is that the elevated risk of a second malignancy remains constant over time but the absolute risk increases substantially as the length of follow-up increases. It is these statistics that bring into question the conception of childhood cancer as curable.

Researchers have been interested in the experiences and the problems of children with cancer and their families. In relation to the family, the psychosocial literature and the nursing literature have been concerned primarily with the family's reactions to the diagnosis, the child's impeding death and the child's care in the hospital and at home. The focus of most of the research has been on the negative impacts of the cancer situation on the family. The everyday life of the families has not been studied. Without knowing how parents, siblings, and other family members experience the illness situation in their everyday life, nurses can not provide the adequate care and support for the children and the families. Since parents are pivotal in the care of the ill child and the whole family functioning, it is essential to understand the meanings they give to the child's illness, their concerns and practices in raising the ill child and in being a mother/father, a partner, and a member of the community where they live.

In summary, childhood cancer is a serious health problem due to its epidemiological and psychosocial implications. It is viewed as chronic disease only in developed countries while in developing countries is still viewed as potentially fatal. Childhood cancer treatment has tremendous consequences for the child's life and future health as well as for the family's processes and everyday life. There are many issues related to childhood cancer that are still unknown. The everyday life and experiences of parents raising and caring for a child with cancer is one of the areas which merits study in order to provide health care providers with an understanding of the parents' world when facing cancer in their child. By understanding the parents' own experiences, nurses might be better prepared to support parents in facing the child's illness. But most of all, overall nursing care might be refocused upon the multiple concerns of caring for the ill child, parents, and other family members. So far the focus of nursing care has been primarily on the ill child, leaving the parents and other family members largely on their own.

Conceptual Frameworks in Understanding Parents and Childhood Cancer

There is no a single theory or conceptual framework which can be used to describe and explain the family or parents' responses to childhood cancer during the entire illness process.

Different conceptual models have been proposed to understand the impact of chronic illness on the person diagnosed with the disease and the family (Bolund, 1990; Cohen, 1995a; Kazak, Meeske, Penati, Barakat, Christakis, Meadows, Casey, and Stuber, 1997; Patterson & Garwick, 1994; Scott-Dorsett, 1991). Most of these conceptual frameworks are focused on the ill person rather than the family or the parents and include cancer as only one among many chronic illnesses. Although no one of these conceptual frameworks guides my study of the parents' experience in raising a child with cancer, all these frameworks form part of my fore-structure or background understanding of parents' experience with childhood cancer (Dreyfus, 1991).

Cohen (1995a) developed her concepts from her grounded theory study of parents with children who have chronic life-threatening illness. She describes three stages for the process parents go through in interpreting the child's symptoms from the time of their initial awareness or suspicion that something is wrong with the child to the final medical diagnosis. The stages are lay explanatory, legitimating, and medical diagnosis. First, parents give a lay explanation to the child's symptoms. Parents do this by retrieving similar instances, normalizing the symptoms, selecting a management strategy, waiting for the effect of the selected strategy, acknowledging the failed strategy, and realizing the discrepancy between what they think about the symptoms and the child's condition. Then, parents realize their limits in identifying the problem and begin to legitimate the need for medical intervention. The parents are concerned in this stage with being made to feel foolish or incompetent, not being taken seriously in the future, being chastised for wasting the physician's time, and spending money that is not necessary. The medical diagnostic stage begins when the parents make the appointment with the physician. The presence of ambiguous physical findings, the degree to which the physician credits or disregards the parents' concerns, and the physician's medical decision making process determine the length of this stage. The announcement of the final diagnosis is often perceived "as a physical assault by a powerful force" (Cohen, 1995, p. 47). The taken-for-granted world of the parents is challenged by the illness diagnosis.

Scott-Dorsett (1991) proposed the trajectory of cancer recovery as a relevant conceptual framework for nursing practice, research, and teaching in relation to cancer patients. This conceptual framework recognized recovery as "a fundamental human process whereby change in wellbeing is absorbed, assimilated, and accommodated over time in the service of both survival and creativity" (p. 178), which goes along with the illness trajectory. This conceptual framework can be used for understanding some aspects of the person with cancer but should be used with caution to explain the parents' responses to their child's cancer, despite the fact the parents are devastated by the child's diagnosis and also need to "recover" physically and psychologically.

Bolund (1990) described the crisis process people go through in learning to live with cancer. The phases of the crisis process are the shock phase, reaction phase, work through, and the reorientation phase. We can assume that parents of children with cancer might go through the same phases described by Bolund (1990). However, we do not know yet if this is the case among Colombian parents.

A posttraumatic stress conceptual framework has been used to identify the psychological impact of childhood cancer in survivors and their parents (Kazak et al., 1997). "Learning that one/one's child has a life threatening illness" was included in 1994 in the DMS-IV, as an event that may cause posttraumatic stress disorder (PTSD). Posttraumatic stress symptoms are categorized as 1) persistent reexperiencing of the traumatic event, 2) persistent avoidance of circumstances that might be reminders, or numbing of general responsiveness, and 3) increased arousal, including hypervigilence and difficulties in concentration. Traumatized persons may manifest posttraumatic stress symptoms without meeting the criteria for PTSD diagnosis, which could be what happens to parents of children with cancer. The above authors identified significantly more posttraumatic stress symptoms in mothers and fathers of children with leukemia than parents of healthy children. Intrusive memories and flashbacks about cancer and its treatment were reported by the parents, especially in relation to common occurrences as cold, aches, and pains in the child. However, there were not significant differences in family functioning between parents of children surviving cancer and parents of healthy children, which could mean the parents have PTSD symptoms but they do not have PTSD as diagnosis.

The Family Adaptation and Adjustment Response (FAAR) model described by Patterson (1988) and Patterson and Garwick (1994) to explain the family response to the stress of chronic illness could also be used when studying parents of children with cancer. This model includes the family's demands, capabilities, meanings, and outcomes as the major contructs in the family response to chronic illness. In this model, the family attempts to maintain balanced functioning by using its resources and coping behaviors (capabilities) to meet its demands (stressors and strains). The meaning the family gives to its demands and to its capabilities is a very important factor in achieving balanced functioning. The result of the family's efforts to achieve balanced functioning is conceptualized as the family's adjustment or family's adaptation. Both of them could range from poor to good. Good adjustment or adaptation is reflected in physical and mental health, optimal role performance for all family's members, and maintenance of the family unit to accomplish its tasks. The FAAR is useful in my study of the parents' experiences because it has helped me to organize the existing knowledge about parents and childhood cancer using the main concepts of the model. The main concepts are also useful when elaborating some of the interview questions for the parents participating in the study.

Existing Knowledge about Parents and Childhood Cancer

The treatment for childhood cancer varies according to the type of cancer and the phase of the illness trajectory, but in any case it is long and involves many painful procedures and events for the child and the parents. I assume that parents have to deal with diverse demands during the treatment, which requires diverse coping strategies and resources that might produce different outcomes for the parents and the entire family. Most of the existing knowledge about childhood cancer has been generated from studies in North America, but there also some studies in European and Asian countries that are important when considering the knowledge about childhood cancer and the family. However, in the absence of contextual knowledge about parents and childhood cancer in Colombia, I need to base my study about parents' experience in raising a child with cancer in the existing knowledge even though it has been created in a different cultural and economic context. Besides, there are meanings, concerns, and practices that are shared by all human beings (Heidegger, 1962).

I will present in the following section of the dissertation a review of the existing knowledge about parents and childhood cancer. First, I will describe what is known about parents' reactions during the time of diagnosis of the child's cancer. Next, I will describe the knowledge about the parents' demands, resources and coping strategies, the meaning of the cancer experience, and the parents' adjustment during treatment.

Parents' Responses at the time of the Child's Cancer Diagnosis

Cancer diagnosis in a child leads the family to experience an array of emotions and feelings. Cancer is associated with death but it is not an illness associated with children by most people (Grootenhuis & Last, 1997a). Researchers who had studied parents of children recently diagnosed with cancer have reported increased emotional stress among these parents compared to normative data (Dahlquist, Czyzewski, & Jones, 1993; Grootenhuis & Last, 1997a). Other longitudinal studies also have found negative emotions such as anxiety depression, insomnia, somatic or social dysfunction right after the diagnosis of the child's cancer (Dahlquist, Czyzewski, and Jones, 1996; Grootenhuis & Last, 1997b). Irritability, crying, trouble making decisions, and lack of interest in sex were found by Manne, et al. (1995). Parents who had severe to moderate symptoms of depression at the time of the diagnosis continued having the same depression scores three months after the diagnosis. These parents reported a less cohesive family, more functional impairment in their child, and more children's behavioral problems than parents with mild depression symptoms (Kazak et al., 1995).

Parents have to deal with uncertainty during the pre-diagnostic phase, (Clark-Steffen, 1993; Cohen, 1993, 1995a) and during the whole illness trajectory (Martinson & Cohen, 1988). Uncertainty is related to the causes of cancer, the treatment and its effects, and the child's health and future. Uncertainty is triggered by routine medical appointments, child's body variability, key words and provocative questions from health care providers, changes in therapeutic regimen, evidence of negative outcomes in the child, new developmental demands in the child, and seems to be experience more intensely at nighttime (Cohen, 1995b). Waiting for the child's diagnosis, the degree of suffering for the child, and management of the household also produce a lot of uncertainty for the parents (Clark-Steffen, 1993). The final diagnosis of the child's cancer is devastating for the parents; it is perceived as overwhelming, and it brings with it a loss of expectations and dreams (Cincotta, 1993).

Most of the published studies about parents during the treatment of the child's cancer have been done without specifying the treatment phase. However, the induction, remission, and relapse phases of the treatment last from months to years and impose different demands on the ill child and the parents. The parents' responses and experiences during each phase might be different too. In the study about Colombian parents' experience in raising a child with cancer, I focused on the remission or maintenance phase but if the child had a relapse I followed the parents during this period too.

Parents During Treatment of Childhood Cancer

During treatment parents have to meet the specific demands from the illness situation well as the normative demands according to the developmental stage of the family and its members, including the parents and the ill child. The parents' capabilities and resources allow them to meet the above demands and to cope with the illness situation. The expected outcome of the family members' coping is their adjustment or adaptation. The existing knowledge about parents and childhood cancer during active treatment will be described in the following sections using the FAAR model main constructs.

Demands

Demands are challenging or threatening conditions that call for change in the family (Patterson & Garwick, 1994, Patterson, 1988). The demands of having a child with cancer vary according to the illness trajectory. For parents, demands come mainly from the specific care and parenting tasks required by the ill child, the pain and suffering due to the illness and treatment effects on the ill child, and the financial expenses of the cancer treatment. Besides the illness demands, families need to meet the normative demands according to the developmental stage of the family and its members. Different terms have been used to refer to demands: stressors, stress, and stressful life events are terms frequently used by researchers.

The main demand parents have is stress from different and multiple sources. During the treatment, the unpredictability of the course ahead increases the parents' uncertainty (Cincotta, 1993). Painful testing procedures like Bone Marrow Aspiration (BMA) and Lumbar Puncture (LP) increased the parents' emotional distress (Kazak, et al., 1995). Uncertainty about the parents' role in preparing the child for the painful procedure and anticipating the child's distress were the main sources of stress for the parents undergoing these painful procedures (LaMontagne, Wells, Hepworth, Johnson, & Manes, 1999). Sterken (1996) found that uncertainty was negatively correlated with the father's age, lack of information, and length of the diagnosis. Younger fathers found the information given about the treatment, the system of care, and the seriousness of the child's illness was vague; this increased their level of uncertainty. The sustained uncertainty that parents experience during the cancer situation has been called "Damocles sword" (Koocher & O'Malley, 1981). This uncertainty is well documented but there are still aspects of it that could be better understood. For example, how do parents live everyday with this unsettling feeling and how does the uncertainty influences parents' practices in parenting, being a partner/spouse, and living their everyday lives?

Other stressors reported by researchers include helplessness, fear of the disease recurrence, dissatisfaction with information provided, physical and emotional stress from caregiving responsibilities, and financial burden (Brown & Barbarin, 1996; Thoma, Hockenberry-Eaton, Kemp, 1993). Lack of recognition of parents' role during the child's hospitalization and lack of attention to parents' concerns by the health care providers were stressors reported by Williams (1992).

Making decisions about the child's treatment is another demand parents face at the beginning and during the illness (Pyke-Grimm, Degner, Small, & Muller, 1999). Parents had different preferences regarding their control over the child's treatment. These preferences which included taking an active role where they kept responsibility for most decisions, a collaborative role where decisions were shared or a role that relinquished control (Pyke-Grimm et al., 1999). More parents preferred a collaborative role with physicians at the time of the cancer diagnosis and during the first year of treatment.

Parents are faced with the demands of caring for and parenting the ill child as well as the other children in the household. There are few published studies related to raising a child with cancer (Brown & Barbarin, 1996; Enskär, Carlsson, Golsäter, Hamrinm, & Kreuger, 1997; Hillman, 1997). Usually, the ill child becomes the center of the family and siblings' care is delegated to extended family and friends as reported by Caucasian and Chinese families caring for their child at home during the first year of treatment (Leavitt, et al., 1999; Martinson, et al., 1999). For these parents the demands included learning complex technical skills like administering I.V. medications, flushing the Hickman catheters, and monitoring the child's need for isolation. Other demands were lack of time and inability to plan, trips to the hospital for evaluation and treatment of severe side effects, managing the child's behavior changes such as increased aggression and irritability, dependence, mood swings, and changes in appetite. Parents' care practices for the child were similar regardless of whether the child was under treatment or off treatment (Moore & Mosher, 1997). Problems related to the child's/adolescent's cancer, as reported by Swedish parents, were watching the child suffer, being governed by the child's disease, experiencing sadness, despair, uncertainty, dealing with the reactions of others, finding support from others, increased expenses, and less opportunities to work (Enskär et al, 1997). Parenting tasks were perceived differently by mothers and fathers depending on the stress, importance, and personal responsibility they ascribed to the tasks (Brown & Barbarin, 1996). Mothers viewed "dealing with medical aspects of illness" as their most important and stressful task. More time and more stress in taking care of household chores were also reported by mothers. Mothers reported more importance, personal responsibility, time and effectiveness in keeping extended family and friends informed. In general, mothers had higher ratings of importance, stress, and responsibility for all parenting tasks than fathers except handling household and medical expenses. Fathers reported spending the most time and experiencing the most stress in handling medical and household expenses; fathers rated as the most important task spending time with other family members. Child-rearing practices were different for parents of children with cancer and parents with healthy children (Hillman, 1997). Discipline, parental expectations, parental concerns/worries, expression of emotion, and overprotectiveness were the areas with more differences between the healthy child's parents and the ill child's parents. Chinese and Caucasian parents reported extra indulgence, problems in setting limits, fear of spoiling, and over protectiveness with the ill child (Martinson et al., 1999). Enskär et al. (1997) also found that parents spoiled and overprotected their child.

Parenting a child with cancer is an aspect of childhood cancer that is beginning to be studied. Knowledge about the parents' experience in raising the ill child is crucial to health care providers, especially nurses, who want to provide comprehensive and supportive care to the child and the family. For example, it is necessary to have a better understanding of the parents' expectations for the child and themselves, the parents' feelings about the child, the parents' child rearing practices and concerns with the ill child, and the differences in parenting the ill child and the other children in the family.

Stress from other events or situations that occur concurrently with the child's cancer are demands that some parents have to face. These stressors could be other illnesses in the child or family member, death of another family member, death of another leukemic child, occupational changes, and other changes in the family's life (Kalnis, Churchill, & Terry, 1980; Moore, Kramer, & Perin, 1986). Families of children with cancer experienced more stressful life events than families of healthy children (Thoma et al., 1993). Career setbacks for the mothers were reported by Overholser and Fritz (1990). Increased concurrent life stressors for parents of children with cancer were also found by Cornman (1990).

<u>Resources</u>. The resources that families use to manage the situation of having a child with cancer are personal, from the family, and from the community (Patterson & Garwick, 1994; Patterson, 1988). Personal resources that have been considered by researchers include parents' characteristics like gender, education, income, self-esteem, and religious affiliation. Family' resources comprise quality of couple and family's relationships, and family cohesion. However, the quality of the couple's relationship and family's relationship have been conceptualized more as a component of family adjustment or adaptation in cancer research and will be reviewed in the section about parents' adjustment. Social support, group therapy, and teaching parents about coping with the child' cancer are the community resources studied by the reviewed authors. This section describes research findings about some of the individual resources as well as social support.

Gender, education, and income did not correlate with coping according to Thoma et al. (1993) and Barbarin and Chesler (1986). Parents' income was not related to parents' levels of depression, anxiety, marital satisfaction (Wittrock, Larson, Sandgren, 1994). Parents with low socioeconomic status had more problems, with mothers reporting higher emotion-focused coping and this type of coping was associated with more maladjustment (Grootenhuis & Last, 1997a; Van Dongen-Melman, Sanders-Woudstra, 1986). Fathers younger than 30 years of age reported greater adjustment difficulties than older fathers did (Morrow, Carpenter, & Hoagland, 1984). Grootenhuis and Last (1997a) also found that being married was a protective factor for fathers.

Parents' gender and its relationship with coping is the variable that has been studied the most but not consistently. Parents' gender and adjustment also has been studied by different researchers. There is evidence of differences in levels of anxiety and depression for fathers and mothers but these differences are not statistically significant (Dahlquist et al., 1993; Grootenhuis & Last, 1997b; Hughes & Lieberman, 1990; Larson, Wittrock & Sandgren, 1994). For both mothers and fathers, open and frequent communication with a spouse about the child's condition positively correlated with personal emotional well being but mothers communicated in a significantly more open manner and perceived the family's emotional climate better than the fathers (Shapiro & Shumaker, 1987).

Social support has been interpreted and measured in various ways in the studies of families of children with cancer. Social support has been described as the perceived availability of friends, relatives, and health care personnel to help the parents to cope with the illness (Overholster & Fritz, 1990). Relatives, especially the spouse, as well as friends, health professionals, and other parents in the mutual support group have been reported as most helpful for better coping with the child's illness (Grootenhuis & Last, 1997a). Social support was defined similarly by parents and health professionals with caring, being available, providing information, and assistance with needs as the most important components of social support (Williams, 1992). Different obstacles to the provision of social support to parents were noted by parents and health care professionals. Parents reported lack of recognition of their role, lack of information about test results, lack of attention to their concerns, and staff inconsistency as obstacles to the provision of social support while health professionals identified lack of staff and lack of time. There was also disagreement between the parents and health professionals about who were the supportive persons for the parents. Health professionals identified themselves as supportive persons while parents identified non-medical personnel as providers of social support.

Mercer and Ritchie (1997) reported that informational, instrumental, and emotional support was perceived as necessary by the parents. Informational support included information about child's care, the illness and treatment, and access to available information. Emotional support involved spiritual support, reassurance in the parents' ability to care for the child, relief from anxiety, and possibility of discussing parents' concerns. Instrumental support included provision of monetary assistance, help with physical care for the child, being able to take time off from work, provision of babysitting and help with house chores. Difficulties in communicating in a second language and lack of local resources when the parents live far from the tertiary center were reported by the parents in Mercer and Ritchie's study (1997). Chinese parents, who were living in the USA for more than ten years, used fewer resources and were more isolated in caring for the child at home than were the Caucasian parents (Martinson et al., 1999).

Nurse's attitudes and physicians' communication were not satisfactory for Chinese parents (Martinson et al., 1993). Similar difficulties in communication between parents and staff were found by Hughes and Lieberman (1990) in England.

Information about the illness, its treatment and prognosis, the child's care at home, and other issues was a very important resource for parents. The parents' informational needs during treatment were studied by Pyke-Grimm et al. (1999). Parents reported needing information primarily about treatment and tests, likelihood of cure from the disease, and child's care. Information was needed, but in lesser degree, about the emotional impact of the illness on the ill child, side effects of treatment, physical impact of cancer on the ill child, the disease process, coping with painful procedures, and the impact of childhood cancer on the family. Fathers and mothers differed in their informational priorities with mothers wanting more information about treatment and tests and fathers wanting more information about the likelihood of cure. There were differences in the parents information needs over time. Caring for the child was the first informational need for the parents during the first six months while information about the disease was relatively unimportant. After six months of treatment, information about treatment and tests was the most important need.

It is important to increase our understanding of how parents find and use resources to deal with the child's illness since these resources vary within the parents' context. In a context like Colombia, where there are very few established resources for the families of children with cancer it is even more necessary to understand how parents find and use resources to meet the demands of the child's illness. Further study is needed to gain insight about the interaction of the parents with the health care providers as this relationship is fundamental to the support of the parents during acute illness and treatment. Understanding the parent-provider relationship may be even more important in a cultural context such Colombia, where the power differential between health care providers and patients and their families can make the situation more difficult for the parents and might influence the parents compliance with the illness treatment.

Very few interventions to support parents during treatment have been studied. Wallace, Bakke, Hubbard, and Pendergrass (1984) studied the effect of two teaching modalities (booklet, classes) on the parents' knowledge about how to cope with child's illness. There were differences between the two parent groups only at pre-test which may mean that effective and appropriate ways to support parents during childhood cancer have not been demonstrated. Kupst, et al. (1984) found that the most important time for psychosocial intervention for the mothers is when the diagnosis is made and during the early stage of treatment. However, the psychosocial intervention provided was not related to parents' coping with the illness at one and two years after diagnosis. The psychosocial intervention, done by social workers and a psychologist, involved establishing a relationship with the family, clarification of information about the illness and treatment in conjunction with the medical staff, anticipation of treatment changes, serving as liaison between family and medical staff, and working with the family to strengthen their support system. The control group received the usual forms of support available to parents in the setting where the study was conducted. There were no differences in parents' coping 1-year and two-years after the intervention.

<u>Coping</u>. Coping, a family's capability to meet the demands of the child's illness, is crucial in the family's adjustment or adaptation to the cancer experience. Coping is a continuous and dynamic process through each stage of the illness. Parents face continuous

changes in situational demands but the parent's resources do not change at the same pace the situational demands change. Therefore, families always have to find new ways to cope with the demands (Patterson & Garwick, 1994; Patterson, 1988).

Several difficulties present when attempting to synthesize the existing knowledge about parents' coping with childhood cancer. Researchers have included parents whose children are in diverse stages of the illness in the same study. The demands on the parents vary greatly in the different stages of the illness trajectory, and one can not expect the same coping behaviors in all stages of the illness. Therefore, reports of parents' coping are difficult to interpret. Another problem is the lack of consistency in the tools and conceptualizations used to study coping (Grootenhuis & Last, 1997a). Some researchers equate coping with family adjustment or adaptation to the illness, so they measured this variable instead of coping, or they measure both as one variable. Lazarus's conceptual framework is cited by some researchers but they do not operationalize and measure coping according to this framework. Coping according to the FAAR model is a family's capability to meet the demands of the illness situation as well as the normative demands the family encounters. Grootenhuis and Last (1997a) acknowledged these problems in their review of the literature. For my literature review, coping will be viewed as different from adjustment. It will be considered as what parents do to deal with the child's illness. Despite the above limitations, I will summarize the existing knowledge about parents' coping during the first two years of treatment as follows.

Researchers have found that parents use a variety of coping strategies during the cancer treatment. Among the most frequently used coping strategies are the following: seeking and using information about the disease, the treatment, and the child's care. Given that parents coping with childhood cancer are thrown into an unknown and quite threatening situation, it is understandable that information seeking is the most frequently reported form of their coping. Looking for options, being hopeful and optimistic, having open communication within the family, relying on faith and religion, denial, acceptance, hiding feelings, blaming someone, wishful thinking, learning to manage the illness, relinquishing and reclaiming control over the illness treatment, and seeking help are also coping strategies frequently used by parents (Aitken & Hathaway, 1993; Barbarin & Chesler, 1986; Cayse, 1994; Crom, 1995; Hardy, Armstrong, Routh, Albrecht & Davis, 1994; Koocher & O'Malley, 1980; Kupst, Schulman, Honing, Mauer, Morgan, & Fotchman, 1982; Martinson & Cohen, 1988; Spinetta, Murphy, Vik, Day & Mott, 1988). Coping can be active or passive depending on the action orientation of the strategies. How well parents coped with the child's illness varied over time (Kupst et al., 1982, 1983, 1984, 1988, 1995).

Petterman and Bode (1986) cited by Grootenhuis & Last (1997a) described five coping styles: experiencing the disease as a challenge, as probation, as misfortune, fate, or punishment. These coping styles are meanings that parents give to the illness so one could conclude that giving meaning to the illness experience is another coping strategy used by parents. Parents also ascribed more cheerful behaviors to their children as a way to cope with the illness situation.

The findings from qualitative studies illustrate in greater detail how parents cope with the illness. Cohen's study (1993) found that parents learn to deal with time, social interactions, information, the illness, the uncertainty, and the environment. Parents manage time by living in the present time and in short time units. Potential stressful social interactions are managed by withholding, limiting or disguising information about the child's status. The management of information by the parents includes strategies such as extracting information from providers, limiting the amount of information they want from providers, discounting information given by unreliable sources, transforming a probabilistic prediction to a binary outcome and modifying the provided information. Routinizing the activities related to the child's illness, keeping busy and restricting their attention to the tasks at hand are strategies used by the parents to manage the awareness of their uncertainty. Managing the environment is another way to decrease uncertainty. However, this is a very difficult task because the environment poses many real risks for the child. Parents also learn to watch for the child's signs and symptoms. At first, they watch for everything but later they learn specific assessment skills and change their constant vigilance to continual scanning and periodic monitoring. Parents talked about developing a sixth sense that helps them to know when something is wrong in Cohen's study.

Some differences have been found in parents' coping. Most of these differences are qualitative not statistical. Coping behaviors of parents with a child who had cancer were similar to coping behaviors of parents with healthy children (Larson, et al., 1994; Thoma, et al., 1993). However, mothers of healthy children and mothers of children with cancer reported more engaged coping strategies and fathers more disengaged coping (Larson, et al. 1994). Mothers had more communication with the ill child than the fathers did (Shapiro & Shumaker, 1987). Mothers reported self-blame more frequently than the fathers according to Eiser, Havermans, and Eiser (1995). No differences between mothers and fathers'rating of usefulness of coping strategies were found by Eiser, et al. (1995); both parents reported social support/information as the least helpful.

Parents' coping has been related to parent and child variables (Barbarin & Chesler, 1986; Kupst, et al., 1982, 1983, 1984; Thoma, et al., 1993). No differences in coping by age, gender, income, number of child's hospitalizations were reported by Barbarin and Chesler (1986) and Thoma et al. (1993). Age of the child, previous coping, coping of other family members, good social support, open communication about the illness within the family, living in the present, father occupational status and lack of additional stress were correlated to healthy coping (Kupst, et al., 1982, 1983, 1984). The correlation of parents' healthy coping with coping strategies changed over time.

Despite the relatively large number of studies about parents' coping consistent conclusions can not be drawn from the literature due to the inconsistency of conceptualizations and measures of coping. As noted earlier, a key coping effort by parents is information seeking. The import and effectiveness of other parents' coping efforts may develop more consistently if researchers specify the stage of the illness trajectory more carefully and use consistent conceptualizations and measures across different parent populations.

Meaning. The meaning of cancer for the parents has not been studied as such during treatment. It has been studied after the death of the ill child. One could interpret some of the findings reported as coping or adjustment as situational meanings the parents had given to the child's illness. For example, the time of diagnosis was seen by parents as "waiting and not knowing"(Clark-Steffen, 1993). The child's death was seen as inevitable by the mothers from South American countries and to avoid it they came to USA for treatment (Crom, 1995). This finding supports the meaning of cancer as a fatal illness for mothers in developing countries and it also shows the lack of the mothers' trust in the available treatment in these countries. The parents' attribution of cancer causality described by Eiser, et al. (1995) and Bearison, Sadow, Granowetter, and Winkel (1993) shows the meaning parents gave to the causes of the child's illness. Mothers believed cancer is latent and blamed themselves more than fathers for the child' illness; fathers did not identify reasons for the child's cancer and blamed themselves less than the mothers. The positive changes reported by these parents in the way they perceive life and death after the child' cancer show the need to understand also other meanings parents ascribe to the illness in order to make something good out of it. There were also differences in illness explanation between Caucasian and Chinese parents (Martinson et al., 1999). Chinese parents' explanation of the child's disease was focused on self-blame for errors in the children's care, retributions for past lives, or God's punishment. Very few Caucasian parents described any involvement in causing the child's disease; they wondered if they should had the child's health status checked more frequently than they had done.

Adjustment. Adjustment and adaptation are viewed as the outcome of the family's coping to meet the situational and normative demands of the illness situation. Even though Patterson and Garwick (1994, Patterson, 1988) conceptualize adjustment and adaptation as two different phases, in the reviewed studies these terms are used interchangeably. Parents' physical and psychological health, parents' psychological adjustment, family relationships, family's functioning, marital adjustment, family adaptation, coping, and psycho-social impact of childhood cancer are all terms that have been used to refer to family's adjustment. Sometimes, researchers report findings about family adjustment but had only studied parents. Adjustment has been studied using cross-sectional and longitudinal designs during the different phases of the illness. Here, only research findings about the parents' responses during the first two years of treatment will be described.

Some researchers have found differences in symptoms of psychological and physical problems between parents of children with cancer and parents of healthy children (Barakat, et at, 1997; Magni, Messina, De Leo, Mosconi & Carli, 1983; Wittrock, Larson & Sandgren, 1994). Magni, et al. (1983) reported that a few days after the disease diagnosis, parents of children with leukemia had higher scores on obsessive-compulsive symptoms, depression, anxiety, and sleep disturbances than parents of healthy children. Eight months later, obsessive-compulsive symptoms were similar for both groups of parents but sleep disturbances, anxiety, and depression were higher among the parents of children with leukemia. Wittrock, et al. (1994) found that mothers of a child with cancer reported significantly more health problems than mothers of a healthy child; a similar pattern was found among the fathers but the mothers reported more problems than the fathers in the cancer group even 1 year later. However, Kazak and Meadows (1989) did not find differences in anxiety and depression between parents of adolescents in the maintenance phase of the treatment and parents of healthy adolescents; the scores were similar to normative data in both groups of parents.

Parents of children with cancer have reported various degrees of adjustment as evidenced by their report of anxiety, depression, and physical problems. Anxiety scores were higher than normative data for most parents (Dalhquist et al., 1993; Hughes & Lieberman, 1990; Schuler, et al., 1985) but comparable to normative data in other studies (Grootenhuis & Last, 1997b). Differences in emotional and physical problems were reported by Caucasian and Chinese parents living in USA (Martinson et al., 1999). Caucasian parents had higher interpersonal sensitivity, depression, anxiety, and hostility; Chinese parents reported higher physical distress and Caucasian parents more emotional distress.

Mothers have consistently reported more symptoms of physical and psychological problems than fathers (Brown, et al., 1993; Cornman, 1993; Dalhquist et al., 1993; Magni et al., 1983; Martinson et al., 1995; Sawyer, et al., 1993; Wittrock, et al., 1994)). Sawyer, Antoniou, Toogood, Rice, and Bagghurst (1993) found that insomnia and anxiety were the most common symptoms reported by the mothers at the beginning of the illness experience while severe depression and somatic symptoms were more reported after 1 year of follow up. Headaches, anorexia, sleep disorders, and weight loss were the most common physical problems. Similar problems were also reported by fathers but with lower scores.

Parents' adjustment changes over time. Some researchers have reported findings that show a decrease in the parents' emotional problems over time (Dahlquist et al., 1993; Grootenhuis & Last, 1997b; Fife, Norton, & Groom, 1987) while others reported an increase in the emotional problems (Barakat et al., 1997). Others researchers like Fife et al. (1987) found adjustment to be relatively constant over time during the first two years of treatment. During the first three months after diagnosis, Manne, et al. (1995) found mild depression among the parents. Depression symptoms and anxiety also decreased after the induction phase of the treatment among Dutch parents according to Grootenhuis and Last (1997b). On the other hand, Sawyer, et al. (1993) noted that parents reported insomnia and anxiety as more frequent at the beginning of the illness while depression and somatic symptoms were the most frequent problem after 1 year of follow up. Fife et al. (1987) also reported an increase in depression 1 year following diagnosis. Families at risk for depression were families with pre-existing problems. During the maintenance phase, mothers and fathers showed poor adjustment according to Cornman (1993). The long-term effects of the childhood cancer on the parents of children under treatment for 1 year or more were manifested as symptoms of posttraumatic stress (Barakat, et al., 1997; Kazak, et al., 1997). However, not all parents met the criteria for posttraumatic stress in Barakat et al. (1997)

study. Intrusive thoughts, hypervigilance, and distress were reported by the parents. From the studies about adjustment over time, one can conclude that depression symptoms are more frequent later in the illness trajectory and anxiety more frequent at the beginning of the illness.

Although childhood cancer can increase marital distress among some parents, especially at the beginning of the illness, no higher divorce rates have been reported among parents of children with cancer by researchers according to the literature review done by Grootenhuis and Last (1997a). No differences have been found in marital problems between parents of children with cancer and parents with healthy children (Larson, et al., 1994; Leventhal-Belfer, Bakker, & Russo, 1993). More satisfaction and closeness within the couple was reported by Barbarin, Hughes, and Chesler (1985), and Koocher and O' Malley (1984) while more marital problems have been widely reported (Cornman, 1993; Dahlquist, et al., 1993; Fife, et al., 1987; Hughes & Lieberman, 1990; Lansky, Cairns, Hanssanein, Wehr, & Lowman, 1978; Thoma, et al., 1993). Korean parents identified changes in the marital relationships such as increased fighting, anger to each other, separation and extramarital affairs by the husband (Martinson et al., 1995); some Korean parents also reported a stronger relationship due to the cancer experience. No changes in marital relationships were found among Chinese parents by Martinson et al. (1993). Koocher and O'Malley (1984) did not find marital problems either.

Parents' adjustment also varies with relapse of the disease, death of the child, finishing treatment and other parent and child variables. According to Grootenhuis and Last (1997b), both parents of children with relapse had more feelings of uncertainty and helplessness; mothers of children with relapse also had more anxiety and depression than mothers of children in remission. Negative emotions were best predicted by having negative expectations, relapse of the disease, and child's depression among both parents. Significant differences were reported by Spinetta, et al.(1988) in adjustment between parents of surviving children and parents whose children died. Parents whose child died had more difficulty in returning to normal activities, making future plans, recognizing and accepting the needs of other family members, admitting need for help, and placing cancer in a more reasonable and less overwhelming perspective. Moore and Mosher's (1997) findings follow a similar trend among parents of children under treatment and parents of children off treatment. Mothers of children who had completed treatment had better adjustment responses than mothers of children receiving treatment and anxiety was higher for the mothers of children in treatment. Mothers' adjustment responses to treatment were explained in good proportion (35%) by the children's adjustment responses to treatment (Moore & Mosher, 1997). Poor adjustment was predicted by death of the child and younger age of the parents (Morrow, Carpenter, & Hoagland, 1984).

Parents' adjustment is correlated with parents' resources and coping. Social support had a buffering effect on psychological stress (Magni, et al., 1986); lower social support predicted increased maternal depression (Mulhern, Fairclough, Smith, Douglas, 1992; Overholser & Fritz, 1990). Social support appeared to be more important for mothers than for fathers (Grootenhuis & Last, 1997a).

Maintaining self-stability and understanding of the medical situation was related to less parental distress. Attributing external causes to the cancer, perceiving the illness as a challenge, having a positive outlook also were predictors of better adjustment (Grootenhuis & Last, 1997a). The findings about poor adjustment and its correlation with coping are less consistent than the correlation of good adjustment and coping (Grootenhuis & Last, 1997a).

Family cohesion and communication about the illness within the family has been found to correlate with parents' adjustment; increased family cohesion and more open communication within the family improved adjustment (Grootenhuis & Last, 1997a). The child's functional impairment, behavioral problems and increased number of hospitalizations were also found to be positively correlated with parents' adjustment by Grootenhuis and Last (1997b).

Considering the existing knowledge about parents and childhood cancer, it appears that additional study is necessary to understand how parents cope and adjust to having a child with cancer during the specific stages of the illness trajectory. Additionally more consistency in the concepts and instruments used to study parents of children with cancer might help move the knowledge about parents' responses forward.

Adjustment as well as coping has been found to range from poor to good but most studies have focused on reporting parents' difficulties in living with the child's illness. This knowledge has brought to light some important risks for parents and families. Very little is known about the parents who adjust well or do not have physical and emotional problems. It might be useful to understand how it is that some parents adjust better than others, which factors support and interfere with the parents' adjustment during which phase in the illness trajectory. It is also necessary to change the way researchers and clinicians are looking at this aspect of the parent experience. Qualitative studies about parents' habits, practices, and skills in caring and raising the ill child are most needed to make the parents' perspective visible and to fill out gaps in the knowledge about their responses to childhood cancer. In understanding parents' coping and adjustment it is crucial to understand how parents perceive themselves as human beings, parents, partners, and members of the community before and after the child's illness. It is also important to understand parents concerns, practices, and habits in their everyday lives when they have a child with cancer.

None of these aspects of the parents facing childhood cancer have been studied in Colombia. Therefore, the phenomenological study of the parents' experience in raising and caring for a child with cancer is intended to describe some of these unknown aspects of the parents' lives when dealing with childhood cancer. It is expected that the findings of this phenomenological study may contribute to the understanding of the parents' experience in dealing with childhood cancer in other contexts.

Aims and Research Questions for the Study

The following are the research questions for the study of parents' experience in caring for a child with cancer In Colombia.

The overall question is what are the everyday meanings, concerns, and practices of parents when caring for a child with cancer during the first year of treatment? The specific questions are:

1) What is the parents' understanding of the illness, its treatment and prognosis?

2) What are the parents' feelings, expectations and concerns about the ill child?

3) What are the parents practices in raising the child before and after the illness?

4) How are parents involved in the care and support of the ill child?

5) What support do the parents get to deal with the illness situation and from what sources they get this support?

CHAPTER 2: METHODOLOGY

The families coping with childhood cancer can be studied using different quantitative and qualitative methodologies. However, the study of the parents' every day experience of raising a child with cancer needs a methodology that allows the researcher to describe the parents' concerns, habits, and practices. Interpretive phenomenology is one of the most appropriate methodologies. In this chapter, I will describe the problems encountered when using the quantitative methods to study families when they have a child diagnosed with cancer, and why the phenomenological method based on Heidegger's philosophy is an appropriate way to study the family' s experience of caring and parenting a child with cancer.

Consequences of Using Positivist Research Methodologies to Study the Family of Children with Cancer.

Childhood cancer is a long lasting disease but at the same time is a life threatening and sometimes terminal illness. The demands on the family, the family's resources, the meanings the family gives to the situation and the family's responses to having a child with cancer change constantly during the illness trajectory. Each family member and each family live the experience of having a child with cancer in a very particular way because each person is interpreting the experience in a unique way despite the shared context in which they live. A large body of knowledge has been generated by the use of quantitative methodologies in studying families caring for a child with cancer as was documented in the literature review in the previous chapter. However, the use of quantitative methods to study such complex phenomena involves some limitations that could lead to incomplete understanding about the family's experience.

Positivist science has been the main stream scientific approach in the Western culture for the last three centuries. The great change in cosmology that occurred in the seventeenth century, from a picture of the world-order based on ideas to one of the world as a mechanism, was the basis of the objectification and the disengaged mode of science (Taylor, 1985). Positivist research methodologies used in the study of human beings are based on the same assumptions as science about objects, animals, plants, and other natural phenomena. Taylor (1985) calls these scientific approaches "naturalism" which are based on the canons that emerged in the 17th century revolution of natural sciences. Naturalism, according to Taylor fails to recognize crucial features of the understanding of humans as agents, persons, or selves. Naturalism views humans as having a disengaged identity with freedom and power. Naturalism hides the way in which persons are constituted by the culture and the language, and maintained by the communities in which they live.

The highest goal for empiricists is to build knowledge from brute data or units of information obtained objectively, that is, data that is not anchored in subjective intuition (Taylor, 1985). The path to true knowledge is based on the correct recording or measuring of the brute data. Verification of such data is central to empiricists and the inferences made from that data in order to be valid must also be beyond interpretation. Only logical and mathematical inferences are accepted by empiricists because they offer certainty.

Naturalism alone does not allow absolute understanding of human beings as persons because a person who exists only in self-interpretation can not be understood absolutely, much less by a scientific method which mainly aspires to neutrality. "Our personhood cannot be treated scientifically in exactly the same way we approach our organic being" (Taylor, 1985, p. 4). The methods from natural sciences tell us how objects work not what the objects are (Dreyfus, 1991). In the following section, I will describe some of the consequences of using positivist methodologies in the study of families with children who have cancer.

Trying to Look at the Family Under a Central Tendency Mode.

The quantitative methods are based on the assumption that quantification is the clearest, and truest ways of knowing and representing phenomena. The central tendency measures such as mean, median, and mode are used to represent the more common or frequent events, which are considered normal or representative of the way the phenomenon is in the population. The family's responses to having a child with cancer are expected to follow this central tendency mode in order to be normal or not pathologic. In other words, researchers seem to assume, for example, that a family whose coping score is not within the expected range of scores on the scale, according to the cutting point selected by the researcher, is "abnormal" or has a pathologic way of coping. These families are classified as maladapted or poorly adjusted to the situation because they do not score in a certain range. For example, Spinetta, Swarner, and Sheposh (1981) studied effective family coping after the death of the child. These authors reported the results about family's adaptation using mean scores and classified the family's responses to the items in the questionnaire as "well adapted" and "adequately adapted" without giving information about how they came up with this classification. They measured the family's adaptation by using the families' scores on a 10-item tool in which the higher mean scores represented higher levels of adaptation.

The central tendency mode of perceiving the family whose child has cancer emphasizes the norm and does not allow researchers to see or to find all the possibilities families have to cope with their child's cancer. But the most dangerous consequence is the classification of families as having pathologic behavior because they do not conform to the "normal standard", which is based on a specific sample or group of participants, a quantitative measure determined by the researcher in a mathematical way, or the dominant values of society and the researcher. The central tendency mode is useful in describing phenomena that can be represented by numbers such as some demographic characteristics of the family members. Much can be learned by describing phenomenon like family coping or adjustment using central tendency statistics but these are not enough to represent how the family is coping and what they do to cope with childhood cancer. Statistical measures need to be complemented with descriptions of the phenomenon as it is lived by the persons involved with it.

Tool Development and Measurement of the Phenomena.

An ideal goal of quantitative methods is that phenomenon can be measured using reliable and valid tools. Therefore, the tools are developed to quantify the variables or phenomenon in a reliable and valid way to assure acceptable results. The tools used to measure the variables in most of the studies reviewed in the previous chapter seem to be developed without taking into consideration the parents or siblings' perspective. The researchers developed the tool for their study according to the positivist method in which the existing literature and the opinion of expert clinicians and researchers are the bases for the development of the tools. The validity and reliability of the tools are also determined by the researchers using research and clinical experts and some statistical methods as it is expected in positivist research. Walker (1988), Spinetta et al. (1988) and Van Dongen-Melman, et al.(1995) considered the data from the participant's interviews in the development of the tool to measure the variables under study.

Research tools developed without the participants' voice may not be valid enough because researchers are leaving out another expert group, the parents and siblings of the children with cancer. This may lead to a partial understanding and knowledge of the phenomenon. Researchers and clinicians are experts in dealing with the treatment of the disease from their perspective as health care professionals. They may not be able to take the perspective of parents or family members because they have not lived the experience of raising and living with the child who has cancer. Family members should be considered the experts in the phenomena or experience of living in that situation. Therefore, their perspective is very useful in the development of tools to measure phenomenon like coping and adjustment to childhood cancer. They can participate by describing their experience to the researchers through open-ended interviews done individually or in-group. They can also participate during the assessment of the tool validity. The process of tool development should be done with the participation of both sides of the experts in the phenomena under study: the researchers and the persons who have experienced or are living the phenomena of interest.

Another issue related to the development of the tools are the lack of clear conceptual frameworks in the operationalization of the variables and the possible implications of using a specific theory to study the phenomenon. The conceptual inconsistency in measuring the variables can be seen, for example, in the study of coping. Coping has been conceptualized and measured in different ways. Coping strategies and coping effectiveness were measured by Sterken (1996), Cayse (1994), Walker (1988), and Barbarin and Chesler (1984). Coping was measured as adjustment by Spinetta et al. (1988), as personal coping by Lauer, Mulhern, Schell, and Camitta (1988), and as coping behaviors by Thoma, et al. (1993). Some authors mentioned Lazarus' conceptual framework but they did not actually use the framework to operationalize coping. The lack of consistent conceptual bases for the development of tools and interpretation of data adds more confusion in the study of the family' responses to childhood cancer because the phenomena and variables are defined in various ways. This leads to findings that are sometimes contradictory and difficult to organize into meaningful categories.

However, the use of a single theory could be problematic because according to Dreyfus (1991) theory disconnects the available from the referential whole, it leaves meaningless elements which makes impossible to understand a phenomenon in its totality. We understand a phenomenon when we see how it fits with other phenomena. Theory reveals the occurrent but it does not construct it (Dreyfus, 1991). Therefore, the conceptual frameworks could also limit the ways in which the phenomena are studied. For example, adjustment has been measured as the presence of behavioral problems of the siblings, psychological or mental problems in the parents, health problems for children and parents, and other indicators of dysfunction in the person or the family. In all these instances, researchers are examining the negative rather than the positive ways persons are dealing with the situation. The above indicators of family adjustment show the researchers are conceptualizing adjustment as the presence of problems or pathologies in the person or the family. Sawyer, et al. (1993) studied the adjustment of the parents and family of children with cancer conceptualizing adjustment, not in an explicit but implicit way, as the presence of somatic and psychological problems in the family members. They used the General Health Questionnaire, which measures non-psychotic psychological impairment and the General Functioning Scale of the Family Assessment Device, which provides rating of the overall health/pathology of a family. The value of having multiple conceptualizations is that they potentially illuminate different aspects of the problems and possibilities that reside in families living with childhood cancer.

In summary, theories about family adjustment might leave out different aspects of adjustment, especially if those theories are developed using positivist methods, which do not take into account the family members' voices. Studies that use tools developed without the family members' participation and without organizing conceptual frameworks could lead to findings which might not describe all the possibilities inherent in the situation. Only the possibilities identified by the researcher according to what is already known are visible. Structuring interventions on these findings alone could be inappropriate for the families and misleading for the clinicians who want to help the families through the cancer experience. Again, caution should be considered in determining the family's normality or abnormality in dealing with the child's illness because the full range of possible healthy responses may not have been articulated. Implicit belief that the family should function according to a narrowly defined normal range denies the complexity of the life situation of many parents and children with cancer. The families of children with cancer are usually young families where the parents are learning to be parents of a healthy child, which is per se a difficult task to accomplish. When the demands of an illness such cancer are added, it is quite unrealistic to expect family functioning that parallels functioning in families where all members are healthy. The family may be only minimally prepared to cope with childhood cancer, or its resources may not be enough to meet the new demands. The family's behaviors observed by others outside the family may not be considered appropriate especially if they have a different theoretical or practical perspective. The possibilities the family has to cope with childhood cancer or any other issue could be widely diverse without being abnormal or pathologic. Positivist approaches to measurement may make it impossible for the researchers to see the qualitative distinctions of the phenomena. For the study of human experiences positivist approaches need to be complemented with qualitative methods in order to get a more complete understanding of those experiences.

Knowledge Developed within a Specific Context

The actual knowledge about families and childhood cancer has been mainly generated from the study of families from a white, middle and upper class, and urban background in the United States of America (USA) and Canada. The question arises about whether this knowledge is applicable to families living in other contexts different from USA and Canada? Does this knowledge describe how families live with childhood cancer in other countries with different cultural and economic contexts? For example, when attempting to apply in Colombia the knowledge about family's coping with childhood cancer, one needs to be aware of possible differences due to the perception of cancer among Colombians, the difficulties in the access to the treatment, the characteristics of the families, and other issues which are different for Colombian families. Therefore, it is not appropriate just to translate this knowledge and transport it into the Colombian context. The ways Colombian families cope with childhood cancer may be similar to USA families or may not. Therefore, questionnaires used to measure coping in USA families may not be meaningful or acceptable to the Colombian families.

The perception of childhood cancer in USA and Colombia, even among clinicians and researchers is not the same. In USA, cancer is considered chronic and curable but in Colombia it is perceived as fatal or terminal. The resources available for cancer treatment in Colombia are limited despite the availability of well-trained nurses and Pediatric Oncologists, and the availability of the diagnostic procedures and medications. These resources are not accessible to most families with medium and low income due to their financial resources or the ideas and beliefs about the health system in general and the cancer in particular. Bone marrow transplant is not an option available in Colombia, again for the lack of financial resources to support the treatment centers.

A special limitation of using positivist methods in Colombia has to do with the structure of the research process. One might assume it is quite easy to get any standard tool used to study families in USA, translate it using the methods suggested by Marín and Marín (1991) and give it to Colombian participants to study the same phenomenon. This is possible and has been done in another areas of research. However, one wonders about the findings of such research where the context of the studied phenomenon is different from the context where the tools were developed. For example, family coping with childhood cancer in Colombia can be studied using the F-COPES inventory. This questionnaire operationalizes the dimensions of coping of the Double ABCX model of family stress theory. It focuses on the ways the family handles problems and demands that arise from family members or from the social environment (Birenbaum, 1990). The concepts and theories on which the tool is based, since they have been generated in a social, economical, and cultural context with different possibilities might not apply to Colombians. It is assumed the items of the questionnaire might not be appropriate either. Therefore, before using the tool, researchers and clinicians need to make it relevant and meaningful to people living in the Colombian context. For example, the item "Seeking assistance from community agencies and programs designed to help families in our situation" are not suitable because there are not community agencies or programs to help or support families with difficult situations like the ones available in the United States. Therefore, families do not have that possibility as a way to cope with their problems. Another item from the same tool "Seeking information and advice from the family doctor" could also be problematic because for most Colombians this practice is not at hand due to the power and class differentials between doctors and patients/families.

In Colombia, people are not used to being research participants in the same way as are people in USA. To send three or five tools in a package by mail is not acceptable and that practice does not exist in health science research. There are many reasons why this practice would violate cultural values in Colombia. First of all, people participating in research expect the personal contact with the researchers or at least with the data collectors. People will not answer any questionnaires sent by mail because they may perceive the research as something that is not private and may not be serious. Second, even though the illiteracy rate is low, there is what is called "functional illiteracy" which does not allow people with low educational levels to understand, much less to answer written tools for who knows whom and why. Besides, the language used in the research tools usually is difficult for participants to understand on their own. Therefore, it is necessary to have a person who could explain the terms and most of the time to fill out the questionnaires. When studying family's responses to childhood cancer, it would be even more inappropriate to send questionnaires by mail. The issues the families are dealing with are very emotional, difficult, and conflicting to be studied in such a cold and detached way. It would be interpreted as lack of respect and sensitivity from the researchers to the participants. Even telephone interviews could be inappropriate to collect data about such issues before a relationship between participants and researcher has been developed.

Interpretative Phenomenology as a Research Method to Study the Parents' Experience in Caring for a Child with Cancer

Hermeneutic phenomenology as a research method is based on Heidegger's ontological philosophy and as such is concerned with understanding the phenomena in their own terms

(Benner, 1994). To accomplish this, meanings, habits, and practices (Chesla, 1995) should be uncovered and understood. The study of the concerns, habits, and practices that parents have in their everyday life, when their child has cancer, is basic to understand, among other things, why Colombian parents sometimes do not follow the treatment and care needed by the child. By knowing the parents' everyday life, we can begin to understand the fears, ideas, financial and social problems which might interfere with the child's care but from the parents' perspective, rather than from the perspective of physicians and nurses. Also we need to understand how parents of children with cancer perceive themselves and their world when raising a child with cancer. By doing this, we might be able to provide care that is more appropriate to the parents' reality. Also we may be able to develop more appropriate interventions to ensure the child's continuous treatment and care.

The following phenomenological assumptions are important in my study of the parents' experience.

Human beings have a world. Dwelling in the world is the basic way of being-in-the-world of human being (Heidegger, 1927). World is constituted by and constitutive of the self. Human beings live in a world, which is different from the environment, nature or universe in which they live. This world is "a meaningful set of relationships, practices, and concerns that we have because we are born into a culture" (Leonard, 1994). Heidegger says that world is given by our culture and language and makes possible our understanding of ourselves and others (Dreyfus, 1991). Language makes possible particular ways of relating and feeling that make sense within a culture. Skills, meanings, and practices make sense because of the shared world given by the culture and articulated by language. This background familiarity is what Heidegger calls world (Dreyfus, 1991). The world is taken-for-granted because it is pervasive and overlooked by human beings; we become conscious of it or notice it only in breakdown situations like an illness in a child. The worlds people live within are not universal or timeless but rather different depending upon the culture, historical time, and the family into which they are born in (Leonard, 1994).

Parents in Colombia have a different world from parents in USA. Their practices in raising a child, for example, are different and may not make sense to parents in USA. For the Colombian parents, a sick child should stay at home and be cared by the mother or grandmother. The child is not expected to go back to school or day care until he or she is completely healthy from the parents' perspective. Therefore, it would be against the parents understanding and practices to ask them to send the child to school during recovery as it is done in USA. In Colombia when a person is ill, it is "normal" or culturally accepted that the person stays at home recovering and being cared for his/her family as long as the person or the parents (in a child case) perceived as needed. The care and protection of the person recovering from an illness sometimes goes beyond the time the person returns to his/her "normal" life. In the case of a child with leukemia, the child would be actively protected by the parents regardless what the physician or nurse says. This protection could be perceived by health care providers and others outside the Colombian cultural context as overprotection.

The person is a being for whom things have significance. The basic way humans live in the world is through engaged practical activity (Chesla, 1995). This mode of being is the ready-to-hand mode, in which persons are fully involved in the everyday action, not noticing their existence. In this mode persons are engaged with things which have significance and value in their world of meanings. In contrast, when the persons are living in the present-at-hand mode, they are aware of their existence. When the child is healthy and everything is going smoothly for the parents and the child, the parents live in the ready-to-hand mode. They live their everyday routines without many interruptions. In a way they do not pay much attention to what they do because they have some sense of routine they have learned over time. In contrast, when the child has cancer, the parents' lives are disrupted and everything in their everyday becomes noticed by them. Parents become more aware of the child's vulnerability. The normal life of the family is no longer normal; it may take long time to find some semblance of normalcy again and there is a great uncertainty which surrounds life. Many things become noticeable and important for the parents that were not noticeable and important before the child's cancer. Events like the child's birthday acquire different meaning and significance for the parents because they are not certain of how long the child is going to live.

Significance is based upon qualitative distinctions or strong evaluations (Taylor, 1985) which are recognized by the person in everyday living. Culture and language shape these qualitative distinctions. For example, for a mother, whose child has cancer, the child's life and well-being become more precious because she does not know for how long she is going to have her child with her. She is more concerned about any cold the child might get and any illness symptom would be interpreted as something very dangerous or related to the child's cancer. However, a mother, whose child is healthy, would not be concerned about a fever, for example, because she expects her child is going to have a cold and because she takes-for-granted her child is going to live to survive her. This does not mean that the child's life is not precious for this mother but it is precious in a different way due to the absence of the cancer. The significance of the child's life for the mother changes with the context and the mother's understanding of that context.

The person is a self-interpreting being. Human beings are self-interpreting beings but in a non theoretical way (Leonard, 1994). Human beings are self-interpreting beings because things matter to them. When human beings express and act on what they are concerned about or what matters to them, human beings take a stand on who they are (Chesla, 1988). Concerns illustrate what is important and stressful about a situation. For example, if parents are concerned with their child's future, they may not agree to radiation therapy for the child's cancer because it might impede the child's future capacity to have children. The parents' understanding and acceptance of the child's treatment would be according to what matters to them in relation to the child's present and future well-being not only in relation to the illness.

Understanding is humans' fundamental way of being-in-the-world. Through understanding we have a sense of the way we are in the world, we grasp meanings through language (Palmer, 1969). Human beings are engaged and constituted by their understanding. Understanding can be different according to the language which articulates a background of qualitative distinctions (Taylor, 1985). Therefore, language serves to depict ourselves and our world but it also constitutes our lives (Taylor, 1985).

The person as embodied. The phenomenological view of the person involves a view of the body different from the Cartesian view which considers the person as having a body separated from the mind, with no intelligence or power to respond to the world (Leonard, 1994). For phenomenology, rather than having or owning a body we are embodied. Being human is having a bodily intelligence, which makes it possible to be skillfully involved in situations. Our common practices are based on shared embodied perceptual capacities (Benner & Wrubel, 1989).

The mother, for example, dwells in the world as skilled body. Her embodied intelligence allows her to respond to her child's needs in a very skillful way even without verbal communication from the child. For example, after a chemotherapy treatment, the mother knows the child is having some side effects just from observing the child's behaviors. She does not know the child has anemia but she knows the child is not feeling well because the child is not playing as he or she usually plays. Therefore, the mother provides the child with toys to play in the bedroom or allows the child to watch more television than other days. Sometimes the nurses ignore the mother's embodied intelligence to care for her child in the hospital. This attitude of the nurses creates problems for the mother, the child, and the nurse. The mother, for example, may be angry with the nurse or may request to be respected as a mother who knows how to take care of the child. But the mother can also have doubts about her skills to take care of the child due to the nurse's attitude. The nurse may be upset by the mother suggestions and ask her to leave because she might perceive herself as having more knowledge to care for the child than does the mother. Then, the child has to suffer her mother absence when she needs her mother most.

Heidegger views **the person as being-in-time**. This time is not a linear or an infinite succession of nows as it is usually perceived in the Western cultures (Leonard, 1994). Linear time makes us believe that existing things are static and atemporal things. In the scientific tradition, this notion of time leads to a system of laws which are supposed to be also atemporal (Leonard, 1994). Time is called temporality by Heidegger (1962) and according to him it is constitutive of being or existence. Being is not timeless, it is temporal because all human beings naturally grow old and die. Merleau-Ponty (1962) also considered time as a dimension of being which arises from "my relation to things. Within things themselves, the future and the past are in a kind of eternal state of pre-existence and survival" (p. 412).

Within things themselves, the future is not yet, the past is no longer, and only the present is (Merleau-Ponty, 1962)). The course of time for Merleau-Ponty must be primarily not only the passing of present to past but also the passing of future to the present. Time is constituted by itself, the essence of time is to be in process of self-production. In our primordial experience of time, time is not a system of objective positions, through which we pass, instead it is a mobile setting which moves away from us like the landscape seeing through a window from a train (Merleau-Ponty, 1962). The origin of objective time should be seen in "the mutual harmonizing and overlapping of past and future through the present, and in the very passing of time" (Merleau-Ponty, 1962, p. 420). Each present reasserts the presence of the whole past which it supplants, and anticipates all that is to come (Merleau-Ponty, 1962).

The above assumptions apply both to the research participants and the researchers (Chesla, 1995; Plager, 1994)). The researcher is a self-interpreting being-in-a-world, for whom things have significance, who has embodied intelligence, and lives in time. The situatedness of the researcher, her or his engagement in the world as a human being and as researcher, and her or his concerns would shape her/his research projects. Adopting as much as possible a Heideggerian understanding of parents of children with cancer opens up new possibilities for understanding their experiences in raising a child with cancer.

When human beings are viewed from the Heideggerian perspective, the interpretive method is an appropriate approach to study them. Heideggerian phenomenology considers it is not possible to have "objective" knowledge about human beings because all knowledge is generated by persons, who are already in a world, trying to understand persons who are also in a world (Leonard, 1994). We understand by comparing what needs to be understood with something we already know. Understanding is circular; one is always within the hermeneutic circle of interpretation (Leonard, 1994; Palmer, 1969). Units of understanding as a whole define the individual parts and the parts together form the circle. A sentence, for example, is a unit of understanding. Words are understood in reference to the meaning of the whole sentence. The meaning of the sentence as a whole is dependent on the meaning of the individual words in the sentence. A concept derives its meaning from the context where it stands; yet the context is made up of the elements which give it meaning (Palmer, 1969). Logic can not account fully for understanding. So a kind of leap into the hermeneutic circle occurs and we understand the whole and its parts together.

The hermeneutic circle assumes an element of intuition. A minimal pre knowledge or pre-understanding is needed for understanding. Without this, one can not leap into the hermeneutic circle. The speaker and the hearer must share the language and the subject of their discourse. “The principle of pre-knowledge operates in every act of understanding and the hermeneutic circle operates on the linguistic and the level of the "matter" being discussed” (Palmer, 1969, p. 88). Understanding has a structure that comes into play in all interpretation. The pre-structure of understanding goes beyond the Cartesian model of subject and object. The hope of interpreting without prejudices and presupposition disappears in the face of how understanding operates. What appears from the "object" is what the “subject” allows to appear. It is naive to assume that "what is really there" is self-evident (Palmer, 1969). The pre-understanding rests in the context of the world. Things themselves come into view through meaning, understanding, and interpretation. Understanding is made explicit through interpretation. (Palmer, 1969). Language is the primary articulation of situational and historical understandings. Without language man could not be understandable to us. “Man does not invent language more than he invents understanding, time or being” (Palmer, 1969, p.153).

According to Heidegger, the fore-structure of understanding has three aspects: fore-having, foresight, and fore-conception (Dreyfus, 1991). We have a practical familiarity or taken-for-granted background practices and shared meanings about the phenomenon we want to study. This familiarity constitutes the fore-having of our understanding of the phenomenon. The fore-sight refers to the perspective from which we interpret the phenomenon; what we see in advance about the phenomenon. The fore-conception involves the way we conceive the phenomenon, which will give us some expectations about the phenomenon. This fore-structure shapes the interpretation or understanding of what is under study. The physical, cultural, and social context where the participants and researcher live determines the fore-structure of the understanding each of them have about the phenomenon under interpretation. Therefore, it is important to consider some aspects of the Colombian context which are described in the chapter about the context of parents' experience.

The goal of interpretive phenomenology is to understand everyday skills, practices, and experiences and to articulate similarities and differences in meanings, concerns, practices, skills, and experiences (Benner, 1994; Leonard, 1994). Interpretive phenomenology intends to develop understanding of human beings which are based on concerns, meanings, and practices (Leonard, 1994). However, human beings as historical, situated, and multifaceted beings are only understood in finite and specific aspects (Benner & Wrubel, 1989). Understanding human beings requires listening to their voices, to their stories, and experiences of their everyday lives.

My Personal Background and Forestructure in Studying Families of Children with Cancer

My interest in studying the families of children with cancer comes from my involvement with teaching nursing care of healthy and ill children to undergraduate and graduate students for more than 17 years. My experience in caring for children with cancer when teaching the students has made me aware of the immense impact of the illness in the child and the family. Parents and all family members from the nuclear and extended family are affected by a life-threatening illness in their child. The suffering derived from the treatment and the illness itself imposes on them great demands as parents, grandparents, siblings, etc. In my observation, everybody in the hospital and at home is focused on the treatment and the child's care. However, health care providers frequently ignore the impact of the illness on the family. Health care providers do not consider the parents and siblings as in need of care due to the psychosocial effects of the illness on them. However, when there are difficulties in compliance or acceptance of the child's treatment by the parents, or the parents are not easy to handle, they are considered in need of psychotherapy and are referred to the Psychologist. There are no supportive care approaches available to the parents on a regular basis. Siblings are completely ignored by the health care system.

My own personal experience with having my mother and a very dear friend with cancer and the lack of supportive care for my family and her family has made me even more aware of the need to include the family in the care of children with cancer but not as care providers for the child but as receptors of the care from nurses, social workers, and psychologists. I also feel a moral obligation to contribute to the development of knowledge generated in our context, since most of the theoretical knowledge used in the care of children and families is imported from USA and other countries with different realities and different cultural possibilities for nursing care of the family.

Specifics of the Research Design

The Study Sample

The participants met the following inclusion criteria: to be the father or the mother of a child, three to twelve years old who is 1) diagnosed for at least three months with Acute Lymphoblastic Leukemia (ALL) and 2) in the first year and a half of treatment. Parents must live in the same house with the child. Parents were excluded if their child had other major physical or mental illness.

The sample is comprised of 8 sets of parents, one dyad grandmother-son, one dyad grandmother-daughter, and two mothers (one single and one married) for a total of 20 participants representing 11 families. The grandmothers participated in the study because they were living with the ill child, were very involved in raising the child, and were also the caretakers for the child. The number of children in each family ranged from 1 to 3 with more parents having 3 children. Two mothers and three fathers had one child from previous relations.

The demographic characteristics of the actual sample of the study are presented in Table 1. The age of the participants ranged from 19 to 62; most parents were 40 years old or younger. Fourteen participants were mothers and 6 fathers. Ten parents were married, six lived with their partners without getting married, two were single mothers, one divorced father, and one widowed grandmother. All the participants were Catholic except one couple who considered themselves non-denominational believers in God.

The educational preparation of the participants varied from second grade to college or university. Ten parents had few years or complete grade school, seven parents had few years or complete high school education, and only three had university or college education. All mothers worked as housewives except one single mother that sold lottery tickets in the afternoon and evenings and one grandmother who worked in the farms collecting crops or doing various chores in people's homes. Fathers were employed as a civil engineer, schoolteacher, bank teller, taxi driver, construction crewmember, and recycling worker.

Table 1. Parents' Demographic Characteristics

Age	
19 - 25 years	3
26 - 30 years	6
31 - 40 years	7
41 and more	4
Gender	
Female	12
Male	8
Marital Status	
Never married	2
Married	10
Partnered	6
Divorced	1
Widowed	1
Religion	
Catholic	19
No-Denomination	1
Education Attended	
Grade School	10
High School	7
College	3

Twelve participants were from the lower and eight from the middle social class. Most parents lived in the city (Cali), four lived in towns 40-60 miles away from Cali, and two lived in the rural area about 50 miles away from Cali.

The parents' income was not assessed due to the fact that there is not reliable way to assess it in the Colombian context. When people are asked about their income usually they give a lower amount because they do not want others to know their true income for a variety of reasons such as wanting to get discounts or lower costs in the services they are looking for in the health system. Sometimes people can not give a specific amount for their income because they do not have a stable job or the income varies so much when they have, for example, family business. The common way to appraise income in the Colombian context is by the geographic location of the family's home. This is applicable only in big cities where there is a classification of the different barrios or neighborhoods. This income measure is inappropriate especially now that the unemployment rate is very high in Colombia because of the bad economy. Also it is common that a family with financial difficulties goes to live with other family members like parents to optimize their merest financial resources. Therefore, the location of their home does not reflect their income especially if the relatives live in a barrio that is classified as middle or high status.

The children whose parents participated in the study had the characteristics shown in Table 2.

Table 2. Children's Characteristics

Age	
3½ -6 years	7
7-12	4
Gender	
Female	4
Male	7
Duration of illness	
3 months	1
4-11 months	3
12 months or more	7
Treatment phase	
Induction	2*
Maintenance	9

*One child did not go into remission and died.

Their age ranged from 3½ to 12 years at the time of the first interview. Most children were under six years of age and boys. Eight children were the first born child; out of these, four were the only child. Most children had been diagnosed for 12 months or more and were in the maintenance phase of chemotherapy at the time of the first interview; the range of time since diagnosis was 3 to 18 months. Out of the four school age children, only one of them stopped going to school after the diagnosis. Only one pre-school age child went to day care, the others stayed home with their mothers.

Recruiting the Participants

The recruitment of the parents was done in the Chemotherapy Unit at the teaching hospital Evaristo Garcia in Cali. From the children's records in the Chemotherapy Unit, I developed a list with the name, address and telephone number of all the parents who met the inclusion criteria. Then, I contacted some of them by telephone and explained the study. All the parents contacted by telephone wanted to talk directly with me in the hospital before consenting to participate in the study. I could not reach some parents because they were not home or the telephone numbers were inaccurate. I found it uncomfortable approaching the parents over the telephone. It seemed to me that the parents also preferred a more personal approach. After a few weeks of trying to contact the parents by telephone without any success, I realized it was not the best way to recruit the parents. Therefore, I changed the way to contact them. I came to the Chemotherapy Unit during the dates the children (whose parents were in my list) had the appointment for the treatment. I asked the nurses in the Unit to introduce me to the parent who brought the child to the hospital. Then, I explained the study to the parents. Sometimes, I gave her or him the informational flier I had developed for the participants. By doing this, the parent could read it at home and talk with the other parent about the study. Some parents gave their consent immediately and we set the date for the first interview; others waited until they discussed with the other parent and asked me to call them or wait until the next appointment to learn their decision about participating in the study. As soon as they told me they wanted to participate in the study, we selected a date and time for the first interview.

Along with the above approach, I came to the Unit every Tuesday and Friday morning from 9 A.M to 1 P.M just to be around the Unit and become a familiar person to the parents and the children. Tuesdays and Fridays are the days only children have Chemotherapy or bone marrow biopsies. The other days are mainly for adults. Every time I went to the Unit, I brought with me lots of stickers. I gave the stickers to the children while they were having the treatment. I showed the child some of the stickers I thought were appropriate depending on the age. Then, I asked her/him to choose the ones she/he wanted. For the younger children, 3 years or less, I put the stickers on the child's hand that was without the I.V but for the older children, I put the stickers on a piece of paper. It was marvelous to see the children's reaction to the stickers. The children stopped crying and being sad or angry. Most children concentrated more on looking at the stickers than on the treatment. The parents also got very excited and happy. After a few days, I became the "sticker lady" who was well accepted by the children and the parents. Sometimes they approached me instead of me approaching them. It was evident that being the sticker lady helped me to get closer to the children and the parents. It also helped me in feeling more comfortable as a researcher because I was giving them something not just asking them to do something for me. As a result of my closer relationship with the parents, I found more parents that were not in the list I had developed and it was much easier to get the parents' consent to participate. During the whole eleven months of data collection, I went almost every Tuesday and Friday to the

Chemotherapy Unit to talk with the parents, the children, the nurses, and of course to give stickers to the children. I also used the stickers when I visited the participants' home. In the Colombian culture, it is important to bring something with you for the persons you are visiting in their homes; it means good manners, respect, and concern for the persons that you are visiting. It is also very important for me even though my visits to the parents were not social visits. I chose to bring little toys for the children in the family. I also brought some food for one family with very low income.

<u>Procedure to Collect the Data</u>

Most parents were interviewed individually during the time 1 interview, together in time 2, and individually in time 3. The interviews were done at home except for three mothers who had one interview in the hospital while their children were having the chemotherapy. One of these mothers did not allow me to go into her home as she preferred be interviewed at the hospital. The other two mothers felt it was better for them in the hospital while they were waiting for the children's treatment. Three interviews were done with each parent following the guidelines (See Appendix B). The parents were asked to talk about their understanding of the illness and its treatment, their everyday practices and concerns in raising the child, the good and bad times they had, how they perceived the child's present and future, their concerns about the other children in the family, and their concerns for themselves. Parents also talked about the support from the health system, the extended family, and community in coping with the child's illness.

The interviews were audio taped to ensure everything the parents said was captured. A typist, with whom I was familiar, transcribed the interviews. I corrected the interview transcriptions while listening to the tapes.

I did some observations of the parents and their children interacting in their home and in the hospital. With some families, I spent about two hours before or after the interviews to observe them. Most of the time after the interviews, I had the opportunity to share a meal or snack with the parents and the children.

Most children were present during the interviews. The children seemed pretty curious about what the parents were talking about with me. Two 4 year olds participated in the interview by filling out the parent's ideas or giving their own ideas. In the presence of his mother, a 12-year-old boy told his own story about his father punishing him; he cried inconsolably when recalling the punishment he considered to be unfair. Other children stayed close to the parent by sitting on his/her lap or in a near chair. Only two of the older children, (age twelve) did not stay around during the interviews. In general, the parents did not ask the children to leave so I did not ask them to leave either. I asked the children to go to play or do something else only when I sensed the parents were not comfortable talking in front of the children. This happened with the older children when the subject of the conversation was the possible death or dying of their own child or other children's death. Sometimes, the parents took advantage of the interview situation to encourage the children's appropriate behavior by telling me how good they were behaving. The fact that the parents allowed the children to listen to what they were telling me about the illness experience surprised me. In a social situation usually the children are not allowed to participate in the adults' conversations. But in this situation the parents seemed to use the opportunity to talk with their child through me, or at least to let them know what was going on in their lives. The interview seemed to create a safe moment for the parents to share their ideas, fears, and concerns with the children. Parents may have been expecting me, as an authority, to do something to take the children out of the interview. As long as the children did not seem upset by what they were hearing and the parents seemed at ease with the child's presence, I did not intervene.

Whenever the children were hospitalized, I visited them and spent time with the mother or the father staying with the child. Notes were taken to record what I considered the most important aspects of what I had observed during the visits to the hospital.

The data collection period extended to almost a year mainly because of the difficulty in getting the parents to keep the appointment that we had agreed on for the interviews and because most of the fathers were available only on Sundays. I developed the habit of calling the parents a few hours before the interview to make sure they would be home by the time I got there. Many times I was surprised to find out they had forgotten the interview or that they had other plans. However, there were few parents who were very careful in keeping the appointments with me. Sometimes, in the middle of the interview, there were visitors coming to the house so the interviews were ended or interrupted for short periods of time. No parent expressed upset in the interviews and all seemed willing to continue in the study. So I learned to be very patient in dealing with the way they handled the interview appointments. Two mothers who did not complete all the interviews never gave me a reason for doing so. Whenever I called them they assured me that we would have the interviews. One of them left me waiting for her at least six times in the hospital; the other mother promised twice to call me but she never did it. Finally, it was obvious to me they did not want to have more interviews regardless of the fact that they did not say it openly.

It was uncomfortable for me to deal with some parents' way of being research participants but I also understand that is part of our culture. Keeping appointments is something most people are not very good at. Being assertive is also an attitude that is not part of most people ways of being. Besides, Colombians are not used to be research participants in the same way most people are in USA. Colombians perceive their participation in research as a favor they are doing to the researcher. Therefore, if something they consider more important comes up, they do not have any problem in doing it instead of keeping the appointment with the researcher.

Analysis of the Data

The interpretation of the text or data was done following Benner's (1994) and Chesla's (Personal communication, July 1997) guidelines. A first-cut interpretation was done during the interview process and the deeper interpretation was done later when the data collection was finished. The whole interview text was read for a general understanding of the parent 's story. Then issues, topics, concerns, or events were selected for a more detailed interpretation. I used an interpretive outline according to my research questions for the deeper interpretation of the interview text. The deeper interpretation of the text was done first by reading and interpreting a whole case. Then, I took up the next whole case, interpreted it, compared it, and contrasted it with the first case. This was done until all whole cases were interpreted and compared. Paradigm cases were written to show strong instances of the parents' ways of coping with the child's illness. Summary cases were also written up to present the parent's story as a whole. Exemplars or parts of the interview text were used to demonstrate the parents' concerns, practices, and meanings. In interpreting the text, I was aware that my pre-understanding of the parents experiences and my own way of being in the world as a person and as researcher influenced the way I interpreted and presented the parents' experience of raising a child with cancer. I also kept in mind the two assumptions suggested by Benner (1994) about the interpretation of a text. First, the text will not be completely rational. In other words, there may not be complete congruency between what the parents say (their ideology) and what they do (their practices). Second, the researcher will not exhaust the meaning of the text. I can offer only a partial interpretation of the parents' experience.

Rigor and Limitations of the Study

This interpretive study can not be evaluated using the same standards that are used to evaluate the rigor of an empirical study. The philosophical assumptions in which this interpretative study is based are quite different from the assumptions of an empirical study. The research method also differs from the empirical method therefore the rigor and limitations of the actual study should be assessed differently. An empirical study intends to obtain an account, which represents an "objective reality" while this interpretative study intends to offer an interpretation of the everyday practices and concerns of the parents raising a child with cancer in Colombia. I am aware my interpretation is just one possible interpretation of the parents' experience and it is determined by my fore structure as person and as researcher. I hope my interpretation would represent appropriately the parents' experience.

The standards to assess the rigor of empirical research are well determined and known but there is not agreement about the standards to assess the rigor of an interpretative account. In order to achieve rigor in this study, I used some of the areas or aspects suggest by Sandelowski (1986) and Packer and Addison (1989). Coherence or credibility of the interpretative account includes the plausibility or readability of the interpretative account as well as its truth value. The researcher continually searches for evidence in the text that verifies or disconfirms the interpretation as a strategy to achieve coherence. Credibility or coherence is achieved when the participants in the study or an unknowing reader are able to recognize the story as a real story. It was my constant concern to make sure my interpretation was supported by parts of the text or the whole text. During the data collection, I clarified with the participants my interpretation of their concerns and practices until I got a better interpretation. I also discuss some of my interpretations with the woman who was transcribing the interviews as a way to get the understanding of a person who I considered to be like some of the parents participating in the study. During the deeper interpretation of the data, the dissertation chair helped me a great deal in this regard. I asked a colleague, who works with families of children with cancer to read my interpretation as a way to ensure that I was getting the parents' story as they had presented to me. I realized this was not appropriate to obtain coherence of the interpretations because my colleague is not familiar with the cultural context where the parents' experience took place. However, my colleague recognized some aspects of my interpretation as holding true for the Hispanic families she works with in California. During the interpretation of the data, I encountered a difficulty in having more opportunities to discuss my interpretations with colleagues because the interviews were done in Spanish and in a cultural context unfamiliar for my colleagues in USA. As a result of this limitation, the interpretation of the parents' experience is mainly the result of my understanding of the parents' story. I did not have the opportunity to check back my interpretation with the participants because they are in Colombia and I am in USA. However, I plan to do so when I get back.

Another criterion to assess the rigor of an interpretative account is its applicability or fittingness. Applicability of this study is obtained if the findings can be applied to other parents of children with cancer in other contexts in Colombia or other geographic regions. The sample of the study represents families from the middle and lower social class living in urban and rural areas. It was impossible to get participants from the upper class because they do not seek care in Colombia when they have the financial means to come to USA to get the needed care. Therefore, the findings of the study do not apply to families of the upper class in Colombia.

Regardless the possible limitations of this study, I expect its findings would be useful to health professionals and researchers in Colombia. Nurses, physicians, psychologists, and social workers would have a different and better understanding of the world of the parents raising a child with cancer. Researchers could use the findings of the study as an starting point to generate local knowledge about families of children with cancer in Colombia.

CHAPTER 3: THE CONTEXT OF THE PARENTS AND CHILDREN'S EXPERIENCE

In the following section, I will describe the context in which the parents and the children were living the illness experience in order to situate them. This would help to understand better the meanings, concerns, and practices that the parents have in living with their child's cancer. First, I will provide demographic, social and economic information about Colombia. Then, I will describe some characteristics of the family and the health system with which the parents attempted to get the care for the children. Finally, I will characterize the teaching hospital and the Chemotherapy Unit environment where the care of the children actually took place.

General Information About Colombia

Colombia is a country with 35,886,280 people according to the census done in 1993; 73.82% of Colombians live in urban areas, 50.80% are women, 49.20% have gone to elementary school, 33.43% to high school, 8.54% to the university, and 8.77% do not have any formal education. There are at least five ethnic groups: whites, mestizos (whites and Indians), mulatos (whites and blacks), blacks, and Indians. The main religion is Catholicism (88%) followed by Protestantism (6%). Spanish is the main language but there are at least 80 different languages spoken among the Indians (DANE, Censo Poblacional, 1993).

The Colombian society is capitalist, patriarchal, and classiest. Women are becoming more active in politics and the economy but there is still a strong gender bias in the society. Although women work inside and outside of the home, they are discriminated against in the work place getting lower positions and earning lower salaries. Women are responsible for raising the children and taking care of the whole family especially when a family member is ill. Many women are single mothers or the head of single parent families. The average number of children per family is 2.7 but this number increases in the low social class (DANE, Censo Poblacional, 1993).

The current economic conditions of Colombia are difficult. Colombia economy is in recession. The growth of the population is eight times greater than the growth of domestic net product (Anif, 1998). The indicators of sectors such as construction, finances, agriculture, and trade business show a negative growth in 1998. The unemployment rate is the highest in the last 50 years, especially in Cali. In 1993, the unemployment rate was 15.7% (DANE, Encuesta Nacional de Hogares, 1993) but in 1998 it is about 20%. In 1993, there were 37.2% of poor people in Colombia (DANE) but the proportion is higher in 1998.

Most Colombians belong to the low socio-economic class (54.1%) and earn the minimum salary which is about $165 a month. The middle class includes professionals and people working in technological or skills jobs. The upper social class includes about 3% of the population. They own most of the industries, land, and resources in the country (DANE, Censo Poblacional, 1993).

Colombia is very diverse country in its people and its land. There are 5 distinct regions in Colombia, each of them with different people, climate, and natural resources. People in each of these regions have specific habits, practices, and meanings. Language is some how different in these regions even though every body speaks Spanish. There are local vocabularies and slang as in any country. Most of the Indians speak Spanish or they come to the hospital with their own translator. Some Indian communities are sending their young members to the universities to get degrees in health sciences and law.

Cali, where the proposed study was conducted, is the second largest city in Colombia, with a population of over 4 million. It is the capital of the state of EL Valle, which is one of most developed in the country. The health system is also more developed in Cali than in other cities. In previous years, all the demographic and social indicators showed that people in Cali have better living conditions than people in most cities of Colombia. However, currently Cali has the highest unemployment rate and the second highest proportion of poor people in the country. The changes in social and economic indicators in Cali might be due to the economy decline, mainly in the construction sector, and the increase in the violence from the guerrillas and paramilitaries in the rural areas. Lots of people from the rural areas and small towns are coming to the city.

The Family in Colombia

According to.Gutiérrez de Pineda (1968) and Rojas de González (1988), the family's characteristics in Colombia vary with the geographic area where the parents are from, the social status, and ethnic group of the parents. The common denominator for the country is the patriarchal structure of the family, which impinges on the children and women's rights. The Catholic Church and the government support this system. Religion has determined the family's attitude and behaviors toward life but there are considerable differences in the way religion affected people's perception of life.

The family in Colombia is going through changes due to the current changes in the socio-cultural conditions of the country, such as the urbanization of the country, the relative strengthening of the middle social class, the increase in the women's access to professional education and the labor force, and the influence of the media especially television, movies, and radio. After the 60s, there have been more flexible or permissible behaviors among the family members in the higher and middle social classes. Also during the last 15 years, a new social class has emerged in Colombia. This social class called "los nuevos ricos" (the new rich) derives its power from its enormous income obtained from the illegal drugs traffic to the developed countries. The members of this social class have moral and cultural values very different from the ones traditionally accepted in Colombia. However, the influence of this class has been quite big especially among people with low education and lots of basically unsatisfied needs (Rojas de González (1988). The actual changes in the family, according to this author can be summarized as follows. First, the family's direct influence has diminished; this implies the strengthening of the person based on his/her job and technical capacity or skills. The family is not as influential as the professional and job environment. Second, men and women need to become independent from their families, they should get an independent life. As a consequence of the decrease of the family influence on the individuals, women have achieved a greater independence, especially in the upper and middle classes. The economic and personal freedom of the woman makes her less likely to maintain a marital relationship which is not satisfactory for her. This has increased the splitting of the couples and divorce. Third, there is a more flexible attitude of the Catholic Church in relation to the family's conflicts, which has made the matrimony unstable. Unmarried couples with permanent or ephemeral relations are more frequent now than 10 years ago. The above situation causes changes not only in the family‘s functions, size, and configuration but in people's behaviors related to the sexual and social division of work and the patterns of marriage and fecundity (Echeverry de Ferrufiño, 1984 cited by Rojas de González, 1988). Fourth, there are increasing numbers of "pathologic" behaviors associated with violence within the family and outside the family. Finally, the media has stimulated expectations, especially among teenagers and young adults, which are completely different from the traditional cultural and social values and are in conflict with people's social and economic reality. Despite all the above changes, it is very pessimistic to say that the family in Colombia has been put in a less important place than some years ago and is suffering a profound crisis. There are many families where the cultural and social values that promote the person's development and wellbeing are fundamental and strongly practiced within the family. The children are raised following these values and all family members live a fulfilled life despite the possible contextual limitations.

The extended family plays an important role in supporting the nuclear family in cases of conflicts or crisis. The extended family is also very important for the support and decision making regarding children's needs or problems; grandparents play a very special role in this. Fathers are the main decision-makers especially among families from lower social class; mothers are almost ignored by health providers in decision making but they are responsible for providing the child's care. Regarding birth control methods, Colombian women make their own decisions regardless of the position of the Catholic Church. Women have understood they are the ones who should decide about how many children they are going to have and when to have them. Their Catholic faith does not impede them to make those decisions. However among married women, men are still very involved in this issue.

Children are considered very valuable for the family; mostly the mother or grandmother takes care of them. The mother is also the primary caregiver when the child is ill. In the families where the father lives in the same household, the father is the main provider for the family and a supportive figure; young fathers are getting more involved in the children's care. Children live with their parents until they get married or are willing and financially capable of living independently. This is even more common among low-income families in which sometimes the children never leave their parents' home; instead they bring their spouses and children to live with their parents.

The Health Care System in Colombia

The health system has been under reorganization since 1993 when the Law 100 was expedited. This law intends to change the old National Health Care System, which was based on governmental assistance and vertical organization into the General Social Security System on Health Care (Colombian Health Ministry, 1999). There are two subsystems: the contributory subsystem aimed at people who can pay because they work or have independent incomes and the subsidized subsystem for people who can not afford any contribution. The government pays the total or partial cost of the obligatory insurance for the people in the subsidized subsystem.

The financial aspects of the contributory subsystem are managed by the Health Promoters Entities, which function like the HMOs of the United States. The financial aspects of the subsidized subsystem are managed by the entities called Subsidized System Manager.

The health care is provided by the Health Providers Institutions, which are private and public hospitals, health professionals, and other entities or persons that provide health care services. Public hospitals and health centers provide the health care for the beneficiaries of the subsidized subsystem. Private hospitals and health professionals in private practice provide the health care for the people in the contributory subsystem. The Social Security Institute (SSI) is the main HMO and health care provider in the country. It provides primary and specialized care to the worker, the worker's spouse or partner and the children. In 1998, the SSI changed the policy about the percentage of health services they will pay. The percentage paid by SSI depends on the numbers of weeks the person has been in the subsystem. The SSI pays one hundred percent of the health services after 100 weeks (2 years) of contributing. The Institute has branches all over the country even in small towns. Traditionally, this Institute has been identified as poorly organized, bureaucratized and the services they provide do not have the quality one expects, especially because of the providers-patient relationship and the time needed to get the services. This Institution is under major but very slow changes and financial difficulties due to poor management of the economic resources.

In Colombia, the power differential between social classes is very evident but it is something that is taken for granted by almost everybody. The relationship between the physicians and nurses and their clients is based on this power structure. Physicians and nurses and other health professionals consider themselves as a source of knowledge (which means power). Therefore, most of the time they do not explain to the patients and their families the diagnosis and treatment. Rather, they make the decisions for the patients and then communicate to patients and families what they have decided. When a patient or the family asks questions or wants to discuss the provider's decisions, it creates tension. Sometimes the physicians do not want to take care of patients because they feel the patients do not trust them, or are difficult to deal with when they question information or care decisions. Nurses are more apt to explain and discuss matters with patients and families but there is still some evidence of the power issue in their relationship with the patients and families. For example, nurses may describe clients as ignorant about health-illness issues. On the other hand, patients and families most of the time do not ask to participate in decisions and do not ask questions about their health situation because of the power difference they see and feel between themselves and the providers. This is more evident among people from lower social class and with low education.

Treatment of Leukemia

Another important issue in relation to the context of the families of children with cancer is the treatment of the disease. The following description of the leukemia treatment depicts only the treatment in the teaching hospital, where the study was conducted. This hospital is the treatment center for children with cancer in the South West of Colombia. The treatment for leukemia is very expensive and lasts at least three years. The lack of all the treatment options and the lack of financial resources to complete the treatment could be the main cause of the still high mortality or low survival rate among children in Colombia, but there are no data or studies about this that can shed light on this issue. The pharmacological treatment available is the same as in USA but the bone marrow transplant is not done, at least in the teaching hospital in Cali. The lack of capacity to make a precise classification of the leukemia is the main problem patients and physicians face. This does not allow the use of more specific drugs, which would make the treatment more effective.

There are written protocols for children with normal risk leukemia and children with high-risk leukemia. Copies of the written protocols are given to the parents to help them to know the drugs and procedures required during each calendar week of the protocol. For both protocols, the induction phase lasts about three months. During this phase the children have chemotherapy every week or more often depending on the risk. At the end of the induction phase the children have a bone marrow biopsy and spinal fluid test. If the child goes into complete remission, the maintenance phase begins. During this phase, the frequency and type of chemotherapy depends on the risk classification. The normal risk children have chemotherapy every month and the high-risk every week or every two weeks depending on the medications they are getting. There are two weeks periods during which the children do not have chemotherapy in both protocols. At the end of the first year, all children have bone marrow biopsy and spinal fluid test besides the blood test. Most children also had radiotherapy. During the second year, the chemotherapy is done every month for all children. Children with the first relapse have two weeks of daily chemotherapy, which is called the rescue protocol. If the bone marrow is normal after the rescue treatment, the high-risk protocol begins again. In the case of a second relapse, the children get another chance with the rescue protocol. If the bone marrow is abnormal, the children in the subsidized system usually do not have another option. Bone marrow transplant is not done in Cali. Children with SSI or private insurance can go to Bogotá and Medellín in Colombia or to USA for the transplant. I do not know the success rate of the transplant in Colombia; it is a new medical treatment for Colombian physicians and patients.

Funding and Support for Children's Care

Most of the families are not covered by health insurance especially in the lower social class. Therefore, the children do not have any health insurance at the time of an illness diagnosis. Usually, the parents assume the illness expenses during the first few months with the help from the extended family, relatives, coworkers, and neighbors. Six children whose parents participated in the study had health insurance with SSI; out of these only three had the insurance before the diagnosis. Two children had the insurance with private institutions; both got the insurance after the diagnosis. Three children were in the subsidized subsystem through the teaching hospital where the study was conducted. Children with health insurance from the subsidized system should be referred by a second level hospital from the city, the state, or other states to the teaching hospital for diagnosis and treatment. The parents do not have to pay for the hospital and physicians services when the children receive ambulatory care. They pay a percentage of the medications, the bone marrow biopsy ($180, this cost is lower than the cost for insurance patients), the blood test ($4.50), the spinal fluid tests (about $15) and the procedure to give the child the chemotherapy. The total amount the parents should pay varies with the treatment protocol. The parents should show the nurse the receipt for the amount that they have paid before getting the chemotherapy or the tests. For the drugs, the parents get a discount that can be from 50% to 90% depending upon the classification done by the Social Work Service from the hospital. The parents get a code that they take to the Drugs Fund where they get the medications. They pay for the medications to the Drugs Fund which is a private institution.

The SSI has a contract with the hospital to provide services to adults and children with cancer. Once the child is diagnosed with cancer in the SSI, she/he is referred to the teaching hospital. The parents have to go sometimes to three different SSI sites to get the medications, the approval for treatment and the tests. The sites are located in the city but in different areas and not close to the hospital. At the end of the data collection period, the SSI opened an office in the hospital to facilitate the process for the approvals but also to collect the payment that the parents were making to the SSI. Children who have been in the system less than two years (100 weeks) do not get full coverage. The coverage percentage varies with the number of weeks they have been in the system. At the time of the data collection, it was 25 % for the first year and during the second year it increased up to 50% and 75%. At the end of each month, the parents get the bill from the SSI for the amount they should pay for physician services, tests, and procedures.

Private insurance companies also had contracts with the hospital. The children need the approval from the insurance institutions to get the services they require at the hospital. For these children there are not differences in coverage percentage but the institutions request letters from the physicians to support some of the medications like the one to improve the immune system when the child is very neutropenic. Only the medicines and procedures that are in the list of the insurance companies are given without more paper work.

Out of the nine children with health insurance, only five children were fully covered by the insurance, three from SSI and two from private insurance. One mother was able to have her child in both subsystems (which was not allowed) and managed to get most of the treatment cost covered but she still was getting the bills for hospital and physician's services from the SSI.

During the second half of 1998, the teaching hospital underwent a financial crisis due to the bad economical situation in the country and the fact that SSI did not pay all the millions of pesos they were in debt with the hospital. The hospital director decided to stop providing the services for all SSI patients for more than one month. Some children had delays in the treatment because of this decision from the hospital administration. The parents were desperate during this time; they had meetings with the SSI executive people, who assured them the SSI had already solved the problem with the hospital but that was not true. They also went to the local television station and newspapers and participated (with some children) in a massive protest march to make known their children's situation. For some children the treatment was delayed a few weeks, which was very frightening for the parents and frustrating for the nurses and the physicians. The female Oncologist, who worked for the SSI wrote letters and talked with the SSI manager to explain the consequences of the situation on the children's health and to request a quick solution. She told me it was very hard for her to be in the middle of this situation. She felt powerless to deal with the SSI inefficiency, the children's well being, and the parents' concerns. She advised the parents to take legal action against SSI. Part of the SSI solution to the problem was to change its policy about the coverage percentage from full coverage regardless the number of affiliation weeks to 25% up to 75 % before 100 affiliation weeks.

For the last three months of 1998, the hospital requested all parents to bring some supplies for the chemotherapy. They were required to bring supplies like the buretrol, the syringes, IV tube, and the needle (intracath). The parents bought these supplies from their own pocket most of the time; after some weeks they learned to get them from the insurance. However, the parents in the subsidized system could not avoid this new expense. There was another big expense added to the sparse budget of these parents.

There is a Parents' Association created four years ago and chaired by the aunt of one of the children under treatment. The main goal of this organization is to help financially the parents in need and to provide psychosocial support to the families of the children under treatment. About 180 parents belong to the association and fewer attend the meetings. During the data collection period, the Parents' Association organized a trip to the San Andres Isle in the Caribbean for 30 children over six years of age that were under treatment. The private industry helped to fund the trip and one of the Colombian airlines provided the airfare. A Pediatrician and some parents accompanied the children in the trip. The association also organized day trips (paseos) for the children and the parents near the city. There were meetings for the parents to discuss issues about the children's care. After the trip to the Caribbean Isle, there was less activity from the association. I could not attend any of the meetings to get a better sense of the way the parents group was working. It seems some parents did not want to have anything to do with the association; they considered it somehow limited to few parents who were friends of the chairperson. When they were organizing the main trip, some parents told me they did not get the information about the trip meetings on time so they did not know the specifics of the trip and their children missed the opportunity to go on the trip. Only 27 children were able to go in the trip instead of the 30 they had planned.

Since 1987, there is a foundation to provide medications for cancer patients who are treated in the teaching hospital. The Drugs Fund (Fondo de Drogas) as it is known sells drugs to patients from insurance companies, which have contracts with the hospital or patient that buy the medications themselves. It also subsidizes the drugs for patients with low financial resources. The hospital Social Work Service does the socioeconomic classification of these patients. There are two sites for drug storage and sales. One site is located in the area of the Chemotherapy Unit to facilitate the acquisition of the medications and the communication between the foundation and the patients and the health team caring for the patients. The other site is located in a building across the street from the teaching hospital. Four families participating in the study benefited from the Drugs Fund.

There are two other private foundations in the city to help with the treatment funding for cancer patients; these foundations are SANAR, which is only for children and UNICANCER that is for adults and children. They are totally independent from the teaching hospital.

Hospital Environment

Whenever the children are sick and come to the hospital, the parents take them to the Emergency Room (ER). The ER for children is located in the same area of the Adult Emergency Room but it is separated by a hallway. Only one person is allowed to stay with the child in the ER so the parent has to do all things the physicians order for the child without any help. In the ER, the parent or family member is responsible for taking the patient to X-ray area and any patient' s specimen to the main laboratory. Children usually do not want to be alone in the craziness of the ER and the parent does not want to leave the child alone either. So the parent has to take the child with her/him wherever she/he goes in the hospital. The ER is a very busy place like most ERs in a university hospital. So it takes a number of hours before the child's clinical condition is determined and care given. Sometimes the child stays 1, 2 or 3 days in the ER and then she/he goes home or to the pediatric ward. Being in the ER was a very tiring, scary, frustrating and anxiety provoking experience for the parents. The ER environment and all the work the parent should do without the support of other family members made the situation almost unbearable for some parents.

The children with cancer are hospitalized in the General Pediatric ward but in a separate area. The General Pediatric ward is located in the fifth floor of the hospital, where the other pediatric wards are located. The General Pediatric ward has 40 beds and usually it is fully occupied. The General Pediatric ward environment is much better than the ER. It is more tranquil and friendly for the children and parents than the ER. In the mornings, there are the usual nursing and medical rounds. Other health professionals like physical therapist, speech therapist, and psychologist come to see the children generally in the morning. The presence of students from the different health care professions, interns, residents, and professors increases the activity in the ward during the morning hours but in the afternoons and evenings there is less activity. There are six beds in the area for the children with cancer. Each child has a small room with glass walls in front and the sides, a TV set, a night table, and a chair. There is a common play, restroom and shower area only for the Oncology children. One parent or relative is allowed to be with the child in the room all the time but at night only the mothers can stay. These restrictions represent some annoyance for the parent because they can not meet some of their basic needs such as eating, taking a shower, and going to the restroom without upsetting the child. They have to wait until another relative comes to be with the child.

There is minimal comfort for the parents in the ward. There is a bathroom with a shower for the mothers and laundry facilities on the same floor. There are not beds or comfortable chairs for the mothers to rest at night; if they want to sleep, they do that while sitting on a regular chair. The parents need to go to the main hospital cafeteria or small cafeterias in the hospital area to get food for them or the child. There are pay phones outside the pediatric ward but on the same floor.

The nursing staff for the whole ward includes one Professional Nurse and five or four Vocational Nurses in the morning and afternoon shifts. In the evening shift, there are only two Vocational Nurses in the ward; one Professional Nurse is responsible for three of the pediatric wards including the General Pediatric ward. The mentioned nurses take care of 40 children with a variety of diagnoses including cancer, renal and cardiac disease, and diabetes among others. The Professional Nurses act as the head nurse of the ward; they spend most of their working hours in issues related to the management of the ward and the nursing care. They provide some of the nursing care for the sicker children and are responsible for teaching parents the most critical aspects of the children's care at home. They also give especial treatments like blood transfusions, chemotherapy, and other medications. The Vocational Nurses are more in direct contact with all the children and their families since they actually provide most of the daily nursing care. In general, nurses are extremely busy managing and providing the essential care to the children that they have little or no time for addressing the children's and family's emotional needs. An intern and a Pediatric resident are available all the time for the entire ward. A Psychologist or Psychology students and one Social Worker are also part of the ward staff.

The hospital has private rooms, which are used for the patients from the contributory health system or those who can pay from their own pocket. These rooms are more comfortable than the rooms in the pediatric floor. The rooms have private bathroom, telephone and a sofa bed and are bigger but more expensive. The children are not hospitalized in those rooms. I am not sure about the reason for not putting the children in those rooms. It could be that the SSI and other insurance companies ask the Oncologist to hospitalize the children only in the pediatric ward. Also it could be the Oncologist prefer to put the children in the pediatric ward because the nurses and the physicians have more experience in caring for children. For some parents it is difficult to cope with the hospitalization because they are not able to rest but mainly because they have to witness many things (the death of a child among the more frightening) that happen with other children with the same diagnosis.

Two Oncologists and a resident who is doing the clinical rotation for Hemato-Oncology see the children in the pediatric ward and in the Chemotherapy Unit. There are some volunteer ladies who come in the morning to bring toys to the children and to help the parents in keeping company to the children while the parents go out of the room to take a shower or eat.

The Chemotherapy Unit is located in the second floor of the hospital, near the Hematology Oncology Laboratory. The unit is open from 7 A.M to 4 P.M, Monday through Friday. It is for adults and children. The staff is composed of two Pediatric Oncologists, a professor and a resident from the Anesthesia department, one Professional Nurse and two Vocational Nurses (one of them is a nun). The oncologists come to the unit two mornings during the week. The male oncologist (who has more than 20 years of experience in the field) does all the bone marrow biopsy and lumbar punctures for the children under treatment and for the children who come to be diagnosed. As soon as he finishes he goes to see his patients in the pediatric ward. The female oncologist (who is young in the field) writes all the prescriptions and answers some of the questions the parents have the chance to ask when she is not too busy. All children get a written protocol for the treatment. The parents must follow the protocol and request from the oncologists the prescriptions and test orders ahead of time. During the data collection period, no parents mentioned that the oncologists or anybody else met with the parents on regular basis to talk about their concerns. The oncologists are available mainly to prescribe medicines or tests and answer quick questions about the treatment protocols.

At the beginning of the data collection period, the professional nurse was one who has a Master degree in Oncology Nursing from a private university in Colombia. He was in the Unit for a number of years; he was well accepted by the Oncologists, the patients and the families but he was transferred to a Nursing Service that was not related to Oncology. The new nurse did not have special training in Oncology. The professional nurse is responsible mostly for the management of the unit. She gives the chemotherapy to the very few children who have a central line and she helps the vocational nurses to give the medications to children and adults. The vocational nurses are busy preparing and giving all the medications and fluids to the patients all day long. There were about 15 to 20 children for chemotherapy and diagnostic procedures during an average day.

One or two voluntary ladies come every day to the Chemotherapy Unit; they are responsible for providing some recreation to the children; they also talk with the parents and watch the children while the parents go out for short periods of time. These voluntary ladies are the same so the parents and the children are familiar with them and as a result these women become a resource for the parents and children during the chemotherapy sessions. During the first few months of the data collection, there was a Social Work student who also did some recreation with the children and talk with some parents. During the last three months of data collection, two Psychology students from a private university came to have their clinical practice in the Unit. They came twice a week to work mainly with the children and parents who were referred to them by the Oncologists or the nurses.

In the Chemotherapy Unit, there are a few cribs for small children, reclining chairs for the older children and regular chairs for the parents. Parents are allowed to bring food and drinks for the children and themselves. Sometimes, healthy siblings come to the unit to be with their brother or sister during the treatment. There are two rooms, one exclusively for children and the other for older children and adults. Both patient rooms have TV and VCR. Toys are not supplied for the children in the unit but they are allowed to bring their own toys.

Treatment Routine, Parents' Responsibilities and Relations during Chemotherapy Sessions

The routine for a child under treatment during the first year of the illness is the following. The day before or the same day of the chemotherapy appointment (depending on the type and duration of chemotherapy), the child should have a blood test. The test must be done at the Hematology laboratory, owned by the University of El Valle and located in the teaching hospital. This test costs 6.000 pesos ($4.50) and is paid by all parents from their own pocket. The schedule for the test is 7 A.M to 9 A.M and 1 P.M to 2 P.M from Monday through Friday. The blood for the test is taken from the child's fingertips. If the test is normal, the child would have the chemotherapy; if it were not but the child is well, the chemotherapy is postponed for a week. The child would have another blood test the following week. The day of the chemotherapy, the child should be in the unit at 7 A.M if the treatment lasts 4 to 8 hours or at 1 P.M if it is 2 hours or shorter. For the bone marrow and the lumbar puncture the children need to be there at

7 A.M. The bone marrow biopsy is done under general anesthesia for all children. The lumbar puncture is done under general anesthesia for children under six or for those older who can not tolerate the procedure under local anesthesia. Older children have the lumbar puncture with local anesthesia.

Most of the chemotherapy is given intravenously; only one drug is given intramuscular. The children get an IV every time they have chemotherapy. The nurses are pretty skillful in getting the IV started but nevertheless sometimes the child would get more than one needle stick. Few parents can afford to buy the anesthetic cream to decrease the pain from the needle sticks, therefore most children have the procedure without any help to minimize the pain. Some children are very scared of the needle sticks but others tolerate it quite well. The stickers that I gave to the children make a big difference for most of them; the stickers were the only anesthetic some children had during the needle sticks. However, I was there only two mornings during the week. Nevertheless very few children, usually toddlers and preschoolers, show a great deal of distress during the needle sticks.

During the chemotherapy, the parents are required to watch the IV and to call the nurses when it is time to put more fluid in the buretrol. While the children are having the chemotherapy, the parents chat and share information about their practices to keep the children the best they could and also about child-rearing practices. They exchange information about fruit juices, foods, remedies, ways to deal with the health system, and ways to control the children's behavior. They also share information about their everyday life and how the children are doing. The death of other children is something they also talk about but in the hallways. Mainly mothers stay with the children during the treatment.

The relationship among the unit staff, the parents and the children in general are positive. Physicians and nurses are kind with the children and the parents. Nurses chatter with parents and children in a very cordial way. Some children have preferences regarding the nurse or the oncologist who would perform the painful procedures. Nurses and physicians seem attuned to the children' s preferences and act in conformity with them giving the children and the parents a sense of control and comfort. Some children come and leave to the unit without fear and discomfort. Sometimes, parents look tired at the end of the chemotherapy session especially when it lasts more than four hours.

CHAPTER 4: PARENTS' WAYS OF LEARNING TO LIVE EVERYDAY WITH A FAMILIAR BUT TREACHEROUS ILLNESS

Facing the diagnosis of cancer in a child is a very frightening and draining experience for the child, the parents, siblings, and extended family. It implies a great deal of suffering, uncertainty, fear, work, and financial resources for the entire family but mainly for the ill child and the parents. It also involves learning to live and actually living everyday with the child's illness in the best way possible for all family members. To understand how parents in this study took up their children's cancer and the impact of the illness on the parents' lives is crucial because it provides insight that can be used to support other parents in coping with the demands of the illness experience in the least traumatic way possible.

From the moment the parents heard the final diagnosis from the Oncologist, they began a continually evolving process of learning to live with the illness as part of their everyday lives. I will describe only the process that parents went through the first eighteen months of the illness experience. It is important to remember this process could be a lifelong process since the child might survive but the shadow of the cancer could be with her/him and the parents forever. In this study, parents went from feeling that their "*world had ended*" at the time of the diagnosis to being able to "*get out of the labyrinth*", and to go on with their everyday lives with a "*familiar but treacherous illness*". Finding meaningful the illness was a very important aspect of this process. The parents' experiential process of taking the illness into their lives was affected by some moments of crisis like hospitalizations due to other illness or abnormal test results, the death of other children with leukemia, and the relapse of the disease. This chapter has two main sections. In the first section, I will describe the trajectory or process that parents went through in living an everyday life with their child's illness during the first eighteen months of the illness experience. This section includes the subsections about the parents' initial responses to the diagnosis, finding the illness meaningful through religion, and having a sense of normalcy when the child went into the remission phase of the disease. The second section of the chapter involves issues regarding the parents' lives as parents and spouses or family members during the eighteen months of living with the child's illness. I will describe the parents' emotional responses, caring roles and concerns, and relationships.

"The World Had Ended": Initial Responses to the Diagnosis

The taken-for-granted reality of the parents began to be disrupted with the first symptoms of the leukemia. At the same time, parents began a journey whose end was unknown to them. The only thing they knew was that they wanted to find out what was wrong with the child. But they did not expect that journey to be as long and painful as it was for most of them, especially at the beginning. Some parents intuitively understood the child could have some serious disease due to the symptoms they observed their child. Even the parents who had experience with cancer in their relatives, friends, or neighbors did not contemplate the idea their child would have cancer. They thought of cancer as an adult rather than as a child's illness. Besides, nobody anticipates this frightening disease for themselves or their loved ones if one does not have a medical or nursing background. Before knowing the final diagnosis, parents were in a state of wonder mixed with great hopes that the child's disease would not be so serious. Then, the parents' world seemed to stop at the moment the Oncologist told them the diagnosis of leukemia. Their taken-for-granted reality was entirely disrupted by the cancer diagnosis in their child. Hearing the diagnosis from the Oncologist meant the diagnosis was an immutable truth for almost all parents; a few of them doubted it was true. Statements such as "*It was the end of the world*", " *The whole world crushed on* *me"*, *"I felt it was the end"*, *"I felt inside a small box, like the world was that small box"*, *"My mind went blank"* show how parents took up the diagnosis of the disease when they heard it for the first time. The diagnosis was a huge surprise for most parents; this was more evident when the diagnosis was made soon after the child began having the symptoms or when the child had unspecific symptoms. Parents felt astonished at the time of the diagnosis. For a few minutes, maybe hours or days they felt powerless to change the situation. Overtime, the state of shock was overpowered by the parents' solid desire to do something for the child's survival.

At the time of the diagnosis, most parents understood their child would die relatively soon from the disease. The parents' practical knowledge of cancer as a fatal disease set up the idea of the child's imminent death in the parents' minds. The physicians played an important role in comforting the parents and in helping them to reframe the disease understanding. The information provided by the Oncologists about the disease, the treatment, and the prognosis gave the parents another perspective on the disease. The Oncologists gave the parents hope when they explained the treatment and the prognosis. So parents understood there was a survival possibility for the child and they should do all that was possible to keep the child alive. This possibility made the parents' world possible again so they reorganized their lives around the child's illness.

All parents wondered a great deal about the concrete causes of the disease mainly at the beginning of the illness experience. Mothers more than fathers wondered if they had done or had not done something to cause the child's illness. Mothers thought they could have done something during the pregnancy or that they had fed the child improperly. Two mothers believed the child's father was responsible for causing the disease. One of these mothers believed "*the father's bad blood because of his alcoholism, smoking, and relationships with prostitutes*" was the cause of the child's leukemia. This mother was no longer in a relationship with the child's father as a couple; they kept in contact only because of the child. The other mother thought the emotional abuse and suffering the father caused her and the child could be the cause of the disease. He abused her verbally and he was having an affair while they were married and living together as family. Later he left the family and went to live with the with whom he was having the affair. This mother came to that conclusion with the help of a nun who told the father the same thing. This mother hung on to that possibility even though the girl was already born and the father did not do specifically anything to hurt the girl. Maybe, this mother believed or wanted to believe that as her way to get the father to feel guilty and assume his role in the girl's care and treatment. This mother was very shy and perceived herself as incapable of doing all the activities related to the girl's treatment at the hospital on her own; she also said her capacity to retain information was very poor due to her bad memory.

The Oncologists' reassurance that the parents were not responsible for causing the disease decreased in some degree the parents' sense of wondering and guilt. However, this seemed to be true for the mothers, who felt guilty, and all but one father. In the one exceptional instance, infidelity by the husband and suspicions by the wife let both parents to suggest that the father's behavior might be the cause of the daughter's illness. Besides, the father thought God had punished him for abandoning another daughter who he fathered as a young man.

The fact that the parents felt responsible and guilty of causing the child's disease caused the parents an additional burden. On the other hand, having those feelings might have helped especially the fathers to get involved in the child's care. It is also possible that parents had the guilt feelings due to the fact they felt accountable for anything good or bad that happened to the children. Regardless of the reasons, parents' expressions of guilt solicited the help of physicians, nurses, psychologists, priests, and friends who for the most part were able to comfort the parents about their role in the development of the disease.

Some mothers did not want others to learn about the child's illness at the beginning of the illness for different reasons they acknowledged during the interviews. One mother was used to keeping things to herself even from her own family so it was a background practice for her. Two other mothers did not disclose the diagnosis in order to avoid discouraging comments and attitudes from people. They feared being asked too many questions out of curiosity, public pity and efforts from others to isolate the child because the disease was thought to be contagious. All these mothers realized after a time that there was no reason for hiding the truth about the illness since it was so obvious to everybody, "*It's like covering the sun with your fingers*". So some months after the diagnosis they were able to share the illness experience with others and felt much better, since that allowed others to help them and be sympathetic with them.

> Entonces pues eso ha cambiado, porque yo antes yo no quería que la gente me preguntara, no quería, no quería hablar con nadie sobre la enfermedad, pero yo ahora he aprendido de que hay que compartir todo, y eso me ayuda. Es que aquí, prácticamente la gente ya sabe de que el niño está en tratamiento de Quimioterapia porque la gente nos ha apoyado. Yo salgo y me dicen como sigue el gordito?, cómo está Carlos?, todo el mundo nos pregunta, entonces yo cambie esa situación, yo ya no vivo en que yo no quiero que los amiguitos del niño sepan que tiene, que fulanito no se de cuenta, que fulanita no se de cuenta, que por toda la cuadra nos van a estar [preguntando], no? Para mi mejor, ojalá yo me asome a la puerta y la gente me diga qui'hay del mono? qui'hay de Carlos? yo me siento bien cuando la gente me pregunta por Carlos.

> That has changed because before I didn't want people asking me; no, I didn't want

> that, I didn't want to talk with anybody about the illness but now I've learned that it's good to share everything and that helps me. Here in town people know that the boy is under chemotherapy because they've supported us. I go out and they ask me how's Carlos? Everybody asks for him so I changed that; now I don't live like I don't want his friends to know about what he has, that somebody doesn't know, that everybody is going to do this and that, right? No, it's better for me; when I open the house door I expect people telling me "How's the boy, how's Carlos?" I feel very good when people ask me about him.

The reluctance of some mothers to allow others to know the diagnosis of leukemia could also have been caused by these mothers' sense of responsibility for causing the disease. Therefore, it is possible they felt ashamed if others learned about the child's diagnosis because of their belief about their own role in causing the disease. As soon as they understood they were not responsible, it seemed possible to change their attitude about disclosure.

Religion as a Way to Find the Illness Meaningful

From the moment parents heard the diagnosis, they asked the question "*why is this happening?*" Answering this question was as a way that parents could make some sense out of the chaos created by the unexpected diagnosis. So after days, weeks, and months of wondering and trying different answers to this question, parents found a meaning for the illness that gave them the strength to continue with their lives. This illness meaning also allowed them to spend their already depleted energy in performing their role as parents in such unknown and frightening conditions.

As Catholics, most parents interpreted the occurrence of the illness as something that came from God. However, some qualitative distinctions are visible in the way parents took up the meaning of God's involvement in the illness. Some parents perceived the child's illness as a punishment for wrongdoing by themselves or close relatives like grandparents. These parents could not understand why God was punishing innocent children for something their adult relatives had done; they believed that they, as parents should be the ones having the disease not the child. Parents said they would gladly trade places with the child to save the child from suffering and dying and also because the parents were the sinners who should deserve the penalty. They were perplexed by the inconsistency of God's fairness until they realized with somebody else's help that God was not punishing them or the children.

> Yo estuve yendo a una Iglesia Cristiana. Muchos allá me decían que eso eran pruebas que ponía Dios, no? Como también me decían que esto era un castigo de algo que yo, yo o mi papá o mi papito había hecho, no? Entonces yo me pregunto por qué? Si prácticamente uno sufre, uno como madre sufre, pero no sufre como sufren ellos, porque ellos son los que están recibiendo los chuzones, ellos son los que están sintiendo el dolor, ellos son los que se están sintiendo mal.

> I was going to a Christian Church. Over there, many people told me [the illness] was a test that God was given me, right? They also said it was a punishment for something wrong I, my father or my grandfather had done. So I asked myself why is that? One suffers as a mother but not as much as they suffer, because they are the ones getting the [needle] sticks, they're the ones feeling the pain, they're the one feeling awful.

Other parents understood the illness as God's way of testing their faith so they felt committed to persevere and even to intensify their faith by restraining themselves from doubting God's power and readiness to help them and the child through the whole illness experience. They were sure that they would go through the illness experience "*held by God's hand*".

> Ell día que me tocó [saber el diagnóstico], yo pensé entre mi "Bendito sea mi Dios, esta es una prueba que me ha dado; por qué me tocó esta prueba a mi?". Esoes muy duro que le digan a uno que un hijo tiene cáncer.

> The day that was my turn [to know the diagnosis], I thought "Oh my God, this is a test He's given me; why am I having this test? It's very hard to be told that your child has cancer.

For other parents, the illness was a bridge to God or they way they could connect with God in a closer and more authentic way as it happened to be for this mother.

> Yo pienso de que mi Dios me tocó muchas veces y yo no le abría la puerta. La enfermedad de Pablo es un puente directo hacia El. El me ha enseñado tantas cosas, a perdonar, a no odiar, a vivir tranquila y eso si es gracias a la enfermedad. Eso se lo tengo que agradecer a esa LLA. O sea pienso que se ve cosas muy malas porque que mas que ser mi hijo, pero también tiene cosas muy positivas demasiadas positivas porque yo tenía muchos problemas internos. .... Yo digo gracias a la enfermedad de Pablo y gracias a Dios, han habido unos cambios pues mejor dicho lo que estaba arriba quedó abajo, lo que estaba abajo quedó arriba.
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> I think that God touched me many times and I didn't open the door for Him. Pablo's illness is a direct bridge to Him. He has taught me so many things, to forgive not to hate, to live tranquil, and all that is thanks to the illness. I have to be grateful with that ALL. That's, I think that there're many bad things because it's my son but also it has many positive things. I used to have many inner problems. .... So I say that thanks to Pablo's illness and God, there have been many changes. In other words, what was up is down and what was down is up now (meaning everything is in its right place).

The belief about God's involvement in the illness changed over time for some of the parents but for others stayed the same. For example, the youngest mother in the study initially interpreted the illness as punishment. This idea did not satisfy her at all due to the unfairness of God in doing that and eventually she came to believe God was testing her faith. Later, when her daughter had the relapse and her religious beliefs regarding the illness were again unsatisfactory for her, she accepted the reasoning a Catholic man gave her. According to him, God was allowing the illness to happen because He was protecting the little girl and the mother from some worse future suffering and pain. The mother from another family never thought of the illness as punishment. At first, she believed God was testing her and later she came to belief the illness was her bridge to get closer to God. Of all the parents, only one father did not change his beliefs; a year and half after the diagnosis, he still believed the illness was a punishment for his wrongdoing. This was the father from family #4, who was very involved in his daughter's care but later he left the family due to the financial and marital problems he was facing.

The parents from three families believed all the time God was testing them through the illness. However, most parents believed God was allowing them to learn something good for their lives through the illness experience like it happened to the father from the following quote.

> **P.-** Yo lo que he dicho es que la gente se encuentre con estas cosas lo mas importante es que cambien su vida no? que no estén buscando de aquí pa'llá, corriendo a un sitio que a buscar milagros que después que uno tenga fe Dios está en todas partes, pero los milagros se dan de acuerdo a la gente. Uno tiene que cambiar la vida, muchas veces dejar vicios o cosas como trago, cambiar la vida es lo importante.
> **E.-** Y todo eso surgió después del diagnóstico?
> **P.-** Noo, no yo mas o menos desde antes venía, pero, pero eso le ayuda a uno no cierto, eso lo hace crecer a uno, o sea, eso no, no es para que la gente se lamente, ni llore ni nada eso, si no para que crezcan espiritualmente, es lo mas importante.

> **F.-** What I've said is that for people who find themselves in these circumstances, the most important thing is to change their lives, right? They shouldn't be looking here and there for miracles because as long as you have faith God is everywhere. Miracles occur depending upon the people. One has to change a lot, to leave out bad habits like drinking. Change one's life is the most important thing.
> **I.-** Did you learned all this after the diagnosis?
> **F.-** Nooo, I was somehow thinking about that before but that (the illness) helped me, right? It made me grow, in other words it isn't for people to lament, neither to cry or nothing like that, instead it's to grow spiritually; that's what is important.

For a few parents it was difficult to differentiate whether the illness was due to their fate or came from God. Only one couple understood the illness as a result of their karma or the child's karma but also as God's will. Both parents from this couple believed in God, the power of the mind, and karma. So parents interpreted the illness as punishment for wrongdoing, as something due to fate, as an opportunity to be closer to God, and as a test from God to their faith. Most parents understood they could become better human beings by means of the child's illness.

As a result of understanding the illness as an opportunity to become better human beings, some parents changed their way of being and their priorities, as the mother who understood the illness as the bridge to God. Before the illness, this mother saw herself as not genuine in practicing her faith, she was attached to things without "*real value*", and she had negative feelings toward her parents and siblings. She found "*inner peace*" after she realized her son's illness had showed her the real values in her life. It seems the child's illness allowed parents like this mother to initiate a healing process that was possible only because they discovered a positive meaning in the illness experience. This inner healing empowered the parents to face the illness in a way that was beneficial for them and the whole family.

After finding a positive meaning in the illness, parents felt more ready to deal with the illness. It took variable amounts of time for the parents to find the positive meaning in the illness. Friends, relatives, priests, and even strangers helped the parents in finding the illness meaningful.

All parents understood the illness as God's will but they did not take a passive stand because of it. They felt compelled to do all they could do to save the child from dying. Parents were not immobilized by their religious understanding of their experience instead they got the strength to move on from it. They lived according to what they believed was God's request "*Help yourself that I will help you*". This understanding was true even for two mothers who seemed to have a feeling of resignation about the child's possible death. Having a sense of usefulness regarding the child's survival plus the strong belief that God was supporting them allowed the parents to respond to the situational demands and also to continue their lives in remarkable ways.

All parents found a great deal of support in their religious faith. God was like "T*he rope from which you hold on when you are drowning*". There were differences in the parents' level of involvement and commitment in religious practices during the illness experience. Parents who were more religious before the illness became more engaged in public religious practices such as going frequently to mass. Parents who were not so religious before the illness kept more private religious practices such as praying everyday at home. Some parents paid special visits (*promesas)* with the whole family to an image of Jesus Christ (El Milagroso de Buga) that is considered to make miracles especially for ill people. It is customary during these visits that people attend the special mass, walk by the image in a long line, pray when they are in front of the image asking for the special favor or miracle they need, and leave whatever amount of money they can by the image. If they had collected the money, left by the image from neighbors, friends, and relatives it would have more value than if the money were taken out of the parents' pocket. Begging others for the money had more value before God's eyes than just getting it from their own means.

There was only one father who stopped going to church because it did not help his child. However, it was a new church from another religion that he was trying. His child did not respond to two different treatment protocols and died seven months after the diagnosis. It seems that this father was not very religious before the illness and probably he became very disappointed or frustrated so he abandoned the public practice but he said that he continued believing that God would be the only one saving his 4 year-old son. Both parents of this child seemed to know deeply in their hearts that the child would not survive but they kept their faith in God; they were hoping "*God would make the miracle to cure him*".

The mother, whose daughter had a relapse, said her faith became stronger after the relapse of the leukemia. She increased her prayers every day to God and the Virgin Mary. This mother needed to have a stronger faith in God curing her daughter through the folk remedy and the medical treatment as her way to cope with the relapse of the disease.

> **M.-** [Esta bien] si Dios quiere darle vida a mas niños con ese remedio; si no (Dios no quiere), pues eso ya es voluntad del Señor y lo mismo pasa con mi hija. Si mi Diosito y la Virgencita me la tienen pa' este mundo, yo se que ella no se me va a ir (no va a morir). Yo rezo todas las noches por eso a mi Diosito y a la Virgen.
> **E.-** Que te hace sentir tanta fe en el remedio?
> **M.-** No se, no se, desde que mejor dicho desde que esa señora entro a mi casa, como que algo me decia aca (en el pecho) Ay! Mi niña por fin se va a aliviar! Como que algo me decia.. en todo caso yo se que Dios dentró en ese remedio.

> **M.-** [It's O.K.] if God allows the children to live thanks to that remedy; but if no (God doesn't want to) that's is His will so the same would happen to my daughter. If God and the Virgen Mary want her (the daughter) in this world, I know she isn't going to leave me (to die). I prayed for that every night to God and the Virgen Mary.
> **I.-** What makes you to have such faith in the remedy?
> **M.-** I don't know, but from the moment that lady came to my home I had an inner sense that Oh, my girl is finally going to be cured!; it was like somebody was telling me that. Anyway, I know that God is inside that remedy.

It seems that most parents regardless of the child's clinical condition continued some religious practices as a way to get courage to face the illness experience. Religious faith was even more important in moments of crisis like the failure of treatment and death of the child.

Parents left the child's present and future in God's hands. They understood God was the best possibility for the children and for them. For some parents, God would be the only one capable of curing the disease. The medical treatment was only to control the disease but with God's help it might cure the disease. This understanding was stronger for the parents of the girl with a relapse and of the child who died after unsuccessful treatment.

> One always thinks the worst but one gets courage because the first thing I do is to ask for God's will, if He's going to leave us [the child] longer or if He's going to take [the child] away from us. So it would be His will. God gave [the child] to us so He would decide when to take him from us"

The parents' strong faith in God's curing the child seemed to be the only refuge for all the parents but especially for those with fewer possibilities. However, it is important to notice that parents did not expect that only God would do the job. They understood that they had some control over the illness by following the treatment and carrying out many practices to protect the children and to help them to recover from the disease. This is a very different stance from the defeated attitude that sometimes I have seen in working with adult cancer patients. Some of them get to the point they do not seem to want to fight more for them. Parents did not express perceiving a sense of hopelessness regarding what they could do for the child, not even the parents of the child who died. If there was not more medical treatment or if there was not high hope for the medical treatment, parents tried alternative treatments and even folk remedies unknown to most people, like the remedy with the scavenger bird that was given to the girl who had the second relapse that I describe in chapter 6.

For the parents in this study, spirituality and religious faith were sources of support they relied on to cope with the illness. Becoming more religious in the sense of praying more often at home, participating in religious rituals in the church, and living more in agreement with their religious tenets provided the parents with the means to continue with their journey in caring for the ill child, the family, and themselves. Religion allowed them to find the child's illness meaningful.

"Coming Out of the Labyrinth": Initial Steps to Recovering One's World

The discovery of a positive meaning in the illness experience allowed the parents to begin the recovery of their world. As one mother put it *"When you're told your child has leukemia, you don't see an exit, you feel like in a complete labyrinth. But later you realize there is a very long and steep-up stairway to go* ". So parents could begin to see the possibilities that were ahead of them a few months after the diagnosis, usually around the time the child's condition improved and stabilized which happened around the third or fourth month after the diagnosis. This section describes the new realizations parents had about the illness as something chronic but treacherous and the continued prominence of the illness in the parents' lives.

Parents came to realize the illness was something that might be with the child and of course, with them for a long time and maybe forever. They interpreted the disease as incurable but treatable and controlled by the treatment. Some parents wished the child would be cured by the treatment. Others acknowledged a belief that biomedical treatment could only cause symptom remission and cure required God's participation.

Most parents saw leukemia as a chronic disease but one that they could not trust, "*It's a time bomb, it could explode at anytime*" and end the child's life. Parents did not know when the illness would strike again so they felt they were living on the edge. They lived in a place of guarded hope but with persistent moments of fear as evidently it was for this father.

> **E.-** En un día común y corriente qué tanto piensan ustedes en la enfermedad de ella?
> **P.-** Yo pienso en que ella no se me vaya a .. se le vaya a complicar o algo, o sea eso es lo que mas a mí [preocupa] de que ella alguna cosa, se le va a complicar o algo, eso es lo que yo pienso. O sea es como un temor ..
> **E.-** Y usted eso lo piensa todos los días, o de vez en cuando, cómo es?
> **P.-** Pues yo, si.. pues yo .. yo, trabajo de noche y hay un momento en que uno está solo, que las calles solas, que uno [está] andando por ahí, entonces yo me pongo a pensar en eso, en ella y de que me le va a pasar algo así mas grave …

> **I.-** In a regular day, how much do you think about the her illness?
> **F.-** I think about she wouldn't get.. she would get any complication or something; that's what most [worries] me, that something, that it would get a complication, that's what I think. It's like a fear..
> **I.-** Do you think that every day, or once in a while? How's that for you?
> **F.-** I.. yes .. I work at night and there're moments that I'm alone, the streets are empty, that one is [going] around so I start thinking about her, about that, and that something more serious might happen to her.

As it happened to the parents of the first paradigm case, all parents lost their tranquility and certitude because the child's life was under the constant threat by the disease reappearance and other sources of possible harm. The parents handled such uncertainty mainly by living just in the present and avoiding thinking, much less living in the future. The next quote represents most parents' understanding of the disease in this sense.

> Yo soy muy real, a veces yo estoy sola y yo me pongo a pensar en que la enfermedad que él tiene es una enfermedad muy traicionera y yo luego digo, por ejemplo ahora con la ida a San Andrés. Yo no lo iba a dejar ir, nosotros habíamos comentado de no dejarlo ir pero yo me puse a pensar si mi Dios quiere llevárselo uno no puede aferrarse a que él no se va a ir, cierto? Entonces, nosotros lo dejamos ir. Pero yo estoy a veces así sola y yo pienso el día menos pensado a mi me llega la mala noticia, porque todo el mundo nos tenemos que morir pero en ese caso tenemos mas, mas oportunidades nosotros de vivir que ellos. Entonces yo a veces me pongo a pensar y yo digo que la vida es muy injusta porque cómo se esmera uno, esa ansiedad que uno quiere de que le digan de que él está curado, pero uno sabe que no es así, nosotros estamos conscientes de que no es así

> I'm very realistic, sometimes I'm alone and I start thinking that the illness he has is a treacherous one. So for example about the trip to San Andres, I wasn't going to allow him to go, we discussed about not letting him go but I thought if God wants to take him, we can't cling to the idea that he isn't going to go, right? So we allowed him to go. Sometimes when I'm alone, I think I'm going to get the bad news at the less expected moment, because everybody has to die but in this case we have more chances to live than they do. Then, I say that life is unfair because one does everything very carefully, one has the desire to be told that he's cured but one knows that isn't like that, we're conscious it isn't that way.

Parents did not become discouraged or decrease their involvement in the child's care and treatment because they perceived the illness as chronic. This is different from what I have sometimes observed in my practice among parents of children with other chronic diseases like diabetes. On the contrary, most parents in this study understood they should be more diligent and careful in adhering to the treatment even though the child did not show any signs of the disease. They understood the disease could relapse at any moment, even in the absence of symptoms like it had happened to other children they had seen in the hospital.

Exceptions to the general rule of continuous attention to and adherence to the biomedical treatment are critically important to understand as they place the child with ALL at risk for death. In three families, treatment was either stopped or interrupted. In the family # 6 (See appendix D), the mother stopped the treatment completely and the child subsequently died. I did not have the opportunity to get data that would allow me to understand this mother's decision because she did not complete the interviews. During the short conversations we had over the telephone, she said the child was doing fine and did not want to come for treatment. There were two other couples who interrupted the treatment before I collected the data: family # 5 described in the first paradigm case and family #2. The parents from family # 5, described in detailed in chapter 3, interrupted the treatment under the advice of the two maternal grandparents who were physicians. Later, when the father and the ill girl went to live with the father's parents because the mother did not want to live with them anymore, the treatment was restarted and the girl recovered. The parents from family # 2 interrupted the treatment due to fears about the medical treatment and some of the teaching hospital practices and also because lack of money to pay for the treatment and tests. Additionally, they began an alternative treatment, which was less expensive and that had previously proven to be effective for a family relative. These parents came back to the hospital immediately after the child became symptomatic again and from there they strictly followed the medical treatment. By this time they had gotten health insurance for the child so his treatment was funded.

None of the parents admitted that the illness had impeded them from going ahead with their lives. However, the illness was present in the parents' lived world in different ways. Everything they should do for the child like giving the medications, keeping the appointments for the laboratory tests and treatment, and carrying out the practices to care for the child were constant reminders that the disease was at home, living with them everyday and all the time. Sometimes, the parents forgot about the disease just for short periods of time but their engagement in the child's care brought them back to the reality where the illness had a predominant place. Parents thought more about the illness and child's possible death while they were alone either at home or at work as this mother did.

> **M.-** A ratos se piensan cosas, a ratos no se piensan; a ratos echa uno como al olvido lo que está pasando, de pronto vuelve y recuerda de manera que no hay seguridad, siempre se mantiene algo negativo en uno.
> **E.-** Siempre está la duda
> **M.-** Si señora
> **E.-** Qué tanto se acuerda usted de la enfermedad de su hijo en un día así común y corriente?
> **M.-** Si, yo pienso y yo miro las cosas y digo yo "Qué será de mí el día que de pronto Carlos me falte?" Yo si, y hay veces lloro; hay veces digo "Ah, esto es berriondo! Yo digo me va hacer mucha falta mi muchacho, me deja muchos recuerdos" .. Hay momentos en que no se, hay días en que como que me levanto con una situación diferente, de pronto y digo "Ay no, Señor dame fuerzas, no me dejes desfallecer, yo no puedo echar para atrás!" y como que me normalizo; de pronto me acuesto y tomo aire profundo unas tres, cinco veces me relajo y digo "No!"
> **E.-** Eso le pasa por la noche?
> **M.-** No, en el día de un momento a otro. No, yo en la noche casi no siento ningún problema porque hay tanta gente (se ríe)

> **M.-** Sometimes, I think things, sometimes I don't; sometimes, one forgets what's happening and suddenly one remembers again so there's not certainty, there's always something negative.
> **I.-** There is always doubt
> **M.-** Yes.
> **I.-** How often do you think about your son's illness in a normal day?
> **M.-** Yes, I think and I see things and I tell myself " What would happen to me the day that I might lose Carlos?" Yes, and sometimes I cry; sometimes, I say "Oh, this is very hard!. I'm going to miss my boy very much, he's going to live me lots of memories". There are moments when I don't know .. there're days like I get up in a different mood and I say "Oh, no Lord give strength, don't let me to desert, I can't fail!" and then I kind of get normal again; I lay down and breath deeply three, five times; I relax and say to myself "No!"
> **I.-** That happens to you at night.
> **M.-** No, during the day at any moment. No, at night I don't have any of this because there are many people (laughs).

Solitariness seems to confront the parents with their deepest fears and concerns. Parents probably felt free to allow those fears and concerns to surface when they were alone since they believed it affected no one else in the family at the moment they were allowing those fears to show up. Also these moments of solitude afforded parents the time to think about the child's illness more than when they were busy doing other chores or dealing with other issues. Many parents expressed a concern to maintain a positive outlook in front of the ill child and the whole family. Therefore, it was only when alone that parents allowed themselves to feel sad, discouraged, and uncertain about their situation.

For most parents the illness was part of their everyday lives but they kept it in the back of their minds as this grandmother pointed it out.

> **A.-** A mi no se me olvida eso, no, no se me olvida. Uno como que se adapta, no se entrega pues a estar llorando o a estar pensando pero si uno se acuerda mucho. Eso son cosas como que no se le olvidan a uno. Que se le olviden a uno así, no. Yo me voy a trabajar y de pronto me acuerdo que él tiene la enfermedad ahí, y quién sabe si se curará? O será que está calmada? O que de pronto le de algo. Entonces yo le digo Ay Señor Bendito! Tu que todo lo puedes permite que él se cure. Yo si todos los días me acuerdo, eso no se me olvida.

> **Gm.-** I can't forget that, no, no I can't forget it. One gets like adapted, one doesn't keep crying or thinking it but one remembers it a lot. Those are things that one can't forget. Nobody easily forgets, no. I go to work and I remember that he has the illness and [I think] who knows if he is going to be cured? Or if [the illness] is just quiet, or that something might happen [to him]. Then, I say Oh! Lord, you who can do all, allow him to be cured. I remember it everyday, that I can't forget.

By the end of the induction phase, parents felt they could recover their world even though there were still many things in their way to have the life they had before the illness. It was impossible for the parents to recover their world when the child was still very ill and possibly dying according to the parent's initial understanding of the disease. But when they had some tangible proof that the child would recover and especially when the Oncologist told them the child had gone into remission, their disrupted world seemed possible to become "normal" again. So having the child's disease in remission was an important step toward regaining one's world as it is described next.

Remission Opened up the Possibility of "Normality"

Parents began to experience a sense of normality some months after the diagnosis, usually after finishing the induction phase of the treatment when the child's condition was stable and the appointments were less frequent. This beginning sense of normality was stronger when the child did not have any sign of the disease and was tolerating the treatment pretty well. The sense of normality was disrupted by the ups and downs in the children's health like colds, low blood counts, and waiting for BMA and LP results. After the first year of treatment, the sense of normality was more real for the parents. Usually at this time the child had completed the maintenance phase of the treatment protocol for the first year. The children also had the yearly BMA, which confirmed the remission of the disease and the oncologist changed the treatment protocol. As a result of the protocol change the parents and children's visits to the hospital decreased considerably. So parents, especially mothers, were able to organize their lives and the child's life without the restraint attached to the frequent visits to the hospital they had before. The parents of two children, who did not have any hospitalization after they went into remission, experienced a stronger and faster sense of normalcy than the parents whose children had at least one hospitalization due to other illnesses.

For most parents, the illness became a part of their everyday lives after they lived with it for approximately one year but if the disease was in remission. These parents perceived this everydayness as good for them since it did not disrupt their lives very much, "*It's like having another routine to do and you get used to it*".

> **A.-** Pues lo que pasa es que al principio si es muy duro, me parece que es como una angustia pero todo se va volviendo como una cosa normal, como una cosa normal.

> Para ella (la hija) es normal, si el Jueves tienen cita ella se levanta a las cinco de la mañana, cuela tinto y toman se arreglan y se van [para el hospital]. Ya es una cosa como normal.

> **Gm.**- What happens is that at the beginning it's very hard, it's like anguish. But everything is becoming like normal, like a normal thing. For her (the daughter) is normal if they have an appointment on Thurday to get up at five in the morning, make and drink the coffe, get ready and leave [for the hospital]. It's a normal thing.

Some parents talked about the illness becoming "*familiar*" for them or they becoming "*familiarized*" with the illness which they interpreted as they being able to go ahead with their lives because they somehow "*knew*" the illness and could ignore it or see it as something recognizable. This feeling of familiarity with the illness and the learning process parents were undergoing in dealing with illness experience allowed the parents to move on the long way that was ahead of them.

> Ya ha habido mas madurez y esa tranquilidad sobre todo en la casa, con los niños, con todo. Yo digo que hemos subido mejor dicho, que nos falta muchos escalones por subir pero que ya vamos subiendo pues a pasos gigantescos. Que nos falta muchos escalones pues son tres años, pero pues yo veo que estamos muy bien, no? No estamos como antes que yo me pegaba, que yo me ponía .. no, ya estamos subiendo los escalones normalmente, no lo veo así como tan difícil como al principio.

> There's more maturity and tranquility especially at home, with the kids, with everything. I say that we've gone up a great deal! that we have a lot more to go up but we're going up with gigantic steps. There're lots of steps because it's 3 years but I see we're doing very well, right? We aren't like earlier that I was stuck, that I was .. no, now we're going up the stairway normally, I don't see it so difficult as at the beginning.

Other parents, especially mothers, found it more difficult to adapt to the new demands because the increased time they spent outside of the home constrained them to do things at home and to pay attention to other things like the small family business and the mother' health.

> **E.**- Para usted cómo ha sido tener a su niño con esta enfermedad ?

> **M.-** Bastante duro, bastante complicado porque ese era un método o un sistema que no estaba dentro de los planes, si? Por ejemplo, la rutina allá era levantarse, hacerlo bañar, mandarlo a estudiar, quedarme en mi casa haciendo oficio y atendiendo el negocio; que ya que hay que hacer tal vuelta, ir y hacerla mientras que ahora, tengo que compartir el tiempo, estirarlo mas. Por ejemplo hoy tenía que lavar, la lavada de hoy se quedó quieta, porque entonces ya me toca mañana. Mañana me toca ponerme las pilas hacer lo que no hice ni hoy ni ayer en la tarde. Si, ha sido duro porque a mi es que me toca mas que todo.

> **I.-** How has it been for you to have your child with the illness?
> **M.-** Very hard, very complicated because it is something that wasn't in my plans, right? For example, the routine used to be to get up, to have him take a shower, send him to school, stay home doing my chores and paying attention to the business; if there was something to do outside the house I would do but now I have to divide the time, to stretch the time more. For example, today I was supposed to do the laundry but that has to wait until tomorrow. Tomorrow I got to work harder to do what I didn't do today neither yesterday afternoon. Yes, it's been hard because I'm the one doing all.

The illness disrupted more the mothers' lives than the fathers due to the increased involvement and responsibilities the mothers had in the child's care. However, some mothers learned quite rapidly to adapt to the new demands in the sense that they organized their activities at home in a way that allowed them to do all their activities without feeling overwhelmed. However, this was not easy for mothers like the mother from the above quote who did not have help with the child's care and house chores and at the same time ran a small business at home. The mother from the above interview also had health problems but she could not go to see her doctor because of lack of time. Only when she could not function at her regular pace did she asked one of her older sons to take the ill child to the hospital so she could go to get medical treatment for the wound she had in one of her legs from varicose veins. The wound caused her such incapacity that she could not take her son to the hospital for about two months. The older son and a sister-in law helped the mother and the child got the necessary treatment without any problem. He even behaved better during the

chemotherapy sessions when his mother was not taking him to the hospital. So, being helped with the hospital visits was an important aspect in decreasing the mother's burden and giving her the time to take care of herself and other things that also were important for her. This help also gave her a sense of normality in her life because she had time for other things she had to do like she could before the illness.

Mothers more than fathers talked about regaining "normality" in their lives because fathers were not as engaged in the ill child's care as the mothers. Most fathers continued their work life, which gave them the sense of less disruption in their lives. Some signals of normality that mothers talked about were the following. Mothers felt they could spend more time with the other children. They actually attended the care of the other children, the house, husbands, and extended family members from both sides of the family. One mother said, *"Now, I know that I have to take care of everybody in my family because all of us are important. We're a like hand with five fingers so each finger needs care and attention because it's important for the hand to function well that all fingers are fine"*. Other mothers began to pay attention to their physical appearance again and were able to do things in this regard like using make up again, buying some new clothing when it was possible, and wearing earrings. Fathers also talked about having a "normal life". Some of them spent time with their friends and attended community meeting they were involved but not at the same level they did before the illness. Some families did some of the recreational activities they were used to before the illness. A few of them even ventured to go other cities or places in the country while others did not do that due to the fear that something might happen to the child and they were far from the hospital and the oncologist they trusted. Two families moved back to their own homes, which they had left right after the illness diagnosis to go to live with either parent's original family. The young mother from one of these families began working for the first time since the child was born and also was planing to go back to school.

Most parents tried to behave with the ill child as they did before once the illness when they recovered a sense of normalcy. The child was normal again so they could be normal also. Therefore, parents became a little bit more flexible in the restrictions they had for the child like allowing more active play activities. But most importantly, parents reestablished limits to the child's behavior and began disciplining them as a signal of normalcy.

In summary, during the remission phase of the disease, parents felt they had recovered some normalcy despite that life could never be like it was before the illness. All parents found a new plane on which they could live a quite calm life. All parents changed in many ways during the first eighteen months of the illness experience. Most parents felt they had grown spiritually and had become more comfortable in dealing with the illness situation as time went by. They knew better how to deal with the illness, they knew the child could survive, and the child was doing well so they were able to focus on other aspects of their world as parents, partners or spouses, and also as members of their original families and their communities.

The parents' emotional responses to the illness, their caring roles and practices as parents, and the impact of the illness on their relationships as couple or family members were very important elements of the parents' world. These issues will be discussed in the following sections. I will try to highlight some patterns that were visible during the whole illness trajectory in relation to these aspects of the parents' everyday lives. However, some issues were sometimes clearer during the diagnostic and induction phase of the disease.

Emotional Responses and Expression: Strong Gender Differences Among the Parents

The diverse emotions parents had were part of living the every day with the illness during the whole illness course. In reflecting about their emotions and feelings during the illness experience, fathers were less likely to describe the suffering and sorrow they felt during the first months of the illness. The following quote comes after I asked the father how he had felt when he heard the diagnosis the first time from the physician in a local hospital.

> **P.-** En ese momento, uno como padre tiene que tratar de controlarse, o sea, así hice yo, traté de controlarme para cuando llegara la esposa con la maleta del niño, ella no me viera alterado, si?.
> **E.-** Qué hizo para poderse controlar?
> **P.-** Bueno, yo para poderme controlar lo primero que hice fue pensar en mi vida y en la vida de mis hijos. Por qué en la vida de mis hijos ? Porque es que ellos dependen de mí. Si yo en ese momento me exaspero, si en ese momento yo me pongo como dicen algunos a gritar, a vociferar, a darme contra las paredes no estoy haciendo lo que debería hacer como persona razonable, si? Uno tiene que razonar frente a las cosas, los problemas llegan y los problemas tienen solución. Eso lo he aprendido de muchos amigos, no? Entonces eso hice ese día. Voltee lo de la razón del ser, o sea, tengo que portarme como me han enseñado, o sea dentro de lo que son las cosas difíciles buscarle soluciones. Y en ese momento así me sentí yo.

> **F.-** At that moment, as a father one has to try to control himself, in other words, that was what I did; I tried to control myself so by the time my wife would come with the suitcase for the boy, she wouldn't see me out of control, right?
> **I.-** What did you do to control yourself?
> **F.-** O.K., to control myself, the first thing I did was to think on my life and my children's lives. Why my children's lives? Because they depend on me. If at that moment I become exasperated, if at that moment I do what people say, like screaming and yelling, or hitting myself against the walls I wouldn't be doing what I should be doing as a reasoning person, right? One has to analyze, think, when facing these things. Problems come and have a solution. That's something I've learned from my friends, right? So, that's what I did that day. That is I had to behave the way I have been taught, that's to find solutions to the difficult situations. And that moment I felt like that.

This father controlled his feelings because he did not want his wife or other people around him like the physician, nurses, and his child to see him out of control. This father understood his path for action was to be in control of his emotions as it is expected from a "rational man". This is understandable since in the Colombian culture men are not supposed to publicly acknowledge or express feelings of sadness or sorrow; they are supposed to be "rational not emotional" under difficult situations. This father, as well as other fathers, controlled his emotions and focused on what was needed at that moment instead of crying and being angry. There were a few fathers who acknowledged crying and being very sad and according to the mothers, they showed those feelings only in the privacy of their home. Two fathers indirectly talked about the overwhelming sadness and grief they felt during the first months of the child's illness. The father from the above quote also acknowledged considering the possibility of taking his life at the beginning of the illness experience as a way to flee from the suffering due to the illness. But with the help of a stranger, he realized that by doing that he would not solve anything for the ill child and the family, instead he would cause them more suffering and the mother might not be able to do anything for the ill child and the healthy children after his death. Another father said he could not eat, sleep and perform at work as he used to for about eight months but he also was able, thanks to his friends' and coworkers' help, to accept the illness as something real that he should take with an optimistic approach. He believed this optimistic approach would be more useful to the ill child, the family, and himself. Most fathers focused on listening to the information given by the physicians, getting the money needed for the tests and treatment, finding ways to help the mother with things at home and to care for the other children. The following quote is from one of the two fathers who acknowledged being very sad and crying at the time of the diagnosis. In this quote the issue of controlling the emotions is also visible.

> **P.-** Entonces yo me alarmé pero no hice nada sino que me contuve por .. pa' no alarmarla a ella (la niña enferma) también. Pero allá a la salida ya yo me.. en el taxi me puse a llorar y todo.
> **E.-** Y venía usted solo o venía con ella (con la niña)?

> **P.-** Con ella pero pues yo no me aguantaba, y [me puse] a decirle que la iba ayudar, que la iban a curar y todo para que ella se sintiera bien. Y ya pues ya me tocó ya tranquilizarme y ponerme ya al tanto de llevarla al Hospital y todo eso.
> **E.-** Qué hizo usted para tranquilizarse ?
> **P.-** Si eso es difícil. Yo tengo mi hermana, mi hermana tal vez sufrió también igual que yo pero nos dimos valor entre los dos y todo, porque pues tocaba, no?
> **E.-** Ella es la única [persona] de su familia que está aquí (Cali)?
> **P.-** Está mi mamá también, mi hermano pero mi hermana es mas allegada a mi, somos mas unidos. Y ella también sufrió mucho, ella también sufrió mucho. Entonces ya hablamos, nos pusimos de acuerdo y ya quedé mas tranquilo, inclusive fuimos donde una sicóloga también.

> **F.-** Then (after learning about the diagnosis), I became very alarmed but I didn't do anything instead I controlled myself to .. so she (the ill girl) wouldn't be alarmed also. However, when we went out [of the hospital] I couldn't .. in the taxi I started crying and all that.
> **I.-** Were you by yourself or with her (the ill girl)?
> **F.-** With her but I couldn't hold it (the crying) any longer [and I began] telling her that I was going to help her, that she was going to be cured and all that so she would feel better. Then, I had to calm me down and do all the things to take her to the hospital and all that.
> **I.-** What did you do to calm yourself down?
> **F.-** That's difficult. I have my sister, my sister probably suffered the same I did but we supported each other and all because we had to, right?
> **I.-** Is she the only one from your family here (Cali)?
> **F.-** My mother also lives here and my brother but with my sister and me are closer, more attached. She suffered a lot, very much, she suffered a lot. So we talked, we agreed on things and I felt calmer, even we went to see a Psychologist.

The following exemplar, from a conversation that I had with one of the children's grandfather who happened to be in the house when I went there to interview the child's parents seems to capture the stance that most men have in the Colombian culture about showing their emotions in public especially by crying.

> **E.-** Por que cree usted que los hombres siempre toman las cosas con mas calma que las mujeres?
> **A.-** Yo no se, será que somos mas mas fuertes que las mujeres?
> **E.-** O será que se hacen los mas fuertes?
> **A.-** Quien sabe? Es como cuando se le muere alguien de la casa a uno, hay personas que les da duro y yo no. Pongamos cuando mi papá murió a mi me dio duro pero sería que no lo demostraba. Eso toda la gente era mas aburrida mantenían era llorando, yo no. El primer día me dió maluco si como aburrido, pero ya pierde al ser mas querido

que es el papá y la mamá y tiene que resignarse a mucha cosa porque pa' lla va uno tambien, si o no?
E.- Yo he notado que en general los papás toman la cosa con mas calma que las mamás.
A.- Si por cualquier cosita están llorando. En cambio uno sabe que .. yo por ejemplo, cuando Cristina me llama que se pone a contarme cosas y que se pone a llorar le digo "No llore que con llorar no sacamos nada, tenga fe de que ella se va a aliviar o alguna cosa pero no se ponga a eso, usted se pone a llorar delante de ella y puede ser un tormento mas pa' la niña".
E.- Entonces usted cree que los hombres son mas fuertes para aguantar esas cosas?
A.- Pero no todo mundo, todo el mundo no. Hay unos que son como mas cobardes que otros, hay unos mas que otros. No se por qué pasará eso.
E.- Y en general los hombres no lloran
A.- Muy poco, por qué pasara eso? De que hay hombres que son como mas fuertes, otros mas blandengues, lloran mas .. hay unos que les da duro. Yo cuando voy supongamos a un entierro yo he visto gente que se pone a llorar porque han perdido una amistad, un ser querido y se ponen a llorar y yo no he sido capaz pero sufro mucho porque me pongo que como que me reviento, como atacado aqui (en el cuello) como haciendo fuerza.
E.- Pero usted ha llorado alguna vez?
A.- Tal vez cuando estoy borracho (se rien). No mentiras, el dia que el día que que me llamaron cuando recién se enfermó la niña, llamaron de aca y nos dieron una razón muy muy muy alarmante, que la niña estaba grave, que tenía la leucemia. Yo ese dia me vine vacío en el camión que yo ando, me vine hasta vacio pa'ca y por lo que uno tan apegado a ella y ella a uno y me daba como ese sentimiento que eso me pegue siempre mi llorada desde alla hasta aquí.

I.- Why do you think that men always seem to take things in a calmer way than women do?
Gf.- I don't know. Maybe we're stronger than women?
I.- Or maybe they act like they were stronger?
Gf.- Who knows? When a loved one dies, it's very difficult for some people but not for me. When my father died, it was very hard for me but maybe I didn't express it. Everybody was very bored (he didn't say sad but that's what he meant), they cried all the time but I didn't. The first day, it was bad, I felt like bored (sad). When one loses the most loved ones which are the parents, one has to have resignation because we all are going there also, right?
I.- I' ve noticed that fathers usually take things with more calm than the mothes (regarding the child's illness).
Gf.- Yes, they cry for any little thing. Instead one knows that .. myself, for example, when Cristina calls me to tell me things and she starts crying, I say to her " Don't cry because crying doesn't give you any good, have faith that she's going to be well or something else but don't do that (crying). You cry in front of her and that could cause her suffering"
I.- Generally men don't cry.

> **Gf.-** Very little, why is that? There are men who seem to be stronger, others are weak and cry more, there're some for whom things are harder. When I go for example to a funeral, I see people crying because they lost a friend or loved one. They cry, I haven't been able to do that but I suffer a lot because I feel like I'm going to explode, like somebody is attacking me here (by the neck), like holding something up very tightly.
> **I.-** Have you cried at all?
> **Gf.-** Maybe when I've been drunk (laughs). No, I'm just kidding. The day they called me, when the girl became ill, they called and told us very, very, very, very alarming news, that the girl was grave that she had leukemia. That day I came here with the truck empty. Because one is so attached to her and she is so attached to us, I had that sentiment (sadness) and I cried all the way from there to here.

This man is puzzled by his inability to express his sadness as well by other men's inability to do the same. It is not easy for him to talk about this issue even thought he seems at ease when talking with me. He does not have the appropriate language to do it; he uses words with different meanings when describing his feelings of sadness and sorrow at his father's funeral but his description of his body sensations really shows how he is holding or controlling for himself those feelings. However, he interpreted those sensations as suffering. For him traveling with his truck empty to see his granddaughter was also a sign that he was pretty upset and sad from the bad news about his grandchild.

Mothers were in a better position regarding the expression of their sadness and sorrow; the culture allows them to do that and even it encourages them to do so in the sense that it is expected they would express their emotions in sad situations. To do otherwise would be perceived by the people around them as a lack of sensibility, which is kind of unusual for women especially when their loved ones are involved in the situation. When women do not show emotions it means they do not care about the person involved in the situation. Therefore, during the interviews some of them openly acknowledged crying, screaming or getting a bit out of control mostly when they heard the diagnosis for the first time. Physicians, nurses, relatives, friends, and other parents listened and comforted them especially at the beginning of the illness experience. However, even for women crying is not always good and they should do it but not in excess. The mother from the next quote felt no restrains to express the sadness in the bus when she was going home, she cried regardless that she was aware of other people watching her. She felt the need to control her emotions only because she was going to face her family and especially her sick son. She did not want them to be so concerned with the illness, which they would do if they saw her crying inconsolably.

> **M.-** Cuando yo me fui de ahí (del consultorio médico), !ay¡ yo no sabía que camino coger, francamente no sabía cómo llegar a mi casa porque yo me sentía ahogada, yo me sentía como.. como <u>algo tan duro</u> para mi. Yo decía, Dios mío pero por qué? en qué fallamos nosotros con este niño? La alimentación no ha sido mala, entonces..? Me subí al bus y era llore, y llore, y llore, todo mundo no hacía si no mirarme, yo no mas, límpieme las lágrimas y límpieme las lágrimas, hasta que se llegó la hora de bajarme y yo nada que me calmaba. Ay Dios mío ! ya me iba acercando mas a la casa, mas <u>duro todavía</u>
> **E.-** Mas ganas de llorar le daban
> **M.-** Si.
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> **M.-** When I left from there (the physician's office) Oh! I didn't know what to do, really I didn't know how I would do to get home, I felt like I was shocking, I felt like .. it was something <u>so hard for me</u>. I thought, "Oh my God, why?, what did we do wrong with this boy? Nutrition hasn't been bad, then what ..? I got in the bus and I cried, cried, cried; everybody was looking at me and I didn't do other thing just to clean my tears from my face, clean my tears off until it was time to get off the bus and I couldn't calm myself down. Oh, my God! I was getting closer and closer to the house, and it got stronger (the crying).
> **I.-** You felt like crying more and more.
> **M.-** Yes.

There was only one mother who did not follow the traditional female way in expressing her emotions. She did not cry, she was calm, and kept her feeling to herself. Because of this, her husband and others perceived her as detached, not caring, and too calm. Her way of being emotionally seemed to upset the others but she considered it as an asset.

> **M.-** En mi casa dicen que yo soy muy tranquila, <u>muy</u> tranquila, que puede suceder

> una cosa y yo no me asaro, yo no me afano. Yo digo que para mi afarnarme o asararme es como tener mas problemas encima. O sea, yo paso las cosas asi pues si las siento yo se que se necesita, o si está pasando algo yo ayudo mientras que necesita pero .. A veces le digo a él "yo no necesito estar llorando, estar echada con la preocupación encima, que atormentarme se puede decir, atormentarse uno mismo con otros problemas yo no soy asi". O sea yo lo llevo si dentro de mi pero no lo demuestro. O sea para mi se puede decir que es como una fuerza de apoyo a otra persona, entonces dicen que soy tranquila pero es otra forma de pensar, otra manera de sentir las cosas. Yo digo que saca con todos asararse si no van a encontrar una solución. Todos llorando y llorando, yo digo que en el llorar no está la solución. ... El a veces me dice que yo tan fría, que yo no siento lo de ella (la niña), que a mi me da igual lo que le pasa. Le digo yo usted que sabe? "Si usted tan tranquila, usted nunca siente nada"

> **M.-** At home, they say that I'm very calm, too calm; that something could happen but I don't get upset or out of control. I say that for me to get wrecked or upset is like having more problems on top of me. In other words, I let things pass by, I do feel and I know what is needed, I do help if it necessary but .. Sometimes, I say to him (husband) "I don't need to be crying, to be so worried about, because that's to torment myself, to torment yourself with the problem, I'm not like that". That's I keep it inside me, I don't show it. For me that's like a way to support the other person. So they say that I'm too calm. But is another way of thinking, another way of feeling about things. I say " What good comes out of all being upset and wrecked if they aren't going to find any solution. Everybody crying and crying; I say that crying isn't the solution... Sometimes, he (husband) tells me that "I'm so cold, that I don't feel what's happening to her (ill daughter), that I don't care about is going on". I tell him "what do you know?". "Yes, you [are] too calm, you never feel anything".

The Colombian cultural gender expectations about emotional expression are quite strong and distinct. For males emotions are to be dampened, contained, and controlled. They belief that they should move quickly to rationality and problem-solving even in the face of an extreme threat or loss like learning one's child has cancer. Clearly there are openings in this cultural expectation, for example the grandfather who admitted crying all the way out from his house to the hospital. But by and large the expression of emotions is social prohibited except for anger. This undoubtedly puts additional burden on some men who experience intense emotions but feel their expression is disallowed even within the family. For women, an equally strong social expectation is that they do express emotions publicly and exuberantly. Lack of such public and excessive expression puts the woman's concern for the situation or the child in doubt. She is coached to respond appropriately by those around her and accused of indifference if she does not. So, women too are socially constrained to respond in a certain way.

There were also some moments of euphoria and happiness for the parents during the illness experience. Parents acknowledged feeling very hopeful and happy every time they reached a milestone in the child's treatment like finishing a treatment phase, getting good test results, being told by the Oncologist the child was doing well, and seeing improvement in their own or others child's health status.

> … La tercera [médula] fue en Mayo, esa tercera fue cuando la niña salió en remisión completa. Yo recibí resultado y eso fue genial, yo llegué aquí feliz. Este año me tocó a mi también [recibir el resultado de la médula] y volvió a salir en remisión completa y el doctor me felicitó por la niña, porque estaba muy bien. Y que como las cosas iban muy bien que fue cuando me dijo que estaba estudiando la posibilidad de no irradiarla, entonces yo creo que fueron dos noticias buenas en un solo día, en una sola semana. Entonces para mi fue increíeble, ha sido una experiencia muy bonita porque he podido venir a traerle a mi mamá la noticia de la niña sigue en remisión completa
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> … The third [bone marrow] was in May, that one was when the girl was in complete remission. I got that result and that was wonderful, I came here very happy. This year, I also got [the bone marrow result] and again she was in remission and the doctor congratulated me for the girl, because she was doing so well. And since things were going so well, he told me they were considering the possibility of no giving her radiotherapy so I think those were two great news in the same day, in one week. So it was incredible for me! It's been a nice experience to be able to come home and tell my mother the good news that the girl continues in remission.

Parents were very grateful for having their children with them, for being able to enjoy them, and for all the happy moments they could have despite the illness.

"One of us Was Calmer": a Way of Self-support

Parents were able to find encouragement and support within their family, themselves and from each other. One of the spouses, in the case of the couples and the parents' mothers, in the case of the dyads were the sources of self-support among the parents. This section describes how this way of self-support worked out for the parents.

In living everyday with the illness, it was clear to me that in all the couples and dyads, one of the members assumed the role of *being stronger*, or *more in control*, or *calmer* than the other in facing the illness. The calmer member of the couple or dyad was the one who felt the need to be self-restrained in her/his feelings of sadness, sorrow, despair or discouragement. She or he was more rational and less emotional than the other person. Also the calmer person comforted and encouraged the other as well as other family members. The calmer person expended more energy and time in finding solutions to the everyday problems and getting more information about the disease. She or he seemed to be *more realistic* about the illness situation. Men and women assumed this role but men assumed it more frequently than women. If the male member of the couple were calmer, the female member would assume the less calm stance and vice versa. In the dyads of grandmother- mother and grandmother-father, the grandmothers assumed the calmer role. The above distinction in how the parents faced the illness situation seemed clearer at the beginning of the illness and in time of crisis like hospitalizations. This could facilitate the parents' coping with the illness situation as it happened in the following couple in which the father was in the calmer person role.

> **P.-** Cuando ella llega, yo le digo que debemos de irnos para el Hospital Departamental con el niño dado de que parece ser que es una enfermedad bastante difícil de tratar a nivel de municipio, como es un hospital de clase I no tiene los recursos suficientes para tratarle la enfermedad a él. Entonces ya en el camino le voy contando qué es lo que pasa. En la Ambulancia le cuento "mirá pasa que el niño tiene esta enfermedad"(leucemia). Lógicamente ella también pues ha oído escuchar de esa enfermedad y ella si pues de pronto por lo que no tiene la misma capacidad que uno tiene, la misma .. la misma fortaleza, ella si empieza a desahogarse. Se desahoga ya diciendo "Pero por qué a mí?, por qué a mi hijo?, por qué teníamos que ser nosotros?" Entonces yo le digo "hay que controlarse que mi Dios es el único que le puede ayudar

> a uno, que Dios es el único que sabe de las cosas. Que nosotros siempre hemos creído mucho en Dios.
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> **F.-** After she gets there (the local hospital), I tell her that we need to go to the teaching hospital with the boy because it seems he has a disease that is very difficult to treat in the local hospital, which is level I and doesn't have the appropriate resources to treat the illness. Then, in our way to the hospital I was telling her what had happened. In the ambulance I told her "look, the child has this illness"(leukemia). Of course, she has heard about that disease too and maybe because she doesn't have the same .. the same strength, she begins to let her emotions out saying "Why me? Why my son? Why it had to be us? So I say to her "You've got to control yourself, God is the only one who knows about things. We have believed very much in God".

One of the grandmothers in her role as the "calmer" person comforted and encouraged her daughter by telling her to leave the child in God's hands, to have resignation, and to be brave and realistic.

> **A.-** Yo le digo a ella (madre) que tiene que ser realista, que haga todo lo que pueda hasta que Dios lo permita. "Si Dios decide otra cosa, usted tiene que tener resignation" (la abuela le dice a la madre). Esas son cosas del destino y uno no las puede cambiar. Una tiene que ser realista en la vida. Me da pesar por ella (la madre) pero yo le digo a ella que debe estar lista, preparada. Ella debe pedirle mucho a Dios que lo cure a él (al niño), que lo sane pero usted tiene que estar lista si algo sale malo porque ese es el destino de uno.

> **Gm.-** I tell her (mother) to be realistic, to do all she can do until God wants. "If God decided something else you got to have resignation" (grandmother tells the mother). Those are things due to fate and one can't change them. One should be realistic in life. I feel sorry for her (mother) but I tell her to get ready, prepared. She should ask God to cure him (the child), to heal him but you got to be ready if something goes wrong because it's one own fate.

Parents' Caring Roles and Concerns: a Matter of Labor Division and Gender Differences

The illness reinforced the parents' role as the children's main providers and protectors as it is visible in the chapter about the parents' concerns and practices. Parents understood they must assume the care of the children and also that they were the only ones responsible for the children's care and wellbeing as this father said it, "We *have only to fight for him, fight for him. In other words, to try very hard to do the maximum one could do for him"*. The parents' role in caring for the ill child confirmed the roles expected in the Colombian society for mothers and fathers. Mothers understood they should be the main caregivers for the ill child in respond to the cultural expectations and also because they did not work outside the home. All mothers were completely in charge of the child's care at home. Also all mothers except one, who had a poor memory according to her and her husband, assumed the responsibility of taking the child for the treatment and tests to the hospital. Therefore, the mothers were dealing with a very demanding job regarding the ill child and the family without additional help. Fathers were responsible for getting the money and helping the mothers but only when the fathers were not at work. Few fathers helped the mother with the house chores, as it is the custom in most families. All fathers helped the mothers in taking the child to the hospital only when they had time off from work or the child was very ill. Most fathers did not receive payment when they took time off due to the child's illness; the money was important for the family so the mothers did not have another option that taking the child to the hospital. Most mothers also managed to find time to do activities that would provide some money such as cooking and selling food, raffles, and selling things to their friends, relatives, and neighbors. As it is obvious from the array of responsibilities, mothers were more taxed with the child and family's care than were the fathers. However, some fathers wanted to be more involved in the child's care but they could not do it because they would lose money from taking time off to be with the child.

The mothers' job became even harder because they were also facing the stress from what they witnessed when they went with the child to the hospital for the treatment and tests. So some mothers interpreted their job as more difficult because of that as this mother expressed it.

> Como madre yo le digo que me toca mas duro a mi, él como padre económicamente tal vez diga de que le toca mas duro a él, pero a mi como mamá me toca mas duro porque yo cada ocho días que yo voy a llevar al niño tratamiento yo vivo experiencias distintas. Por ejemplo a que le tomen examen de sangre. A la hora que están chuzando al niño para el examen yo estoy rezando que el examen le salga bien y no solamente por él sino por todos los niños que están enfermos. Y yo digo Dios mío, ojalá que a todos les salga el examen bien y que nunca le den una mala noticia a uno. Pero las cosas no salen como uno quiere, entonces yo he oído muchas malas noticias… Pero para mi como madre me parece que me toca, me tocó la peor parte a mi, que es estar allí metida allí en el tratamiento de Carlos.

> As a mother, I tell you that I got the hardest part. For him, as father, maybe economically is harder but it's harder for me as mother because every week, when I take the boy for the treatment, I go through different experiences. For example, when he had the blood test. At the time they're pricking him for the test, I'm praying that the test would be fine and [I pray] not only for him but for all the children who are sick. And I think "Oh my God! I hope the test is fine for all of them and that they never give us bad news". But things don't go the way one wants, so I heard lots of bad news. I think I got the worst part which is being involved in Carlos' treatment.

This mother perceived her role as more difficult because of her weekly encounters with her son's pain from the needle sticks, the uncertainty of the test results, and the suffering from other children and parents. The mother' s job was also harder because they had to face the child's questions, fears, and concerns when the child saw other children getting worse. Sometimes, the mother did not know how to answer effectively those questions and ease the child's fears and concerns. It is clear that the mothers were more engaged in the child's care and because of that they were more taxed and more liable to have greater physical and psychological stress. On the other hand, fathers had to cope with being unable to participate directly in the child's care due to the fact they had to work outside the home. They also were dealing with not knowing what was happening right away with the child so they had to wait until they got home or could call home or the hospital. Fathers felt very taxed by their responsibility to provide the financial means for the family and the child's treatment. The financial burden was a strain for most fathers since the expenses increased a great deal but the income stayed the same if they kept their jobs, less if they did not have a steady job or was null if they were unemployed.

Being more engaged with the child's care also allowed the mothers to develop a great sense of reward and satisfaction from her role as main caregiver. They felt they had invested all they could in caring for the ill child, which was their duty but they did it out of their love and desire to fulfill their role as mothers. They felt very close to the child since they had shared many critical moments, had spent more time with her/him, had comforted her/him, and had being able to provide for her/him most of what she/he needed despite the financial limitations they had. Sometimes, mothers also felt torn by the impossibility of caring for the healthy children as they would like or were used to. This concern was especially evident for mothers with children younger than the ill child.

To cope with the fact they could not be involved in the child's care as they wanted, some fathers kept in constant contact with their homes by telephone, going home during the day, and getting home earlier after work. They also took advantage of the weekends and evenings to be involved in the child's care and to be updated by the mothers about the child's condition. The following quote illustrates what one of these concerned fathers did.

> **P.-** Tal vez he estado como mas pendiente de ellos. Yo salgo y yo estoy llamando, está uno .. eso si he notado está uno como mas pendiente de la casa, yo llamo por la mañana, yo llamo temprano cuando calculo que ya se han levantado [y pregunto] "Ya desayunaron?" No, que no han desayunado. "Pablo ya desayunó? No. "Entonces pásemelo por teléfono" Yo le digo a él y yo le hablo"
> **E.-** Antes podía pasar el día y usted no llamaba a la casa ?
> **P.-** Si de pronto que era mas despegado, no? Yo siempre he llamado pero había estado como mas despegado.
> **E.-** Y en usted ha habido algún cambio o usted sigue siendo el mismo papá de antes?
> **P.-** No. Si ha habido cambio, por ejemplo ya no me ilusiona como ir a .. yo me iba con los amigos que una fiesta o una reunión política. Ya no voy porque tengo que estar temprano en la casa con los muchachos. Yo los he sacado mas; como yo se que la debilidad de ellos es estar en Bomberos entonces yo los llevo a instrucciones a las prácticas

F.- Probably now, I've paid more attention to them. I go out and I call often. I've noticed that I'm more attentive to what's going on at home, I call in the early morning when I guess they are up [and ask] "Have they had breakfast?" No, they haven't had breakfast. "Has Pablo eaten breakfast?" No. Then "Put him on the phone so I can tell him" I talk with him and I tell him [to eat breakfast]
I.- Before you could go all day without calling home?
F.- Yes, maybe I was less attentive, right" I've always called but I was less attentive.
I.- Have you noticed any change in you as father or are you the same father [you were before the illness]?
F.- No. Yes, there's been changes, for example it doesn't motivate me to go .. I used to go out with my friends to a party or a political meeting. But right now, I don't go because I got to be early at home with the kids. I've been going out with them more now; I know they love to see the firemen so I take them there for the instructions and practices we have.

Few fathers acknowledged and appreciated very much all the mothers did for the ill child and the whole family but most of them took it for granted. Having a very responsible and diligent mother was crucial for the ill child's recovery and the whole family's wellbeing.

E.- Qué lo ha ayudado a "familiarizarse" con la enfermedad?
P.- Pues hombre yo diría que si a mi me hubiera tocado tal vez solo, que no tuviera esposa sería ciento por ciento pues un negocio muy grande; tendría que dejar los niños en manos de que quisieran hacer el favor, lo que hicieran a la buena, pero pues es que ella ha hecho .. en este caso yo creo que la esposa es un 70, 80% de todo lo que tenga que ver con la enfermedad de el niño. Cuando las madres son así ellas están pendientes. Por eso tal vez para mi, ahora ya es mas tranquilo, no se yo no veo como dificultad ya; uno tiene nervios del niño cuando lo van a inyectar, esos son los momentos que son difíciles, la canalizada cuando no le cogen la vena, pero es como un momento ya uno después de que le ponen la droga se viene uno tranquilo ya pa'la casa.

I.- What has helped you to become "familiarized" with the illness?
F.- I think if I would have to deal with this by myself, if I wouldn't have a wife, it would be a business a 100% huge for me; I would have to leave the kids with whoever wanted to do the favor and to do whatever that person wanted it but it's that she has done .. in this case, I believe the wife is a 70%, 80% of everything related to the child's illness. When the mothers are like that they are very attentive. That's why it's more tranquil for me, I don't know but I don't see any difficulty now. I get anxious when they are putting the IV, when they can't get the needle in the vein those are the most difficult times but it's just a moment because after that I leave calmly for the house.

Parents faced different critical moments during the illness experience that disrupted the sense of normality parents were feeling in their every day lives. Waiting for the results of the bone marrow biopsy, changes in the treatment protocol, very low blood counts, other illness, and hospitalizations were frequently mentioned by the parents. Nonetheless hospitalizations generated the worst moments for the parents and the entire family especially when there were small children at home as it was for 4 year-old Pablo's family.

> **P.-** Si ya como que se llena otra vez (el vacío dejado por la ausencia de los padres), estamos todos juntos porque eso si nos reclamaban mucho en Diciembre. "Papá, mami, porque no estamos todos?" decía la niña. "Por qué mi mamá está en Cali, por qué mi mamá no viene? "Porque esta cuidando a Pablo"
> **E.-** Eso pasó cuando estuvo él hospitalizado?
> **P.-** Si, porque ella se iba [a la casa] y llegaba por ahí a esta hora (4pm) y a las cinco o seis de la tarde volvía y se iba. Yo me quedaba remplazándola o mi hermana, o algún amigo o un vecino. Entonces esa era otra, en Diciembre casi los niños, casi, casi casi que estuvieron muy solos, nosotros no les pudimos dedicar mucho tiempo en Diciembre; hasta ahora mas o menos que en este mes y Enero es que estamos [en casa] pero en Diciembre fue muy poco (01, P1, 26)

> **F.-** Yes, it's like it's filled up again (the emptiness of the parents' absence), we're together again. They asked a lot in December about it. "Papa, mama, why we aren't together?" used to say the girl. "Why mama is in Cali, why mama doesn't come?" Because she's taking care of Pablo"
> **I.-** That happened when he was hospitalized?
> **F.-** Yes, because she went [home] and got there around this time (4pm) and around six or five in the afternoon she would leave again. I stayed with the boy or my sister, or some neighbor or friend. So that was another thing, in December the kids were almost, almost, almost were alone, we couldn't be with them much of the time; only now more or less and in January is that we're [home] but in December it was too little.

The most disturbing aspect of the hospitalizations was the separation. Mothers spent all nights and the mornings with the ill child and went home during the afternoon to take care of the rest of the family and bring to the hospital all they needed for the child. Mothers did not rest at all during the children's hospitalization. Therefore during hospitalization mothers were again more taxed. Mothers assumed their role as main caregivers during this time with the ill child but they also were expected to continue their caregivers' role with the whole family. Some mothers felt they neglected the other children but they were relieved by knowing that they had the support from the father, the extended family, friends, and neighbors in caring for the children at home. Everybody, including the mothers took for granted that the mothers were the main caregivers for the ill child as well as for the whole family. Nobody seemed to be concerned by the excess of the mothers' work during the illness experience and especially during the child's hospitalizations. It was amazing to see the mothers doing that without complaining or showing signs of despair. The mothers assumed their responsibility with stoicism.

Sometimes, hospitalization represented a serious threat to the parents' hope because the child was very ill or the parents feared the child was having a relapse of the leukemia. Each new hospitalization seemed to be more draining for the child and the whole family especially when the hospitalization lasted a week or longer. In these cases the child was sicker, there was more medical tests and treatment and of course the parents, the ill child, and the healthy children were separated longer.

In Colombia, there are some constraints and possibilities of being a woman and mother as well as being a man and a father in many senses. The qualitative distinctions between mothers and fathers' expression of emotions and practices of care observed in this study are expressions of such possibilities and constrains. The mothers have added work since it is expected they will do most of the hands-on care of the child's medical treatment and care. Besides, they continue taking care of the family and housework, working or helping the father to obtain the financial means for the family, and finishing school if they have not done so. The advantage of the mothers' position is that they have closer proximity to the ill child and can get a sense of fulfillment and satisfaction from their role as the main caregiver. They get to observe the child closer and to know how the child is doing. They also have moment by moment the opportunity to express their love, affection, and caring to the ill child. It is expected that in a situation where one fears that one might lose her child, this must be a good possibility to have.

Fathers, on the other hand, have the 'lightness" of having little or less involvement in the child's illness. They return to work after a few days the child is diagnosed and their everyday functioning is less disrupted by the practical requirements of the child's illness. Yet, they are for most part emotionally afraid for the child and yet at a distance, depending on others to keep them abreast of the news on the child's condition. Being at a distance from the child most of the days also constrains the fathers in how close, attentive, and expressive of their caring they might be with the child. Besides, they are torn by the lack of opportunity to support their spouses in dealing with the illness demands and with the care of the whole family.

Parents' Feelings of Attachment to the Children and Future Concerns

Parents acknowledged changes in their feelings and expectations toward the ill child and sometimes also toward the healthy children. All parents admitted they got more attached to the ill child after the diagnosis. They wanted and actually spent more time with the child especially during the earlier months after the diagnosis. Parents also indulged the children and allowed them to do almost everything they wanted as long as the parents considered it was not harmful for the child. Parents also became more affectionate with the children. The changes in feelings and expectations also included the healthy children. Parents were afraid the healthy children would get sick with the leukemia. They also realized the mortality of the ill child, the healthy children, and their own so they were more concerned about any illness the children could have and about losing them. However, all parents except one grandmother recognized the ill child had much probability of dying sooner than the parents or any of the healthy children.

It seems parents reflected a lot on their parenting role and the value of their children even though they did not express it openly during the interviews probably because I did not ask them directly about it. As a result of the above concerns and beliefs, parents changed some of their parenting practices especially the practice regarding the use of corporal punishment with the children as it is described in the chapter about the parents' concerns and practices as follows.

> Entonces debido a lo que le ha pasado a Laura yo he cambiado mucho con ellas. Yo no las trato tan mal; yo trato de no ofenderlas, de no tratarlas mal sino que castigarlas en una forma pues mas no castigándolas así con correa sino que yo las castigo con algo que les guste. Pero entonces con Laura, ella es muy sentimental; ella llora si uno la regaña; ella es muy sentimental uno no le puede decir nada porque llora.
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> Because of what had happened to Laura, I've changed a lot with them. I don't treat them badly; I try not to treat them badly instead I punish them in a way more, not with a belt but with something they want. But with Laura, she's so emotional, she cries if I scold her; she's very emotional so I can't say anything to her because she cries.

The following quote from the father of a 4 year-old boy summarizes the parents' attachment with the ill child regardless the length of the child's illness.

> **P.-** Si, estoy mucho, muy, muy, muy apegado de él.
> **E.-** Y cuando decimos apegado es que?
> **P.-** Estar pendiente de él en todo momento, tenerlo al pie mío, que si está afuera estarle poniendo ahí cuidado que no me le vaya a pasar nada [malo]. Yo estoy muy apegado de mi niño y él también, él se ha apegado mucho a mi; yo a veces lo siento porque a veces nos acostamos allá (en la cama) y él se pone a jugar, brincar encima mío y a lo último se me tira encima me da besos. Entonces yo me he apegado mucho

> al niño y yo he visto que eso ha sido un cambio por la misma enfermedad del niño. No es que anteriormente tampoco lo quisiera no, pero, si ha habido mas, mas atención hacia él. .... Si yo llego y yo me acuesto a ver televisión y yo pendiente, no me gusta que esté en la calle porque pues en la calle cualquier muchacho me lo pueda hacer llorar y ya eso me le va afectar a él.
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> **F.-** Yes, I'm very, very, very, very attached to him.
> **I.-** When you say attached is what?
> **F.-** Paying attention to him all the time, having him next to me; if he's outside, to watch him so nothing [bad] is going to happen. I'm very attached to my child and he's the same, he's become very attached to me; sometimes I feel it that way because sometimes we lay down there (on the bed) and he plays with me, jumps on me, and then he comes and kisses me. So, I'm very attached to him and I've seen it's because of the illness. It isn't that before I didn't love him, but there's been more and more dedication to him .... When I get home and lay down to watch TV, I'm attentive, I don't like that he stays outside on the streets because there somebody could make him to cry and that is going to affect him.

Parents understood the child's future to be a possibility like for anybody but they wondered more about the ill child's future than about the healthy children's future; parents also wondered about what would happen after finishing the treatment. Parents concerns about the future seemed to surface when the child had completed the first year of treatment; prior to that, parents seemed to focus more on the present. Even though the end of the treatment was pretty far parents were concerned how the child's life would be after.

> Yo pienso después del tratamiento, cómo será la vida de ahí para allá, qué le dirá a uno el médico, si hay que cuidarlo o tal cosa. Entonces a veces a los niños les da mucha gripa, se caen y se golpean, entonces uno si piensa eso pero, según me explicó el médico ellos les dan controles para mantenimiento.
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> I think about the end of the treatment, how life would be after it, what would the physician say, if he has special care or something. Because kids get lots of colds, they fall and hurt themselves so one thinks about that but according to what the physician explained to me they (physicians) give them (the kids) maintenance appointments after.

Parents did what all parents do, to be concerned about their children's future. Parents hoped the children will be alive and well but they were not sure the children would be free of the disease. Parents focused their concerns mainly on the children's health and capacity to have a normal life like having their own family and children.

> Pues si yo a veces le digo a ella "Ve, vos de pronto charlas con el doctor decile que si él (el niño) si él algún día podrá casarse y podrá tener hijos sin problema" Yo a veces pienso, yo a veces me pongo a verlo a él que está creciendo y los años van pasando y yo digo quién sabe si él podrá tener una tener hijos por el problema pues de tener el virus (ella cree que la leucemia es acusada por un virus.
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> Sometimes, I tell her (her daughter), "If you talk with the doctor, ask him if he (the boy) someday could get married and have kids without problem" Sometimes I think, sometimes I look at him and he's growing and the years go by so I say who knows if he could have kids because of the problem of having the virus (she understood the disease was caused by virus).

The Illness Experience and the Parents' Relationships

The impact of the child's illness on the couple's relationship and dyad's relationship varied among the parents of this study; some relationships steadily improved, others stayed the same as before the diagnosis, and others improved for some time and then returned to be as they were before the diagnosis.

The relationship between the grandmothers and their children as parents of the ill child was not affected negatively by illness; on the contrary they became closer and very supportive of each other with the grandmothers being very respectful of their children's decisions about the illness situation. The parents assumed their role as the main caregiver of the ill child most of the time. They did not expect the grandmother to be responsible and take care of their ill child whenever they were around the child. As it is described in the first paradigm case (family # 5), the grandmother assumed the role as the child's primary caregiver only because the father returned to work. In the other family (# 7), the mother was the main caregiver of the ill child all the time. She did not return to work so she could be home taking care of her son.

The majority of the couples did not face negative changes in their relationship; for some couples the relationship stayed the same and for others it improved. For example, both parents from one couple and the mothers from other three couples admitted the illness had improved the relationship as this mother said.

> Yo he considerado que nosotros hemos tenido un hogar sólido, pero ahora lo veo mas unido, o sea nunca hemos tenido problemas de pareja no, pues alguna discusioncita que teníamos antes o cositas así, pero ahora no. Pienso de que lo de Pablo tuvo cosas positivas y cosas negativas, entre esas por ejemplo estamos mucho mas unidos que antes.

> I've considered that we have a solid family but now I see it more united, that's we never had had problems as a couple, just small arguments or things like that but now no. I think that what Pablo's illness has had positive and negative things, for example we're much closer now than before.

Parents whose relationship improved after the diagnosis acknowledged greater closeness between them. They felt they had a shared goal to achieve which was to protect the ill child and fight for her/his life and well being. They also shared the suffering due to the illness and the need to keep the family life the best they could. They spent more time together, they stopped any arguing or fighting, they comforted each other, and they shared the children's care more than the other couples. The fathers in these families were the ones who acknowledged the mothers' skillful care and involvement in caring for the child. The parents from family # 8 who were not married wanted to get married after the death of their child. During the illness experience the father learned to appreciate more the mother and the mother's extended family; he was sure he wanted to live the rest of his life with the child's mother. The parents from family # 11, who used to fight before the diagnosis, increased their fighting at the beginning of the illness but later they stopped the fighting behavior. They realized the fighting would be detrimental to their daughter and it would not help them in their fighting for their daughter's life. The father learned that leaving his wife alone and going out until she calmed down was the best way to avoid the fighting.

> **M.**-... Al principio teníamos muchas peleas. A veces él estaba decidido a irse, entonces yo cuando ya estaba calmada entonces yo le decía "No, como se va ir? Piense en la niña, [no se vaya] hágalo por ella y no por mas". Entonces pues siempre volvemos asi nos unimos nuevamente. Ahora hay asi peleas pequeñas que uno tiene común y corriente pero pues no han vuelto asi tan fuertes como antes.
> **E.**- Y cúanto hace que no tienen peleas fuertes?
> **M.**- Ya va para tiempos. Yo soy de mal genio, él me dice que yo soy muy .. yo con rabia le he tirado a él. Pero él en ese sentido si me ha respetado porque si hubiera sido otro hombre me coje y me manda su puño y ahi me dejó, pero no él en ese sentido él me respeta a mi.
> **E.**- Y cúal era el motivo de las peleas?
> **M.**- Yo creo que eran cosas sin importancia. [Yo pienso que] de pronto estábamos con ira hacia adentro por los problemas que teníamos con la niña. Yo creo eso eran como los desahogos de uno contra el otro. Pero en el momento que nosotros empezamos como a ayudar a la niña y lo que sentíamos por dentro por lo de la niña porque pues siempre había dolor por la niña .. ya no hay esas peleas que teníamos.
> **E.**- Y antes de la enfermedad de la niña había esos disgustos?
> **M.**- Asi tanto no, tan seguido no, si los habia pero tanto no seguido. Una vez cuando estuve en embarazo de la pequeña pues si fue una fuerte. Pero ahora .. yo a veces soy la que comienzo [la pelea] y él se queda callado y dice "Déjeme yo me voy por allá, cuando le pase su rabia entonces yo ya vengo". Entonces, asi ha sido. O sea, él por lo menos en ese sentido me ha comprendido porque pues él no me segui la corriente de seguirme alegando.
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> **M.**- At the beginning, we used to fight a lot. Sometimes, he wanted to leave us, so when I calmed down I would tell him "No, how are you going to leave? Think about the girl, [don't leave] do it for her and for nothing else". So always we've stayed together. Now, there're some small fights, the common ones, bu they are not as big as the ones before.
> **I.**- How long has it been since you don't have one of those big fights?
> **M.**- It's been a long time. I get upset easily, he tell me that I'm .. I had hit him sometimes when I got very mad. But he has respect me in this sense because if he were like other men, he would punch me back. But no, he respects me in that regard.
> **I.**- And what was the reason for the fights?
> **M.**- I think it was things that were not important. [I believed] maybe we're very angry inside due to the problem we had with the girl. So it was the way to show that anger to each other. But when we began helping the girl and what we felt inside, because there was pain for what happened to her .. Now, there are no fights anymore.
> **I.**- And before the girl's illness, did you fight?
> **M.**- Not so often, yes there were fights, but not too often. There was a big one once, when I was pregnant from the little one. But now .., sometimes I'm the one who

> begins [the fight] but he stays quiet and says "Let me go out somewhere, when you calm down, I would be back". That's, in that sense he has understood me because he doesn't get into the fighting.

There was only one family (family # 10) in which the couple's relationship deteriorated later after the diagnosis. In this instance, the relationship between the mother and the father became worse because he did not help her with the child's care and treatment neither with the house chores or the care of their other child. She was thinking about ending the relationship because it was another source of increased stress for her to live with a man who seemed indifferent about what was happening but demanded a lot from her as a wife. I wondered if this father did not support his partner because the ill child was not his biological daughter but the mother said that was not the case. Also the financial burden for this father was quite high and the girl had a relapse so he might have interpreted that they were wasting the little money they had in a treatment that was not working. The mother said he acted like that because "*He cares only about money to pay his bills but not for things that are really important for the children, himself, and for me. He's that kind of man, nothing moves him besides finding the money to pay his bills so he has a good name".*

In one couple who had problems before the diagnosis, the mother said the children were the only string for the couple's stability. At that time, there was no love or understanding between the couple. But after the diagnosis, they became united again by the pain and suffering they saw in each other and because children, especially the ill child, were very happy with they changes they observed in their parents. Love and the desire for being together refreshed the couple's relationship.

> Nosotros habíamos, mi esposo y yo habíamos llegado a una situación de que prácticamente nos soportábamos era por los hijos. Prácticamente el soporte de nosotros eran los hijos, ahí no había amor, no había comprensión, no había nada. Discutíamos a toda hora y no nos importaba que los niños nos vieran. Cuando llegó

> esta enfermedad, eso fue lo que me hizo cambiar. Esto nos unió mucho. Nos unió bastante, el sufrimiento de los dos; él ve mi sufrimiento, yo veo el sufrimiento de él, esto nos unió bastante. Y que cuando estaba, por ejemplo el niño hospitalizado que él (esposo) llegaba, se le veía la felicidad que él (niño) tenía al vernos juntos. Se le veía la felicidad y no todavía, él nos ve viendo televisión, yo sentada en un mueble y él en otro y ahi mismo nos llama "Sientensen aquí" [juntos en el sofá] Ellos (los niños) han cambiado mucho, también [dicen] "Sientensen aquí los dos".

> We had, my husband and me had got to the point that practically we're together because of the kids. Our support was the kids, there wasn't love, understanding, nothing. We fought constantly and we didn't care the kids were watching us. When this illness arrived I changed. That united us very much. Our suffering united us a lot; he saw my suffering, I saw his suffering and that got us close again. And when for example, the boy was in the hospital when he (husband) arrived there you could see his [boy's] happiness because we're together. His happiness was pretty visible and even now when he sees us watching TV, seated in different chairs, he immediately calls us "Sit in here [together in the sofa]. They (the 3 kids) have changed a lot, all of them say the same "Come here, sit down together".

For almost a year, this couple did not have problems but the problems reappeared according to the wife, because the husband was seeing another woman and according to the husband because the wife was very possesive and was keeping him from having the freedom to do things he had to do outside the home due to his involvement with the Teachers Union; he was part of the Directive Board of the union. In the last interview he was planing to leave his wife but to continue to be involved very closely in the children's lives. "*I don't need to live with her to be a responsible father*", he said. Two months later, when I had the third interview with the mother, she told me they were still together and had resolved their difficulties once more. The other couple who had previous problems also followed a similar path. For more than a year they were doing fine but the wife learned about his extramarital relationship and confronted him; the husband left a few weeks later.

From the above accounts about the effect of the illness on the couple's relationship, it was clear that couples with difficulties prior to the illness continued having those difficulties because the source of them were not related to the illness. Two factors related to the illness experience that affected the relationship for one of the couples were the lack of money to deal with the illness expenses and the lack of support from the father. In the Colombian context, it is expected that fathers find the money that is imperative to meet the family's needs. So if the father fails to do it, the mother resents that especially if she does not see any real intention from the father to do it. Feeling the father's lack of support in other issues related to the child's and family care is also important in keeping a good relationship between the couple. The mother's resentment plus the physical and emotional strain from the illness situation and the child's care on her creates the path to build difficulties within the couple. The mother does not feel committed to her partner so he resents that and a vicious cycle sets in. If the mother feels competent enough to go on with her life without her partner, she perceives ending the relationship as the best option for her. However, she might keep the relation just for the sake of the children as it happened to the mother of this family. The decision of maintaining a deteriorated relationship without getting any counseling to solve the problems obviously increases the deterioration of the couple's relation. This is also true for the couples with difficulties related to the father's extramarital affairs. Their difficulties decreased while the parents were focussed on the child's care and survival but they surfaced again after the family's life became normal or similar to what it was before the illness.

In this chapter, I describe the trajectory parents went through during the first eighteen months of the illness experience. The disease was a disaster for the parents at the time of the diagnosis. Most parents felt overwhelmed but in the midst of such a state they understood that they must act to save the child from an imminent death. Dread of the child's possible death was a moving force for the parents after learning from the Oncologists and other parents that the child could survive. It also helped them to overcome the sense of shock and powerlessness they felt when they heard the diagnosis. Once the parents decided to fight for the child's life and the treatment was producing good results in the child's clinical condition, the parents slowly began searching for meanings of the illness experience. Religion was the way they found the illness meaningful. In summary, the parents' trajectory in living everyday with the child's illness involves the loss of the parents' worldhood at the time of the disease diagnosis followed by the initial recovering of their world at the end of the induction phase of the treatment. The parents' trajectory continues with the setting in of a sense of normalcy in their lives during the maintenance phase of the treatment. This normality was disrupted by ups and owns in the child's health conditions, mainly hospitalizations and other illnesses in the child.

Socially expected gender differences in the parents' emotions and caring roles were visible as well as the impact of the child's illness on the parents' relationships. Cultural expectations shaped the parents' possibilities and constraints in their being with the children. Mothers' involvement with the child's illness and care was more taxing but also more rewarding. Fathers were more distant due to their role as the main providers for the family but equally concerned for most of the time. Relationships between the parents as couple and family members were positively and negatively affected by the child's illness. Most parents shared concerns and goals regarding the ill child and the entire family so they experienced increased closeness and love. Parents with previously disrupted relationships improved their relations for some time but the difficulties resumed when the sense of normality set in their lives.

The wealth in understanding parents' everyday life that is embedded in the above interpretation of the parents' ways of taking up the illness can illuminate health professionals in understanding and caring for other parents of children with cancer in Colombia and similar cultural contexts.

CHAPTER 5: PARENTS PRACTICAL CONCERNS AND ACTIVTIES IN CARING FOR THE CHILD REGARDING THE DISEASE, ITS TREATMENT, AND PROGNOSIS

The parents' personal history, their understanding of the illness as a life-threatening disease, and their uncertainty about the cure of the cancer set up the concerns in relation to the child's well being and survival as well as their practices to care for the child. Parents did not have a clear understanding of all the biomedical aspects of the leukemia but this did not preclude them from knowing and doing what was best for the child. They were quite eager to learn about the child's care instead of getting information about the disease. Some mothers clearly stated that they did not want to learn about the disease because it would not do any good for them or the child; it might be detrimental to them because knowing would cause more anxiety and stress to them. As one mother said, "*I'm afraid of asking and that they tell me something bad or negative so that's why I don't ask. I don't want to know anything about a relapse, I prefer to think everything is going well*". All parents, especially the mothers only want to know the practical aspects of the child's care as a way to carry out their role as parents. Protecting the child from further illness, harm, and death was the parents' paramount concern. Everything they did was to achieve that goal.

Initially, all parents, except one father, thought the child could get sick and die at any time after the diagnosis. Having the illness made the child very fragile, vulnerable, and of course, more prone to die than the healthy siblings or anybody else. Therefore, parents felt the need to protect the child from anything that could be harmful such as other illnesses, physical and psychological harm. The illnesses parents feared most were infections but any illness could be a threat to the child's life. Physical harm included falling, being hurt by others, exposure to sun and chemicals. Psychological harm involved suffering from knowing they had the illness, from feeling and looking different, pain and fear caused by the treatment. Mothers, as the main caregivers, felt more than fathers the need to create ways to protect the child. So they continuously searched and developed specific practices that they carried out regardless of what they had to do to get the child involved in accepting and actually doing what was needed to assure his/her protection. Only one mother, whose son was refusing almost everything that she did for him expressed the drain that she felt from carrying out the practices to protect her son

The parents behaved like any social group in the sense of passing on ideas, values, and practices in raising and caring for their ill children; they learned practices that might be considered good or potentially harmful from a biomedical perspective. The lack of counseling and information about the child's illness and care from nurses and physicians probably lead the parents to become their own sources of support and information by sharing all their practical knowledge about the child's care and the illness experience. Sharing information and knowledge is also a natural occurrence among people with similar situations who develop a sense of community because of shared concerns or history. Parents did not know and were not interested in the rationale supporting the caregiving practices learned from other parents. To know that it was something which could help their child was enough reason to implement the practice. So traditional and practical knowledge from others was equally important to the parents, as was the scientific and technological knowledge from the physicians, nurses, and psychologists. Parents did not question or challenge this knowledge and advice except when somebody advised them to change some of the medical prescriptions as it happened with the other from the following quote. Scientific and technical knowledge was important because it came from experts, who besides the knowledge, also had the power to save the child's life and the authority given by their social status. Traditional practical knowledge was valuable because it had been proven to work for others with similar situations and because a good proportion of Colombians use traditional treatments when ill. Besides, parents were very open to accept and try anything that could help their child. The following excerpt from an interview illustrates how the parents were sharing their knowledge and caregiving practices to care for their children.

> **M.-** Venga le cuento, creo que yo le dije algo y creo que fue al principio o algún día que charlamos, la falta de información. Entonces uno nunca sabe nada, uno está como le digo yo? en ese laberinto que usted no sabe si pa'ca o pa'lla. Entonces uno muchas veces escucha cosas y uno las va recogiendo, así como por ejemplo recogí lo de la acelga, lo de la espinaquita, cosas de pronto que son beneficiosas. También uno escucha cosas que no lo son, por ejemplo el sol, por ejemplo lo de la piscina, por ejemplo lo del Aracen, por ejemplo lo de las pasticas que dicen que eso da anemia. No le he preguntado a la doctora y lo escuché a una mamá, "ay! dáselas día de por medio porque eso baja la hemoglobina" Entonces yo dije no pues si la doctora la mandó todos los días yo mañana voy a preguntarle. El día que le tocaba Metrotexate al otro día de recibir la tal dosis, me dice una señora dizque "Ay! no se las de esta semana, désela la otra porque recibe por intravenoso y en pastas lo pone mal, y entonces yo llegué al otro día "Ay! en nombre de Dios" y se la di porque la doctora dijo. Entonces a veces, habemos personas que no contribuimos en nada a mejorar sino que no pensamos que de pronto con una palabra podemos hacer daño entonces a veces eso también lo pone a uno... (01, M2, p.34, 991-1009)

> **M.-** Let me tell you, I think I told you this at the beginning or any day that we talked. There's no information. So one knows nothing, one is like how can I say it? In that labyrinth and one doesn't know which way to go. Therefore, lots of times one hears things and one take them in, like for example I learned about the spinach and the chard, things that are beneficial. Also one hears things that aren't like the sun, the swimming pool, about Aracen and the pills that cause anemia. I haven't asked the doctor and I hear it from a mother, who said "Oh! don't give them (the pills) this week to him (her son) every other day because those lower the hemoglobin" Then I say no because the doctor prescribed them everyday, tomorrow I'm going to ask her. The day he had Metrotexate, the following day when he got so called dose, a woman told me "Don't give them this week, give them next week because he's getting it intravenously and those pills make him sick. The next day, I said "Oh, in the name of God! And gave it to him because the doctor prescribed it. So sometimes there're people who don't contribute to improve things; we don't think that maybe by saying just a single word we could damage somebody so that makes one wonder.

This quote also exemplifies how parental advice can set up conflicts and dilemmas for other parents, especially if the advice concerns situations that are unfamiliar and if it conflicts with advice given by the physicians. The conflicts and dilemmas faced by the parents regarding the children's care are increased when the staff in charge of providing the treatment is unavailable to provide useful information. My observation during the time of data collection was that the parents got information about the children's care from the nurses and physicians very infrequently. The physicians focused on making sure the children were getting the treatment and the nurses focused on giving the treatment. Therefore most of the provided information was about the drugs and its side effects that could be more threatening for the child. Even this information was given mainly when the parents asked for and not on a regular basis. Lack of time from staff might be the reason for this occurrence.

Parents were capable of learning and building the skills needed to take care of their children and to cope with the illness mainly because of their thoughtful engagement and love for their children. Parents learned and built their skills by trial and error, sharing skills and ideas from other parents, noting the changes in the child over time and shifting their practices accordingly, and by anticipation and preparation for upcoming events.

This chapter describes some of the concerns parents have regarding the child's illness, its treatment, and prognosis. The practices parents establish as their way to promote the child's recovery and to prevent further illness in the child, which in the end would prevent the child from dying, are also described. The subsections included are: protecting the child from infection, practices to strengthen the child's immune system, protecting the child from bleeding, protecting the child from exposure to the sun and chemicals, protecting the child from the immediate side effects of the chemotherapy. The last section includes protecting the child from psychological harm related to the suffering from knowing the kind of illness the child has, from the fear and pain caused by the treatment, and from the suffering due to the changes in physical appearance.

Protecting the Child from Getting an Infection

Infection was perceived by the parents as a serious threat to the child's life because of the child's *low body defenses*. Some parents understood the decrease in the immune system function as a component of the disease and others as a side effect of the chemotherapy. Having a minor infection could lead the child to have a more serious infection and maybe die. So any degree of fever would be a reason for being very scared and getting to the hospital, especially during the first six months of the illness experience. All parents remembered pretty well the physicians' advice about the child's fever so they went to ER whenever the child had fever. This understanding and way of coping with fever in the ill child is quite different from how parents understand and cope with fever in their healthy children. In our context, usually parents manage the children's fever at home with over the counter medicines such as Acetaminophen for a few days before calling their physician or taking the child to get medical care. However, in the study some parents seem to become over time more self-confident in managing the child's fever at home but only for a short time (12 hours or less); other parents did not follow this practice regardless of the length of their illness experience. Parents, who felt sure about managing the child's fever, learned to give the antipyretic to the child and wait to see if the child would improve. If the child's fever lowered they would wait longer but if that is not the case, parents would go to the hospital for further evaluation and treatment.

> **M.-** Porque ella cuando salió del hospital si hubo como 3 veces que tocó llevarla al hospital
> **E.-** Ah! si?
> **M.-** Si le dió fiebre. Porque ellos como que quedan como una tos, algo ya bronquial,

algo muy leve. Entonces hubo un caso que tocó llevarla como a las 4 de la mañana; el papá cogió y la llevó.

Yo ahi mismo le dije "No, espera hasta mas temprano que de pronto te demoran". "No yo me la llevo" y é l se la llevó y la trajo al dia siguiente; que era una infección en el pulmoncito, una leve por la tos porque siempre estaba con fiebre alta y las 3 veces fueron fue por eso. Entonces yo dije no pues ya es algo que va con ellos como resultado de la enfermedad. Entonces cuando ya ella me le da una tos pues yo ya tengo los medicamentos que los doctores le han enviado anteriormente entonces me ahorro eso de estarla llevando al hospital. Cuando yo vea algo que ya no reacciona al tratamiento que me le han mandado entonces ya cojo nuevamente con ella pa'l hospital.

E.- Hoy en dia si le da fiebre qué hace?

M.- Yo en el momento empiezo darle Dolex; si ella en el transcurso de por ahi a las 12 horas que haya estado tomandolo ella no ha reaccionado con el Dolex, no le ha bajado la fiebre entonces ahi, o sea inmediatamente tuvo ahi pa' llevarla al hospital. Pero pues cuando ella yo le doy el Dolex y esta con fiebre y le baja y ya es una fiebre muy leve, entonces yo digo "no, ya está reaccionando" y se puede decir que uno se vuelve como práctico en la enfermedad de ella y ya entiende todo

E.- Ya no se asusta tanto como al principio

M.- No, ya no me asusto tanto; cuando ya la <u>veo grave</u> entonces si ya corro pero nosotros al principio cualquier cosa era corra al hospital, corra para allá, no nos importaba las horas. Pero ya gracias a Dios pues con ella hemos como aprendido a convivir con ella, con su enfermedad.(11, M1, p.11)

M.- After she got out of the hospital [the first time], there were three times that she was taken to the hospital.

I.- Oh! What happened?

M.- She had fever. There's a cough that they're left with, something in the bronchus, something mild. There was one time that we had to take her around 4 in the morning; the father took her. I told him "No, wait until it's earlier maybe they could keep you waiting". "No, I'm taking her " and he took her with him; he came back the next day with her. It was an infection in her lung, a mild one, from the cough; she had high fever and it was the same three times. So I told myself there is something that goes with them as a result of the illness. So now when she gets a cough I give her the medicines they have prescribed before. In that way I avoid taking her to the hospital. When I see that she doesn't react to the treatment they have prescribed, I take her to the doctors in the hospital.

I.- Now days, what do you do when she has fever?

M.- I begin by giving her Dolex; if around 12 hours later she doesn't get better with the Dolex, the fever hasn't come down immediately I take her to the hospital. But if I give her the Dolex and the fever lowers some and the fever is mild, the I say "No, she's getting better" It could be said that one gets good at handling her illness and understand everything better.

I.- You don't get so scared as at the beginning

M.- No, I don't get so scared; when I <u>see her grave</u> then I run but at the beginning

> anything would make us run to the hospital, run to there, we didn't care about the hour. But now, thanks God we have learned to live with her illness.

Elena and Felipe, parents of 4 year old Pablo, were especially concerned the first time Pablo had fever. Over the telephone, Elena described to me how they coped with the first fever episode. In the late evening, she took the child's temperature because his skin was hot while she touched him. The child's temperature was 37.5 °C so Elena immediately called Felipe. They waited for a few minutes and took again the child's temperature, which this time was 38°C. They did not wait any longer and took the child to the teaching hospital, which is located in a different city from the one where they live. They got to the ER almost at midnight. In the hospital ER, physicians ran all the tests to rule out any infection. They found the child had gastroenteritis; he was in the hospital over the weekend.

Elena was able to sense her son's fever right before it actually was visible in the thermometer. Both parents were scared by a minimum increase in the child's temperature so they did the only thing they knew would be safe, to seek professional help in the teaching hospital. They did not go to the hospital in their city. Instead they went to the institution and professionals that they trust, because they knew how to treat their son's illness. It did not matter to the parents that it was midnight and the hospital was about 1 hour driving from their home.

Elena's narrative about her apprehension that her son would get an infection or any illness while they went to the Pediatric Ward to ask a physician about some test results, a few weeks after the child was hospitalized, illustrates how parents take up this concern.

> **M.-** Y me tocó subir al quinto piso y me encontré con un niño que yo con la mamá había hablado, y el niñito estaba en la camita, pero "Ay, dije Dios mío mi hijo, no!" Ese día bajé mal y yo me salí del hospital, yo no esperé a la Doctora a que..y yo llamé a Felipe "venga por mí". El fue y me recogió y cuando él me recogió, porque yo me salí, porque yo dije de pronto me le pasa algo al niño.. Yo le dije a una doctora, le dije

> doctora cierto que aquí hay mucho, como.. como, no doctora? Ella hasta me contestó, no la sala de infecto queda alla. Ahhh! No de pronto algún virus me coge a mi muchacho, él bien débil, no purrundún mija bajé. Y yo siempre le digo a él cuando paso por ahí, como por Urgencias que se tape, yo siempre le llevo una cobijita no? Entonces yo le dije a Pablo tápese . ... Porque siempre tengo como un temor de pronto siempre como pasar uno como por por determinado sitio donde le peguen una enfermedad al niño, como está bajo de defensas. (01, M1, p.18, 552-570).
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> **M.-** I need to go up to the fifth floor and I met with a child whose mother I had talked to, and he little boy was in bed but Oh! God, no my son, no I said. That day I came down feeling very bad and I walked out of the hospital, I didn't wait for the doctor. I called Felipe "Come to get me". He came and got me and when he came, I got out of the hospital because something might happen to my child. I told a doctor "doctor, is it true that here there are so many like .. like [children with infections] She said no, the infectious disease ward is over there. Ahhhh! Maybe a virus would get my boy, he's so weak! Oh, no I got out of there. I always tell him (the child) when we're passing by the ER to cover his face, I always bring him a blanket. I always have this fear about passing by certain places where the child could get an illness, because of his low defenses.

Silvia, the young mother of a 4 years old Camilo understood that leukemia leaves the child without defenses and platelets and because of that any virus could easily attack the child. She said, "*the children don't have protection, they don't have white blood cells so it is easier that any illness gets them and easier that they die from it. It's easier that a child without defenses and with bronchitis could die, that's more dangerous*". Silvia could not articulate clearly her understanding of the relationship between the disease and the lack of *defenses in the child* but she had a clear grasp of the meaning of it and the implications for the child as all parents did. Therefore, parents did not need to have all the technological knowledge and understanding about the illness to care for the children.

Practices to Improve the Child's Body Defenses

Parents found diverse ways to build up the child's immune response as the means to protect the child for getting an infection such as cold, gastroenteritis, and pneumonia. The following are the practices that the parents developed to avoid the possibility of infections:

keeping the child at home instead of sending her/him to school or preschool, separating the child from persons with colds or other visible illnesses, increasing the measures to keep the house clean, and avoiding swimming in public swimming pools. Two families moved into one of the parents' original family home for about six months after the diagnosis due to their understanding that the house they were living was a less healthy environment for the child. Some parents wondered that their concerns were exaggerated but they preferred to continue their practices so they would be on the safer side. Elena was a mother extremely concerned with her son getting sick. At the beginning of the illness experience, she acknowledged all the extreme measures she took to prevent any infection in her son. Three months after the diagnosis, she perceived herself as less compulsive about cleanness in the house and with the food. However, six months later during the third interview, she still was very afraid about her son getting infections. Elena understood that getting an infection was a strong possibility for her son because of the realities they had gone through; the child had been in the hospital twice for gastroenteritis despite all her caring practices.

> **M.-** Si, porque ya uno ya .. imagínese que Pablo, antecito por ejemplo yo no permitía visitas (se ríe) yo preguntaba y decia si tienen gripa no, no que no. Ahora se tienen cuidados pero no tan exagerados, pues como era yo. Yo llegué al extremo de a veces echarle agua hervida a todo, cosas así por el estilo y yo pienso de que de pronto, no, no hay que exagerar tanto. El es un niño normal, que no tiene una enfermedad contagiosa ni mucho menos sino que eso va en la sangrecita y que ya se está sanando. (01, M2, p4, 98-105)

> **M.-** Yes, before I didn't allow visits (laughs). I would ask and I would say if they have a cold no, no, no. Now, I cared well for him but no so extremely as I did it I got to the point of putting everything in boiling water, things like that. I think that maybe, it isn't needed to exaggerate so much. He is a normal child, he doesn't have a contagious disease or nothing like it, instead his illness is in the blood and he's healed.

Giving the child specific foods such as pigeon soup, fish, cheese, cow's liver, salads, vegetables and fruit juices were also very prevalent practices among the parents. They learned from each other and from a local physician who had a daily program on the radio about natural treatments for people with cancer and other disease. They also learned a balanced diet and natural foods were very useful in providing the child with the means to fight the disease and the side effects of the treatment. One child was vegetarian before the diagnosis; the parents continued giving the same diet to the child but they increased the child's intake of fruits and vegetables. The few times the child had low counts the mother increased the amount of green vegetables in the child's diet. Fortunately her child enjoyed eating all the salads. She did not allow the child to eat any candies because she believed sugar lowers the body defenses.

Parents of preadolescent children had a more difficult time in getting the child to avoid unhealthy food than parents of younger children. For Marta, the mother of a 12 year-old boy, her son's preference for junk food was a constant source of concern for her and conflict between them. To deal with this situation, Marta first tried loving and kind ways to get her son to eat the appropriate food but she was not successful. So she became frustrated and began using harsh ways, which she thought would yield better results. Her embodied knowledge and understanding of her son's way of being allowed her to find ways to be more effective in getting her son to eat healthy food. The following interview excerpt shows Marta's way of getting her son to do what he should do.

> M.- .....Yo por ejemplo que su jugo, que su leche, que ya esto, que cómase lo otro. Pero él es el que me hace las embarradas a mí; a veces le preparó su verdura y me dice yo no quiero eso. Entonces le digo, no vas a comer, después de que te he preparado algo que no te va hacer daño sino que te va hacer provecho? No. Se come cualquier tostada de plátano y me dice no quiero comida y va y se sienta por allá. Entonces como yo siempre cocino para todos lo mismo, sirvo al resto del personal y digo "Bueno, Alejandro no quiso comer, yo trato de sacarlo adelante pero él no se ayuda. Entonces qué hago?" le digo al papá, qué hago? No puedo hacer nada, él no quiere ayudarse. Cuando ve que todo el mundo ha comido, se ha arreglado cocina, a eso de las dos horas va y me dice "donde está mi comida?" (se ríen) Entonces yo le

> digo, su comida vea allá está tapada, si tiene hambre allá está, busque a ver que come porque no hay mas. Se va y busca y come lo mismo que le di a los demás. Había cogido una pendejada conmigo, él seguro pensaba que si él se iba a morir, entonces él me dijo "yo me tengo que morir entonces pa'que me obliga a comer tanto y hacer esto y hacer lo otro?" Alejandro por Dios, colabóreme, tómeselo, por lo menos que no termines mal le dije un día, por lo menos no te moris tan acabao. Se quedó pensando y me dijo !ah¡ definitivo no quiero nada y me cogió la comida y me la puso por allá. Entonces me sacó la rabia y le dije "sabe qué, usted dice que se quiere morir, cierto? muérase pero se muere usted sólo porque yo no me voy a morir con usted, yo no, yo quiero vivir y voy a ir al médico porque yo me siento enferma, voy a ir al médico que me manden droga, me manden vitaminas porque yo si quiero vivir, lo que usted no quiere lo quiero yo". (03, M1, p.30, 884-926)

> **M.-** I give him juice, milk, this and that. But he's awful; sometimes I prepare him vegetables and he tells me I don't want that. Then, I say to him "you're not going to eat what I've cooked? It's something that is beneficial for you; it isn't something that would damage you". No [he said]. He eats a piece of fried plantain and tells me "I don't want any food" and he sits somewhere over there. I always cook the same food for the whole family so I served the food to all of them and said "O.K., Alejandro doesn't want to eat, I try to help him but he doesn't want me to do that. What can I do?" I tell his father, what can I do? I can't do anything, he doesn't want to do anything good for him. After everybody has eaten and I've cleaned the kitchen, around two hours later, he comes and says to me "where's my food?" (laugh) Then, I say "your food is there, if you're hungry and want to eat, see what you can find because there isn't anything else". So he goes and eats the same food I gave to the others. He was doing something silly, maybe he thought he was going to die so he said "I'm going to die so why do you force me to eat so much and to do this and that?" Alejandro, please for God's sake cooperate with me, eat some so you won't end up very bad I told him one day. At least you won't die too skinny. He was thinking and then he said "Oh, I don't want anything!" and he got the food and threw it over there. So I got angry and I told him" you know what? You say that you want to die, right? O.K, you can die but you got to do it alone because I'm not going to die with you, no, I want to live. And I'm going to see my doctor because I'm feeling sick so he can prescribed some medicines and vitamins for me. I want to live, I want what you don't want"

It seems Marta was protecting her son from himself. She perceived her son's desire for junk food as self-destructive. So she decided to change her tender approach to an acrimonious one because it was the only choice she thought would work. Besides, the later way of being with her son was more in agreement with her way of being as woman and as mother. Marta learned from her father that being aggressive and tough with men is better if women want to be in control. Marta has practiced that with her husband and three sons. It also could be that Marta understood she should treat her son the usual way since he did not have any signs of the illness, he was just being rude and making her life more difficult. Marta achieved what she wanted from her son using the acrimonious approach.

> **M.-** Yo lo trato duro a ratos porque él es rebelde conmigo, él es muy duro conmigo, es muy agresivo, entonces yo a ratos lo trato con dureza. Que dia le dije "Si usted quiere juete, yo juete le doy, si lo que quiere es mala vida, entonces la que va a tener, porque aqui se le alcahuetea mucho y si usted va a venir a montármela a mi, conmigo te vas a estrellar" ... Yo le dije a él '"Cualquier cosa puede causarnos un problema grandísimo"; él estuvo con las defensas bajiticas tres semanas, no ve que no se le subían esas defensas con nada y yo le dije "Lo mas cruel es que de pronto le de alguna enfermedad que lo patea y se lo lleva. No vale nada [para salvarlo]". Hasta le dije Pues se quita uno del problema, se descansa pero se queda la cosa aquí, sufrir por elque se fue". Si asi le dije a él "pues si descansa usted y descanso yo, descansamos todos".
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> **E.-** Y que le contestó?
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> **M.-** No contesta nada, no contesta nada. Y el habia cojido se acuerda que yo le dije que había cojido a decirme que él se iba a morir, que él se iba a morir que mejor morirse. "Pues muérase, pues ahí, tiene si quiere coma o si no muérase pero yo con usted no me voy a morir". Y no volvió a molestar con eso, no volvió; hay que trancarle porque si no; si yo tengo a ratos mis altercados con él.

> **M.-** I treat him harshly sometimes because he's rebellious, he's difficult to deal with, he's very hostile so sometimes I treat him roughly. One of these days, I told him "If you want to be hit, I would do that; if you want a rough life, you would get it because here we tolerate you a lot and if you're going to get on top of me, you're going to find me"... I told him "Anything could cause us a huge problem"(meaning anything could be deadly for you). He had the body defenses very low for three weeks, they didn't increased at all so I told him "The cruelest thing is that you might get other disease that hits you and takes you away; nothing would work [to save you]". I even told him "Maybe we'll get rid off the problem, we'll rest but something would be left inside of us, suffering for the one gone". I told him that "O. K., you would be relieved, I would relieved, all of us would be relieved"
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> **I.-** What did he say to you?
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> **M.-** Nothing, he said anything. I was telling me remember that I told you that he was telling all the time that he was going to die, that it would be better if he dies. "O. K., die; here is the food if you want to eat, eat it; if not [want to it] no, O.K. die" And he never said anything else like from that day on, he didn't; it's that I have to be rough with him because otherwise .. yes, I have serious fights with him.

Maybe the mother's shift to a gentle mode scared her son; maybe it made him think, "Shoot if she's treating me so nicely then I must really be sick almost to death". A shift back to a strict way may have made him think there was hope or he was not really so sick as he was thinking.

In contrast with Marta, Rosa the grandmother of 12 years old Luis used a different approach to accomplish the same objective. Rosa and her daughter developed a successful approach, which could be considered appropriate for a child who is beginning the adolescent stage like Luis. They asked Luis to select the food they were going to cook for him. Grandmother also explained to Luis the reasons for him to eat a balanced diet. By doing that they allowed the boy to feel that he was in control of his diet but he also understood the reason for doing so.

The above mothers seemed to be very attuned to the child's way of being and needs. They were capable of finding the manner to make the child do what they valued as best for the child. Marta's way of getting her son to eat healthy food could be perceived by others as harsh but she knew that was the only way to capture her son's willingness to change his harmful eating habits. Rosa's kind approach was in harmony with her grandson's gentle disposition and smartness to understand the benefits from the new diet. The practices these mothers established show once more the embodied knowing-how of the parents when caring for their children.

Nubia, the mother of 12 years old Lorena was also very concerned with her daughter eating unhealthy food instead of healthy food but she could not get Lorena to change her practice because she did not have the support of Lorena's father. The father did not do anything that would upset his daughter because he did not want to cause her more suffering than the suffering she was going through due to the illness. Lorena, who knew she had an alliance with her father, established a very effective means to get his sympathy. She cried whenever she did not want her parents imposing on her things she did not like. For Nubia to be successful in changing her daughter's eating habits, she would have first to change her husband's understanding of his attitude toward his daughter and the benefits of a balanced diet for her. Then, he too would try to persuade his daughter to change her eating habits. But Nubia did not feel strong enough to modify her husband's practice perhaps because of the difficulties they had as a couple and thus she was not successful in managing her daughter's diet.

Showing love to the child by caressing, kissing, and telling him how much he is loved was a practice that Elena incorporated to her routine to strengthen her child's immune system function after being advised by a psychologist to do it. This practice was very important for Elena because later she interpreted the boy's normal blood counts as the result of such practice. This practice also allowed her to modify her way of being in this sense with her ill son. According to her she has been more affectionate with her youngest son than with her ill son before and after the diagnosis. She realized after getting the advice that she needed to improve her way of showing love to her ill son. I understand that by carrying out the new practice, Elena also was getting some relief from the uneasiness that she could get from the fact she had begun another new practice: using corporal punishment with her ill son, which be described later in this chapter in the section about setting boundaries and disciplining the child.

Some mothers realized the child should also be involved in her/his care so they taught self-care to the child. These mothers were concerned about the fact they could not be physically with the child all the time to watch for her/him. Preschool age children were more receptive than school age children according to the mothers. These young children learned to do what they should do to avoid getting sick like the following child did.

> A él le habla uno las cosas y él le entiende bien a uno. Por ejemplo si él se va a montar en la cicla y yo veo de que no le conviene, yo [le digo] "Carlos a usted no le conviene por esto y esto" y él no se monta. El va a una fiesta y usted puede pasar así con su bandeja dando pastel y él dice"No, gracias". Y usted le puede insistir, y él dice "sabe que démelo yo se lo llevo a mi mamá" pero él no se lo come, él no se come, ni se le toma la gaseosa porque él está muy consciente de las cosas que le hace daño.

> I tell him things and he understands me pretty well. For example, if he's going to ride on the bicycle and I see it's not good for him I [tell him] "Carlos that isn't good for you for this and that" and he doesn't ride it on. He goes to a party and you can offer him the cake and he says " No, thanks". And you can insist but he says "you know what, give it to me that I would give to my mother"; he doesn't eat it, he doesn't eat it neither he drinks the soda because he's very conscious of the things that are bad for him.

All school age children except one were more reluctant to accept the restrictions imposed on them due to the illness probably because they interpreted those limitations as something that made them different from the other children and friends. Parents used rewards to reinforce the children when they adhered to the restrictions.

Protecting the Child from Bleeding

Parents were concerned about the child being physically hurt by falling or hitting. Most parents understood bleeding is caused by low platelet counts; other parents did not understand the physiological reason for the bleeding but they followed the same practices. Parents interpreted bleeding as something very dangerous for the child. Parents were very afraid of bleeding probably because most children have different types of bleeding as sign of the illness at the time of the diagnosis and during chemotherapy. Also parents observed the progress of the disease in children other than their own, which increased their fear about bleeding. Some parents saw a dying child in the pediatric ward who had very low platelets and was bleeding very badly. This experience remained vivid in the parents' recollection because it was so frightening; the parents shared their concerns and experience with the other parents so most parents had similar understanding and concerns regarding bleeding. The parents of a 4 year-old boy also learned from their own experience with their son that bleeding was something grave. At the time of the diagnosis, the boy had very low platelets and because of this and the multiple needle sticks the nurses did on him in the ER, he got a hematoma on one of his arms. Later, when the hematoma got infected and drained by itself, it led to a deep wound that took weeks to heal. Parents became very concerned about the possibility of bleeding as an outcome of the above instances or realities they had experienced. From the oncologist's advice, parents knew that the bleeding could be internal and external so they should watch for any blood in the stool, urine, gums, skin, mouth, and nose.

Mothers were looking constantly for new non-medical ways to improve the child's blood counts including platelets. Parents and children were not willing to accept blood transfusions as the only means to improve the blood counts. Feeding practices were also used to increase hemoglobin and platelets, especially giving fruits and vegetables juices to the child. Juices made from blackberry, blueberry, beet, guava, and grapes were frequently used alone or mixed with spinach.

There were some differences in the feeding practices carried out to protect the child from bleeding. For example, one mother gave crushed spinach seeds with milk and bee's honey to the child everyday; another mother used peanuts, milk, and bee's honey. Some mothers were pretty consistent in giving the juice everyday, others alternated the juice so the child would not get tired of it and refuse it. It was harder for some mothers to keep the practice of giving the juices either because the children did not like them or because the mothers got somehow tired of carrying out the practice. However, the mothers resumed the practice a few days or weeks later. Lack of money to buy the fruits was another impediment to carry out regularly the feeding practice for two mothers with very low and unstable income.

> **E.-** Used le da los jugos todos los días?
> **M.-** El que es para el cancer si se lo doy cuando se pueda aunque a veces las frutas son mas caras. Usted sabe que para estarle dando todos los días sería la uva que es cara y la mora siempre son [caras] en cambio pues las verduras son de bajo costo, mientras que las frutas son las de alto costo. Entonces yo se las doy cuando yo pueda, cuando tengo la oportunidad entonces yo se las doy.

> **I.-** Do you give her the juices everyday?
> **M.-** I give her the ones that are for the cancer whenever I can because sometimes the fruits are more expensive. You know [it's not possible] to give her grapes that are expensive and the backberry is always very expensive. The vegetables have low cost but the fruits cost a lot. So I give them to her when I can, when I have the chance I give them to her.

Avoiding any spanking or physical punishment to the child and limiting the child's involvement in active play and games like soccer and bicycling were other practices parents implemented to avoid harm and to prevent bleeding. Keeping the child at home also prevented bleeding because that would decrease the possibility of the child being hurt by other children or by falling. One family did not allow the child to continue the usual practice of helping in the house chores because he could get hurt in doing that.

> **E.-** La enfermedad ha cambiado en algo la manera como tratan al niño?
> **M.-** Un poquito si porque nosotros acostumbramos el día Sábado, bueno el día que están aquí todos, acostumbramos.. yo por ejemplo, yo digo, yo hoy no hago nada, solo voy hacer el almuerzo, lavo y no mas. Entonces la niña coge un oficio, Carlitos coge otro, Jorge cogía otro, y el papá otro. A Carlos le poníamos lo mas sencillo que era barrer el patio y barrer la calle. Ahora nosotros llegamos y bueno quien barre? hoy es Sábado qué vamos hacer? No pues que yo hago esto, que yo hago esto, y esto y esto y esto y lo que le toca Carlos lo hago yo. Entonces yo [digo] por qué, Carlitos también puede. No, no, no, Carlitos no, vaya mijo vea, ahi mismo lo mandan a ver televisión, o lo sientan aquí en la mesa usted no haga nada. Entonces yo he visto de que si hay cambios, porque ya no quieren hacerlo dejar nada. .... O sea, yo al

> principio si tomé una situación que no quería que ni saliera, que no jugara, que no brincara, que se aporriaba pero no, ya no. Yo tengo que dejarlo haga una vida normal . (02, M1, p.29, 834-870)
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> **I.-** Has the illness changed the way you treat the boy?
> **M.-** A little bit because we usually on Saturdays, when everybody is here, we are used to .. for example I said "today, I'm not doing anything else, I'm going to prepare lunch and do the laundry, nothing else. So the girl does one thing, Carlitos does other, Jorge would do other, and the father other. Carlos would do the easiest thing, which is to sweep the patio and the street in front of the house. Now, we come and O.K. who is going to sweep? Today's Saturday, what are we going to do? So they say I 'll do this, I'll do that and so on and what Carlos is supposed to do I 'll do it also. Then, I asked why? He can do it too. No, no, no Carlitos no, go and watch TV. Immediately they sent him to watch TV or they sit him on the table so he won't do anything. At the beginning, I didn't want him to go out, to play, to jump because he'll get hurt but now, it's different. I got to let him have a normal life.

Protecting the Child from the Exposure to the Sun and Chemicals

All parents except one couple imposed restrictions on the child as a means to protect him/her from the sun and the chemicals. Parents learned from the physicians their children were getting drugs that were strong chemicals. Therefore, the parents felt responsible for decreasing the child's contact with any other chemicals. To do so, parents strictly followed the physicians' advice of avoiding the use of chemicals for cleaning the house and controlling the mosquitoes. They also avoided canned and processed food and sodas in the child's diet. The parents were very concerned about exposing the child to the sun. They prevented that by limiting swimming and going out during the hours the sun is brighter. This was not easy to accomplish especially with older children in a quite hot environment where swimming is an everyday practice for children. When parents did allow it, swimming in rivers was preferred over swimming in public swimming pools because of the chlorine and the germs found in the public pools. Parents understood rivers did not have the chlorine that swimming pools have but they were not aware of other invisible sources of contamination that the rivers could have such as bacteria from organic disposals. One mother did not like the idea of her son swimming in rivers or swimming pools but she allowed the boy to go swimming since it was one of the few opportunities he had to have fun without spending money she did not have.

Parents did not have a specific story about the dangerousness of the chemicals to the child other than chemicals are bad for anybody. Besides, the child already was getting the chemotherapy agents, which the parents understood were very strong chemicals so it was the parents' responsibility to strictly follow the physician's advice regarding chemicals. Parents also knew the exposure to the sun is not good and they got specific advice about it from the oncologists too.

The parents' disposition to comply with the oncologists' advice without questioning it implies the value most Colombians attach to the expert's advice. Physicians are perceived as experts and they are expected to know what is best for their clients. Physicians are also powerful because of their knowledge and social status so most people are willing to comply with their recommendations, assuming their advice is always good for the patients. Physicians are aware of their authority and power to influence families but they can not spend more time with the patients and families because of their busy schedule. The Oncologists caring for the children of this study were able to spend only small amounts of time with the children and parents.

The parents did not use medicinal herbs on a regular basis with the children because they were afraid of mixing the medications with herbs. Some parents gave herbal teas to the children at the beginning of the illness but they stopped this practice later. It was surprising for me to find parents did not carry out this practice since the use of herbs is common in other childhood illnesses and symptoms and very prevalent among adults with cancer. My understanding is that parents believed the children were already getting the best possible treatment with very "strong medicines", which were chemicals, so they should not get any other substance that could damage the children when being mixed with the antineoplasic medications.

Protecting the Child from the Immediate Side Effects of Chemotherapy

Most children had mild immediate reactions to the chemotherapy especially at the beginning of it. Vomiting and lack of energy were the most common side effects right after having the chemotherapy in the hospital. Children had the possibility of getting the medicines that the oncologist prescribed to control vomiting. The nurses in the Chemotherapy Unit and the parents at home gave the medicine when it was available. It seems to me that most parents understood the immediate side effects of the chemotherapy as something they did not have to be concerned with because the effects were mild and the child recovered pretty quickly from them. Some parents understood the lack of side effects to the chemotherapy as a good signal: the child's body was tolerating and accepting the treatment. There was only one mother who was very concerned about being unable to see the discomfort her son was having from the chemotherapy. She understood her son could not tell her what he was feeling due to his age and his way of being. She used any opportunity she had to ask adults patients about the side effects of the chemotherapy. Then, she developed new practices to care for her son based on what she learned from the adult patients. She found out chemotherapy produces nausea and it is good to eat “soft food’ before the chemotherapy. So she did not give her son eggs at breakfast the day of the chemotherapy because it would make him more prone to have nausea and vomiting. She learned that chemotherapy causes constipation so she asked the physician to prescribe something for her son because he had the same problem. She also found out the intrathecal chemotherapy causes strong headaches specially if the person sits up or stands up soon after it. On their way home, she carried her son lying down on his belly and she did not allow him to sit or stand up for a few hours at home.

The parent couple who believed in the power of the mind and had a great faith in God taught their 4 year old son to pray before leaving home for the chemotherapy as a way to prevent the negative side effects. The prayer included blessing of the drugs, asking God that the drugs would produce only good effects on him and the other children. They never mentioned to their son the possibility of nausea and vomiting nor asked him about it during and after the chemotherapy. Their beliefs and practices were reinforced by the lack of chemotherapy side effects in their son. This child was amazingly comfortable during the chemotherapy sessions. He did not show fear of the needle sticks. It seems the parents did a great job in preparing him for the treatment and also that he had learned a lot from his parents in coping with the illness.

All parents recognized changes in the children's mood after a few months of the illness experience. The mothers were the first to notice the changes probably because they spent more time with the children. Irritability was the most visible change in the child's way of being. It seems that some mothers, who were more attuned to the child's needs and changes learned quickly that the Prednisone was the drug that caused the child's irritability; one mother identified another drug as the source of the irritability. Other mothers could not identify the source of the irritability but they were aware of it as something related to the chemotherapy. Knowing the specific drug that caused the child's irritability seemed to allow the mothers to understand and accept better the irritability and to cope better with it probably because they knew the irritability would be present only while the child was taking the medication. At the beginning of the treatment, some mothers were prompted by other mothers about the child becoming more irritable due to the chemotherapy so they were not surprised when it happened. The advanced information seemed to help them to tolerate the child's irritability and aggressiveness better. Most mothers could differentiate when the child was irritable due to the chemotherapy from when the child was misbehaving for other reasons.

Parents, especially mothers were touched by the children's new way of being. The child seemed so different to the parents that they were struck by the child's behavior.

> **A.-** El era de muy buen genio, muy cariñoso, y él es cariñoso todavía pero hay días que se levanta que uno le dice va a desayunar? Ay ahora! así como que
> **M.-** Si como que no le gusta, le choca.
> **A.-** A él uno le decía mijo venga desayune o por la mañana para ir a la escuela mijo venga desayune, él se desayunaba se cepillaba y se iba [para la escuela]
> **M.-** Porque ahora muchas madres me han dicho que se les daña el genio, si todas dicen que el genio.
> **A.-** Ha cambiado mucho el genio.
> **E.-** Y ustedes se han dado cuenta, por ejemplo si alguna droga en especial le produce ese mal genio o es toda la droga?
> **M.-** No, dicen que es toda la droga?
> **A.-** Es que hay días que
> **M.-** //Es que hay días que él amanece de buen genio.
> **A.—** Hay días que se despierta, él lo llama a uno pa' saludarlo y él charla … hay días que no, días que como que no le gusta, como que le choca
> **M.-** No le gusta ni que le hablen.

> **Gm.-** He used to be in good mood always and very loving, he still is loving but there are days when he gets up and I ask him "Are you going to have breakfast?" " Not now" (with angry tone)
> **M.-** Yes, like he doesn't like [to be asked], like he's upset
> **Gm.-** Before, we used to tell him "son, come to have breakfast" in the morning when he was getting ready to go to school and he ate breakfast, brushed his teeth and went [to school]
> **M.-** Many mothers have told me that they (children) get a bad mood.
> **Gm.-** His disposition has changed a lot.
> **I.-** Have you noticed, for example if a specific drug or are all the drugs cause his bad mood?
> **M.-** No, they say it's because all the drugs

> **Gm.**- There are days that
> **M.**- // There are days that he's in good mood
> **Gm.**- There are days that he wakes up and greets me and talks … there are days that no, days like he doesn't like, like he's bothered for something.
> **M.**- He doesn't want us to talk with him.

Parents described the behavior of the children in the following way. Older children talked back to the parents, they wanted to be alone, they did not want to go out of the house or to see their friends, and they could not tell the parents what was wrong or bothering them. They also cried for things that the parents did not consider worthy of crying about. Young children cried a lot, fought and hit the siblings, sometimes they destroyed toys or things that were close to them when they got very angry. Older children also became very egocentric and asked for many things that parents could not afford to give them. This behavior caused difficulties among the family members, which resulted in a lot of tension among all of them. One mother described this in the following way.

> **M.**- Ahora por ejemplo él se ha vuelto bastante egoísta, !uy¡ es un egoísmo tan espantoso con los mismos muchachos grandes. El dice "yo prendo este televisor y que ay de que me lo vayan a mover de ahí". Tengo que estar encima de ellos a toda hora porque los grandes ya pelean con él, ya dejaron las consideraciones y ya pelean … mas sin embargo él quiere manipularme, él quiere ponerme a mí así, el me dice "yo quiero tal cosa" y que de una vez diga tenga. Ahora en Diciembre tuvimos un agarrón ahí en el Éxito.
> **E.**- Qué pasó ?
> **M.**- Que él quería unos guantes de béisbol, el bate y la pelota. Cuánto cuesta todo eso? Yo fui, era cierto yo llevaba cuarenta mil pesos que pa' comprarle por lo menos algo, empezar con algo, cuando fui y miré los guantes costaban sesenta y pico de mil de pesos dije "Nooo, yo con sesenta mil pesos le doy de comer ocho días".

> **M.**- Now, for example, he's become very egoist. Oh! it's an egoism so awful with his older siblings. He says "I turn on this TV and nobody could change it". I need to be on top of them all the time because the older boys fight with him. They left out all considerations with him and fight him … he tries to manipulate me, he wants to put me like that, he tells me "I want that" and he expects me to say immediately "here, it's [what you want]". In December, we had a big fight in el Exito (a big department store).
> **I.**- What happened?

> **M.**- He wanted the baseball gloves, the bat, and the ball. How much is all that? It was true I had forty thousand pesos to buy him something, to begin with something but when I saw [the price] the gloves were over sixty thousand pesos, I said "Noooo, with sixty thousand pesos I feed you one week".

Most parents described the children's behavior as an unusual, rude, aggressive, getting out of control, and very difficult for them to tolerate. Parents were very concerned about the children becoming fixed in that kind of unwanted behavior.

Mothers reacted in different ways to the child's irritability. One young mother tolerated it just for about the first three months of chemotherapy and after that she told the child she would not tolerate that anymore. She began punishing him by hitting the child with her hands or not allowing him to do what he liked more. She also explained to him why he should not continue behaving like that. So the child changed his behavior in a few weeks. Mothers also learned that leaving the children alone and not disturbing them was a good way to ease the child's irritability and prevent more troubles for the child and for them. One mother sent her other two children with relatives when the ill child was irritable. She left the child alone in a room and she went to do whatever she needed in the house. It seems that the mothers who could differentiate the irritability due to the treatment from other forms of misbehavior were able to deal better with the child's irritability because they were more ready to accept it than the mothers who did not know that. Setting limits on what the child could do also helped a great deal to decrease the child's irritability and other unwanted behaviors as is evident in the statement "*He seems to know that he can do whatever he wants and to get away with it without any punishment*". It seems to me that the children became more irritable and aggressive with the siblings and the parents when they understood their parents would not control their behavior.

In general, parents were more tolerant of the ill child's misbehavior after than before the diagnosis as this mother described it:

> Ahora yo la regaño, pero ella se ha vuelto muy sentimental. Pues yo la reprendo, es muy grosera conmigo, es groserísima, no me colabora, pero pues yo le he pedido a Dios mucha paciencia, mucha paciencia y yo hay veces la entiendo. Hay veces la regaño y todo eso pero yo caigo en cuenta que pues ella se siente mal cuando uno la regaña entonces mejor yo hay veces no le digo nada.
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> Now, I scold her but she's become very emotional. I reprimand her, she's very rude with me, extremely rude, she doesn't help me at home but I've asked God to give me lots of patience. Sometimes, I sympathize with her. Sometimes, I scold her and all that but I realized she feels bad when I do that so sometimes I don't say anything to her.

Parents admitted feeling more love, empathy, and compassion for the ill child. Parents also thought the child was undergoing a terrible illness that causes lots of suffering and pain so they should refrain from causing additional suffering to the child. Most importantly, parents realized they were not sure for how long they would enjoy having the child with them so they truly were afraid of causing more pain to the child or doing something they would regret later if the child died. It is obvious the child became more precious for the parents so they took a stand that showed their concern about losing the child. Many of their caregiving practices and ways of being with the children were aimed at protecting the child's life.

Setting Boundaries and Disciplining the Child

Corporal punishment is a common practice among most Colombian parents to control what they perceived as the children's misconduct. The use of corporal punishment varies with the parents' social class. It is more commonly use among parents from the lower social class presumably because they have not learned other ways to discipline the children or because it is a background practice that they learned from their parents. Some parents use a belt, a thin rope or some flexible object to hit the children either in their buttocks, legs, or back. Objects are usually used to punish preschool age and older children. Parents use their hands to hit younger children on their hands or buttocks. Therefore, for most parents to refrain from spanking the ill child was a pretty drastic change in their everyday child-rearing practices because the use of corporal punishment to discipline the children is an embedded practice in the Colombian context for most people. However, child abuse is recognized by the Colombian society when corporal punishment is used often and in a way that leaves marks on the child's body. Corporal punishment is also perceived as child abuse if it is the only way parents and adults have to control the children's misbehavior.

Not all parents in the study used corporal punishment with the child but most of them did mainly with the boys. The main reason parents acknowledged they had to avoid physical punishment was their concern for causing any bruises or bleeding in the child. Besides the above reason, some parents did not punish their child because they did not want to cause the child extra suffering. The pattern of using physical punishment was pretty similar among all the parents who had that practice. This pattern mirrored the parents' change in the illness understanding and the child's recovery. Parents did not punish the child during about the first 4 or 6 months after the diagnosis when the child was sicker and showed the signs of the leukemia. They resumed this practice when the child's clinical condition improved and the child's misbehavior became intolerable for the parents.

The parents' ways to discipline the children by using physical punishment makes sense to me for at least for three reasons. First, the child became healthier, had more energy, and understood her/his parents would do all in their power to gratify her/him. Parents indulged and pampered the child for the first months after the diagnosis. Therefore, the child felt in control and acted out in an unusual manner. Second, parents became more confident in being the parents they were before the diagnosis when they perceived the child was healthy again.

Third, the child's behavior was too much for them to ignore it so parents perceived they needed to discipline the child since they understood the child would survive. It was crucial for the parents to preserve the child's appropriate behavior in the present and future time. Statements like the following illustrate how parents took the need of disciplining the child by using corporal punishment. " *It's necessary to punish him because he's getting spoiled and we can't leave him like that".* *"I explain to my son I punish you because I love you. If I would allow you to do whatever you want to, it means I don't love you. I want him to be a good boy for me and for everybody".*

Mothers more than fathers were concerned and involved in controlling the children's misbehavior probably because in the Colombian family the mother is responsible for disciplining the children on regular basis and also because they spent more time with the children.

> **M.-** Yo no admito que me haga un berrinche, no. Ahí llego y lo casco y ya se calma, ya se calma. Tampoco es que yo a toda hora le esté pegando a él porque no es asi, yo a él le tengo paciencia, le hablo le digo no hagas eso. Le hablo dos veces y a la tercera ya no le hablo sino con una palmada. No me gusta pegarle con correa, me da pesar pegarle con correa. O sea yo le pego con la mano y aquí en la nalga o aquí (en las piernas).

> **M.-** I don't accept that he has a tantrum in front of me, no. If that happens I hit him and he calms down, he calms down. It isn't that I'm spanking him all the time because it isn't like that. I have lots of patience with him, I talk with him and I tell him don't do that. I tell him that twice; at the third timeI don't say anything, instead I spank him with my hand. I don't like to hit him with a belt, I feel sorry for him if I hit him with a belt. That's I spank him with my hand in his buttocks or here (in the legs).

Mothers felt discomfort when they punished the child but they did it because they interpreted as their duty. Some mothers were more tolerant of the children's behavior than others but all of them except one understood they needed to discipline the child despite the illness so the child would not become spoiled in the future.

Lilia, the mother for whom was difficult and sometimes impossible to exert authority with her 8 year-old son, used corporal punishment with him before the illness but after the diagnosis she stopped it because she could not stand her son's crying and tears. She thought she should not cause him more suffering since he was suffering a great deal due to the illness. She said

> El no me obedece, me la tiene montada; a veces él me grita y yo le digo "Mira papi le voy a pegar si hace eso" pero él sabe que no le pego entonces me la tiene montada. Mi cuñada me dice por qué no le pegas? Y yo le digo porque yo no le pego a él, solamente lo grito. A veces yo le hago esto (tocarlo suavemente con la mano con la intención de pegarle) y él llora y yo siento pesar por él porque él sufre mucho por esa enfermedad y eso es todo.
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> He doesn't obey me, he's on top of me; sometimes he screams at me and I tell him "Look my dear I'm going to hit you if you do that" but he knows that I don't hit him so he's on top of me. My sister-in-law says to me why you don't hit him? I say because I don't hit him, I only scream at him. Sometimes, I do this (touching him softly with her hand with the intention to hit him), he cries and I feel pity for him because he's suffering a lot from that illness, so that's it".

This mother and child did not come back to continue the chemotherapy after finishing the radiotherapy at the end of the first year. I have the sense that the mother's decision to abandon the illness treatment was related to her unwillingness to set boundaries and limits to her son but I am not sure about this. I did not have the opportunity to get a better understanding of this mother because she completed only one interview. She never told me that she did not want to continue the interviews; most of the time she gave me sound reasons for missing the appointment such that she was sick from a cold, she had taken her mother to the hospital or that she had something else important to do at the same of the interview. She agreed to set another date for the interview but she never showed up so after five or six times I declined to call her more. Therefore, I do not have data to understand her subsequent decision to abandon the treatment.

During the interview, she did not express anything that showed she did not understand the seriousness of the illness or the need of the treatment. In talking about this, she said:

> **M.-** Que le digan a uno que su hijo está enfermo de una enfermedad como esta tan grave .. yo ese día me sentí que ya me iba a morir, me provocaba como coger irme bien lejos.. Yo me puse a pensar que no podía hacer eso porque yo tenía mi hijo y estaba enfermo y tenía que estar al lado de él, dándole fuerzas y estoy ahí con mi hijo. Me toca traerlo cada ocho días, no me importa si pierdo mi trabajo pero vengo con mi hijo a traerlo, voy y le hago las vueltas de la droga, si me toca ir a Bellavista voy.
> **E.-** Usted sabía algo de la Leucemia ?
> **M.-** No, yo <u>nunca</u> pensaba nunca, yo escuchaba si que eso era un cáncer cierto? pero nunca me pregunté ni nada de esas cosas.
> **E.-** Pero usted sabía que era un cáncer ?
> **M.-** Escuchaba que mucha gente se había muerto por eso, entonces nada mas, ya cuando me dijeron que mi hijo tenía eso, una se siente muy !ay¡ yo no se, se siente como que uno ya se va a morir, con esa tristeza. Bueno yo todos los días pienso en eso, le rezo mucho a mi Dios que me cure mi hijo.

> **M.-** To be told that your son is ill from such a grave illness .. That day I felt like I was going to die, I wanted to go very far away .. I thought I couldn't do that because I had my son and he was ill and I should stay with him, helping him so here I'm with him. I had to bring him every week, I don't care if I would lose my job but I come here to bring him, I also go to do all the things to get the drugs, if I have to go to Bellavista I would go there.
> **I.-** Did you know anything about the leukemia?
> **M.-** No, I <u>never</u> thought about it, I did hear that it is a cancer right? But I never asked about it or anything.
> **I.-** But you did know it is cancer?
> **M.-** I did hear about people dying from it, nothing else. So when they told me that my son had that, I felt Oh! I don't know, I felt like I was going to die from the sadness. O.K., every day I think about it, I pray a lot to God to cure my son.

This mother's main concern, as it was for most parents was that her son would die because of the illness.

> **E.-** Y las preocupaciones sobre su hijo han cambiado o son las mismas de antes [del diagn'ostico]?
> **M.-** Ahora son mas porque yo no se me da miedo que de pronto se me muera, me dan nervios que de pronto se me muera, yo que voy hacer si mi hijo se me llega a morir, si?
> **E.-** Usted antes de la enfermedad nunca pensaba en que se su niño se iba a morir ?
> **M.-** No, no, nunca.
> **E.-** Y ahora si piensa eso?

M.- Porque yo escucho que se murió tal niño, que se murió tal otro, entonces me dan nervios .. entonces a mi me van dando como esos nervios, y así .. Eso es lo que mas me preocupa, en que algún día me vaya a quedar sin mi hijo, nada mas, eso es lo único [que me precupa].

I.- Your concerns about your son have changed or they the same you had before the diagnosis?

M.- Now, there are more because I don't know but I'm afraid that he might die, I get anxious because he might die, what would I going to do if my son dies, right?

I.- Before the illness you never thought about his death?

M.- No, no, never

I.- And now you do think about it?

M.- Yes because I heard about the children who died so I get very anxious .. I get like very anxious .. That's what worries me most, that any day I would be without my child, nothing else, that's the only thing [that worries me].

The fact that she left the child without treatment despite this concern makes her decision even a greater puzzle for me. However, I belief the strongest possible interpretation of her decision to quit the treatment is that she felt she could not force her son to have more treatment and to cause him more suffering.

E.- Usted nunca lo forza hacer las cosas?

M.- No, nunca lo forzo

E.- Utiliza alguna otra manera para castigarlo o para controlarlo a él ?

M.- Nada, hay veces le digo que no lo voy a dejar salir pa'la calle, entonces él se pone a llorar entonces me da mucho pesar [y le digo] "vaya pues un ratico y vuelva y entra" O cuando, o así viendo televisión que le digo "no te voy a dejar ver televisión" y se pone a llorar, entonces "vaya vea televisión"

E.- La conmueve cuando llora ?

M.- Claro! O sea así me da mucho pesar, me da mucho pesar de el.

E.- Y, que es darle pesar ?

M.- No se, no se no me gusta verlo triste, no me gusta que llore, no me gusta nada de eso.

E.- Entonces él llora y rapidito usted le concede lo que él quiere.

M.- Pues si

I.- Do you ever force him to do things?

M.- No, I never force him

I.- Do you have any way to punish him or to control him?

M.- Nothing, sometimes I tell him I'm not going to let him go out so he starts crying and I feel very sorry for him and [I tell him] "O.K. go for a while and come inside" or

> when he's watching TV and I tell him "I'm not going to let you watch TV" and he cries so "go and watch TV"
> **I.-** So gets to you when he cries?
> **M.-** Of course! I feel very sorry for him, very sorry for him. **I.-** And what is to feel sorry for him?
> **M.-** I don't know, I don't know but I don't like to see him sad, I don't like to see him crying I don't like anything like that.
> **I.-** So he cries and quickly you give him what he wants
> **M.-** Yes.

She was not aware of the child being more in control of the situation than she was. But she was aware of her unwillingness to do anything to upset or make him suffering as it is evident in this quote.

> **E.-** Y él se da cuenta de que si él llora consigue lo que él quiere? O usted cree que él no se ha dado cuenta?
> **M.-** No, porque yo me lo pongo seria y entonces él se me queda mirando. Entonces si .. no .. a mi de da mucho pesar pero por ejemplo él anoche no quería tomarse el jugo de zanahoria entonces le dije yo que se lo tomara si no no lo dejaba salir a la calle. Entonces dijo "que no", entonces yo le dije "que si" y me fui pa'dentro. "Bueno, no se lo teme y no hay calle" Entonces dijo "Venga pues mami yo me lo tomo y me deja salir" Le dije "Bueno pues". Se lo tomó y así..

> **I.-** Does he realize that if he cries he would get what he wants? Or you think that he's not aware of that?
> **M.-** No, because I get serious and then looks at me. So yes .. no.. I feel very sorry but for example last night he didn't want to drink the carrot juice. Then I told him to drink it otherwise he wouldn't go outside. Then he "no" so I said "yes" and I went inside. "O.K. don't drink it and you won't go outside" Then he said "O.K. mummy, I would drink it and you let me go out" O.K. He drank it and he went out.

In my several contacts with her over the telephone, she mentioned the child did not want to come back to the hospital. Although, it is possible that there may be other reasons for her stopping treatment including misunderstanding of the treatment, running out of resources, and being tired of all the hassles with SSI.

Fathers involvement in setting boundaries and limits to the child was different in some ways to the mothers' involvement. Fathers were outside of the home most of the day so only in the evenings and weekends they witnessed the child's behavior. Whenever the father had the opportunity to see with their own eyes what the mothers had told them about the children's behavior, they also got concerned and involved in setting limits sometimes by using corporal punishment. There was only one father who disagreed with the mother about how to handle their daughter's behavior. Elena's narrative about this issue is quite illustrative of the parents' concern and struggle with physically punishing the ill child.

> **M.-** ...... Un dia le pegué, le pegué y llamé y le dije a Felipe, "Felipe yo le pegué al niño por tal cosa"
> **E.-** Con qué le pegó?
> **M-** Con una correa en las piernas. Al otro dia al niño le tocaba quimio. Primero fue grosero conmigo y no lo castigué. Luego el niño pequeño estaba jugando y cogió al niño y me lo golpió asi (le dio un puño fuerte en la espalda) yo estaba viendo y entonces ahi si no me aguanté y cogi la correa y le pegué. A su hermanito no le pega y pum! le pegué. Al otro dia le tocaba el examen y
> aparece Pablo con las defensas en el piso. "Sigale pegando" me dijo Felipe a mi. A los 8 días me paso lo mismo, una pega y otra baja de defensas. Entonces otra vez Felipe me reprochó a mi, entonces ahi yo le dije Pablo está muy grosero ya no me lo aguanto de lo grosero.... Entonces un dia cualquiera él estaba aqui y él vió entonces él dijo "A su mamá la respeta Pablo". El [niño] siguió y Felipe llegó y pum y no se le bajaron las defensas

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> **M.-** ..... One day I hit him, I hit him
> **I.-** How did you hit him?
> **M.-** With a belt on his legs; the following day, the boy had chemo. First he was rude with me but I didn't hit him. Later, the youngest boy was playing and Pablo hit him very hard on the back. I was watching them and I couldn't tolerate it so I got the belt and hit him. "You don't hit your little brother like that" I told him and pum! I hit him. The following day he had the test and he came out with the defenses on the floor (very low). "Keep hitting him" Felipe told me. The following week, the same thing happened, hitting and low defenses again. Again the father reproached me so I told him "He's been very rude with me and I can't stand him anymore his rudeness. .... One day, he (Felipe) was here and he witnessed it; he told Pablo "you have to respect your mother" but he continued and Felipe came and pum! hit him and the defenses didn't lower

This mother realizes the need of setting limits to her son's misbehavior but only after enduring it for months because of her fear of causing any harm to the child. It seems the child's behavior went out of control because the parents did not set any limits during the first months after the diagnosis and also because the child was pretty susceptible to the irritability caused by the oral steroids he was taking. The increased irritability and the lack of limits probably led the child to think he could do whatever he wanted so his misbehavior became worse and worse. The mother was very concerned about causing any suffering to her son by disciplining him but she was even more concerned about her son becoming a spoiled child who was hurting his siblings and his mother. After hitting the child with a belt for the first time, she interpreted the boy's low white counts as a consequence of the hitting. Later, when her husband punished the child and the blood counts were normal, she doubted the truth of her idea. She also understood her duty was to control the child's misbehavior otherwise it would get out of control and be more difficult to rectify it later.

> **M.-** Now, we don't hit him <u>always</u> but if he gets rude we punish him. I've told him even though your defenses get lower you can't be rude with your siblings or your mother. I wouldn't let him to get on top of me, and he was already a little bit there, and to take him down is difficult but I have to do it.

It is important to keep in mind that when the children did not show any signs of the illness the parents treated them as normal children, which meant as they did it before the diagnosis or as they treated the other children at home. So the use of corporal punishment to discipline the child became again part of the everyday practices the parents had to raise their children. However, they were aware they needed to be very careful about it in the sense of not doing it in a harsh way or too frequently.

Some mothers described other means instead of physical punishment to control the child's misbehavior. When the child did something that the mother disapproved, the mother would distance herself from the child by not making eye contact and not talking with him/her until the child stopped the unwanted behavior. The mother continued ignoring the child for some time afterwards. In this instance the mother intended that the child felt rejected by her so the unwanted behavior would end. Mothers also restrained themselves from giving the children something they wanted as a way to stop any undesired behavior.

Other Psychosocial and Spiritual/Religious Practices to Protect the Children

Parents also used an array of psychological practices to help the child's recovery. Special prayers to God and having faith in Him when the child's blood counts were low was another practice parents had to protect their child from getting any infection or bleeding. Parents gave different instances where they understood the child's blood counts were restored without any medical intervention but because of God's intervention in answer to their prayers. Two families attended what they called healing mass at the Catholic Church, as a way to get the child's free of any illness including the leukemia. These families found a great deal of support from attending the healing masses and did all they could to attend them, especially if the child's condition was not very good.

> Por ejemplo, el día Domingo que me toca ir allá (a la iglesia), él (esposo) se queda con mis hijos. El sabe que a las cuatro y media es la "imposición de manos" y él me lleva a mis tres hijos; o sea él me colabora allí, y él sabe que los Viernes yo salgo como una loquita con tres muchachos. Si él no está tengo que coger un taxi y voy y él me recoge, porque hemos visto que Dios está con nosotros.

> For example on Sundays when I go there (to the church), he (the husband) stays with the kids; he knows that at 4:30 is the "hands imposition" and he takes all three kids; in other words, he helps me with that and he knows that on Fridays I leave home in a hurry with all three children. If he isn't home I take a taxi and I would go and he picks me up; we've seen God is with us.

One father developed a ritual every night to transfer his good energy to his son through his hands. He established this ritual after learning from his wife that people have healing energy that could heal others. Another couple who strongly believed in the power of the mind refused to think or speak about the illness among themselves or with others. They did not repeat the name of the illness during the interviews, they only talked about their son having had the diagnosed of "L". When I asked about this practice they told me they did that because "W*hat you have in your mind is what you get so we don't say that word and we also said that he had 'that diagnosis'"* to mean it is a past event. These parents were not denying the illness but their specific belief about the human mind capacity to make things happen in reality constrained them from even thinking about the disease much less to talk about it.

Protecting the Child from Psychological Harm

Psychological suffering and pain could be cause by diverse sources. Knowing the kind of illness the child has, knowing other children with the same diagnosis die, feeling and looking different, and having painful and scary procedures were the reasons for psychological suffering that concerned parents the most. Seeing their parents suffering was also a reason for the children's suffering that parents became aware of. Protecting the child from any of those sources of suffering and pain was something parents were very concerned about.

Protecting the Child from the Suffering due to Knowing the Child Had a Life-threatening Illness

Telling the child the diagnosis was something parents agreed on but not at first and in a direct way. Marta, the mother of 12-year old Alejandro, was very concerned about her son knowing he had cancer at the time of the diagnosis. The boy had learned in school that cancer is fatal. So when he asked her the kind of disease he had, she could not tell him that he had cancer because it meant she would tell him that he would die soon. Instead of doing that she tried to minimize the seriousness of the diagnosis by telling him it was a tumor the doctors would dissolve with medications but it was not cancer. Marta did not deny to herself and others her son's disease but she understood she had to hide the truth from her son to ease his anxiety and pain from knowing that death was a strong possibility in his very near future. Marta was also very afraid of letting the boy know about other children's death. She probably thought that knowing other children had died would reinforce her son's understanding about the cancer as a deadly disease, which would cause him more suffering.

> M.- .... Y en esas entró Alejandro, claro pues vio las caras como se dice todos con la vista mojada, una cuando llora se le nota entonces me dijo mami qué pasa ? le dije no mijo no pasa nada. Dijo no me diga mentira, le dije no "no pasa nada" Me dijo si, tengo cáncer cierto? así me dijo. Entonces le dije "como así?" Me dijo "Si, esto es un tumor canceroso cierto que si?" Le dije usted porque me dice eso? Dijo porque como yo veo películas, he leído, la profesora nos ha explicado, dijo acaso yo soy bobo, yo se. Le dije no mijo usted no tiene cáncer. Dijo uh! quién sabe? y se puso a llorar. Me dijo lo único que me da pesar es que yo no me quiero morir, así me dijo y se abrazó a mí, me dijo yo no me quiero morir. Entonces le dije "papi usted de eso no se va a morir" Me dijo entonces qué tengo? Le dije tiene tumor pero lo van a tratar con droga, van a tratarlo, van hacer lo posible por desbaratarlo para que usted siga adelante. Dijo "pero es un tumor canceroso, cierto? Entonces le dije "no mijo no es canceroso" Dijo"bueno no me diga nada que yo siempre me doy cuenta", así con esa cabeza así. Le dije "bueno, definitivo tenemos que seguir adelante lo que sea mijo" El se puso a llorar y se encerró en la pieza y se quedó pensando.

> M.- ...... Then, Alejandro came in, of course he saw our faces with tears on, one can see when somebody has cried. He told me "Mom, what happens?" I told him " no son, nothing happens. He said "don't lie to me" and I said "nothing happens". He said " Yeah, I have cancer, right?" Then, I told him "how come?" He said "yes, this a cancerous tumor, right?" I said to him "why are you telling me that?" He said "because I watch movies, I've read, the teacher has explained to us. You think I'm dumb, I know" I said "no son, you don't have cancer" "Uh! Who knows? And he started crying. He said the only sad thing is that I don't want to die; he said that and hugged me. "I don't want to die" he said. So I said to him "you aren't going to die from it" He asked me "Then, what is it what I have? You have a tumor they are going to treat with drugs, they're going to do all in their power to dissolve it so you can go on ahead. "But it's a cancerous tumor, right?" I told him no my son, it isn't cancerous. He said to me "O.K. don't tell me more that I know it" I said O.K, regardless of it we need to go ahead with whatever it is, son. He cried and he went to his room and was thinking.

Later in the course of treatment, Marta's son became seriously depressed after a trip he had with a group of other children with cancer to an isle in the Caribbean Sea. For the next two months He refused to go to the hospital for the treatment and tests because, according to Marta, he thought he would die regardless of all they were doing. The boy was able to come out of the depression with Marta's help and the help of a pediatrician from Adolescent Medicine. Therefore, it was very significant for Marta to avoid anything that could intensify the boy's belief in the possibility of dying. Marta understood that she should not talk about death with her son or in front of him. So she established this practice just to protect him not because she could not cope with the idea of his son's death.

A similar situation was encountered by Gloria, the mother of 6 year old Carlos. When they were in the hospital, Gloria could not tell him that the child in the next room had died. While reflecting on that moment, Gloria interprets what she did as her only way to protect her son from the anxiety and fear caused by knowing he would die also because both children had the same illness. Gloria acknowledged feeling discomfort while hiding the truth from his son but she did not see another alternative to withhold his suffering at that moment. Gloria perceives herself as *realistic* with her son regarding the knowledge he should have about the illness but she could not discuss with him the possibility of death as a consequence of having the illness.

> **M.-** Eso lo hace sentir mal a uno, a mi por lo menos me hacía sentir porque lo que hace que Carlos tiene la enfermedad yo he sido muy realista con él, yo lo tengo consciente a él de que él sufre la enfermedad, de que él tiene que ir al tratamiento, de que él debe dejarse aplicar la droga, o sea a mi no me ha gustado mentirle, lo que hace que él tiene la enfermedad a mi me aconsejaron que le mintiera, que le dijera que eso era algo que tenia pasajero, pero no yo desde el momento que Carlos tiene la enfermedad yo lo concienticé a él de que él tenia la enfermedad, y para mi era duro mentirle, era muy duro mentirle pero yo en ese momento no quería que él se diera cuenta de que ese niño había muerto de la misma enfermedad que él tenia.
> **E.-** Y por qué era importante mentirle a él en ese momento?
> **M.-** En ese momento? Se me hacia muy importante porque él cada rato me preguntaba que si él iba a morir
> **E.-** Carlos le preguntaba que si él se iba a morir?
> **M.-** Si, me decía "Mami, será que yo me voy a morir? Yo no voy a alcanzar al Niño

> **Dios?" …. O sea él a toda hora me atacaba con eso de la muerte, entonces para mi era en ese momento era muy importante mentirle al niño de que ese niño se había muerto. Yo no quería como él tenia metido eso allí de que si él se iba morir, que si la enfermedad era algo que lo mataba, que qué iba a sentir cuando se muriera, que cómo iba a quedar, todo eso me decía él. Yo cómo voy a quedar cuando me muera, yo que qué voy a sentir? Todo eso me atormentaba a mi mucho, yo no quería que él se diera cuenta en ese momento que ese niño había muerto de esa enfermedad.**

> **M.- It made me feel bad because since he was diagnosed I've been very realistic with Carlos; he's conscious about having the illness, about going to the treatment, that he got to have the chemotherapy. I don't like to lie to him. I was adviced about lying to him, that I should tell him it was a temporary illness what he had. But from the moment he got the disease, I tried to make him conscious that he has the disease. So for me it was hard to lie to him, very hard but at that moment I didn't want him to know the child had died from the same illness he had.**
> **I.- Why was so important for you to lie to Carlos at that moment?**
> **M.- At that moment? It was very important because many times he asked me if he would die.**
> **I.- Carlos asked you if he would die?**
> **M.- Yes, he told me "Mom, am I going to die? I'm not going to be able to wait for Baby Jesus?" … That's he all the time attack me with that about death so it was very important for me to lie to him about the child's dying. I didn't want it because he had the idea he was going to die and that the illness would kill him. What would he feel when he die, how he would be like, he was telling me all that. How am I going to be when I die? What am I going to feel? All that tormented me very much, so I didn't want him to know at that moment the child had died from that illness.**

Parents were really unable to talk about death in front of or with the child if the child was six years old or older. Death was a taboo topic even for a father who considered that he understood death as something inherent to human beings and had gone through many workshops to understand death and dying as something *natural*. So the possibility of the child's death was something parents seemed willing to discuss only with adults but never with their children. They refrained from the discussion of death even with the healthy children much less with the ill children who were old enough to fully understand death as the end of their world. Parents of younger children felt they could talk about death in front of the child because the child did not have an understanding of death as an irreversible event.

Therefore, parents' concerns seemed to be that by talking about the possibility of the child's death they would cause psychological suffering to the child. Forcing the child to face the existential terror of one's own death or even somebody else's death was an unacceptable practice for the parents. When the children asked about their possibility of dying some parents reassured them that would not happen to them now. Other parents avoided talking about the topic with their children. Parents were not aware of the possible benefits of allowing the children to express their fears about death and dying with the parents. Two mothers of older children considered the children might benefit from talking with a psychologist; only one of them actually took the child to the Adolescence Physician, which the child refused after some visits.

The following quote from the interview with a young mother represents the understanding most parents had about the possibility of their child's death. It also describes how parents took up this possibility which corroborates my understanding that they did not discuss this possibility with the children only because they were protecting the children from the suffering that facing death would cause to the children. Parents differed only in the level of acceptance of this possibility. Some parents acknowledged it is easier to say they have accepted the possibility of the child's death that it was to actually accept their child's death when it would happen.

> **M.-** …. Yo me pongo a pensar que hay que ver las cosas como por el lado positivo. Saber que nosotros siempre cumplimos, tenemos un ciclo nacimos para volver a morir. Nacimos para morir pero que no hay que ver la muerte como algo desastroso sino como un paso a otra vida y que algún día tenemos que morirnos y si al niño le llega a pasar eso en este momento hay que aceptarlo. Hay que saber que iba a morir, podía ser ahora o después. Hay que aceptar la muerte como tal, como que en cualquier momento nos ha de llegar y que ninguno de nosotros estamos libres.

> **M.-** …. I think that one should see the positive side of things. To realize that we have

> a cycle, we have a cycle, we're born to die. We're born to die but we shouldn't consider death as a disaster instead as a step to another life. Someday we would die and if that's going to happen to the child in this moment we have to accept it. We need to realize that [the child] is going to die, it could be now or later. So we got to accept death as it is, that it comes at any moment to us and that none of us is free of it.

In the Colombian context, death is perceived as a possibility for human beings, mainly adults, elderly, and ill people. Generally, people do not talk about it even now that violence has become prevalent in the country and death is on the media everyday. Children learn about death mainly in school and from the everyday exposure to it. Death of a loved person is taken as a very sad event. The death of a child is even sadder because she or he has not lived a life and also because it seems to mean the loss of the future for the parents. Therefore, to think and talk about the child's death was not a desired or welcome topic for the parents in most circumstances much less if the child was capable of understanding the existential meaning of death.

Protecting the Child from the Fear and Pain Caused by the Treatment.

Some parents were very creative in acquiring practices that would decrease or hinder the suffering from getting the treatment. Parents realized on their own that it was better to prepare the child ahead of time for the treatment events that would occur. Some parents tried to incorporate the visits to the hospital for treatment as another routine in the children's life. A father initiated the practice of preparing his daughter for the chemotherapy session as follows:

> **M.-** El papá y yo le decíamos que tenia que ir al hospital, que estaba enfermita que por eso habia estado hospitalizada que entonces la droga que le iban a aplicar era para ayudarla a ella para que no se volviera a ir al hospiatl a estar en cama. Que iba a veces dias seguidos o dias asi intermedios, que la iban a estar chuzando la manito pero pues que era el chuzoncito no mas y ya volvia y salia ya no se quedaba mas en el hospital. Y asi pues ella fue entendiendo, yo creo que ella captó la idea y se acopló.
> **E.-** Y a ustedes alguien les enseñó esa manera de enseñarle a ella?
> **M.-** No pues el papá empezó. Pues hay que enseñarle a la niña pa' que se vaya

> acostumbrando porque cada 8 dias que empezamos nosotros a llevarla y ella va a sentir algo extraño, algo para que ella ya se acostumbrara al dolorcito, al chuzoncito y a la estadia que le tocaba. Y asi fue
> **E.-** Fue idea de quién?
> **M.-** El que tuvo la iniciativa fue él
> **E.-** Pero lo hacian los dos
> **M.-** Si lo haciamos los dos
> **E.-** Y por ejemplo , si la niña tiene la cita mañana cúando empiezan a prepararla?
> **M.-** Nosotros le deciamos, asi como está ahora tambien le decimos "mañana le toca irse para el hospital, o sea que mañana le toca madrugar o mañana le toca en la tarde" y ella ya sabe. Ah! entonces me voy pa'l hospital, hasta ella le dice que mi hospital. No ve que estuvieron dando una entrevista y dice ah! ese es mi hodpital donde yo voy. Entonces es como otra parte de ella, como irse uno a un lugar que ella mantiene se puede decir como un colegio o la escuela.
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> **M.-** The father and I would tell her that she had to go to the hospital, that she was a little bit sick and that why she was in the hospital. The medicines they were going to give her were to help her so she wouldn't be in the hospital bed anymore. That she would go sometimes everyday and sometimes every other day, that they would stick her hand but that would be all and she wouldn't stay more in the hospital. She was understanding what we said, I think she got the idea and adapted to it
> **I.-** Who taught you his way to teach your girl about the treatment?
> **M.-** The father was the one who started it. We have to teach her so she's going to get used to because every week we're taking her to the hospital and she's going to feel something strange, she isn't going get used to the needle stick and to stay there and all that.
> **I.-** It was an idea of
> **M.-** // He was the one who initiated it.
> **I.-** But both of you did it ?
> **M.-** Yes, both did it.
> **I.-** For example, if she's the appoitment tomorrow when do you start preparing her?
> **M.-** We told her like it is now; we tell her "tomorrow, you got to go to the hospital, that's tomorrow you got to get up very early or tomorrow you go in the afternoon" and she knows already. Oh! I'm going to the hospital, she even says my hospital. One day there was an interview on TV and she said Oh! that's my hospital where I go. So it's like is another part of her, like going to a place she usually goes, like school one could say.

Preparing her young child for having radiotherapy without general anesthesia was the way Elena could protect her son from the unwanted anesthesia and the fear of being alone in the radiotherapy room. She was very creative in finding a familiar event outside the hospital for the child so he could understand what would happen to him and how he should behave.

Elena's background as a preschool teacher might have helped her in creating ways to communicate effectively with her son.

> **E.-** Ya empezó radioterapia?
> **M.-** No pero yo ya lo llevé a él para que no me lo vayan a anestesiar. He preguntado a todo mundo y que si el niño no es voluntario entonces como yo no quiero eso entonces yo ya lo llevé. Primero fui yo y miré y todo, luego lo llevamos a Foto Japon y le tomé una foto y entonces le dije Pablo mira que en el hospital necesitan tomarte una foto de todo tu cuerpo pero va a ser con una cámara muy especial y vas a salir por televisión. Y entonces él se quedó callado y entonces al otro dia que lo llevé al hospital le dije ay! camina acompañame a donde te van a tomar las fotos pero allá es asi como acá que no te podes mover porque si te moves no sale bien la foto, te tenes que quedar quietico y asi como acá yo no puedo entrar sino vos solito y cuando yo vi que salió y se fue. Porque es que hay que irlo preparando para que no me le coloquen anestesia.
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> **I.-** He already began radiotherapy?
> **M.-** No but I took him so they wouldn't give him anesthesia. I've asked everybody and if the child isn't voluntary (the child wouldn't cooperate) and because I don't want that (anesthesia) I took him already. First, I went to see all that (the radiotherapy unit) and then I took him for a picture taken at Foto Japon. I told him "Pablo, look in the hospital they need to take a picture of your whole body but they're going to take it with a very especial camera so you can be on TV. He didn't say anything. And the next day, when I took him to the hospital, I told him Oh! let' s go with me where they are going to take your picture but there's like in the store that you can't move so your picture comes out very good, you got to stay quiet without moving, and like in the store I can't go in with you, only you can go in. It's that I should prepare him ahead so they won't give him anesthesia.

Elena's skillful knowing of how to prepare her son for the radiotherapy shows another aspect in which parents were quite experts in caring for their children without any teaching from the nurses or psychologists.

Some fathers played an important role in providing psychological support for the child before and during the painful procedures. Felipe was the one who prepared Pablo for the treatment and the needle sticks at the beginning of the illness experience. Elena did not see the benefits of doing such preparation; she thought it was not good idea to do so "W*hy to mortify him a week ahead?"*. Felipe used what was familiar and important for Pablo in order to encourage him to endure the pain from the needle sticks. He told Pablo to be brave because he is a macho and a fireman. Felipe is a fireman and he takes his children to the fire department on the weekends for the practice the firemen usually have.

Protecting the Child from Suffering Due to the Changes in their Physical Appearance

Some parents also prepared the child for the way they would look after losing their hair; they also bought hats for the child to wear and special shampoo and vitamins to decrease the hair loss. Parents consoled the children by telling them that the hair loss was temporary, they would have nicer new hair and that hair loss was a minor discomfort they should suffer in exchange of getting free from the illness. Keeping the child at home if she/he did not want to go to school due to the way she/he looked was another practice to decrease the suffering from being different. Keeping the teacher and students uninformed of the diagnosis also was a practice a mother did to prevent her son's suffering from being different because he requested her to do so. Another mother, also on her daughter's request, asked teachers to do something with the child's classmates so they would know what was happening to her daughter and would behave properly with her. It seems that with older children parents were willing to go along with what the child felt it was better for her/him and they did what the children requested to feel more comfortable in dealing with the physical changes. With younger children, parents were not concerned about the impact of the physical changes on the children because it did not seem to concern the children and also because the children accepted those changes faster.

Some parents were surprised and grateful that their children did not lose their hair and did not seem to look like having the disease at all. Some parents were glad the children gained weight due to the increased appetite during the time they were taking high doses of

Prednisone. Very few parents of older children mentioned that they and the child were uncomfortable with the changes in the child's face from the Prednisone but they understood these changes were also temporary and inevitable.

In summary, the parents were concerned mainly about protecting the children and helping them to recover. As one father pointed out "*The priority is to treat and control the illness and prevent other things that might impede his recovery, other things can wait*". In response to their concerns parents developed and established an array of practices as their way to protect the child and also to protect themselves from losing the child. Parents learned from each other about most of these practices; some parents created their own practices; other parents shifted their practices according to the changes they noticed in the child's condition. The parents' reflective engagement and love for their children allowed them to learn ways to cope with the illness and to keep up with the intense laborious work of building the child's immune system and protect the child from physical and psychological harm. Parents concerns and practices were primarily directed to protect the children from events that would endanger the child's life such as infection and other illnesses, bleeding, exposure to the sun and chemicals. Other practices were aimed to decrease the child's discomfort and suffering from having the immediate side effects of chemotherapy, the pain and fear related to having a deadly disease and the treatment procedures. The care providers provided very little counseling to the parents in caring for the children. The marvelous way most parents were taking care of their children without the providers' guidance indicates that parents, regardless of the dreadful situation they were going through developed the practical knowledge and skills necessary to take care of their children. Much can be learned by the health care professionals from the parents as truly skillful experts on their children and

CHAPTER 6: PARADIGM CASES OF LIVING WITHIN OR OUTSIDE OF A COMMUNITY OF SUPPORT IN CARING FOR A CHILD WITH CANCER

In this chapter, I will present two paradigm cases to illustrate how families from a very religious and catholic society explain the suffering caused by children's illness and death. Facing suffering and death is universal but the struggles in facing a child's suffering and death are concrete and particular for each parent. The theodicies parents use to explain such an evil for their child and for them are visible in the two paradigm cases. In other words, theodicy is an important issue in these parents' particular stories. The paradigm cases also show how families took up the illness into their lives. Most of the themes described in the earlier chapters are evident in the story of these two families. The parents' resolute commitment, everyday struggles, habits and practices in caring for their child as well as in living with the child's illness are discernible in these paradigm cases.

The first paradigm case is about Fernando, the youngest father in the study and his mother Lucia who joined their efforts to provide and care for their daughter and granddaughter Patricia. They were a middle class family with a great sense of internal and external support. The second paradigm case is about Cristina, the youngest mother in the study. Cristina had very little psychosocial support in coping with her daughter's illness. She was from the lower social class and had very few financial resources to cover the illness expenses. She also lived far way from her parents so she did not have the psychosocial support that Fernando had from the extended family. Laura, Cristina's daughter had a relapse of the leukemia so Cristina faced a more intense and extreme suffering due to her child's near death. The following sections will describe Fernando and Cristina's stories.

Finding Possibilities within the Losses

Fernando, 27 years old, is the father of Patricia, a 5 years old beautiful girl who has been

under treatment during 18 months. They live with Fernando' s parents, twin brothers, and 11 years old nephew in a city 30 minutes driving from Cali. Lucia, 56, the paternal grandmother is acting as the mother since Patricia' s mother left them two months after the diagnosis of the Leukemia. Fernando' s father is the only provider for the family except when Fernando finds a temporary job. At the time of the diagnosis, Patricia did not have health insurance but later she got health insurance through her mother with a private HMO.

Patricia' s illness has affected all the members of Fernando' s family but especially Fernando and Lucia, who are the ones in charge of the care and treatment. So this paradigm case is to describe the way Fernando, Lucia and the whole family successfully cope with the multiple losses they suffered due to Patricia' s illness. The first loss that Fernando suffered was his healthy daughter; then he lost his wife and the mother of his daughter. Lucia also lost her healthy granddaughter, her everyday peaceful routine as mother, wife, and grandmother. Both, Fernando and Lucia lost their tranquility and the relative certitude of their everyday life. However, they find they have been able to get over all these losses thanks to their strong religious faith and the loving and caring relationship among them, which enable them to care for Patricia and continue with their lives in a way that really could inspire other families.

Their story also shows how important is the support from the extended family for a young father, when dealing with a dreadful situation without having his wife's support. Stories like Fernando' s are becoming more common in the Colombian context. Before, mothers did not leave their ill children but now it is something that happens quite often, at least in the context where the study was conducted. In 1996 when I did the pilot study, there were not such stories but two years later I knew about 3 similar stories when I was recruiting the participants. In other words, this is a new and very surprising phenomenon in our context.

We are used to see fathers moving away from their responsibilities with their children but we are not used to see the mothers doing the same, especially when they are ill.

The data about this family was collected through the interviews mainly with Lucia and Fernando. Sometimes the paternal grandfather participated in the interviews with the grandmother. Patricia also participated in the interviews with both Lucia and Fernando. I did not interview Patricia' s mother because Lucia and Fernando told me she did not want to talk with anybody about Patricia' s illness. I did not know how to contact her either.

Losing a Healthy Child

Patricia' s illness began with a simple fall in which she hurt one of her feet. She got a hematoma and could not walk without limping so Fernando took her to see the Orthopedist. He did x-rays but did not find anything wrong. He prescribed orthopedic shoes, which Patricia wore for some time. The limping got worse so they went to another Orthopedist, who sent her with a Psychologist because she was using her pain to manipulate her father. Instead of going to the Psychologist, they went to see the Pediatrician who diagnosed anemia and prescribed iron. The girl became sicker with fever, vomiting, and inability to walk. Lucia advised Fernando to take Patricia to an Orthopedist in Cali. As soon as the Orthopedist saw Patricia, he knew the diagnosis, which was confirmed by the blood tests. So he referred her to the Oncologist.

Getting the diagnosis of leukemia meant, for everybody in the family, that they would lose Patricia relatively soon. Lucia remembers how hard was for all of them but especially for Fernando to learn the diagnosis.

> A.- Entonces, ya le digo yo "Doctor que tiene la niña?" Me dijo "La niña tiene una Leucemia". Oyó esa palabra él (Fernando) y se puso a llorar como un niño chiquito, lloraba y lloraba y entonces el Doctor se calló. "Esperemos que se tranquilice" y entonces le dije "No, doctor siga hablando". Entonces ya fue cuando él nos dijo pues

> de que el caso era delicado, que era bastante grave, pero que él le da un 70% de supervivencia; que había que hacerle la Quimioterapia, que pues las posibilidades de que se le cayera el pelo, que pues era lo mas seguro que todos los niños se les caía pero que eso les volvía a salir. Que eso (la quimioterapia) no les hacía nada, que de golpe pues si le daban sus trastornos vomitaba y le daba tantas cositas, pero entonces ya era lo normal, pero que todo eso le pasaba. Pero pues el momento fue duro, duro, duro pues porque este muchacho quedó deshecho. Yo no hallaba pues como consolarlo, a mi tocó hacer de viga, de fuerte..... y pues el mundo se nos vino encima a todos. Se volvió el caos, ya nadie comía, todos bajamos de peso, esto mejor dicho fue el acabóse.

> **Gm.**-Then, I tell "Doctor, what does the girl have?" He said to me "The girl has leukemia". He (Fernando) heard that word and he started crying like a little boy, crying, crying, and crying and then the doctor stayed quiet. "Let'swait for him to calm down" and I said to him "No, doctor keep talking. So he told us the illness was serious, very grave but that he would give her 70% survival; that she needed the chemotherapy, the possibility that she would lose her hair which was pretty sure because all the children lose their hair but it would grow again. He said that (the chemotherapy) would cause any problem, maybe she would have some problems like vomiting and other minor things, but all that was normal and it would go away. That moment was hard, hard, hard because the boy was shattered. I didn't know how to console him; I have to be the joist, to be strong one. ..... the whole world crushed on all of us. That was chaos, nobody wanted to eat, and everybody lost weight; in other words, that was the end.

Lucia saw herself in her son's pain; she understood her son's suffering as being similar to her suffering when one of her twins babies was very ill in the hospital. She could relate very much to her son's suffering because both are parents and could know the meaning of having and losing a child. She understood pretty well what Fernando was going through. Both use similar language to describe their feelings at the time of the diagnosis.

> **A.**- A mi se me juntó el cielo con la tierra, mejor dicho como si el mundo se acabara, porque yo me ponía en lugar de él. Mi hijo está sufriendo lo que yo sufrí en aquella época, pensar que voy a perder mi hijo; él ya lo ha tenido entre sus brazos, él ya tiene recuerdos, tantas cosas, no ? Pero lo mismo le da a uno que tenga los recuerdos a no, porque yo no tenía ningún recuerdo de mi bebé y me se estaba muriendo, estaba lleno de cables, lleno de cosas y yo ni siquiera podía meter las manos entre esa encubadora pa'tocarlo. Entonces yo sentía que, mejor dicho, el mundo me estaba apachurrando a mí. Entonces yo decía él debe estar sintiendo lo mismo que yo siento, porque es papá. El debe estar sufriendo lo mismo que yo, siente lo mismo porque él ya es papá, él sabe lo que es perder algo que es de uno, así sea prestadito porque Dios le presta a

> uno el hijo por cierta época, los hijos se van y ya no es de uno sino de otra. Entonces yo por eso decía ¡uy se acabó el mundo, esto es horrible! Es que uno no le encuentra, en ese momento uno como que no encuentra solución, como que todo se le cierra, todas las puertas las ve uno cerradas, como que uno se está ahogando ahí si como en un vaso de agua, no?
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> **Gm.**-For me, it was like the sky got on top of the earth, like the end of the world because I was in his position; my son was suffering what I suffered at that time thinking I was going to lose my child. He has had her in his arms, he has lots of memories, so many things right? It's the same to have or not to have memories because I didn't have any from my baby and he was dying, with all those cables and all those things and I couldn't get my hands in the incubator to touch him. So I felt the world crushing me. I thought he's suffering as I suffered, he's feeling because he's a parent. He knows how it's to lose something is his own; it doesn't matter it's ours just for a while because God lets our children for some time, then they go away with somebody else. That's why I thought Oh, this is the end of the world! This is horrible! It's that one doesn't find, at that moment, it's like one doesn't see any solution, it's like all the doors are closed for you, like one is drowning in a glass of water, right?

Fernando was desolated by the diagnosis despite his prior intuition that his daughter's illness was something serious. He felt alone even though he was with his mother in the physician's office and outside were his father and sister. His wife was not with him at this moment probably because she was working. He thought his daughter would die. So, it was the end of his world.

> **E.**- Fernando, cómo fue para ti ese momento en que oiste el diagnóstico?
> **P.**- Horrible! La reacción mia fue muy, muy, muy, muy .. de pronto yo lo esperaba.
> **E.**- Y por qué?
> **P.**- Por los resultados del exámen. Cuando yo tenía el resultado del examen el día anterior, tenía hemoglobina de 5, plaquetas en 20.000, o sea yo ya
> **E.**-Tu por qué sabías que no era normal ?
> **P.**- Porque nosotros, o sea, una Leucemia no pero si algo malo, grave porque eso no es normal, o sea normal que tenga, que tenga sus cosas, su hemograma en eso no es normal. Entonces ya esa cosa que iba yo prevenido, guardando una esperanza que me digan no tranquilo vamos a .. pero cuando me dijo eso el doctor .. o sea, asi como lo dijo mi mamá yo empecé a llorar y yo lo escuchaba, yo me ahogaba, a mi me dieron muchos nervios. Yo sentí que hasta allí llegó mi vida, el mundo a mi se me acabó. Eso para mi fue muy duro ..... fue horrible, horrible, horrible y yo estaba con mi mamá pero yo estaba solo, en ese momento o sea a yo estaba con mi mamá pero yo me sentí muy solo. Mi mamá, gracias a Dios siempre he tenido a mi mamá ahí para lo

> que sea he contado con mi mamá. Pero a ver de pronto, por qué le digo que yo me sentía solo? Porque yo creo que una cosa de esas es con la esposa y pues yo, o sea yo he sido, yo era muy.. yo siempre .. mi papá y mi mamá ya llevan treinta y pico años de casaos. Cuando yo me casé, yo esperaba eso que mi matrimonio fuera así pero no yo nunca tuve la compañía de ella y menos en ese momento, para mi eso fue muy duro, para mi fue muy duro eso.
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> **I.-** Fernando, how was for you that moment when you heard the diagnosis?
> **F.-** Horrible! My reaction was very, very, very .. maybe I expected it
> **I.-** Why?
> **F.-** Because of the test results. When I got the test results the previous day, it showed hemoglobin of 5, 20.000 platelets, that's I already
> **I.-** Why did you know it was not normal?
> **F.-** Because we, that's, not a leukemia but something serious because that isn't normal. That's normal to have some things but a hemogram like that it isn't normal. So I was expecting but hoping they would tell me "Don't worry". When the doctor told me that (the name of the disease) like my mother has said it, I began crying. I listened to him, I felt suffocated and very anxious. I felt that was the end of my life, the world ended there for me. That was very hard for me….. It was horrible, horrible, and horrible. I was with my mother but I felt that I was alone at that moment. I was with my other but I felt alone; this news thanks God I've always had my mother with me whenever I need her. But let's see why I felt alone. Because I think you should share something like with your spouse. I've been, in other words, I was very .. I've been always .. My mother and father have been married for more than 30 years and when I got married I was expecting my marriage would be like theirs. But I never had her company so it was very hard, very hard for me.

In recalling the moment of the diagnosis Fernando is struck with both his bond to his mother and his sense of isolation and distance from his own wife. The moment is deeply relational in that it raises for him this issue of his bonds across generations to both his mother and his daughter.

Fernando could not see a solution for his daughter's situation neither he could see the future. Getting the diagnosis was like losing his future life because Patricia was going to die and she was everything he had. This a feeling most parents have; losing a child means losing the parents' future.

> **E.-** Para mi es importante entender, o sea ustedes los dos han dicho "se nos acabó el mundo". Qué es eso de que se nos acabó el mundo ?

> **P.-** Yo qué pensé en ese momento ? Se me va a morir mi hija, eso fue lo que yo pensé, inmediatamente eso fue lo primero que me llegó a mi a la cabeza, se me murió mi muchacha, y por qué se nos acaba el mundo? Porque es mi vida, ella significa todo para mi y que se le muera un hijo y tan pequeña. Eso fue lo primero que yo pensé, entonces ahí es donde yo digo se me acabó el mundo, o sea yo sentí que todo se me acabó, era como que uno ya no, para adelante que ve uno? Negro, negro, yo veía negro, uno no ve, no ve uno como una lucecita al fondo, no? Es lo primero que se me vino a la cabeza.

> **I.-** It's very important for me to understand, both of you have said "the world ended for us". What is it that the world ended for us?
> **F.-** What did I think at that moment? My daughter is going to die, that was my thought, immediately that was what came to my mind, my girl is going to die and why the world ended? Because it's my life, she means everything to me and if your child die and so young. That was my first thought so there's that I say the world ended for me, it was like one doesn't see anything ahead. Black, black, I was seeing it black; one doesn't see even a tiny light at the end, right? It's the first thing that came to my mind.

Fernando and his parents had previous experience with leukemia and cancer. They knew three children with leukemia; all three children died including the one who came to USA and had a bone marrow transplant. There are also relatives from both sides of Fernando' s original family who died from different types of cancer. The above experiences taught Fernando and Lucia that Leukemia is a fatal disease. Therefore, the diagnosis was devastating for them regardless that they were somehow intuited the diagnosis and that the physician told them it was a 70% chance of survival for Patricia. Lucia knew some of the symptoms from the children she had known so she thought that Patricia might have leukemia before the Oncologist told them the diagnosis. Fernando also thought ahead that his daughter's illness might be grave.

The idea of doing something for his daughter and the support he got from everybody in the family gave Fernando the possibility to move on and to do what was expected for his daughter. So they started the treatment in the teaching hospital. Two days later, the maternal grandparents took Patricia to their home and interrupted the chemotherapy. They signed a voluntary discharge from the hospital and took Patricia with them without asking the consent of the paternal grandparents; they called Fernando at work to let him know what they did with Patricia.

The maternal grandparents are physicians; the grandmother sometimes was Patricia' s Pediatrician and the grandfather practices alternative medicine. They told Fernando and the whole family Patricia would die regardless of the chemotherapy, which reinforced Fernando' s understanding of the disease. They also said treatment would prolong Patricia' s life and cause her more pain and suffering. Therefore, it was better to take her home and try an alternative treatment grandfather would do. In so doing the girl could die among her family with less pain. The maternal grandparents continued the alternative treatment but Patricia did not get better. On the contrary, she got sicker and sicker. Only the parents and the maternal grandparents took care of Patricia; nobody else was allowed to see Patricia during that time. No family member from the father's side was allowed to visit the girl purportedly because she was inmunologically depressed. Patricia did not have chemotherapy for four months.

At first, I could not understand Fernando readiness to abandon the treatment. He did not fit into the stereotype of parents who usually abandon the treatment. Typically parents who stop treatment are poorly educated, with very few financial resources, and many children to care for. Fernando is an educated person, he does not have stable job but he has his parents' financial support, and Patricia is his only child. His reasons for abandoning the treatment included his understanding of the disease as fatal, his genuine desire of protecting his daughter from suffering from the treatment and maybe by prolonging her life, and his need of having his daughter close. He also said *his parents-in-law were #1 Psychologists in getting* *him to agree*. This could mean he, a young and inexperienced man, was very susceptible to the influence of old and experienced persons who also were physicians and seemed concerned about his daughter. It also could mean he was so confused and hopeless that he could not see what was better for his daughter.

> **E.**- Que te hizo estar de acuerdo con ellos, en lo que ellos hicieron en ir solo a la homeopatía. Si yo te preguntara cual fue esa cosa, podrías señalar eso que te hizo
> **P.**- Por qué tomé esa decisión ? Creo yo, que yo tomé esa decisión, o sea me tocaron la niña, no? Me dijeron que iba a ser algo donde la niña no me la iban a martirizar, no me la iban a chuzar ni me le iban a hacer sufrir, no ? Y dije pues, hagámole por acá es. Eso es lo que mas influyó, eso fue lo que mas influyó.
> **E.**- Evitarle sufrimiento a ella ?
> **P.**- Si, si, si. Si a mi me dicen no a la niña vamos a ponerle unas inyecciones por no se donde, si lo había pensado no? Lo había pensado porque es diferente a usted que le estén chuzando aquí la mano para ponerle la droga, a que la chucen por aquí, hacia arriba y le metan un líquido especísimo. A mi me dicen eso, lo había pensado muchísimo. Pero como ellos me dijeron no hay nada de chuzones, no hay tortura para la niña, esas eran las palabras no? Pero pues, ya en este momento, ya no me puedo poner a pensar, si no lo hubiera hecho, si de pronto hubiera dejado, no porque ya no saco nada con eso, ya no saco nada con eso, ya lo hecho, hecho está, como se dice a lo hecho pecho, ya uno no tiene
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> **I.**- What was it that made you agree with them, with what they did about only having the homeopathy? Can you tell me one thing that made you to agree with that?
> **F.**- Why did I make that decision? I think that I made that decision because they told me the girl wouldn't suffer with the treatment they were going to do, that it would be something wouldn't hurt her, that she wouldn't get needle sticks neither she would have pain. So I said "O.K, let's do it!". That was what most moved me.
> **I.**- To prevent any suffering for her?
> **F.**- Yes, yes, yes. If they tell me that they're going to give her some injections, who knows where? Yes, I would think it more carefully. Because it's different when they're sticking the needle in your hand to give you medicines to when they're sticking up here and injected a very thick fluid. If they tell me that I would think more carefully. But they told there're not needle sticks, no torture for my girl; those were their words. But at this moment, I can't allow me to think on that because there isn't anything I can do to change what I did, I did it and that's it.

It seems that Fernando and everybody else in the family were very hopeless and they began mourning Patricia' s death in anticipation. Fernando was somehow paralyzed and unable to see other options for his daughter. Perhaps because of their belief in the disease as

fatal, all family members on Fernando' s side of the family felt ambivalent but supportive of the alternative treatment. Their relative distance from the child may also have contributed to their acceptance. However, when finally Lucia saw her granddaughter, who at that time was gravely ill, she took all action possible to re-enroll her granddaughter in chemotherapy. After four months without chemotherapy, Patricia was allowed back into the treatment only with the promise of the grandmother and father to follow strictly the oncologist's orders. Since that time Patricia' s health has improved, despite having had appendicitis with peritonitis and one episode of bronchopneumonia. During the interviews she was doing very well, only having low blood counts a few times after getting the chemotherapy. She was getting loving care from her father and paternal grandparents.

Illness Understanding Over Time

The parents' understanding of the illness influences their concerns, practices, and habits related to the care of the ill child and the entire family as well as the possibilities they find in their lives. The parents' grasp of the illness changes over time based on their experience with the illness and the actualized realities they perceive in their own child and in other children.

At the time of the diagnosis, both Fernando and Lucia understood the disease as fatal and hereditary. After 1½ year of treatment, they perceived it as chronic but controlled by the chemotherapy. Both parents also perceive the illness as God's will, so there is nothing they can do about it other than accept it and try to get the best from it. They try to keep the illness out of their minds, which sometimes leads them to forget to give Patricia the medicines on the exact time they should.

> **E.-** Doña Lucia, en un día común y corriente usted piensa en la enfermedad de Patricia?
> **A.-** No, no señora, a veces pasan los días que a la única hora, como en estos momentos que no se le está dando droga de esa sino la Mercaptopurina, entonces

> llega uno por las noches ¡ay ! el remedio de Patricia, y a veces es que se nos quiere escapar; que a las 10 de la noche ¡uy ! el remedio de Patricia. A mi digamos de que se me olvide dárselo nunca se me ha olvidado, en cambio aquel (Fernando) si se le pasa, a él si se le pasa la media pastillita
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> **I.-** Doña Lucia, in a regular day, do you remember and think about Patricia' s illness?
> **Gm.**-No, no; sometimes the days go by and the only time, like right now that she's getting only the Mercaptopurina, so at night Oh! The medicine for Patricia; sometimes it's like we almost forget; at 10 P.M, oh! [we forgot] the drug for Patricia. I never have forgot it but that one (Fernando), he has forgot the half pill.

From the time of diagnosis to the point of the interviews, Fernando changed his assessment of leukemia from that of an inevitably fatal disease to one that can be controlled by treatment, but could relapse at any time. He also sees the illness as something real that is still with them but does not cause Patricia and them the same suffering it caused at the beginning. Fernando needs to believe her daughter does not have the illness in order to be able to go on with his life and make plans for the future. Fernando, as other parents, does not understand the biological aspects of Leukemia but this does not preclude him from taking good care of Patricia. He just understands it is a disease of the bone marrow with an increase in WBC, which attacks and destroys the RBC and other cells in the blood.

Fernando does not deny the illness; he has learned to live with it and to see it as something real but at the same time something that is under control. Time and their everyday experience with the illness have made it familiar and less terrifying for him. The great clinical evolution of Patricia, especially in the last nine months is the paramount event in the new way he now understands the disease. In a way he has recovered his healthy daughter and he is going to enjoy her as long as he can.

> **E.-** En este moment han habido cambios en la manera como percibes o entiendes la enfermedad?
> **P.-** Pues la percibo si porque la tengo allí, cierto? La he tenido ahí con ella. La he aceptado, tocó aceptarla porque si no se aceptaba qué se hacía? Porque es algo que es

> real, no cierto? Que ahí está, y no ya no, de pronto ya no, de pronto será que coge uno como la experiencia, no? la experiencia lo va a uno como … tomando las cosas mas calmado. Aunque sigue un temor, no?, Que es el temor que yo a usted le he dicho que de un momento a otro uno no sabe qué pueda suceder porque casos se han visto, ahí en el hospital. Pero pues de resto, las cosas creo que han mejorado en ese sentido no? Porque uno se compara, entonces yo me he comparado las veces que yo he ido yo me he comparado con señores, padres de familia que llegaban por primera vez. La cara de tristeza, esa amargura tan grande, <u>como ese dolor</u> que siente uno adentro y que uno ya no lo está sintiendo no? Ya lleva uno año y pico en eso. Entonces uno si ha cambiado mucho, mucho porque ya uno ve las cosas de acá ya está uno metido en el cuento, ya lo aceptó, está viendo uno la evolución de la niña entonces está uno mas tranquilo, mas tranquilo.
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> **I.-** Have you changed the way you perceive or understand the illness?
> **F.-** I perceive it because I have it there, right? I've had it with her (Patricia). I've accepted, I have to because if I don't accept it what I would do? Because it's something that's real, right? It's there and I don't, maybe it could be that one gets familiar; the experience with it makes you take things with more calm, even though there's a fear, right? I've told you before that I'm afraid that in any moment something, that we don't know, can happen because there have been cases like that in the hospital. But other than that, things have improved because I compare myself with the parents who come for the first time; [they come with] sadness in their face, with great sorrow, with <u>the pain</u> that one feels inside. I'm not feeling that way, I've been in this for more than a year. So I've changed a lot because one sees the things differently when one has gone a long way; one has accepted it. I've seen my daughter's evolution so I'm more tranquil, calmer.

Lucia was less optimistic about the illness prognosis than Fernando but she also acknowledged that Patricia might survive free of the disease for a long time, "*we might die before"*. However, for Lucia and Fernando any change in Patricia' s condition or the death of other children implies a shift in their grasp of the illness and of course in their possibilities as Patricia' s grandmother and father.

<u>Losing the Wife and the Mother</u>

Almost two months after the diagnosis of the leukemia, Fernando lost his wife. One day that both parents took Patricia to get a blood transfusion prescribed by the grandfather, Patricia' s mother told Fernando she was tired of living with him and did not want to do so anymore. Without any discussion of the mother's decision, Fernando went to live with his parents. However, he requested to visit Patricia every day which he was allowed to do.

> **P.-** Eso sucedió cuando ella me habló fue el primero de Diciembre del noventa y seis. Ella me dijo, estábamos en la Cruz Roja transfundiendo a la niña, ella me dijo que tenía que hablar conmigo algo muy serio. Le dije pues hablemos. Qué es? De la niña o qué será? O del trabajo, porque ella me comentaba y yo le comentaba. Entonces yo le pregunté que qué era. No, que se había aburrido de vivir conmigo, no quería vivir mas conmigo, en ese momento ella me dijo pero que le dejara la niña, que no quería perder la niña. Yo le dije "Es que yo a la niña no se la voy a quitar porque pues por derecho le toca, los hijos están con la mamá", cierto? Eso es lo que uno siempre ha visto. Yo si le dije que yo todos los días iba a ver la niña en cualquier momento, porque pues en ese momento, donde yo estaba trabajando era con una tía y ella me colaboró mucho en las cuestiones del tiempo, de dedicarle un tiempo a mi hija. Ella, yo le decía para, cualquier cosa y ella me colaboraba. Entonces yo por eso le dije a ella eso, le dije que lo único que yo le pedía era que yo a la niña la quería ver todos los días que yo quisiera
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> **F.-** It happened, when she called me was December 1st/96. She told me, we're in the Red Cross
> Having a blood transfusion for the girl, she told me that she needed to talk with me about something very serious. I told her O.K. let's talk. I asked her what was it? She got tired of living with me, that she didn't want to live together; she said that to me at that moment, that she wanted the girl with her, that she didn't want to lose the girl. I said "I'm not going to take her from you because you have the right to have her, children belong with their mother", right? That's what one always has seen. But I told her I would visit the girl every day, at any moment. Because I was working with my aunt and she gave me all the time I needed for my daughter. That's why I told her that the only thing I would ask was to see the girl whenever I wanted to.

Fernando was very amazed by his wife's decision about not wanting to live with him. According to Fernando they had a good relationship before and during the early months the illness. They did not have much money because sometimes he did not have a job but they were able to satisfy their needs. Fernando acknowledges that she always did help him with the money needed for the family. She worked all the time as preschool teacher and whenever Fernando was not working he took care of Patricia. They used to have the usual arguments couples have but they talked and were able to live for four years without greater problems.

Fernando also had good relationship with his parents-in-law. Most of the time they lived either with Fernando' s parents or with her parents. Fernando has not talked with Patricia' s mother about the reasons for her decision.

He did not seem to expend much energy in dealing with her reasons for ending the marriage; "*she got tired, all right, that's it. I stop there. I didn't look for more reasons*". It was a huge surprise for him because he felt they had a good relationship as a couple. It was also very painful especially because he thought they should be together at that moment for their daughter. It was very clear for him she did not want to share her life with him and she did not love him anymore regardless that he could not find the reasons for her decision. Fernando did look for the reasons within him; the only possible reason he found was his way of being impatient and hot-tempered.

One week after Fernando went to live with his parents, Patricia' s mother called Fernando to ask him to go the following day to get Patricia. Fernando thought she wanted him to have his daughter for the weekend but when he got to the house, he was surprised by the fact that Patricia' s mother also got tired of taking care of her daughter. She had packed Patricia' s belongings in a suitcase and asked her sister to tell Fernando he should take Patricia with him. So Fernando took Patricia with him to live with his parents again. The alternative treatment was continued for about another two months.

> **P.-** El 7 de Diciembre me llamó a la oficina, el 6 , [me dijo] que fuera el 7 por la niña. Me llamó que fuera por la niña, yo me imaginé que era el fin de semana por ser el alumbrado.
> **E.-** Ahi fue cuando le tenían todo listo
> **P.-** Si, me tenían todo listo y me dijeron que me trajera la niña. Inclusive ella no estuvo presente para que yo me llevara la niña, pero después me dijo que si la niña algún día, si Dios quiere la niña se curaba que se la devolviera. Las palabras mías fueron "aquí no vamos a decidir ni usted ni yo solamente la niña, y Dios proveerá y veremos que es lo que pasa".

F.- On December 7, she called at work, it was the 6. [She told me] to go on the seven for the girl. She told me to go and get the girl, I thought it was because of the weekend
I.- That was when she had everything ready
F.- Yes, she had everything ready and I was told that I should bring the girl with me. She even wasn't there to ask me that but later she told me if the girl would get better someday to bring her back with her. My words were "Neither me nor you are going to decide that, only the girl and God will provide so we'll see what happens"

Fernando began to get over losing his wife when she gave up on their daughter. At that moment, he felt very angry and disappointed at her; he began disliking her. Seeing his wife as a mother who rejected or distanced herself from the daughter allowed him to distance himself emotionally from his wife.

E.- Aceptaste ya eso (la separación) y dijiste "sigamos de aquí para adelante"
P.- Usted por su lado y yo por el mío. Me dio muy duro, a mi lo que me ayudó a salir adelante fue cuando me entregó la niña, pues yo le cogí rabia, si le cogí rabia. Cómo es posible que una mamá que le había dolido el tener su hijo, pues yo se, yo vi nacer mi hija, y me di cuenta que sufrió mucho, la deja diciendo que está aburrida con la enfermedad de la niña, que está cansada. Eso me dio a mi mucha rabia, eso si me dio rabia y le cogí fastidio a ella. Entonces de ahí eso me ayudó mucho. Claro, ahora nos sentamos, hablamos, nos reimos, llega y me llama a decirme y a contarme cosas y yo tambien le comento a ella.
E.- Tienen una buena relación
P.- Si por teléfono
E.- Personalmente no?
P.- No, personalmente nos vemos y hablamos pero procuro no .. porque yo me exalto mucho y son cosas que son difíciles de olvidar, no? Son difíciles de olvidar. El hecho de que yo tenga mi niña a mi eso .. yo me he puesto a pensar yo me enfermo y yo a quien busco a mi mamá, la primera persona que yo busco es a mi mamá, a mi mamá.

I.- You accepted that (the separation) and told yourself "Let's go ahead"
F.- You go your way and I will go my way. It was very hard for me; what helped me to go on was when she gave me the girl because that made me angry with her, I got angry with her. How is it possible for a mother, who has felt the pain of giving birth to her child, I know that because I was there when my daughter was born and I saw her pain, to leave her because she is bored with the girl's illness, that she' s tired of that. That made me very angry and annoyed. So that helped me a lot. Of course, now we talk and laugh; she calls me to tell me things and also tell her things.
I.- You have a good relationship with her
F.- Only over the telephone

> **I.**- In person, not?
> **F.**- No, we get together and talk but I try not to .. because I get upset very easily and there are things that difficult to forget, right? Those are difficult to forget. The fact that I have my girl with me that is .. I've thought I get sick and the person I go to is my mother, the first person that I look for is my mother, my mother.

Fernando has tried to understand Patricia's mother but he can not accept her giving up on her daughter when she needed most. In all three interviews he talked about being incapable of understanding the reasons the mother had for leaving her daughter when she was so in need of her love and care. For him, it is something that is almost against the nature of a mother. Fernando can not forgive her for doing that to their daughter. He still resents her for doing it. But he somehow tries to relieve her from the blame of what she did. He thinks she does not have support and help from her parents but the main reason might be she did not receive love and care from her parents so she could not give that to her daughter. He did not criticize her mothering and said only that he was the one taking care of their daughter even when Patricia was a newborn and when he was working. My understanding is that having the support and the help from his parents and especially from his mother in caring for Patricia has been the main reason for Fernando to be able to go on with his life with relative ease, despite his situation.

> **P.**- ….. pero no me ha preocupado no tener el apoyo de ella en la cuestión de la educación de la niña, el cuidado de la niña, no me ha preocupado para nada.
> **E.**- Ni te preocupa para el futuro ?
> **P.**- Mientras las cosas sigan como están, no, no.
> **E.**- O sea, mientras cuentes con el apoyo acá de tu papá y de tu mamá
> **P.**- Si, si. Yo se que eso es incondicional, eso es incondicional porque en todo los he tenido gracias a Dios, y de muy buena voluntad, de muy buena voluntad. Entonces, yo mientras las cosas sigan así no, no, no me preocupa, no me preocupa.

> **F.**- …… But I haven't been worried because I don't have her support in raising and caring for the girl; that doesn't worry me a little.
> **I.**- It doesn't worry you in the future either?
> **F.**- While things are like they are now, no, no.

> **I.-** That's while you have your parents' help?
> **F.-** Yes, yes. I know that is unconditional, unconditional. I've had them always thanks God! And they do it because they want to. So I'm not worried as long as things are like that, I'm not worried.

One year after the separation, Fernando is in another relationship with a Physical Therapy student. He is very much in love with her and Patricia and everybody in the family have accepted. It is very important for him that the woman who is involved with him should love his daughter also. During the last interview, Fernando talked at length about her and all the things they are planing for their future together. He also has been able to accept that Patricia' s mother takes Patricia with her over the weekends, even though he is not obligated to allow her that since he has sole custody. He does that mainly for Patricia; he does not want her to grow up without her mother neither he wants her to reproach him later for depriving her of the mother.

Losing the Everyday Tranquility and Certitude

Lucia and Fernando highlight the ways in which their lives are no longer the way they were before the illness. Living with Patricia' s illness has impacted their lives in many senses. All the demands of the illness situation change the everyday smooth routine for everybody in Patricia' s family. Fernando stopped working; he dedicated all his time and energy to care for his daughter with his mother's help. Lucia took on more responsibility besides caring for her husband and children. Both learned to endure the uncertainty about Patricia' s future.

> **A.-** Pues una cosa tenaz, una enfermedad tenaz, mejor dicho un cáncer que pues hasta que lo que uno ha sabido, se da cuenta hasta ahora pues no ha sido curada, no? Entonces uno vive como preparado, nosotros aquí decimos no es que a Patricia le regalan una cosa y se la ponemos inmediatamente, porque mañana no sabemos. Entonces nosotros sabemos que es una enfermedad grave que hasta ahora como le digo uno no le conoce cura. Nosotros tuvimos la experiencia con una niña, era de un trabajador allá de la finca de un tío, de un hermano de Hugo que le dio Leucemia, y ella allá la tuvo el Doctor Pereira, le hicieron la quimioterapia y todo el tratamiento, pero a pesar de los esfuerzos que se hicieron con esa niña, ella falleció. En esa época

yo no me imaginaba que la enfermedad fuera tan deteriorante; ahora ya me doy cuenta de que si, que hay unos que se deterioran mas que otros y que me he dado cuenta que niños que ya están dados de alta vuelven a recaer, porque hay niños que duran seis meses que al año recaen y ya varios casos conozco así. Entonces uno, Patricia se ve excelente, ella está increíblemente bien
P.- // Pero hasta cúando?
A. Pero hasta cúando? Entonces nosotros mantenemos a Patricia
P.- //Yo lo catalogo como una lotería, así la catalogo yo.
E.- Por qué ?
P.- Porque usted el día menos pensando se puede ganar un premio.
E.- Y ese premio ?
P.- Puede ser malo o puede ser bueno, en el sentido como dice mi mamá. Nosotros pues si nos preparamos pero una cosa es decirlo y otra cosa que le vaya a suceder a uno. Porque mire que si uno está preparado a que la niña le puede dar cualquier cosa pero cuando le dio la apendicitis, fue tremendo y mas cuando el diagnóstico era con peritonitis localizada

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Gm.- It's something awful, an awful illness; a cancer is something for which, at least from what one knows, there isn't a cure, right? So one lives somehow prepared, if somebody gives Patricia a gift immediately we would put it on because we don't know what is going to happen tomorrow. We know it's an illness without cure. We had the experience with the girl of one of the workers from my brother-in-law's farm who also had leukemia. She was seem by Dr. Pereira (the same oncologist seen Patricia), she had chemotherapy and all the treatment but despite all what they did she died. At that time, I didn't know that the illness was so deteriorating; now I know it's so, there are children who deteriorate more than others; we've known children that had finished the treatment and later have a relapse. There're children that after 6 months or a year had a relapse, I know a few of them. Patricia looks excellent, she's doing unbelievably well.
F.- But for how long?
Gm.-But for how long? So we keep Patricia
F.- // I consider it (the illness) as a lottery, that's how I see it
I.- Why?
F.- Because you can win a prize the less expected day.
I.- And the prize is
F.- It could be bad or it could be good in the sense that my mother says. So we're prepared but there's one thing to say it and another what would happen. We're prepared to face anything that happens to her but when she had the appendicitis it was awful and even worst when they said it was a localized peritonitis.

Lucia's understanding of the disease as something that is chronic is the motive for her to expect that any day something bad would happen to Patricia. She fears there would be a moment when Patricia can die from the disease or from a complication such an infection. So there is a constant fear within their lives despite Patricia' s recovery.

> **Ao.-** Pero en estos momentos yo digo que .. yo ya he visto que salen niños de alli, no? Y hay casos ahi como este peladito de
> **A.-** El Luz Estela, ya era un niño con recaída y le hicieron los dos años siguientes y hasta ahora salió en Enero, en Noviembre salió y hasta ahora va bien. Entonces ya no la veo asi como tan mortífera. Pero de que mantiene uno con temor, si mantiene uno, será lo normal y natural pero si siente uno siempre el temor.
> **E.-** La incertidumbre de que va a pasar?
> **Ao.-** Hasta cuando nos va a acompañar?
> **A.-** Si pues cúantos años mas se le alarga la vida o si va a ser que nos morimos nosotros primero.
> **E.-** En este momento usted cree que es una enfermadad tratable o curable ?
> **A.-** No, puede ser tratable, la cura la tenemos en duda, digamos yo; de golpe se pueda tratar y por muchos años.
> **E.-** O sea que se vuelve como crónica
> **A.-** Exacto!
> **Ao-** Puede ser como lo que decíamos ahora lo del mantenimiento, puede ser con el mantenimiento que se vaya alargando la estadia de ella.
> **A.-** Si, yo cura, cura segura, es muy difícil porque hasta ahorita el cáncer no lo hemos visto curar, cierto? Pero
> **Ao.-** // Pero hay casos excepcionales, dicen que son milagros
> **A.-** Pero puede que [ella] se sostenga ahí con su mantenimiento y que sea su tratamiento largo, pero pues que se pueda mantener allí.

> **Gf.-** Right now, I think that .. I've seen children getting out of there, right? There are cases like the kid
> **Gm.-**Luz Estela's; he was child with a relapse and they treat him for another two years and now he's fine; he got out of there in January or November and he's doing fine. Then, I don't see it as lethal . But one is afraid, yes one has that fear; maybe it's normal or natural but one always feels that fear.
> **I.-** The uncertainty of what is going to happen"
> **Gf.-** For how long is she going to be with us
> **Gm.-** Yes, for how many more years she's going to live or if we're going to die first.
> **I.-** Right now, do you think it's a treatable disease or a curable disease?
> **Gm.-** No, it could be treatable; we doubt the cure, at least for me. Maybe, it could be treated it for many years.
> **I.-** In other words, it becomes chronic
> **Gm.-** Exactly!
> **Gf.-** It could be as we're saying now with the maintenance, it could be that with the maintenance [treatment] her staying is going to be longer.
> **Gm.-** Yes, the cure, the final cure is very difficult because so far we haven't seen the cancer to be cured, right? But
> **Gf.-** // But there're exceptional cases, they say those are miracles
> **Gm.-** But it could be that [she] stays there with her maintenance and her treatment is

long, but she could keeps there.

They celebrated each of the last two Patricia' s birthdays as if it were the last one; they try to do everything for her in the present moment since they do not know for how long she is going to live; they do not postponed things for her. For example, whenever Patricia gets a present like a dress they put it on her immediately. Patricia is the center of the family's attention and care; they try to give her almost everything she asks for. Grandmother does not go out of the house without Patricia for long time even when Fernando is at home. They take care of Patricia with great consistency and discipline despite Patricia' s excellent health status. They try to keep the illness in the back of their minds by avoiding any thoughts or ideas about it. The grandparents tolerate her misbehavior and argue with Fernando because he puts limits on Patricia. At night, when Patricia is sleeping, Fernando gets up and checks on her to see if she is alive. So they understand Patricia' s finitude in this world. Their experience of her temporality has changed as a result of the cancer. Future horizons are uncertain. Fernando perceives the illness as a lottery, in which you do not know the prize ahead on time, only when you get it.

Fernando and Lucia seemed to feel they are living on the edge all the time, anything could change the way things are with Patricia and the worst (her death) could occur at any moment. Witnessing the downturns of other children with the same diagnosis reinforces Fernando' s and Lucia's notion that they are living on the edge. The death of other children really shakes the ground where these parents' hopes and beliefs are based. In talking about other children's death, Lucia said

> E.- Por que se siente usted desanimada?
> A.- Pues de ver esos niños que van cayendo y que son niños que llevan mas tiempo que ella y que iban muy bien, niños que ya han estado irradiados y vuelven a caer...
> E.- Pero a ustedes les impresiona mucho es porque ustedes han estado viendo a los

niños
A.- Viéndolos bien y todo y que pues uno ve a Patricia como está ella con ánimo y ni siquiera gripa. Entonces como que a veces uno ve que a esos niños allá pues yo no sé como que sabiendo que están bien entonces uno siempre se siente deprimido.
E.- Es decir es porque uno dice "bueno, si a ellos les pasó
A.- // De golpe a uno le puede pasar, claro es que no estamos libres

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I.- Why are you feeling discouraged?
Gm.-Because of the children who are falling, those are children who have been in treatment longer that she and were doing pretty well; children who have had radiotherapy and they fall again.
I.- It strikes you so much because you've seen the children
Gm.-Seeing them so well and all that and one sees Patricia how she's full of life and having not even a cold. So, it's like sometimes one sees those children there I don't know like we know they're fine, so I get depressed.
I.- In other words, it's because one says "All right, if that happened to them
Gm.-Maybe the same could happen to you; of course we aren't free.

Fernando concedes his dread after other children's death, especially the death of a girl he never saw ill. She was like Patricia in the sense she did not have the illness signs. She looked pretty healthy as Patricia does; a fact that makes him live in fear, even observing his daughter's health.

E.- Me imagino que tu te diste cuenta de los niños que fallecieron en el Hospital
P.- Claro!
E.- Como tomaste tu eso ?
P.- Me dio muy duro, me dio miedo en el sentido de lo que le decía yo ahora, que he visto casos que hay niños que van bien y se van, se van. Me dió miedo, me dió duro, me dió muy duro.
E.- Alguno de ellos en especial?
P.- La niña, Luz Karime. Ella porque ella se veía bien, bien, uno nunca la veía mal. Pero el que mas duro me dió que me hizo llorar mucho, mucho fue Julian
E.- Cuando murió él?
P.- Eso fue como por el año pasado como en Septiembre, no en Noviembre, como en Noviembre creo que fue pa' esa época creo, no me acuerdo bien. …. Y todavía lo recuerdo mucho y ahora pues con lo de esta niña, si me dio duro. Y que fueron varios que murieron, no? No se cuantos pero fueron varios. Entonces eso me afectó mucho, al menos él porque lo vi enfermito, pero a esta niña no la vi, yo no la había visto enferma, de un día para otro falleció. Entonces es duro para uno como padre que está viviendo ese .. que está uno cargando esa cruz, es duro, es duro, de todos modos eso afecta a todos nosotros.
E.- Y por qué crees que es así ?

> **P.-** Porque nosotros estamos viviendo lo mismo, todos estamos viviendo lo mismo
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> **I.-** I suppose you knew about the children who died in the hospital
> **F.-** Of course!
> **I.-** How did you take it?
> **F.-** It was very hard for me, I got afraid in the sense I was telling you a moment ago: I've seen cases in which the children are doing well and they go, they go. I got very scared; it's hard, very hard for me.
> **I.-** Is there any of them especial for you?
> **F.-** The girl, Luz Marina. Especially her because she looked fine, fine; I never saw her sick. But the one who really was hard for me was Julian, I cried a lot.
> **I.-** When did he die?
> **F.-** It was last year like in September; no, in November I think, I don't remember it well. And still I remember him pretty well and now with the death of the girl, it was also hard. There were a few of them that died, I don't know how many but there were some. So it affected me a lot; I saw him (Julian) very ill but the girl I didn't see her ill, ever I saw her sick and suddenly, she passed away. So, it's hard for me as father who is going through that, who is shouldering this situation, it's hard, very hard; anyway it affects all of us.

One of the greatest threats for the parents' tenously re-established calmness with the chronic illness was the death of another child on the chemotherapy unit. Fernando and Lucia comforted themselves through the fear and sadness that arose in another children's death, with knowing they were taking excellent care of Patricia and with their faith in God keeping her well. Small illness and low blood counts were further causes for disruption as these were interpreted as potentially life threatening. The parents heard stories of other children which only intensified their feelings of vulnerability; for example a child who died from an infected mosquito bite. Even small changes in the child's habits were noted as potential signs of a down turn in the illness. Thus the parents were in a constant state of vigilance about what Patricia felt and did.

> **A.-** Lo que pasa es que uno vive con temor siempre, un temor infundado o temor de verdad o pero mantiene uno con temor, que si estornuda si sera que le va a dar gripa? Que si de pronto entró mas de dos veces al baño sera que le va a dar daño de estómago? Y comienza uno con esas, Patricia no ha orinado, por que sera que no orina? Entonces comienza uno pues como alla le adivierten tantas cosas entonces uno

se mantiene pues pilas. Entonces uno se mantiene en ese pensar de que porque si ya fue mucho al baño o si no fue tambien porque cuando le dio la apendicitis era que no, no le funcionaba el, dejo 3 dias de funcionarle el estómago y ella decia me duele y uno ni se imaginaba que iba a ser la apendice.
E.- O sea, para usted como mama de Patricia, cualquier cosa es interpretada como relacionado con
A. // Con la enfermedad si y de golpe no es asi porque cuando le dio la apendicitis, de todo menos eso, no tenia nada que ver con su problema. Cuando le dio la bronconeumonia que no le acertaba bien que era lo que tenia, le buscaba y como que no encontraban, entonces la doctora nos decia estamos pendientes de que no sea una recaida y el problema es que Patricia no tiene hermanos, si porque una recaida significa ya pues un transplante, no? Y bueno es que la persona mas compatible con ella pues es un hermano y que tiene que ser hermano de papá y mamá, no hermano medio sino completo, y ella ni medio ni completos pues ella es sola. Entonces eso lo mantiene a uno.....
E.- Como en vilo
A.- Si aqui todo el mundo se mantiene asi, erizado todo el tiempo pensando.

Gm.-What happens it's that one lives with this fear, always; a real or unreal one but one is always afraid. If she went more than twice to bathroom [I would think] maybe she's going to have diarrhea. And one begins with that Patricia hasn't urinated why is it that she hasn't urinated? So one begins because there they warn us about some many things, then one is on top of that all the time. So one is always thinking that because she's going too frequently to the bathroom, or because she doesn't go. When she got the appendicitis, her intestine didn't function, it didn't work for 3 days and she said I have a stomachache and I didn't imagine that would be the apendix.
I.- That's for you, as Patricia' s mother, any thing is interpreted as related to
Gm.-// To the illness, yes and maybe it isn't like that because when she had the appendicitis, it wasn't like that, it wasn't related to her problem. When she had the bronchoneumonia that they could find what she had, they look and since they didn't find anything, the doctor told us we hope isn't a relapse because the problem is that Patricia doesn't have siblings, a relapse means transplant, right? The most compatible person would be her sibling from the same parents, not half-sibling but she doesn't have any since she is the only one. So that's what keeps us
I.- Like up in the air?
Gm.-Here, everybody lives like that, everybody has goose-bumps from thinking.

Finding the Possibility of Being a Loving, Caring, and Expert Mother for her Granddaughter and the Joist for her Son and Family

Lucia's way of being with Patricia is continuous with her mothering. It is calm, unruffled, and focussed on easing the way towards a harmonious solution. This way of being is smooth and fluid for the granddaughter but not without risk for Lucia. She seems to be showing signs of wearing down physically.

Grandmother Lucia has a loving relationship with her grandaughter.They became very close before the illness when Patricia and her parents came to live with them for sometime. At that time, Lucia resented in some way she had to take care of Patricia because nobody asked her to do so. Patricia's parents assumed she should take care of her grandaughter so they went to work leaving Patricia at home without telling grandmother anything. Patricia was not used to be with Lucia therefore it was hard for both of them the first few weeks. Later, when Patricia came to live with the grandparents again, it was not a problem for them. They already knew and accepted each other very well and Lucia was glad and relieved she could take care of Patricia. She has accepted her responsibility in caring for Patricia. Grandfather shares the grandmother's feeling. They take care of Patricia because they are protecting and helping their son Fernando and their grandaughter who need them very much and also because it is their role. Patricia has responded to her grandmother's care and love with love. The granddaughter's expressions of love are very important for the grandmother. She interprets that as a sign that Patricia sees her as her mother.

Lucia recognizes it is important that Patricia lives a normal life, as much as it is possible. It is not neccesary to exagerate in the restrictions for her. It is necessary to avoid spoiling Patricia too. To do so one should separate the illness care from good child rearing practices. So Lucia is tolerant but to a point. She does not use physical punishment with Patricia; she uses loving and kind ways to control any difficulty resulting from Patricia' s irritability ad stubbornness.

One ritual that Lucia has for calming Patricia demostrates her attentive, skillful care.

When Patricia is upset or having a tantrum, Lucia picks her up and sits her in a spot in the kitchen they called Patricia's throne. Then, she calls Patricia her little queen, kisses and hugs her. She also gives Patricia food if she wants some and talk with her to make her understand whatever is needed. She considers it is important to be tolerant with Patricia because she is too little to suffer more than what she is suffering due to the illness, besides they love each other very much.

Lucia does not see her doing anything differently with Patricia from what she did with her own kids. She learned from her parents, especially from her father her way of being a loving and understanding mother.

> **E.-** En sus sentimientos hacia ella, su manera de tratarla, en todo eso han habido cambios?
> **A.-** Yo no, yo sigo igual con ella y ella conmigo porque ella me quiere con toda su alma y ella es especial y yo a ella pues mejor dicho.
> **E.-** Son dos amores correspondidos
> **A.-** Amores locos, oyó! (E.- se ríe) Son amores locos, no uno con ella y yo creo que es muy difícil así el muchacho cambie porque de golpe se vuelven como displicentes o menos amorosos, pero yo creo que uno ya como adulto ya uno sabe que el muchacho de golpe cambia y te dicen no te quiero, eso lo dicen pero no lo están sintiendo.
> **E.-** A veces algunos padres cuando ya ven que los niños están mejor, no ven signos de enfermedad, ellos
> **A.-** // Ah! cambian
> **E.-** Digamos como que disminuyen un poquito, por ejemplo la tolerancia, o cosas así. A usted le ha pasado eso ?
> **A.-** No yo todavía sigo tolerante, y es que yo he sido muy tolerante con todos los míos, con todos mis hijos. Mi esposo y yo hemos sido muy contemplativos con ellos.
> **E.-** Eso le iba a preguntar, usted siempre ha sido asi con sus hijos, o es diferente con ella ?
> **A.-** No, no, no, no es que la gente dice que uno a los nietos los quiere mas. Claro que con ella hay algo de especial, no? por su enfermedad, y porque pobrecita, tan pequeñita y ha tenido que pasar por tantas cosas. Pero, nosotros hemos sido supremamente contemplativos y vea estos muchachos grandes y el papá se los mete aquí (debajo del brazo) y yo no se como él es gordo, no? Entonces esos muchachos se los mete debajo del ala (E.- se ríe) suprema, si hemos sido muy contemplativos con todos.
> **E.-** En qué consiste eso de ser contemplativos ?
> **A.-** No se eso le nace a uno,

E.- Y cómo es una mamá contemplativa, qué hace usted para ser contemplativa ?
A.- Yo digo contemplativa, que los mimo, procuro darles lo que quieren. Mejor dicho procuro en las capacidades, en las medidas que tenga uno para poderlos complacer y darles gusto. Mas sin embargo, hay que imponerles sus castigos si se están portando mal. Yo a los míos poco les .. yo no, digamos castigos corporales poco me han gustado, pero yo les quito lo que mas les guste. Ellos les fascinaba ver televisión e irsen para la piscina. Entonces esta semana no hay ida a la finca, no había piscina y no hay televisión toda la semana y quince y hasta un mes les quitaba la televisión cuando se portaban mal. A ella no puede decirle uno le quito la televisión porque pocón, no le gusta (se ríen)
E.- Y, usted donde aprendió eso ?
A.- Vea como le parece yo no se, pues en mi casa mi papá me contempló mucho, porque yo era la niña de los ojos de mi papá.

I.- Are there changes in your feelings toward her and in the way you handle her?
Gm.-No, no, I'm the same with her and she is the same with me, because she loves me very much and I love her much more
I.- That's you love each other very much
Gm.-Crazy love, right? (Laughs) We're are crazy about each other; sometimes they change and they become somehow unkind or less loving but I think that, as an adult, one should know they change and they tell you they don't love you, they say that but they really don't mean it.
I.- Some parents, when they see the children are doing better, when they don't see signs of the illness, they
Gm.-// Oh! They change
I.- They decrease a little bit, for example, the tolerance or something like that. Has anything like that happened to you?
Gm.-No, no still I'm tolerant, and besides I've been very tolerant with my own kids, with all of them. My husband and myself have been very contemplative with them.
I.- I was going to ask you that. Have you been like that with your children or only with Patricia?
Gm.-No, no, no. People say that one loves the grandchildren more. Of course, with her is even more especial, right? Because of the illness and because poor little one, so little and she had suffered so many things. We've been extremely contemplative; you see these grown up boys and gets them and put them under here (his arm), I don't know maybe because he's big and fat also, right?
I.- And how is it, what you called contemplative?
Gm.-That's within you
I.- And how is a contemplative mother? What do you to be contemplative?
Gm.-I say contemplative because I pamper them, I try to give them what they want to. In other words, I try within my capabilities, with the means I have to please them and give them what they want to. However, one should punish them when they are misbehaving. For my kids, I don't, very little, I haven't liked corporal punishment but I take away from them the things they like. They loved to watch TV or to go to the swimming pool. Then, that week there wasn't trip to the farm, no swimming pool, no

> TV for the whole week; sometimes, I took the TV away for two weeks or one month. To her, I can't say there isn't TV because she doesn't like it (laughs)
> **I.-** Where did you learn to be like that?
> **Gm.-**I don't know, in my home my father pampered me a lot, because I was his favorite child.

Lucia is very engaged in Patricia 's everyday care; she established new practices to care for her granddaughter. The practices are intent to increase the child's strength to fight the disease, to decrease the possibility of getting other illness, and to alleviate the side effects of the chemotherapy. Lucia knew quite well the side effects of the medicines and Patricia's reactions to them. She also knew how to take care of mouth sores and to deal with Patricia' s increased irritability after getting the chemotherapy. She gave her the medications when Fernando was not in the house. She was the only mother who learned to give a drug subcutaneously. She learned from a nurse that smashed spinach seeds with milk are good for increasing the hemoglobin, so she gives Patricia that almost every day. She also gives her multivitamins, and two products made out of Aloe Vera. She learned from the radio that bananas, fish, cheese, and *miel de purga* (especial honey from sugar cane) are good for increasing the body defenses. She increases Patricia's intake of bananas, cheese, and fish when the blood counts are low and give her the honey for a few days. Lucia has told the Oncologist about all she gives Patricia. They agree with her in doing that. Feeding Patricia well is also very important for Lucia, she gives her a very balanced diet. Patricia has great appetite most of the time and she has gained weight.

Lucia has organized files with all the papers concerning Patricia' s illness. In these files, she has all blood and bone marrow tests, the written protocols for the treatment, the prescriptions, and literature about leukemia. She has done that because it is a practice she has for her family. Having Patricia' s papers in files could be very useful in case they need to take her to other places someday. The following account how Lucia takes care of Patricia' s mouth sores shows the expertise of this grandmother in caring for her granddaughter.

> **E.-** Los otros comportamientos que ella tiene como el de chupar la lengua y el de morderse
> **A.-** // El de morderse ha mermado bastante, ha mermado bastante desde la última vez que ..... Ah! después de que hablamos, ay! viera como se volvió esa boca ! Ay! esto era que eran peladuras de acá hasta acá (Hasta la oleja dice la niña), hasta la oreja, (Y no podía mamar boca dice la niña). No podía mamar, eso era lo que mas la mortifica ella no poder mamar boca, no podía tomar tetero, no podía comer, eso eran gritos. Y diga pues con mucho pesar y todo hay que limpiarle la boca pa' poderle hacer los remedios. Entonces yo le limpio con aguita de piedra lumbre; hiervo una chuspa de esas chuspitas que venden, es eso no se si serán gramos o que, en una botella de agua. La ponemos a hervir [el agua] y ya cuando está fría la estrego aquí. Ella no sabe hacer bien los buches y la primera limpiada es cruel porque yo le quito toda esa lama blanca no? Y luego le echo el remedio que nos dijo la doctora Margarita, el Kaopectate con Benadril mezcladito por partes iguales, se mezcla y se le aplica en toda la boca y es fabuloso pero si no se le hace con la piedra lumbre no crea pues que eso [sirve].
> **E.-** Y con qué frecuencia le hace esa limpieza en la boca?
> **A.-** Eso se le hacen unas tres veces al día
> **E.-** Y en cuanto tiempo se cura ?
> **A.-** Se le ve el mejoramiento casi al segundo día, después de estar así que se le pone la boca que es imposible por ahí a los dos tres días ya comienza ella a poder comer.
> **E.-** Doña Lucia pero esas lesiones de la boquita se las hace ella misma o es por la droga?
> **A.-** Mire, hay una droga que si las pela que es la Metrotexate, no? cuando le ponen en alta dosis pero para eso le mandan el Acido Folínico para contrarrestar eso. Ella a veces, así le de uno muy puntual cada seis horas su pastica, siempre se le hace tal que otra llaguita pero no le había vuelto a dar. La primera vez se peló un poquito y no le había vuelto a pasar nada. Ahora esto si fue
> independiente de la droga porque es que ella .. cúando fuimos a la misa de sanación? Un Viernes antes de la Semana Santa. Y de la misa de sanación salió así; yo no se si es ansiedad o qué pero salió con la boca hecha nada. Ya esta vez fue sin estarle aplicando el Metrotexate; porque el Metrotexate es de la drogas que los pela, los ampolla hasta por encima no ?

> **I.-** The other behaviors that she has like sucking her tongue and biting herself
> **Gm.-**Biting herself has decreased a lot since the last that .. Oh! After we talked oh! you should have seen how got her mouth. Oh! She has sores from here to here (every where inside her mouth) {up to the ear says Patricia} up to the ear {I couldn't suck my mouth says Patricia}. She couldn't suck and that was the hardest part for her; she couldn't suck her tongue, she couldn't take her bottle, she couldn't eat; she screamed a lot. I was very sorry for her but I had to clean her mouth, todo the remedies for that. I clean her mouth with **piedra lumbre**; I boiled a small bag of that, I don't know if

> those are grams or what in a liter of water. I boiled that and when it's cold, I clean her mouth with it. She doesn't know how to rinse her mouth with it. So the first cleaning is very cruel for her because I take out all the white stuff she gets, right? And they I put the remedy that doctor Margarita told us, Kaopectate mixed with Benadryl, equal parts of each well mixed and then, I applied that every where in her mouth; it works marvelously. But if I don't use the piedra lumbre, she doesn't get better.
> **I.-** How long does it take to heal the mouth
> **Gm.-**You can see the improvement more or less after the second time; after having the mouth so bad, usually after 3 days she starts eating again.
> **I.-** Doña Lucia, are these lesions in her mouth self-inflicted or because of the drug?
> **Gm.-**Look, there's one drug that burns the mouth, it's the Metrotexate, right? When she gets high doses but they prescribed Folinic Acid to control that. Sometimes, even though I give her the pill every six hours, she gets a sore here and there but she didn't have this in a long time. The first time she got a few sores and she didn't have that anymore. But this time wasn't because of the drug because she's .. when we went to the healing mass, I don't know if it was anxiety or what but she got out of with her mouth destroyed. This time was without giving her the Metrotexate because the Metrotexate burns and peels all the inside of the mouth, even on the palate, right?

Caring for the ill child is especially overwhelming at the beginning of the illness experience. There are many and unfamiliar things the parents must do for the child especially when the child is very ill. With passing of time, parents acquire expertise in handling the new situation and feel more in control but only if the child's clinical condition does not change. With the passing of time, parents also feel the strain from the illness experience and care on their bodies. Initially, Lucia seemed to be stressed and fatigued by the care required by Patricia. When Patricia had serious downturns with appendicitis and pneumonia Lucia was further taxed. Care in the hospital was taxing enough because of the long hours. However, when Patricia was discharged the care demands were tremendous because in her severely ill state she regressed to needing diapers and a level of total physical care during 9 months. Besides these tremendous demands Lucia was also caring for her own family with no extra help.

> **E.-** Para usted que ha estado como muy involucrada en el cuidado de la niña, en satisfacerle sus necesidades tanto por la enfermedad como para el tratamiento, cómo ha sido eso para usted doña Lucia ?

> **A.-** Como le digo? Pues al principio fue duro porque estar uno siempre pendiente de que no se le pase a uno la hora de esto, y de que estarle pendiente de que si la encía le sangra, de que si .. a estar pendiente del popó porque pues como en todo eso lo ponen a uno. De que mire a ver si sangra haciendo popó, que si la orina, entonces uno se tensiona. Yo terminaba de catre; les decía yo a ellos "Estoy de catre. A mi me provoca es no volverme a levantar" y me acostaba y yo me quedaba dormida porque esa ventaja tengo yo, yo puedo tener el moribundo al pie pero me acuesto y me quedo dormida. Pero me levantaba , o sea que no .. me dormía pero no descansaba y al principio fue duro.

> **I.-** How has it been for you to be involved with the girl's care? To meet all her needs from the illness, the treatment, how has it been for you Doña Lucia?
> **Gm.-**How can I say it? At the beginning, it was hard because to be so attentive about so many things, the hour for the medicine, if she bleeds from the gums, to check her poop because they ask you about all that. If she gets blood in the poop, in the urine so one becomes very tense. At the end of the day, I was exhausted. I used to tell them "I'm exhausted, I don't want to get up any more". And I went to bed and fell asleep immediately because that's an advantage I have, the dying person could be next to me but I lay down in bed and I fall asleep. But I got up, that's I went to sleep but I couldn't rest, so at the beginning was very hard.

Lucia' s narrative about the time Patricia began walking after months of being unable to do so illustrates the long way Patricia has come through. It also portrays Lucia's embodied skill in being able of taking advantage of a very sad situation in another child to encourage Patricia to walk.

> **A.-** ….. esta señorita (Patricia) pues todavía no caminaba y tocaba era cargándola pa' un lado, cargándola para otro; pesado, pesado, pesado era, y esto fue siempre como hasta a mediados de Febrero que ella empezó ya a caminar, que ya comenzó uno de los mellizos ¡ah ! porque vimos un niño allá en el Hospital, Carlos Rodríguez, él no tenía leucemia, él tenía un sindrome
> **E.-** Hodgkin?
> **A.-** Ay ! yo no me acuerdo, lo que le diga yo en este momento es mentira pues yo tengo memoria de gallina. Vea ese niño parecía una rama seca, con un estómago así (muestra con la mano el volumen del estómago) y pues ya no le estaban aplicando droga. Entonces, ella le estaban haciendo su quimioterapia y ese niño a ella le impactó. Es que era impactante el niñito; el niño caminaba y era un esqueleto forrado con [la piel], haga de cuenta ver un esqueleto que pa' que no se desbarate lo meten como entre guantes de cirugía, haga de cuenta el color así, no? Entonces ella quedó impactada. Un día aquí ella no .. entonces aquí luchando pa' que caminara. Patricia bájate que tu puedes caminar. No puedo. Entonces la senté yo allí (en el piso) y le dije yo "Patricia tu te acuerdas de Carlos Rodriguez ?" Y me dice si. Le digo "Y te

acuerdas cómo entró él? Cargado o cómo?. Me dice caminando. Le dije yo " Ahhh! Te acuerdas de Carlos Rodriguez, estaba bien flaquito y bien enfermo, mas enfermo que tu, y caminaba. Tu puedes caminar" Y me dio ¿Si? Le dije yo "Claro, puedes caminar" Entonces se estiró allí, se resbaló del asiento y aquí estaba el mellizo, "camine Patricia" y entonces yo la puse allá y él acá a esperarla. Claro, ella al principio se ponía haga de cuenta un bebé empezando a caminar. Y así poco a poco la fuimos haciendo .. entonces ya empezó a caminar, claro que ella caminaba de aquí allí y se cansaba; llevaba desde Octubre sin caminar. Octubre no, yo cuento Octubre porque fue cuando a ella ya le diagnosticaron, todo Octubre, Noviembre, Diciembre, Enero, Febrero, cinco meses sin caminar. Lógico ella se tenía que cansar porque estaba inactiva; a ella las piernas se le habían vuelto, se le estaban atrofiando, eran de este grueso (muestra con la mano el diámetro pequeño de la pierna) y ella era piernona, porque ella ha sido gorda y se le veían las piernitas parecían un par de palillitos, era impresionante, pero empezó a caminar.

Gm.-...... This lady (Patricia), she still couldn't walk and I had to carry her everywhere; it was hard, hard and that was up to mid February, when she began walking because one of the twins ah! we saw him in the hospital, Carlos Rodríguez, he didn't have leukemia, he had a syndrome
I.- De Hodgkin?
Gm.-Oh! I don't remember, whatever I tell you now isn't true because a chicken memory. That boy seemed like a dried stick, with a belly this big (she shows with her hands) and he wasn't getting more treatment. They were giving her the chemotherapy and that child shocked her. The child was shocking; the child walked, he was just bones covered by the skin, it was like a skeleton that you don't want to be broken so you put it into surgical gloves; the color was like that, right? So he stunned her. One day that she didn't want to walk and we're trying very hard to get her to walk. Patricia, come down, you can walk. "I can't". Then, I sat her there (on the floor) and I told her "Do you remember Carlos Rodríguez?" And she told me "Yes". And I said to her "Do you remember how he got here? Carry by his mother or how?" She said "Walking" And I said Ahhh! Do you remember Carlos Rodríguez? He was very thin and very ill, sicker that you and he walked. You can walk too. And she said "It's that true?" I said, "Of course, you can walk. Then, she slipped down the chair and one of the twins was here "Walk, Patricia" and then I put her there and he stayed here waiting for her. Of course at the beginning, she was like a baby learning to walk. And little by little we made her .. so she began walking but she walked just from here to there and she got tired; she hadn't walk since October. I said October because it was when she was diagnosed; it was five months without walking. Of course, she got tired because she was inactive; her legs were atrophied, they were this thick (she shows with her hand the small diameter) and she used to have thick legs because she's been fat and her legs were like a pair of thin sticks; it was shocking but she began walking again.

After Patricia's clinical condition stabilized and improved, Lucia felt it was easier to take care of her grandaughter since Patricia was healthy and able to be on her own while Lucia did the house chores. Lucia also acknowledges that her family and Fernando help her with Patricia's care so she has not been overwhelmed. At the time of the third interview, Lucia was caring for Patricia without Fernando's help because he got a job. However, he cared for Patricia on the weekends and after getting home from work.

Patricia' s illness has also caused changes in Lucia's life and way of being. She found new possibilities in her way of perceiving life. So she learned to appreciate more when one is healthy, to live life the best one can, and not to be afraid of dying. She became more religious and strongly believed in a better life after death.

Patricia's illness has disrrupted Lucia's everyday life in different ways. She does not have time to go out to visit friends and relatives or do whatever she needs outside the house, her work load has doubled, she can not be available to other family members like her daughter and mother-in-law. However, Lucia does not complain about taking care of Patricia, she assumed her responsibility as something a mother and grandmother should do for her son and grandaughter. When ever I saw and talked with Lucia it was clear to me she was carrying out her duty with love, responsibility and joy. Of course, at times she felt tired, as would anybody in such situation for that long.

In the last interview, Lucia expressed her concerne about becoming sick and be unable of care for Patricia. She was losing lots of hair and her fingernails were pretty damaged. She was told by her physician her blood pressure is a little high. Her physician prescribed medicine for the hypertension, Folic Acid and Calcium and ran all the tests to diagnose osteoporosis. She understands her symptoms as caused by the stress she endures when she goes to the hospital for chemotherapy. She is there all day, sometimes Patricia gets very anxious and does not allow her to leave her alone not even for a few minutes so she can not eat or drink anything. She stays in the hospital all day seeing different problems in other children and parents. I understand that she is fatigued after 18 months of enduring the physical and psychological demands of Patricia' s illness. Her statements about her involvement demonstrate absolute commitment coupled with nagging concerns about her own capacity to carry on.

> **E.-** Hasta cuando piensa usted que sera mamá de Patricia?
> **A.-** Pues mientras Dios me de licencia y salud que es lo que me preocupa porque ya uno no esta de quince, aunque los de quince tambien se mueren pero mientras Dios me de esa licencia yo pienso ser mamá de ella o al menos mientras necesita su tratamiento. Porque mientras ella esté conmigo yo sé que el tratamiento se le hace a la niña porque yo cuando me comprometo a hacer una cosa yo soy muy responsable de mis cosas. Y yo me comprometí , ya tengo ese plan trazado y lo tengo que acabar con la licencia de Dios que me de. Si porque uno tiene que contar con El porque si me enfermo ...
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> **I.-** For how long do you think you're going to be Patricia' s mother?
> **Gm.-**As long as God gives me permission and health. That is what worries me because I'm not fifteen anymore, even though the fifteens also die. But as long as God allows me, I would be her mother or at least until needs the treatment. While she stays with me, I know the treatment is done to the girl because when I commit myself with something I'm a very responsible person. I committed myself with it, I have planned that and I have to finish it with God's will. Yes, because one has to have His help because what if I get sick.

Lucia's way of being as human being seems to facilitate her coping with the illness situation. She is calm but always doing what is needed including reminding God to help her. Getting upset and overreacting are not part of her way. On the contrary being tranquil and having faith that she can go on is what she thinks and does. She considers herself *la viga* (the joist) for the whole family so lives up to her own expectations.

> **E.-** Y usted siempre ha sido asi ? Me da la impresión de que usted es una persona tranquila, calmada, si es así ?
> **A.-** Si señora
> **E.-** Siempre ha sido usted?
> **A.-** Yo siempre he sido asi
> **E.-** // O es algo que se aprende con el paso de la vida ?

A.- No, pues como le parece que yo creo que si se aprende pero yo creo que eso viene como con uno. Yo he sido calmada, yo cuando se necesita pilas, yo soy pilas pero que yo me angustie yo no soy angustiada. Mi esposo si, entonces yo pero pa' que te angustias? Espérate que de algún lado resultan las cosas le digo yo. Es que les digo yo es que si uno angustiándose, pataliando y llorando le resultan las cosas, vea <u>yo era la primerita que me sentaba</u> ahí a llorar y a pataliar, pero no, hay que tener paciencia y esperar, mirar a ver de donde van a salir las cosas.
E.- O sea no sentarse ahí a que le lluevan pero
A.- No a que el maná le llegue del cielo, no pero si tiene uno que calmarse. Es como con ese (se refiere a Fernando) que a veces se me quiere como que se me quiere salir de casillas y digo yo, pero pa' que ?

I.- Have you been like that always? You give me the impression that you're a calm person, tranquil. Am I right?
Gm.-Yes, I'm
I.- Have you been always that way?
Gm.-I've been like that always
I.- // Or it was something that learned with time?
Gm.-No. Let's see, I think one learns some but that comes with you. I've been calm but when it necessary to do things I do it. But I don't get anxious, I'm not anxious. My husband is anxious so I say "why you get anxious?". Wait, maybe from somewhere we would get this problem solved I say to him. I tell them if by being anxious, kicking, screaming, and crying one solves the problems, look <u>I would be the first one sitting</u> there to cry and kick but not, we got to have patience and wait but to look for the solution.
I.- That's, not just sitting there waiting for things to come to you
Gm.-Not to wait until the manna comes from Heaven, no but yes one has to calm down. It's that him (Fernando), sometimes he wants to get out of control and I tell him "What good you get out of that?".

<u>Finding the Possibility of Strengthening his Love with his Daughter and Improve his Role as Father</u>

Within the illness situation, Fernando finds the possibility of continuing his involvement with his daughter's care in a stronger sense and with greater satisfaction. This is possible due to the readiness of his father and mother's support and his commitment to his daughter. Being Patricia's father is not smooth for him because of his bad temper, which he acknowledges as a personal trait that has been increased by the lack of a stable job. Fernando has found his parenting very fulfilling but now he has a greater feeling of fulfillment because he has been able to maintain his commitment to his daughter during the bad times when she needed him more. He also feels proud and delighted because he did not do what most fathers would do in a similar situation.

Fernando' s engagement with his daughter's care is something not frequently seen in the Colombian culture. Before the diagnosis, he played the mother's role and he continues doing so even after moving in with his parents. His way of being a parent does not follow the general pattern for men, especially for somebody so young who could be out having fun instead of staying home caring for his daughter. He joked about being an abandoned single mother at the time Patricia' s mother left them. This shows how engaged he was in caring for his daughter. He did not say that in a resentful or sarcastic way; he said it because that was how he perceived himself at that time. He was taking care of his daughter and he did not have a job; this is what mothers usually do in Colombia. But men regardless of their job status do not get that involved in the children's care.

Fernando has been very involved in Patricia's care since she was born. He learned very quickly to bathe and dress her, to change her diapers, and feed her. It seems that at home, he was the main cargiver for Patricia before the illness. He took care of her day and night during the time he was not working and at night when he was working. Fernando' s responsibilities and involvement with Patricia' s care continued after the wife's leaving them. He did not transfer the child's care to his mother; he did most of the everyday care whenever he was in the house like bathing, dressing, playing, feeding, and giving the medicines. During the interviews, he was the one who gave the bottle to Patricia and helped her in the toilet. He also went with Patricia to the hospital and did all the paper work and all the activities to get what was needed for the treatment. While he was working, he continued his involvement with

Patricia' s care in the evenings and over the weekends. He does not feel that he can not do things he would like to do as a young single man because his tied to his daughter's care. However, he acknowledges that sometimes he feels tired of some of the activities he does for Patricia like bathing and cooking.

Fernando truly enjoys caring for her daughter; he perceives his role as father very rewarding and feels a great deal of satisfaction by doing his job as father, especially when he sees the difficult and long way his daughter has gone through. He does not acknowledge having thoughts about getting tired of caring for his daughter.

> **E.-** Cómo ha sido para ti estar involucrado en el cuidado de Patricia en relación con su enfermedad, con su tratamiento ?
> **P.-** A mi me ha gustado, me ha gustado por qué porque de una u otra forma yo he disfrutado mi hija, he estado en las buenas y en las malas con ella.
> **E.-** En algún momento has sentido como que esto es mucho para ti, como que ¡ay ! esto me
> **P.-** // Gracias a Dios no, porque el día que lo sienta ese día me preocupo. El día que sienta, el día que yo llegue a sentir eso, me preocupo. Pero no lo he sentido, de que quiera tirar la toalla y no quiera seguir adelante, no, no porque es que no es tirar la toalla y ya, porque si tiro la toalla, detrás qué se viene? Entonces no, no, no y ni me ha provocado no.
> **E.-** Nunca te ha pasado por la mente?
> **P.-** No, no, no. Por lo que le decía no, he disfrutado mi hija, he sufrido, he llorado, he reído, me alegra mucho ver la evolución que ha tenido.
> **E.-** Y pues entiendo que tu antes cuando ella no tenía ningún problema de salud estabas muy involucrado en el cuidado de ella también.
> **P.-** Si, si, cuatro años que tiene la niña ha estado mas conmigo que con la mamá.

> **I.-** How it has been for you to be involved in Patricia' s care regarding the illness and the treatment?
> **F.-** I've liked it, I've liked it. Why? Because in one way or other, I've enjoyed my daughter, I've been with her in the good and bad moments.
> **I.-** Have you felt, at any moment, that this is too much for you, like Oh! This is
> **F.-** // Thanks God, I haven't because the day that I feel like that that day I would be very concerned. The day that I feel, that I come to feel that would worry me a lot. I haven't felt like that giving up and not wanting to go ahead, no, no because giving up is, if I give up what is behind me? So, no, no, no neither I've considered it, no.
> **I.-** It hasn't crossed your mind
> **F.-** No, no, no because what I already told you; I've enjoyed my daughter, I've

suffered, I've cried, I've laughed, I'm very pleased to see the evolution she has had.
I.- And I understand that before, when she didn't have any health problem, you're also very involved in her care.
F.- Yes, yes; four years has the girl and she's been with me more than with her mother.

Lately, Patricia has become more affectionate with Fernando and easy to handle for him. It could that she has more possibilities now because she is healthier. Over the 1½ year of the illness, she went from being very ill and dependent to be a girl who plays all day, eats and sleeps very well, is toilet trained again, and soon will go to preschool. She also changed her emotional status from being very attached to her father and grandmother and irritable most of the time to being less attached and more social with others in the hospital and at home. Patricia is no longer a toddler but a preschooler with more control of her behavior and emotions. Fernando' s description of how Patricia shows him her love is very revealing of their relationship.

E.- Qué otros cambios le has visto a ella ?
P.- Qué otros cambios? A ver que le digo, como mas amorosa conmigo, me contempla mucho.
E.- Ah! si?
P.- Uf!
E.- Cómo te contempla, qué hace?
P.- Ella me dice, me consciente, me coge así la cara y me dice "mi nenecito, de quien es este pelito y estos cachetes?" Ella todo el día le dice así a mi mamá "te amo con toda mi alma"
E.- Y ella dónde ha aprendido todo eso?
P.- No se, de pronto yo soy muy, o sea son los dos extremos, no? La consiento mucho también, pero también me exalto con ella muy facilito, muy facilito. Yo le digo palabritas como lo que ella me dice, no? Te adoro, te amo y la consiento y cosas así. Entonces digo yo que es de eso
E.- Qué mas hace para consentirte?
P.- Me abraza, me recuesto en la cama y ella va y me dice "vení te regalo un abracito" y me abraza, y me da abrazos y me cosquillas, cositas así, muy ricas que me encantan.
E.- Tu crees que si ella fuera un niño varón, tu relación con ella sería diferente?
P.- No me he puesto a pensar en eso, no que si ella fuera niño, no, no creo, o sea igual mi hijo es mi hijo y yo creo que uno al hijo hombre o mujer lo ama.

> **I.-** What other changes have you seen in her?
> **F.-** What other changes? Let's see what I can tell you, she's like more loving, she pampers me a lot
> **I.-** Oh! Really ?
> **F.-** Uff!
> **I.-** How does she pamper you? What does she do?
> **F.-** She tells me, she pampers me by taking my face with her hands and she tell me " My little baby, whose is this hair, and these cheeks?" She tells my mother all day "I love you with all my heart"
> **I.-** How has she learned all that?
> **F.-** I don't know, maybe I'm very, that's both extremes, right? I pamper her a lot also but also I get upset very easily with her, very easily. I tell her words like the ones she tells me, right? I adore you, I love you and I pamper her things like that. So, maybe that's how [she has learned]
> **I.-** What else does she do to pamper you?
> **F.-** She hugs me, I lay down in the bed and she comes and tells me " Come, I give you this hug" and she hugs me and tickles me, things like those, very delicious and that I like a lot.
> **I.-** Do you think if she were a boy, your relationship with him would be different?
> **F.-** I haven't thought about that, if she were a boy, no, no, I don't think so; it's the same is my child and I think one loves his child regardless if is a woman or a man.

Fernando has a fulfilling and loving relationship with his daughter. The intensity of their relationship is evident in the time they spend together and their physical closeness. For example, they share the same room. At night, he prays to God for her, he checks on her often, he wakes up easily when she moves in her bed or makes sounds. Every morning, he thanks God for having her. They play and go out on their own especially on the weekends. They express their love to each other quite easily and frequently.

Fernando perceives that the background for being the father he is comes from the way his parents have raised him and his siblings. They have been very loving, dedicated, understanding, and willing to give them whatever they need and want. So he has embodied their ways of being as parents and put into practice what he has learned from them.

> **E.-** Todos estos comportamientos que tu tienes con la niña, la manera de ser tú como papá de Patricia, de donde viene esa manera de ser, de donde crees que viene ?
> **P.-** Primero o sea yo siento que me nace, de pronto el trato que nos han dado a nosotros aquí, la crianza. Siempre mi papá y mi mamá han estado muy pendientes de

> nosotros, ha habido amor, comprensión, nos han dado gusto en lo que se ha podido. Entonces yo creo que eso a uno se le queda no, yo creo que uno, cuando desde pequeñito le han dado, entonces cuando le toca a uno, uno da, pero si uno nunca ha recibido, qué va a dar? y aparte de eso porque, me gusta. Hay ciertos .momentos que yo actúo es como protegiendo la niña, lo que le decía ahora, me da miedo que vuelva y caiga a lo mismo, es el asunto de protegerla, pero yo lo hago porque me nace, me gusta y porque lo he vivido aquí en mi casa ..... Yo aquí lo he tenido todo por mi papá y por mi mamá, he tenido mucho amor, mucho cariño y comprensión, todo, me han ayudado. Entonces yo por qué no, si todo eso me lo han dado a mi, yo por qué no voy a poder dar a mi hija. No creo que me toque ir a buscar una ayuda de un libro. De pronto me siento con mi papá y hablo. La experiencia que tiene él en todo, o con mi mamá nos tenemos confianza y hablamos. Entonces es lo mismo con la niña pero es que vuelvo y le digo, cuando uno de pronto nunca ha recibido nada del papá .. porque mi papá siempre ha trabajado pero él llegaba por la noche y nos acostábamos y luego nos chocholiaba y nos consentia y las cosas pero hay papás que dicen que están trabajando entonces como llegaron cansados se acostaron a dormir y ya

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> **I.-** All these behaviors that you have with your daughter, the way you're her father, how is that you do that? Where do you think they come from?
> **F.-** First, I feel like doing it. Maybe the way we've treated here, how we've been raised. My father and my mother always have been very concerned about us; there has been lots of love, understanding; they've given us all they could. I think one learns that, that stays with you; when you have had since you're little, later when you have to give it to somebody you can give it but if you haven't received any thing, what are you going to give? And besides that it's because I like it. There are moments that I act like to protect the girl, like what I told you; I'm very afraid that she would fall again (have a relapse), so it's to protect her. But I do it because it comes from my heart, I enjoy it, and because I've lived that here at my home ..... Here, I've had everything because of my mother and father; I've had lots of love, affection, and understanding, everything; they've helped me. Then, why not to give all that to my daughter. I don't think I need help from a book. Maybe, I sit down with my father and talk with him. He has experience with everything. And with my mother, we're pretty close and we talk. So it's the same with the girl. I tell you once more if you haven't received anything from your father .. My father has always worked, but he used to come home in the evenings and we went to bed and he cuddled us and he pampered us and all that but some fathers who work come home and because they are tired they go to sleep and that' all.

Fernando repeatedly and consistently acknowledges that his form of involvement with his daughter is possible not only because of his upbringing but because of his parents seamless support of he and his daughter today. The only thing Fernando has not been able to learn from his parents is to be tolerant with Patricia and everybody else. He has been kind of irritable and impatient all his life. He gets upset easily and sometimes without reason. As a result of this, he finds himself arguing with Patricia, yelling at her, and not giving her what she wants right away. He does not like his way of being in this sense and it is not fair for him to behave like that with his daughter.

> **E.-** El hecho de que ya no estas con ella sino en las noches y fines de semana ha ayudado a que seas mas tolerante con ella ?
> **P.-** Si el cambio con ella si, tolerante. Cada rato me cuesta trabajo
> **E.-** // La vez pasada me dijiste que
> **P.-** Le digo que no es solamente con ella, es con todo mundo. Llega un momento que ni yo mismo me tolero, tuve un problema bastante grave.
> **E.-** Y en estos últimos meses no ha habido cambio en eso?
> **P.-** Pues yo creí que si, pero la semana pasada me di cuenta que no (se ríe). Pero no, hay que seguir intentando mejorar eso, mejorar eso.

> **I.-** The fact that now you're with her only in the evenings and weekends has helped you to be more tolerant with her?
> **F.-** Yes, the change with her yes, tolerant. That's often hard for me
> **I.-** // Last time you told me that
> **F.-** It isn't only with her, it's with everybody. There's a moment in which I can't stand even myself, I had a serious problem.
> **I.-** In the last months, have there been changes in relation to that?
> **F.-** I thought that was the case but what happened last week shows me that it's not (soft laugh). But I would keep trying to improve that, to improve it.

Fernando is trying to improve that part of his parenting and way of being with others because it also has caused difficulties with his new girlfriend and maybe that was the reason for his wife leaving him. In recounting a recent similar loss of temper with his girlfriend Fernando was quite self-critical, "*I questioned myself, I felt bad, I felt ashamed*". He notes that his anger now diminishes more quickly but still regrets that he gets irritable at all for things that he should not. Although he feels he needs to work in all his relations, he has felt the greatest success with his daughter. It seems as another sign of his attachment and devotion to his daughter that he has been able to shift this pattern of interaction with her.

At the time of the diagnosis, Fernando thought he had done something to cause his daughter's diesease. He felt relief when the Oncologist told him nobody was responsible for causing the disease but he did a self-evaluation anyway. He has not resented his daughter's illness. He understands it as something he has to face the best he could. Fernando sees his daughter's illness as an opportunity to learn to be more sensitive to other people's needs and concerns and to become closer to God.

During the last interview, Fernando seemed aware of Patricia's care being overtaxing for his mother because she did not have his help during the weekdays and especially when she and Patricia went to the hospital for chemotherapy and tests. It seems that Fernando understood the only aspect of Patricia's care that was taxing for his mother was going to the hospital and doing all the paper work needed to get the treatment. Caring for Patricia at home was something he took for granted. He was assured it was easy for his mother which in a way agrees with his mother's perception. I did not have the opportunity to discuss with Fernando if he was aware of and attuned to the toll Patricia's illness and care were taking on his mother's health. Fernando is very aware of his responsibility with Patricia's care when he is home at night and during the weekends. He clearly expressed his gratitute to his parents and especially to his mother for all their unconditional support through the illness experience. He is aware that Patricia is his responsibility not his parents. Fernando also is planning to get his own place for him and Patricia in a few months when he would feel more stable in his job and have more money.

Finding Support from Religion and Others

Both, Lucia and Fernando had numerous sources of psychological, moral, and financial support. God has been the greatest source of support according to Lucia and Fernando. Both are very religious but Fernando talked more about his rituals for getting God's help. He asks

God's help but also thanks him every night and day. Fernando has been devoted of *El Milagroso de Buga* (a local representation of God) all his life, he has a stature of him in his bedroom. One night at the beginning of the illness he asked El Milagroso's permission to put his daughter picture on his shoulders. Since that night Patricia' s picture has been on God's shoulders. This is a beautiful metaphor of God helping Fernando with his daughter situation. Lucia believes that God is always helping but especially during the transitory difficulties like when Patricia' s body defenses are low.

> **E.-** A qué cree usted que se debe que usted no se ha sentido en una situación así? (Una situación de no saber qué hacer)
> **A.-** Por qué? Porque tengo fe. Yo le pido mucho a Dios, yo conversó con El y yo le peleo, no? Cuando veo que como que las cosas no esto [no salen bien] que se ponga pilas [le digo] Entonces yo le peleo pero yo creo que en medio de todo esto es la fe, la fe que uno tenga.
> **E.-** O sea usted siempre siente que tiene ayuda del de arriba (Dios)?
> **A.-** Del de arriba, el de arriba no me suelta. Mire en días pasados al término del otro protocolo anterior, se le bajaron las defensas. Le formularon cinco inyecciones de Leucomax. Se fueron averiguar y eso valía como dos millones, esas no las daban [la EPS]. Tocaba uno conseguirlas. Y llega mi hijo y me dice "Mamá, qué hacemos pa' esa droga?" Le digo yo "Vea mijo, pues plata no tenemos, no nos desesperemos que allá está el de arriba, El nos va a resolver el problema; consigamole los bananos a Patricia, démole la miel, démole todo lo que le seguimos dando y Dios proveerá. Si la tiene pa' este mundo, aquí nos la deja, o si no se nos la lleva, pero no nos desesperemos" De dónde sacábamos dos millones? Ah no! Pues entonces la dejamos asi y al Lunes siguiente la llevamos a que le hicieran el examen. Le habían subido las defensas y todo. Le dije yo "Para que vea, el de arriba ahí está, El le pone a uno pruebitas y le pone sus cascaritas a ver uno que hace, no?

> **I.-** Why isn't that you haven't been in a situation like that ? (Situation in which you've felt lost)
> **Gm.-**Why? Because I have a lot of faith. I pray God a lot, I talk with Him and I also fight with Him, right? When I see that things don't [go well] hurry up! [I say to Him]. So, I fight with Him but I belief that in the middle of all this faith, the faith you have is what counts.
> **I.-** That's you always feels you help from the one up there (God)?
> **Gm.-**From the One up there; the One over there doesn't let me down. One of the last days, at the end of the other protocol, [her] defenses went down. They prescribed five injections of Leucomax. We found out how much they cost and they cost like two millions, those weren't given [by the health insurance]. We have to buy them. My son

> comes and he says to me 'mother, what are we going to do to get that drug? I tell him " Look son, we don't have money; let's don't get desperate that there's the One up there, He's going to solve the problem; let's get the bananas for Patricia, give her the honey, give her everything we give her and God would decide. If she is for this world, He would let her stay; if not, He's going to take her but let's don't get desperate" From where were we going to get two millions? Oh, no! So we didn't get the drug and on the following Monday we took her to get the [blood] test. The defenses and everything went up. I told him "You see, the One up there is helping, He's testing us out to see what would we do, right?

The Catholic priest in their church has been very supportive. He has helped them to view the illness as God's will but for their good not as punishment. They go to the healing mass the priest holds every week. The priest's way of being and preaching gave them comfort and courage. He tells them to be patient, to have faith and hope, and to keep going on. Fernando got a great deal of comfort from the testimony of God's help he gave during the mass. During that moment, he felt positive energy and solidarity from the people attending the mass.

The relatives from both sides of the paternal grandparents' family give them financial and moral support. They organized different events, especially at the beginning when Patricia did not have health insurance, to obtain money for the treatment expenses. They also call them almost everyday to find out how Patricia is doing. They visit them often and make them forget about Patricia' s illness by chatting, laughing, and telling jokes. During the first months of treatment, Fernando and Lucia also got financial help from the Drugs Fund.

The nurse nun from the Chemotherapy Unit is another source of moral support for these parents. However, there was a head nurse from the same unit who made things very hard for Lucia at the beginning of chemotherapy. Lucia perceived this nurse as unkind and tyrant. Lucia understands the nurse's way of being is something that everybody with some power does to the one with no power. So Lucia did not confront the nurse because she was afraid of retaliation. She was able to cope successfully with the situation by letting the problem to be solved by God and by behaving the best she could but without losing her dignity. Later, the nurse was fired because another mother complained to the hospital administration.

> **E.-** Fueron duros esos primero días con ella (la enfermera jefe)?
> **A.-** Ah! esos primeros días fueron durísimos, durísimos porque yo creo que eso lo tienen todos los jefes, cuando llega la persona nueva [ellos] son duros; es que uno no entiende, uno no sabe lo que hay que hacer. Entonces uno pregunta, uno está seguramente muy ansioso y pregunta mucho y todo eso les molesta.
> **E.-** Pero solamente le pasó con ella?
> **A.-** Con ella. Cuando un día llegué yo iba cuando me encontré a Angélica, ella es muy querida y todo pero eso .. no se con la demás gente, conmigo ha sido desde un principio muy formal.
> **E.-** Usted alguna vez le dijo algo a la enfermera jefe?
> **A.-** No nunca, nunca porque yo qué le voy a decir algo, si después me la echo encima, y usted sabe lo que es una persona encima de uno, que le coja a uno entre ojos.
> **E.-** Si, a uno ahí le toca agachar la cabeza
> **A.-** Y no es que allí le toca a uno porque es que uno no sabe que es lo que hay que hacerle al niño, ni sabe como es que se trabaja allá. Uno va y lo único que le enseñan a uno es que tenga cuidado que no se desocupe [el buretrol] y avise. Entonces uno está pendiente de eso, pero de allí pa'allá, uno es nulo para eso. Entonces todo eso si es duro, eso es duro, <u>bien duro</u>. Es así como me comentaba una señora, es que ella se estrelló con muchas mamás, hasta que se estrelló con la que no debía estrellarse, porque esa señora dizque pasó cartas a raimundo y todo el mundo, y como que a raíz de eso fue que salió. No se, ese comentario lo hizo una mamá y me había comentado también otra señora de aquí de Palmira, que con ella también había sido al principio, que la ponía a llorar; es que uno va destrozado.

> **I.-** Those days at the beginning with her (the head nurse) were pretty difficult?
> **Gm.-**Oh! Those beginning days were extremely hard, extremely hard because I think all chiefs have that. When a new person comes in, [they] are harsh; one doesn't understand, one doesn't know what to do. So one asks, maybe one is very anxious and asks too much and all that bothers them.
> **I.-** But that only happened with her?
> **Gm.-**With her. One day I came in and I met with Marta Lucia, she's very nice and all that .. I don't know how she is with other people; she's been very kind with me.
> **I.-** Did you say something to the head nurse?
> **Gm.-**No, never because I didn't want to tell her anything. What if she would get mad at me? And you know how that is when somebody is against you, when they don't like you.
> **I.-** Yes, one has to lower the head
> **Gm.-**Yes, there one has to do that because one doesn't know what to do for the child. One goes there and the only thing they teach you is to watch carefully so that (the buretrol) won't be empty and call them. So one is watching that but other than that one is useless. So all that is very hard, that is hard, <u>very hard</u>. Another woman told

> me, it's that she (the head nurse) had a confrontation with somebody who fought her back; that woman wrote letters to everybody and that was how she was removed. That was another mother's comment and also another woman from Palmira; she was like that with her, she made her to cry; it's that one goes there destroyed.

Through the above account, Lucia also acknowledges the lack of information and guidance from the nurses in the Chemotherapy Unit; it seems the parents learn by themselves most of what is necessary and they feel lost in the new situation with very little support from the nurses. Lucia admits there is lots of work for the nurses to do but they should be more sensitive, caring, and take some time to be with the new parents coming to the unit. She accepts it is very important to have somebody guiding and supporting the parents mostly at the beginning, when they are suffering so much and do not know what to do in the new circumstances. The following account is a very strong instance about how significant is for the parents the nurses' support and caring disposition.

> **E.-** Claro, se necesita una persona que lo guíe
> **A.-** // Si, uno no va a decir pues muchas veces ellas están muy ocupadas, pero [pueden decir] mas tardecito le puedo explicar todo lo que quiera, es que uno puede sacar tiempo para todo. Al principio pa'mi fue muy duro, a mi me tocó muy duro porque pues ese trato que le dan a uno al principio allí es duro.
> **E.-** A qué cree usted que se debe ese trato, doña Lucia ?
> **A.-** Yo no se. Ahí si no se si será que les hace falta capacitación, no se algo de Sicología o qué les hace falta? Porque ellas son graduadas en su Universidad y todo pero algo les hace falta. Como ser mas <u>humanas;</u> está bien, están tratando con el dolor y se tienen que volver un poquito duras, porque pues ellas no se puede morir con todo el paciente que llega ahí porque se pararían, cierto? Pero no volverse tan demasiadas duras; les hace falta mas sensibilidad. Se les acaba la sensibilidad a tal punto que se olviden que la gente que hay allí es humana que está sintiendo y que están sintiendo un dolor muy grande.
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> **I.-** Of course, they need a person who can guide them
> **Gm.-**// Yes, I'm not going to say, many times they're pretty busy, but [they could say] later I can explain you whatever you want to; one can have time for everything. At the beginning, it was very hard, it was very hard for me because of the way they treat me there at the beginning.
> **I.-** What do you believe is the reason for them being that way with you?
> **Gm.-**I don't know. Maybe their training lack I don't know something about

> Psychology or they lack something else? Because they graduated from a university and all that but they're lacking something. Like being more human (more caring); it's all right, they're dealing with suffering and they need to become a little bit tough because they can't die with every patient who comes in because they would be paralyzed, right? But not to be too tough; they lack sensitivity. They lose the sensitivity to a point they forget that the people who come there are human beings, who are feeling a great pain.

Lucia's interpretation of the advice giving by the nurse to the parents about disciplining the child illustrates the parents' need of having support in parenting the ill child but it also points to the timing of this advice. It seems that at the beginning of the illness experience they are not ready to hear such advice since they are very concerned about the child's surviving the disease.

> **E.-** Y llega uno a un medio totalmente desconocido
> **A.-** // Hosco
> **E.-** Hostil
> **A.-** Si, completamente donde no le dan a uno .. de golpe la monja, pues si yo me acuerdo ese día que me habló la monja que llego a pedirle .. Digo yo a esa monja no debía ni de meterse porque es que ella no es mamá. Me dijo que uno tenía que educarlos, que no podía yo no se que, que porque los niños se volvían groseros y que había que tratarlos con dureza, que no se les podía dar de todo lo que pedían. Les digo yo acá "Esa monja, tan metida dizque ay no .. claro pues como no son hijos de ella" Pero mentira, de golpe lo dice como con unas palabras .. es que el tono de voz de ella es duro, no? Pero mire que uno se pone a pensar luego y si es verdad, uno tiene que quererlos, consentirlos pero trancarles porque entonces se lo llevan a uno mejor dicho, porque los malcría uno, los vuelve insoportables, groseros, no? Entonces si, si tal vez si.

> **I.-** And one comes to a completely unknown place
> **Gm.-**// Unfriendly
> **I.-** Hostile
> **Gm.-**Yes, completely where they don't give you .. maybe the nun; I remember that day that she told me when I came to ask for .. I told myself, that nun shouldn't say anything because she isn't a mother. She told me that one should discipline them (the children), that one couldn't, I don't know what, because the kids would become spoiled so we should treat them harshly, that we shouldn't give them everything they ask for. I told them here at home "That nun is so nosy, of course [she said that because] they aren't their children" But no, maybe she said in a way that isn't .. it's that the tone of her voice is harsh, right? But, later you think about it and it's true; you have to love them, pamper them but also to discipline them because if you don't do

> that they would go out of your control. They would become spoiled, intolerable, and rude, right? So, yes, yes maybe yes.

Fernando and the entire family get courage from Patricia. She has learned to endure the pain and fear from the needle sticks. Through playing with her dolls and the family members, Patricia rehearses what is happening to her. So Fernando understands her playing as a way to show them she is not suffering because of the illness.

> **A.-** Y la niña le enseña a uno tantas cosas, porque vea que ella viene de allá de ese Hospital como maluca pero ella misma le da a uno ánimo. La niña viene con ánimo y se ríe y coge su almohada y mama lengua y se ríe. Entonces uno dice pero si ella está así
> que es la que está sufriendo todo, por qué nosotros no podemos ir pa'arriba, no? Entonces ella le enseña a una un resto de cosas que es increíble.
> **Pp.-** Y los juegos de ella, no? Ella tiene una muñeca en la que ella interpreta todo, lo que le hacen a ella ella se lo hace a su muñeca . Sor una vez le regaló una bolsita de suero con el tubo y ella se lo pone debajo de la manito a la nena y que no le duele, que el chuzón en cuál mano. Y va y saca un papel y escribe y esta es la.hemoglibina, tiene la hemoglobina en dos, y está muy bien. O sea ella, su misma vida la refleja a la muñeca.
> **A.-** Ella le tiene el maletín y ella le carga ahí las fórmulas y ella cuando va a ver la hemoglobina ella coge una crayola roja y escribe y la oí decir tiene la hemoglobina muy buena y las chaquetas las tienes buenas.
> **Pp.-** La chaquetas son la plaquetas.
> **A.-** Si las chaquetas y ella todo y ella la pesa y ella le habla
> **Pp.-** Ella me da a mi mucho ánimo, mucho, mucho, mucho ánimo...... Me gusta [verla jugar] porque vive su mundo, ella creó su mundo y lo vive y lo disfruta. Porque se ve que disfruta ella eso. Con su muñeca le pone que el suero, a nosotros mismos a uno se lo pone aquí debajo del reloj, pero ella siempre nos pone suero. Ella mantiene allá, su bolsita usada, la infla y le pone el taponcito, luego nos la pone y ella goza.

> **Gm.-** The girl teaches us many things because she comes here from the hospital feeling sick but she cheers us up. The girl comes in good mood, she laughs, gets her pillow, and sucks her tongue. So one thinks if she is like that and she is the one suffering all, why we can't go on, right? So she teaches us a great deal.
> **F.-** And the way she plays, right? She has a doll in which she rehearses everything; she does to the doll all what they do to her. The nun nurse gave her a saline solution bag with the tube and all that and she puts it on the doll's hand saying "it doesn't hurt, on which hand do you want the [needle] stick? And she takes a piece of paper and writes the hemoglobin is two. That's she reflects her life in what she does to the doll.
> **Gm.-** She has a suitcase for the doll and she puts there all the papers she writes for her. When she's going to write the hemoglobin, she takes a red crayon and you hear

> her saying "she has a good hemoglobin and also the platelets, She also weights the doll and talks to her.
> **F.-** She gives me a lot of courage, lots, lots of courage ..... I like it (watching her playing) because she recreates her world in that and she enjoys it a lot. Because it seems that she enjoys it. She gives the saline solution to the doll or to either one of us under the watch. She keeps the used bag there, she inflates it, and she puts in the little thing to block the air and then she puts it on us; she enjoys that a lot.

Fernando also finds courage in seeing his daughter full of energy, behaving and looking like a normal girl, as if she would not have the disease. So Fernando and his parents felt they should learn from Patricia how to overcome suffering and pain from the illness.

Next to God, Fernando' s parents have been the main sources of support. His father helps him with money and advice and his mother with caring for Patricia most of the time. Fernando has a girlfriend who provides support by finding scientific literature about the disease, talking with him about what is going on, and helping him to calm down when he is anxious about not having a job or other things. Fernando likes very much to talk with other people who are genuinely interested in listening to his story about Patricia. So he does that quite often, he feels better after he talks with others. He gets angry when a person shows him pity saying *Oh poor guy*! He understands this expression as lack of respect and sensitivity. He gave a narrative about a mother whose child died from leukemia and was telling him bad things about the doctors from the hospital and how sorry she was for him.

> **E.-** Algunas personas me han comentado que hay algo que se les hace muy difícil es cuando les dicen ¡ay pobrecitos! Cómo
> **P.-**// Cómo reacciono yo ?
> **E.-** Si.
> **P.-** Me da rabia, me da malgenio, a mi me provoca coger a esa gente y desaparecerla del mapa, no? Porque eso es falta de caridad con uno, falta de respeto tal vez con uno. Hombre ellos no saben, mucha gente no sabe qué es lo que uno siente. Que respeten lo que yo siento y sepan .. y respeten lo que uno siente, y que no traten de tumbarle como la fe que uno tiene. A mi eso me da mucho malgenio, yo no les pongo cuidado. Yo trabajé el año pasado en Seguros Bolívar, había una señora que tuvo una niña y se le murió de Leucemia. [Un día] se me arrimó y me habló, digamos así, pestes del Doctor Pereira, del Hospital Departamental, que eso era malo, que eso era lo peor. Le

> dije yo "Vea, hagamos una cosa, usted habla así porque su niña desafortunadamente le tocó morirse. Dejemos las cosas así, a mí no me importa lo que usted sienta" O sea, me dió rabia, me dió rabia, me dió rabia. "A mi no me importa lo que usted sienta o haya sufrido, déjeme que yo sienta lo que estoy sintiendo y crea en la gente que yo estoy creyendo" Pero por qué me contesta así? me dijo la señora. Le digo "porque es que no me gusta la gente que me habla de esa forma, si usted sintió lo suyo, listo muy duro tuvo que haber sido, obvio es su hija, pero a mi no me venga a decir las cosas y mucho menos de esa forma. Respéteme, respete mi dolor". Esa señora nunca mas me volvió a hablar, nunca mas me volvió a hablar. A mi eso me da rabia.
> **E.-** Qué es menos molesto para uno que le digan "Pobrecito que pesar! o que le digan "No, eso no es nada, eso aquí no ha pasado nada, sigamos adelante!"
> **P.-** Ah! si yo prefiero esa gente, yo prefiero a la gente que me diga esto no es nada, vamos para adelante, hay que vivir, busque por un lado y busque por el otro. Pero la gente que me diga !Pobrecito! esa persona que está hablando tiene el espíritu muerto.

> **I.-** Some people have told me about that is difficult for them when people say "Oh, poor little thing! How
> **F.-** How do I react to that?
> **I.-** Yes
> **F.-** I get angry, I get mad, I would like tovanish those people, right? Because that is lack of charity with you, lack of respect with you. They don't know, a lot of people don't know what you're feeling. So they should respect what you feel; they shouldn't try to destroy your faith. That makes me very angry, I don't listen to them. Last year, I worked in an insurance company and there was a woman whose girl died from leukemia. [One day] she came to told me, let's say, bad things about doctor Pereira (the Oncologist) and the hospital; that all that was bad, the worst. I told her "Look, let's do something, you talk like that because unfortunately your girl died. Let's leave things alone, I don't care about what you feel" In other words, I was angry, I was mad, I was mad. " I don't care about what you felt or suffered, let me feel the way I'm feeling and to believe in the people I'm believing" The woman told me "But why are you answering me like that?". I told her "Because I don't like people talking to me that way. If you felt that way, all right maybe it was very hard for you, obviously it was your daughter but don't come here to tell me that stuff and much less in that way. Respect me, respect my pain". That woman never talked with me again, ever she talk with me. That makes me very angry.

Fernando prefers people who encourages him by saying *Hey, nothing has happened here, keep on going on with your life, look for help here and there!* Other parents from the hospital also helped Lucia and Fernando by sharing their experiences and ways of caring for the children. The Parents' Association has organized trips to different places for the children; Patricia and Lucia went to the trip to the recreational club with the parents and children.

Patricia enjoyed a lot being for the first time after the diagnosis in the swimming pool.

By the time of the last interview, Fernando was working again and making lots of plans with his girlfriend for the future. He was even thinking about the possibility of having more children; it seems he has overcome that idea of leukemia being hereditary and the fear of repeating the illness experience later in his life. In the near future, he expects to move out of his parents' house and be on his own but with Patricia staying with grandmother during the days after school and going home with him in the evenings. He is also considering going back to school to finish his studies.

Lucia in her roles as grandmother and mother and Fernando in his role as father find many positive possibilities in the middle of the multiple losses that they encountered because of the illness experience of their child. Their loving and caring previous relationship is invigorated by the pain and suffering from the experience. Their commitment to care for their ill girl and their religious faith along with the extended family and friends support allow them to cope with the girl's illness in a way that ensures the girl's recovery and the somehow smooth functioning of the whole family. Losing their healthy child moved them to gather the strength within themselves and the resources to successfully recover their child. Fernando lost his wife and the mother of his daughter but he finds the possibility of continuing his commitment to care for his daughter with his mother's unconditional support. Lucia lost her everyday peaceful routine but she finds the possibility of caring for her granddaughter, which gives her a great deal of fulfillment despite the toll it is taking on her health. Both Lucia and Fernando find ways to endure the everyday uncertainty they live due to the girl's prognosis. They understand they are living on the edge but they learn to live in the present time regarding the girl's life. Fernando has been able to find another relationship and he plans for his future in which he hopes to be with his daughter. Love, care, and faith help this family to find possibilities within the multiple losses generated by the girl's illness.

In this paradigm case, the family moved from their fatalism at the beginning of the illness when they were expecting Patricia's death and rejected harsh intrusive therapies to seeing the survival possibility, embracing the medical regimens of chemotherapy, and living on the edge with a wary vigilance. Patricia's life constantly seemed to hang in the balance. They managed to discipline Patricia, but Patricia also learned to be strong for the family. There is very little denial of the disease or its potential life threatening implications. One only can surmise that is difficult for the child to be the focal of such attention and concern. That the father once again had energy and time for another loving relationship is a sign of the sense of increased possibility.

Facing Suffering without a Community to Share it

Cristina's everyday experience in coping with her daughter's illness shows all the challenges and struggles a mother faces during the child's illness. Cristina's story also illustrates the endurance and resilience of a young mother determined to fight for her child's life with minimum resources. Cristina's story could be very encouraging for other parents living a similar situation and in a similar socioeconomic context.

Cristina is 19 years old and Francisco is 29. They are the parents of Laura (the ill child), age 4 and Nancy, age 2. Cristina and Francisco are not married; they have been together for 4 years. Before the illness, they lived with Cristina's parents in a small town about three hours driving from Cali. Laura's illness forced them to move to Cali and live with Francisco's relatives. They live in a neighborhood quite far from the treatment hospital, more than 1 hour by bus. Cristina, Francisco, and the girls sleep in the same bed but in their own bedroom.

They share the kitchen, bathroom and other areas of a very small house with Francisco's mother and brother. They also share the rent and utilities. There is no telephone in the house but nearby there is a paid telephone. Francisco has a job in sales earning the minimum salary ($165 per month) and Cristina is a housewife. Laura was born from another relationship but Francisco has taken her as his daughter.

Discovering the Diagnosis that Changed her Life

Cristina's ordeal because of Laura's illness began with two months of futile visits to physicians. Cristina found herself going from one physician to another without getting any effective treatment for Laura's sickness. Cristina followed their prescriptions except giving Laura an antibiotic that the lay pharmacist told her it was strong for the girl. Finally, after visiting four different physicians, a pediatrician from a second level hospital referred Laura to the teaching hospital, where the leukemia was diagnosed

Getting the diagnosis was a step by step process. The Pediatrician who did the referral did not give Cristina and Francisco any diagnosis; he told them there was necessary to do more tests on Laura so the physicians in Cali would tell them the diagnosis. As soon as the physicians in the ER at the teaching hospital began asking Cristina the usual questions to assess Laura's condition, Cristina sensed her daughter might have leukemia. Maybe she sensed that even before when a neighbor told her the possibility of Laura having leukemia because of Laura's paleness. Cristina understood all the questioning about cancer antecedents in their families as a clue for the diagnosis. However, she had to wait until the next day to learn the diagnosis. A pediatric resident told the parents the diagnosis at once.

Cristina' s pre understanding of leukemia as a fatal disease set her reaction to the diagnosis. She was terrified by the diagnosis. She got out of control when the physician told them the name of the disease. She cried and screamed until the physician told her she needed to calm down because it was bad for Laura to see her reaction.

M.- No pues él empezó pues a.. a hablar que .. él nos dijo que la niña tenía
P.- // El, él nos llamó, nos llamó y nos dijo no se vayan subir, no se vayan a ponerse a,
M.- // Alterarnos
P.- A alterarse nada, que
M.- // Que eso le hacia daño a la niña. Entonces yo le preguntaba qué, qué pasaba, que nos dijera y ... y ... él me decía que me tranquilizara que .. pues yo si me desesperé, no?
P.- Ella si, se subió y se puso a llorar ahí
M.- Entonces, el doctor dijo que no podíamos hacer eso, pues que la niña estaba presente
P.- Eso, adelante de la niña no se le podía hacer nada, de esa
M.- Lo que la niña tenía la podía perjudicar mal, las lágrimas no? que nos calmáramos para él podernos explicar lo que pasaba. Entonces ya nos dijeron que .... El doctor dijo la niña tiene leucemia según los análisis, la niña tiene leucemia, no vayan a creer que, que porque sea leucemia la niña se les va a morir, y se les va a morir, y se les va a morir. No, la niña tiene leucemia pero la niña se puede mejorar, hay muchas posibilidades de vida, hay que mirar qué clase de leucemia es, porque a ella no le han hecho la médula todavía sino el hemograma. Según la, la clase de leucemia hay una leucemia que en un 80% de niños se salvan, como hay otra que es un 40 no mas, entonces...

M.- Then, he (the physician) began ... to... to talk that ... he told us that the girl had
F.- // He, he called us, he called us and he told us don't overreact, don't go to
M.- // To be upset
F.- Not to be upset because that
M.- // Because that would harm the girl. Then, I asked him what, what happened, to tell us and ... and ... he told me that I should calm down that ... I really got desperate, right?
F.- She became very upset and started crying
M.- The, the doctor told us that we shouldn't do that because the girl was there
F.- Right, in front of the girl we shouldn't do anything like that
M.- That could harm what the girl had, the crying right? That we should calm down so he could explain us what was going on. Then, they just told us that ... the doctor said the girl has leukemia according to the tests the girl has leukemia; don't think that because it's leukemia the girl is going to die, and she's going to die, and she's going to die. No, the girl has leukemia but she could get well, there're lots of possibilities to live; we need to see what kind of leukemia she has because she hasn't had the bone marrow yet, only the hemogram. According to the type of leukemia there's one type of leukemia in which 80% of the children survive, as there's another type that only

40%.

Cristina was able to calm down following the physician's request in the middle of such terrifying moment. Calming down allowed Cristina to listen to what the physician was explaining to them about the treatment and survival possibilities for Laura. His discussion helped to decrease the dreadful idea of Laura's imminent death and ease some of the overwhelming panic she was feeling. Controlling the overreaction to protect her child seems to be a very appealing request for Cristina because it calls for her role as her daughter's protector. During the interviews, she acknowledged that seeing Laura so frightened by her reaction was the main reason for her to become tranquil at the time of the diagnosis. At that instant, Cristina learned to hide her sorrow from Laura; she only cries when Laura is sleeping or when she can not see her. The few times that she has cried in front of Laura, Cristina tells her she has a headache so Laura does not worry about why her mother is crying. Crying is the way by which Cristina can get some relief from the affliction she feels due to the illness situation.

> **E.-** Bueno entonces volviendo a mi pregunta de cuando les dieron el diagnóstico. Entonces, tu (Francisco) pensante que la niña se iba a ir y tu (Cristina) pensaste no ella no se va ir. No, no puede ser que ella se va ir, cierto? Qué hicieron para tranquilizarse? Por ejemplo, Cristina que era la que estaba mas …
> **M.-** Pero pues ya él, él lloró pero pues ya cuando el doctor dijo que eso le podía hacer daño a la niña pues vernos a nosotros tan mal, entonces ya él, ya él dejó y me calmó a mí no.
> **P.-** Porque ella si nos preguntó, la niña nos preguntó, qué, qué le pasaba? Cuando nos vio llorando ya ella se puso a llorar.
> **M.-** Ella se puso a llorar …Ya, yo cuando ya vi que ella empezó a preguntarme, yo ya me calmé un poquito, y ya.
> **E.-** O sea la ayudó a calmar fue,
> **M.-** // Prácticamente ella porque pues ella me este con la preguntas me, ya no, yo no quería pues cierto que si eso la iba a perjudicar pues entonces no, no hacerlo no, aunque tenía un nudo aquí, pero pues yo esperé que ella ya, a ella la subieron pa' arriba, la/ ya se acostó a dormir, ya entonces yo me desahogué no, ya uno se va desahogando, poco a poco, porque pues yo no lo hago delante de ella no, pero pues uno poco a poco se va desahogando, mas que todo cuando ella duerme, o así.

E.- Desahogar es llorar?
M.- Si
E.- Llorar sin que ella se de cuenta?
M.- Sin que ella se de cuenta

I.- O.K., going back to my question about when they gave you the diagnosis. Then, you (Francisco) thought that the girl would go but you (Cristina) thought no, she won' t go; no, it couldn't be that she's going to go, right? What did you do to calm down? For example, you Cristina who was the one more …
M.- But he already cried, he cried but then when the doctor said that could harm the girl seeing us so bad, then he stop and he calmed me down, right?
F.- Because she did ask us, the girl asked us what was happening to her? When she saw us crying she also started crying
M.- She started crying … When I saw that she began asking me then I calmed down myself a little
I.- That's what helped you to calm down was
M.- // Practically was she with the questions, I didn't want .. Because if that would harm her then don't, don't do it even thought I could feel a lump in my throat. I waited until she, she was taken up [to the pediatric ward and, she went to sleep. Then, I got it out of my sytem right? One is going to get it out of one's sytem little by little because I don't do it in front of her no, but little by little I'm getting it out of my system mainly when she sleeps or something like that
I.- Getting it out of your system is to cry?
M.- Yes
I.- Crying without letting her to see it?
M.- Without letting her to see it

Cristina's understanding of the illness is similar to other parents' understanding. At the diagnosis, she understood leukemia as cancer and cancer as death because it kills people due to the lack of treatment for it. Over the first year of treatment, she learned leukemia could be treated but she was not sure about leukemia being cured. Seeing other children becoming sicker and dying despite their parents fighting against the disease makes Cristina wonder about Laura's survival possibilities. Cristina prefers Laura would die quickly if she gets to the point that there will not be any more treatment for her. She rather loses her daughter than seeing her suffering. But if there is treatment for Laura, Cristina would do whatever the physicians tell her to save her daughter.

Cristina got her pre understanding of leukemia from her experience with the disease in her extended family. There had been cases of leukemia in children and cancer in adults in both sides of Cristina's family. All of them died so cancer is a fatal illness for her. In talking about her thoughts at the time of the diagnosis, Cristina did not admit thinking about Laura's death due to the leukemia, instead she talked about having faith her daughter would not die from the illness. She also referred to her father's thought about Laura's death. It seems that Cristina relates the diagnosis of leukemia to death but she is not willing to talk about it or she does not remember having this thought at the time of the diagnosis. However, her response to the diagnosis illustrates what she was thinking at that moment. Francisco, Cristina's partner, was very surprised by the diagnosis; he openly talked about thinking that Laura would die soon. Both parents had similar pre understanding about the leukemia but Cristina did hear about the treatment and survival possibilities, which gave her hope and the courage to begin the long battle against her daughter's illness.

After the cancer diagnosis, the entire family went to live in the city so Cristina found herself facing Laura's illness away from her parents and siblings. Cristina's life changed dramatically. She went from being a mother taking care of two healthy girls with her parents' support, in a small town to being the mother and the main caregiver for her ill daughter in an environment foreign and unfriendly to her. She has been able to endure living with her unknown and distant mother and brother-in-law. She negotiated with her husband and mother-in-law what she was expected to do in the new home while doing everything regarding Laura's treatment in the hospital.

Cristina's understanding of the biological aspects of the disease is very concrete. She understands there are tiny animals that eat the body, the white and red cells, and everything that is in the blood. There are more and more tiny animals every day. Also the body defenses, meaning all that is in the blood, can not reproduce well. The drugs kill and destroy the tiny animals so it is very dangerous for Laura to delay the treatment for any length of time.

> **E.-** Qué es lo que hace el tratamiento o la droga. Por ejemplo, qué hace la droga en el cuerpo de la niña y a la enfermedad qué le hace, cómo es eso ? Qué han leído, qué ha oído, qué le han dicho?
> **M.-** Pues yo he leído y he oído, que pues que la droga le entra y le acaba con los animalitos que se están comiendo el cuerpo.
> **E.-** Qué está haciendo la enfermedad, cómo es eso de la enfermedad primero ?
> **M.-** Pues son que unos animalitos, prácticamente pues nos dibujan unos animalitos que se están comiendo los glóbulos blancos, los rojos que se los están comiendo, están comiéndose todo lo que produce la sangre, lo que produce las defensas todo, no?
> Entonces cada día va habiendo mas animalitos que se comen los otros y como también o sea, no alcanza a veces a reproducirse bien lo que son las defensas pongámole no alcanza a reproducirse y ya los otros se están comiendo lo que se ha distribuido. Entonces que?
> **E.-** Entonces la droga ataca esos animalitos?
> **M.-** Si los ataca y los mata, los quema, los destruye
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> **I.-** What does the treatment or the drug do? For example, what does it do to the body and the disease? How does it work? What have you thought, learned or heard about that?
> **M.-** I've learned and heard that the drug gets [into the body] and ends (kills) with all the tiny animals that are eating the body.
> **I.-** What's the disease doing? First, how is that about the disease?
> **M.-** There're tiny animals, practically they draw us tiny animals that are eating the white blood cells, the red cells, they're eating all what is in the blood, what produces the blood and the defenses, right? So every day, there are more and more tiny animals that eat the others and there isn't time for the body defenses to reproduce well and the tiny animals are eating all that's been distributed. So..
> **I.-** So the drug attack the tiny animals?
> **M-.** Yes, it attacks them, kill them, and destroy them.

Cristina has been very active in finding information about the disease and the treatment. She asks the nurses and the physicians and she reads some booklets from pharmaceutical companies that one of the nurses sometimes gives her. She shares her knowledge with her partner but only if he shows interest in learning about the disease. Cristina sees the

chemotherapy as good and bad for Laura. It destroys what causes the disease but it also lowers her defenses. Low defenses do not concern very much Cristina because she expects that to happen as a consequence from the chemotherapy. Laura's hair loss was not a big deal for them either. Cristina got scared at first when she was combing Laura's hair and it came out in a big bunch but soon she remembered it was something caused by the drugs. She did not continue combing Laura's hair at that moment. She waited until all the hair fell and then she cut the thin hair l to make it look nicer. Cristina prepared Laura for the hair loss. She told her it would happen and showed her the other children without hair in the hospital. Cristina, as other mothers, used some products to protect Laura's hair. She put pure crystals of Aloe Vera mixed with white wine and oil made from the cow limbs.

Struggling with the Illness Unexpected Course

Cristina decided to fight for Laura after knowing there was treatment for the leukemia; she said her faith in God saving her daughter also gave her strength to go on. The treatment started and Laura was recovering but the bone marrow biopsy done at the end of the induction phase showed she did not go into remission. Cristina calls this a relapse but it is not a relapse from the clinical point of view. Probably due to the lack of specific diagnostic techniques the Oncologist could not identify the type of leukemia Laura had so the treatment was not specific enough to cause the disease remission. Then, the treatment protocol was changed from normal risk to high risk. At this time, Cristina was again devastated because she understood the lack of Laura's response to the chemotherapy as the end to Laura's life. She believed the disease had spread all over Laura's body and the Oncologist would have to give her a very dangerous treatment. She understood the treatment could kill Laura so she did not authorize the rescue treatment at first.

> **M.-** Los exámenes, le hicieron la médula, ya dijeron que la enfermedad era una enfermedad leve, que ella tenía riesgo normal y le dieron salida. Empezaron la quimio y a los cuatros meses la niña recayó, a los cuatro meses de la quimio recayó, le hicieron otra médula, ya pasó de que la niña la estaba invadiendo el cuerpo
> **E.-** Y en esa médula le salió qué había hecho recaída ?
> **M.-** Que había hecho recaída, que el cuerpo se le estaba invadiendo, entonces ya el doctor dijo que, la doctora Margarita pues.... Él (el esposo) estaba trabajando y, me llamó a mí. Entonces me dijo que llamara ... que necesita hablar conmigo pero con alguien de mi familia, no? con mi esposo o alguien mas. Entonces pues yo le dije que él no podía porque él estaba trabajando pero que yo iba a llamar una tía. Llamé a mi tía y mi tía fue. Habló con nosotros y nos dijo que con la niña no habían esperanzas, que lo único que .. lo único que había pues para este, era una droga que era demasiado fuerte, que podía que ella no la pudiera resistir, que podía ser que ... que la misma droga la fuera afectar. Entonces yo le dije que no se la pusiera, yo le dije que no, que si se la iban a poner ..... que si la niña se me iba a ir por culpa de esa droga, que mejor no.
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> **M.-** The tests, they did the bone marrow and then they said that the disease was mild, that she had normal risk, and they discharged her from the hospital. They began the chemo and at four months the girl had a relapse, at four months of chemo she had a relapse; they did another bone marrow, then it happened that the disease was invading her body.
> **I.-** And the bone marrow showed she had a relapse?
> **M.-** That she had a relapse, that the disease was invading her body, then the doctor said that, doctor M. said, he (Francisco) was working and she (the oncologist) called me. Then she told me to call ... that she needed to talk with me and other family member, right? My husband or somebody else. I told her he couldn't come because he was working but that I would call my aunt. I called my aunt and she went with me. [The doctor] talked with us and told us there was not hope, the only thing they could do was a drug which was very strong that she might not resist it, that it could be that the drug might affect her. Then, I told her not to give it , I told her not to, if they would give to her ... if the girl would go because of that drug that would be better not to give it.

The Oncologist talked with Cristina's maternal aunt, who was the support person at that moment for Cristina. Cristina's aunt helped Cristina to understand better the rescue treatment; she was able to convey faith and treatment as the only possibilities for saving Laura in a way that was more appealing to Cristina so she accepted the treatment for her daughter. By the first week of the rescue treatment, Cristina was very happy and surprised to see how well Laura tolerated the treatment and fully recovered after having an episode of pneumonia.

M.- Entonces ya ella (la oncóloga) habló con mi tía y le dijo pues que …que eso era una posibilidad cierto? que si no se la poníamos entonces había un riesgo de que mas fácil se fuera y mas rápido, y poniéndosela confiando en Dios se iba a mejorar, de pronto no? que no ella no nos iba a dar a nosotros esperanzas no, porque pues daba mal darnos esperanzas y de pronto fuera … Entonces ya mi tía habló conmigo me dijo que se la hiciéramos poner, que confiáramos en Dios, que ... y al fin de tanto hablar mi tía yo pues hablamos, y lo llamé a él y le dije que … pues él me dijo que si que se la pusiéramos. Entonces le dije a la doctora que si y empezaron el tratamiento de la droga. Gracias a Dios le fue muy bien, no? Los síntomas que me dijo la doctora que podía presentar la niña, ella no los presentó, el único síntoma fue la caída del cabello pero ni vómito, ni malestar, nada, normal. Yo le di gracias a Dios pues, mas sin embargo le hicieron otra médula. No había salido muy buena que digamos, no había salido muy buena pero pues le empezaron el mapa de riesgo alto, le empezaron el mapa y se lo, no se lo alcanzaron a terminar cuando la niña volvió y se me enfermó. La volvieron a hospitalizar pero ya no fue de recaída de eso sino que del pulmoncito. Y la hospitalizaron y ahí en esa hospitalización le hicieron otra médula, ya en esa médula ya salió de que ella había entrado a remisión y que ya el tratamiento iba ser pues mas, mas leve, y, y ahí está con remisión.

M.- Then, she (the oncologist) talked with my aunt and told her that …that was a possibility, right? If we did not give it [the drug] then there would be the risk that [she] would go and faster but if we give it to her thanks to God, maybe she would get better, right? That she didn't give us hope, because it was bad to give us hope since maybe she would … Then, my aunt talked with me and she told me that we should give it, that we should trust God, Finally, after we talked a lot, my aunt and me, I called him and I told him and he said yes, that we should give the drug to her. Then, I told the doctor to give it and they began the treatment with the drug. Thanks God, it went well for her, right? The symptoms the doctor told us that she would have she didn't have them, the only symptom was the hair loss but no vomiting, no discomfort nothing, normal. I thanked God for that; they did another bone marrow. It wasn't very good as we would like, it wasn't very good but they began the high risk map (protocol). They began that map but before it was finished the girl got sick again. They put her in the hospital but it wasn't because of the relapse, it was because of her lungs. And they hospitalized her and during that time they did another bone marrow. This bone marrow showed that she went into remission and the treatment would be would be less strong and since that she's in remission.

After the rescue treatment Laura went into remission and continued the maintenance phase of chemotherapy. She did pretty well during the following months of treatment. During this time, Cristina struggled mainly with the lack of money for the treatment and other family needs. Despite of Laura's health improvement, Cristina was torn between feeling optimistic

and pessimistic about her daughter's future. She tried to be optimistic but her hopes and optimism blurred every time a child under treatment died. The death of other children made Laura's death a reality for Cristina. Her grief became very intense and the only way she could get some ease was by crying.

> **M.-** Me da como una cosa aquí (en el corazón), como que yo .. como que .. que pienso no, que de pronto yo voy a estar en las mismas. Qué irá hacer de mí, cómo lo iré a tomar. Yo quisiera saber cómo lo voy a tomar si llega a pasar, no creo que llegue a pasar pero si llega a pasar, cómo lo iré a tomar, si lo voy a soportar ..... si voy, si me va hacer mas duro como mas duro de lo que se me ha hecho. A veces quiero como desahogarme, no solo por la enfermedad de ella, sino por muchos problemas que, que pues puede uno tener no? Entonces como que se me revuelven entonces yo quiero como desahogarme, y yo me siento como que yo me voy ahogar y voy a estallar, yo digo que si, irá hacer mas duro no, que yo siento un dolor grande, un dolor como que, como que yo quisiera gritar que todo el mundo me escuchara, ya? Digo que si va hacer igual no, pues me pregunto yo no se, pero pues yo digo que de pronto no sucede, que pues mas que todo yo pienso mas que todo eso cuando .....
> **I.-** Cuando se entera de algún niño
> **M.-** Si cuando me doy cuenta de eso

> **M.-** I feel like something here (in the heart), like I .. like that.. I think that maybe I'm going to be in the same situation; what will happen to me? How will I take it? I would like to know how I'm going to take it if that would happen; I don't think is going to happen but in case it would happen, how I' ll take it, if I would tolerate it ... if I'm, if it's going to be very hard, harder than it's been so far. Sometimes, I feel like I want to get it out of my system not only because of her illness but because of the many problems that I have, right? I feel awful and I want to get it out of my system, and I feel like I'm going to drown and to explode. I ask myself if that is going to be harder and I feel a very intense pain, a pain like, like I would like to scream so the whole world would hear me, right? I ask myself if that is going to be like that because I don't know, but I think that it might not happen. It's that I think more, I think more about it when ...
> **I.-** When you learn that other child [dies]
> **M.-** Yes, when I know about that

When Laura was scheduled to have radiotherapy, Cristina did not want her to have that treatment because she was afraid that radiotherapy would awaken the disease. Francisco and his mother as well as Cristina's mother held this belief about radiotherapy so they advised Cristina to avoid the radiotherapy for Laura. Cristina got information about the efficacy of radiotherapy by talking with nurses, physicians, and the oncologist. All of them were pretty clear about Laura needing this treatment option. Therefore, Cristina made the decision about giving the radiotherapy to Laura after understanding it was part of the treatment and it would be her responsibility if anything would happen to Laura because of withholding the radiotherapy. Cristina was able to put aside her fears and to accept what was best for her daughter.

It is remarkable the way Cristina handled the conflict that she faced in accepting the radiotherapy for her daughter given that she is 19 years old, away from her family and hearing the advice and persuasion of her partner and his family. Cristina was very resourceful in getting the information she needed to reach the decision about radiotherapy but she did that out of her love and care for her daughter.

Laura had the radiotherapy. The bone marrow biopsy done at end of the first year of treatment showed Laura had a true relapse of the leukemia. I really wonder if the fact that the relapse was diagnosed after the radiotherapy would strengthen these parents' belief about radiotherapy. I remembering feeling awful when I learned she had a relapse that was diagnosed exactly after finishing the treatment they were so afraid of. Knowing the way most parents make connections between concrete events, I am sure that Francisco and maybe Cristina will continue to have the same understanding about the radiotherapy's capacity to awaken the disease. The temporal relationship between the two events may corroborate their belief. Besides, nobody took the time to discuss this issue with them while I was collecting the data from them.

Cristina was alone when she got the news about the relapse. The oncologist told her that the bone marrow results were abnormal so Cristina understood Laura had a relapse. She immediately recalled the bad dreams she had few weeks before. When she had the dreams, Cristina did not connect them with her daughter, she was doing pretty well; she connected them with illness or problems to her parents or other family members but after learning Laura's relapse she was sure the dreams were telling her what would happen to Laura. The news about the relapse created an upheaval of emotions in Cristina which she described as more intense that the emotions due to the news about the diagnosis one year before. Cristina felt lost and wanted to disappear at that moment but at the same time she felt very much in need of sharing her suffering with her family. The closest family member was her maternal aunt so she went to see her. Cristina's aunt has been like a mother for her; she has shown empathy and solidarity to Cristina. The aunt was not home so Cristina walked across the street and told the hairdresser what had happened. She got some comfort from talking with the woman. On her way home, Cristina cried all the way after Laura fell asleep in the bus. At home, she did not face her partner who was already home, instead she went out to call her parents. After knowing her parents would arrive that evening, she faced Francisco and told him the bad news. He told her *"There is nothing we could do, we have been waiting for this to happen from the moment she was diagnosed"*. It seems Francisco was expecting that to happen at any time. Cristina's parents came that evening and the next day she went with her mother to talk with the oncologists. They told her they would try the rescue protocol for two weeks again. If the bone marrow continued showing the relapse, they would stop the treatment. Cristina interpreted the oncologists' message to be that Laura will die soon. Cristina knew from observing the care of other dying children, that Laura would get the palliative care she needed in the hospital. However, at this time, no one on staff discussed with her or reassured her of their continued support.

The relapse was totally unexpected for everybody because Laura did not have clinical symptoms; Cristina felt it destroyed all she and Laura had achieved. "*It is like when you have build something and suddenly a strong wind comes and destroys all you built*". The new situation was even worse for Cristina; she did not have hope now because for her it was the second time Laura had a relapse. From the medical point of view in this hospital context, it is like a second relapse due to the high-risk classification of Laura's leukemia. This time, Cristina did not trust the rescue treatment as she did the first time but she agreed to it once more. Laura had the rescue chemotherapy for a week and she became very ill from it. Cristina had not seen her daughter so ill. It was terrifying and very sad for Cristina to see that Laura did not eat or drink anything, she did not want Cristina to pick her up; she was so weak she stayed in bed day and night. Cristina was very scared and took Laura to the ER. All her blood counts were very low and she was in and out of the hospital for 9 days. Then, Laura went home and recovered quickly. By the time of the third interview, Laura was having the second week of the rescue chemotherapy and was doing fine. Again, her child looked healthier so Cristina felt hopeful and optimistic once more.

Wondering and Making Sense of the Nonsense

At the time of the diagnosis, the Oncologists told Cristina the causes of leukemia were unknown. Besides, Cristina did not have concrete story about the physical causes of Laura illness either so Laura's illness was an enigma for Cristina. At first, she believed it was a punishment for her or her parents' wrongdoing but she did not find any sin big enough to grant that punishment from God. On the other hand, the one suffering most was Laura and she had not done anything wrong; "*she is an angel*" (with no sins). So, she came to the conclusion it was their fate. But Cristina was confused about this too, "*God and fate is the* *same because God determines fate. But how does God punish innocent people if He is fair?"* The fact that Laura had been punished for something that Cristina was not aware of did not make sense to Cristina.

> **M.-** Si pues yo no quiero que mi niña vaya a sufrir mas de lo que esta sufriendo porque, pues yo me pregunto muchos dicen ay que ! Yo estuve yendo a una Iglesia Cristiana. Muchos allá me decían que eso eran pruebas que ponía Dios, no? Como también me decían que esto era un castigo de algo que yo hab. o sea algo que yo, yo o mi papá o mi papito había hecho, y eso venía por los hijos de uno, no? Entonces yo me pregunto por qué? Si prácticamente uno sufre, uno como madre sufre, pero no sufre como sufren ellos, creo yo, porque por una parte ellos son los que están recibiendo los chuzones, ellos son los que están sintiendo el dolor, ellos son los que se están sintiendo mal, malucos con vómito, uno mejor dicho uno con un vómito une se siente muy maluco. Entonces yo digo que yo sufro, no? pero pues yo digo que mi niña sufre mas, aunque yo no la veo que ella, ella, ella me acuerda que vaya al .. cuando tenemos que ir al hospital, qué droga me toca hoy, es rápida, me toca suero? Todo, ella me pregunta todo eso, me acuerda de las pastillas que se tiene que tomar. Entonces yo digo cierto, una parte yo pienso será que la niña no siente o Dios hace que ella no sienta o qué, pero cuando la veo allá llorando que la van a chuzar [creo que ella sufre].
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> Yes, I don't want that my girl to suffer more than what she's suffering now. I was going to a Christian Church; there, many people said to me that these are tests that God give us, right? Also they said it was a punishment for something that I, for something that I, or my father or grandfather had done, and that came to our children, right? I asked myself why? Because one suffers, one suffers as a mother but one doesn't suffer as much as they suffer, I think. Because they're the ones who are getting the needle sticks, they're the ones having the pain, they're the ones feeling bad, feeling awful vomiting, because when one is vomiting one feels awful. I think that I suffer but I think that my girl suffers more even though I don't see her suffering. She reminds me when we have to go to the hospital; what drug would I have today, she asked? Is it the fast? Would I have saline solution? Everything, she asked me about all that. She reminds me of the medicines she has to take. So I think that she isn't feeling [the suffering] or that God makes her insensitive to it but when I see her crying there when she's going to get the needle stick [I think she's suffering].

Cristina thinks she should be the one having the disease since she is the one who did something to deserve it. She would rather be in her daughter's place when she sees the pain and suffering that Laura has because of the treatment. However, Cristina gets some comfort from the fact that her daughter seems to accept the illness situation without much suffering most of the time.

> **M.-** Yo digo por qué, por qué no a mi? Vea a mi se me ven las venas, por qué no a mi? si yo fui la hice lo que dicen, entonces por qué no a mí, por qué a ella?
> **E.-** O sea por qué no le dio la enfermedad a usted?
> **M.-** A mí, si que fui yo la pues como dicen no? quizque los hijos pagan por lo que hagan los padres no? Pues no, no debería ser así.
> **E.-** Y usted cree en eso?
> **M.-** Pues, por una parte, pues cierto? como que se me envuelve todo, no? en la cabeza porque pues yo digo que eso no es justo, eso no creo que sea porque no es justo, pero también me pregunto, si no fuera así por qué le pasó eso a ella? si ella no ha hecho nada, es un angelito. Entonces ya se me revuelve, no? la pregunta si, si fue por algo que yo hice y a veces como que digo no, no puede ser por algo que yo hice porque entonces me tenía que pasar a mi. Entonces a veces digo y por qué a ella? si ella, por qué lo está viviendo ella si ella no ha hecho nada, ya
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> **Mm.-** I said why? Why not me? Look, I've had good veins, why not me? If I was the one who did what they say, then why not me? Why she?
> **I.-** You asked yourself why you didn't get the illness?
> **Mm.-** Yes, if it was like they say, right? That the children pay for what the parents do, right? But it shouldn't be like that; no, it shouldn't.
> **I.-** Do you belief in that?
> **Mm.-** Some, right? It gets all mixed up in my head right? I think that isn't fair, I think it isn't fair because it isn't but I also asked myself if it weren't like that why that happened to her? She hasn't done anything, she's a little angel. Then, I get all mixed up, right? The question about if it was because I did something. Sometimes, I think it isn't, it couldn't be due to something that I did because it should happened to me. Then, I say why she? Why is she going through that if she didn't do anything, right?

The embedded belief among Catholics that any children's illness is a consequence of their parents' sins does not persuade Cristina as it does other parents. It seems this idea really upsets Cristina and causes her more anxiety. It does not stand to reason for Cristina that the illness is caused by a sin she is not aware of or even worse by an unfair God. Francisco's and other people's ideas about the reason for the occurrence of the disease contribute to Cristina's confusion about this illness issue.

> **E.-** Entonces eso me da para preguntar qué creen que creen ustedes que causó la enfermedad?
> **M.-** Pues yo .. él me dice pues que esos son cosas de mi Dios, no? Que son cosas que Dios manda que tenemos que recibirlas como de lugar, no? y entonces pues yo a

veces como que me entra no se, cómo le digo? a veces me pregunto tantas cosas, pero a veces me pregunto si fue algo que yo hice, qué? yo le pido a Dios, acuérdame, acuérdame a ver si puedo corregirlo. Pero a veces también digo pues si debe ser como dice él, debe de ser verdad lo que él dice, no? cosas de mi Dios, que tiene que suceder.
E.- Ha encontrado algo que usted cree que hizo?
M.- No, no, no, no he encontrado nada, no he encontrado nada, que no he visto nada, nada, pues sea que uno comete muchos errores en la vida no? comete pecados como dicen no, pero pues yo no creo que haiga hecho un pecado tan grande pues para merecerme esto no. Entonces a veces digo que, que debe ser verdad lo que él me dice no, son cosas de mi Dios y que tenemos que recibirlas.
E.- Y usted por qué cree eso que le dice a Jhoana?
P.- Que cosas de mi Dios, pues si cosas de mi Dios que manda, así
E.- Como castigo también
P.- No, como, cómo le dijera? como ... cosas normal de mi Dios que cualquiera le puede suceder.

E.- Ha encontrado algo que usted cree que hizo?
M.- No, no, no, no he encontrado nada, no he encontrado nada, que no he visto nada, nada, pues sea que uno comete muchos errores en la vida no? comete pecados como dicen no, pero pues yo no creo que haiga hecho un pecado tan grande pues para merecerme esto no. Entonces a veces digo que, que debe ser verdad lo que él me dice no, son cosas de mi Dios y que tenemos que recibirlas.

I.- That gives me the opportunity to ask what do you think that caused the illness?
M.- He (her partner) tells me that's God's will, right? That those are things that God sends us and we have to accept them without questioning, right? Sometimes, something gets to me that I don't know how to call it, I don't know how to tell you. Sometimes, I asked myself so many questions but sometimes I also asked myself if it was something I did, what was it? I pray God, please, help me to remember! so I can correct it. Sometimes, I also think, yes it's like he says; it has to be true what he says, right? It's God's will, things that must happen.
I.- Have you found something that you did?
M.- No, no, no, I haven't found anything, I've found nothing, I haven't seen anything, nothing. One makes lots of mistakes in life, right? One sins as they say, right? But I don't believe I've done a sin so huge to deserve this. Sometimes, I think it must be true what he says to me, that it's God's will and we got to accept it
I.- And why you belief what you say to Cristina?
F.- Those are things that come from God, yes things that God sends us
I.- As punishment too?
F.- No, like how I should say it? Like ... normal things from God that could happen to any body.

After the relapse Cristina became even more centered in refusing the fact that Laura's illness was God's will. Accepting this meant Cristina was somehow guilty of Laura's illness and possible death, which was too overwhelming and unfair for Cristina since she believed she did not deserve that kind of punishment.

> Yo quiero aceptar lo que le va a pasar a la niña o lo que le puede pasar, porque no le ha pasado nada, lo que le puede pasar yo lo quiero aceptar y le pedido a Dios que me de mucho valor para aceptarlo. Pero en estos momentos quiero como .. como salir de lo que .. en lo que estoy, no? lo que me siento como acorralada, no se, en este momento practicamente y en realidad quisiera como desaparecerme y olvidarme de que algún día fui mamá. Porque yo me pongo, a veces he hasta rechazado lo que me está pasando, lo he rechazado y no se si será malo. Es como yo digo ir a donde doña M., cierto? A comentarle lo que me está .. doña M no me entiende, o yo veo que no me entiende porque yo le digo pero es que por qué a mi? Y ella ah! Pero es que usted por qué hace recriminaciones? Que yo me he alejado de Dios y que yo .. pues me da como .., cierto? Como que yo soy culpable, me hace sentir culpable a mi. Eso no es lo que yo quiero, yo no quiero sentirme culpable porque yo por qué?

> I want to accept what is going to happen to the girl, or what could happen to her because nothing has happened. I want to accept it and I ask God to give me lots of strength to accept it. But at this moment I want to ... like to get out of where I'm now, right? I feel like cornered, I don't know, at this moment I really would like to disappear and forget that one day I was a mother. Because I feel ... Sometimes, I've rejected what is happening to me, I've rejected it and I don't know if it's bad or not. If I go to see Mrs. M to tell her what is ... Mrs. M doesn't understand me; that's, I see she doesn't understand me because when I tell her why me? She says, Hey! Why you do those recriminations? She also says that I've got away from God and that I ... I don't feel like I'm guilty but she makes me feel guilty. That is something I don't want to; I don't want to feel guilty because I don't see any reason?

Sometimes, Cristina even argues with God about the unfairness of her situation. She gives God examples of bad mothers who are not facing what she is facing as a way to show her rejection of the unfairness.

> Yo me estuve haciendo preguntas pero por qué a mi? Por qué no a otras que van y tienen los hijos y ni dos días tienen, o el mismo día y van y pum! Lo tiraron a un caño o lo mataron, o van y abortan. Por qué no a ellas? Y ahora tienen sus hijos y son felices con sus hijos. Porque yo veo mucho el ejemplo de mi cuñada, veo mucho eso, no? Aunque no le deseo nada malo a las niñas de ella, pero veo mucho en que ella no se ha entregado a las niñas. Ha sido una mujer que ha botado hijos y no le ha importado, los ha regalado y no le ha importado. Entonces, yo veo de que .. le doy ejemplos, me pongo a conversar puede decirse que con Dios, no? Yo me pongo y le doy como ese ejemplo a Dios. Por qué no a una persona como a ella? Por qué a mi?

> I was asking myself why me? Why not others who have their children and when the children are not even two days old, or even the same day they go and pum! they throw the child into a waterway, or kill the child, or have an abortion. Why not those women? And now they have their kids and are happy with them. Because I pay attention to my sister-in-law, I see that a lot, right? Of course, I don't wish anything bad for her girls but I see that she hasn't devoted herself to the girls. She's been a woman who has given her children away and she doesn't care about it. Then, I see that … I give examples when I kind of talking with God, right? I give that example to God. Why not somebody like her? Why me?

Cristina understands Laura's death as something she is going to face soon but she struggles in accepting this possibility. A few days after the relapse, Cristina met in the nearby shopping center a man from the Catholic Church. This gentleman knew about Laura's illness. Cristina told him the news about Laura after he asked for the girl. This gentleman was able to relieve Cristina's struggle related with the illness and the relapse occurrence. He also helped her to understand the meaning of Laura's death from a religious perspective that made more sense to Cristina. He advised her to change her belief about the illness as a punishment. "*God does not do that to his children like a good father would not punish his children's children*", he told Cristina. He assured Cristina that Laura's death would happen because God was protecting her from something worse later. God was also protecting Cristina from greater pain and suffering because if Laura dies Cristina would know for sure that Laura was in heaven and not in this world being abused by a man or becoming a bad person or who knows what. Cristina also perceived great empathy from the man since recently the man's son almost died from an illness, so he was in a situation similar to the one she is now.

> Entonces el señor ayer me dijo, nada de lo que la gente le diga es verdad porque Dios no va a poner a un nieto, prácticamente porque nosotros somos hijos de Dios y como nosotros llamamos le llamamos a nuestros padres abuelos, o sea, que Dios es abuelo del hijo suyo, o él es el hijo de El también. Cómo lo va a poner a él a sufrir, solamente que porque usted le hizo algo malo. Es como si usted, cómo va a poner al hijo de su hija a sufrir que porque su hija se portó con usted.
> … Entonces él me hizo sentir muy bien, muy bien y me sentí muy bien conversando

> con él. Entonces él me dio como ... me sentí muy muy bien hablando con él. Primer vez que me siento tan bien hablando con alguien, porque con las personas que he hablado no se como que se les da lo mismo y como que pues si ella tiene que .. qué mas va a hacer? Resignarse cierto? Entonces no me parece correcto. El me dijo es muy duro porque yo hace poco el hijo mio estuvo muy malo, estuvo pues a punto de .. él lo vio pues casi que se moría, no? Aunque ya está bien pero él sintió como que el hijo se le iba a ir, entonces él se sintió muy mal. Entonces él me dio este, que yo no me sintiera culpable por lo que estaba pasando, que no me sintiera culpable porque eso no era asi y tampoco le echara culpas a Dios de que hizo eso, de por qué me está castigando de esa manera. Porque uno hace eso, yo hago eso.

> Yesterday, the man told me "nothing of what people tell you is true because God is not going to put His grandchild since practically we're God's children and we call our parents grandparents, that's God is the grandfather of your children or they're His children also. How is He going to make your child to suffer only because you did something wrong. It's like if you would ... how would you make your daughter's child to suffer just because your daughter didn't behave well with you ..." He made me feel very good, very good and I felt very well while talking with him. He gave me like ... I felt very very well talking with him. It's the first time I feel so good while talking with somebody, because the people to whom I've talked to, I don't know, it's like they don't care; it's like they think "she got to ... what else is she going to do? She got to resign herself" That doesn't seem right to me. He told me it's very hard because "recently my son was very ill and he almost ..." He saw him almost dying, right? Regardless that he (the son) is now well but he (the father) felt like his son was going to go, then he felt very badly. He gave me some ... that I shouldn't feel guilty because of what is happening since it wasn't like that; neither to think that God is responsible for doing that. Not to say that why is He punishing me this way? Because one does that, I do that.

Cristina had battled with herself and suffered with the notion that God was punishing her daughter for Cristina's transgressions. Although she could not fully accept this idea, particularly when it appeared her daughter might die, she latched another interpretation to make of her situation. She was ready to hear the alternative explanation offered by the gentleman from her church. His experience with his son's illness gave him added authority, his manner comforted her, and his vision of an empathetic God, God as father, resonated with her intuitions and thus she readily and quickly found solace in this new perspective.

Fighting the Health System and the Immediate Context

During the first year of treatment, Cristina struggled with many issues related to the illness experience. The most pressing issue for Cristina was to get the funding for Laura's treatment. Laura got health insurance with the Social Security Institute (SSI) through her working father. The SSI paid fully for the treatment during almost the first 10 months of treatment. Then, the SSI policy coverage changed to cover only 25% of Laura's care expenses. Although, it is against the rules to have dual coverage, Cristina managed to get additionally the subsidized insurance for Laura because there was no way they could afford 75% of the medications and tests.

At the beginning, they got help from Cristina's family, neighbors, and Francisco's coworkers. Laura's biological father provided money all the time. Cristina was very active in getting funding for the treatment. She tried all that was in her power to get the necessary money for the treatment. Delaying the chemotherapy was very dangerous for Laura according to Cristina illness understanding. She fought with Francisco to get some money from him, she asked Laura's biological father to give her money, she cooked and sold tamales, and she made and sold girl dresses to make money. The financial struggle became worse after the relapse; the treatment and tests were done more frequently. It seems that Francisco did not want to spend more money in Laura's treatment. He told Cristina that he would not give her money for the rescue chemotherapy. That made Cristina very mad and disappointed at him. She was considering the possibility of leaving Francisco and moving back to her town with the girls if the treatment failed.

Cristina felt overwhelmed by the burden the illness situation was posing on her, especially because of the lack of money for the treatment.

M.- No, yo me desespero mucho, yo no se como que quisiera , a veces como que quisiera <u>salir corriendo</u> y, y ay no volver a saber nada de nada.
E.- Cuénteme un día que se haya desesperado así
M.- Un día que me haiga desesperado, desesperado, qué día fue
P.- Un día de la semana (se ríen)
M.- No pues, con, mas que todo cuando la niña, que yo necesite ir pa'l hospital y se llega el día,
P.- Pa'l examen
M.- Pa'l examen y eso y no hay nada no hay plata. Yo le digo a él, vea que yo, yo le estoy diciendo a él desde el primer desde el Domingo, mañana ya tiene que vea, tal día me toca ir así sea el Viernes que me toque ir, no se le olvide conseguir. Entonces ya él, en esos días .... ya llega el Jueves, el Miércoles y no ha conseguido nada, entonces yo me desespero,
P.- Uno le dice a la gente cierto? y ah! a la gente de tanto molestar uno como que se siente como azarado cierto? le da hasta pena a uno ya pedirle favores y
M.- // Yo hay veces me da como, como rabia con todo el mundo como, como con mi mamá, como con yo quisiera como salir corriendo y, y olvidarme que yo tuve familia, como inclusive olvidarme hasta que tuve hijas, como irme y decir puedo volver a nacer. A veces yo quisiera, porque pues a veces yo me desespero pero porque yo digo bueno, yo pudiera trabajar, pero si mi mamá estuviera aquí, que estuviera con las muchachas.

M.- No, I feel desperate a lot, I don't know it's like I would like, sometimes, I would like <u>to run away</u> and to know nothing else about anything
I.- Tell me about a day that you felt desperate like you just said
M.- One day that I felt desperate, desperate, which day was that?
F.- Any day of the week (they laugh)
M.- No, it's mainly when the girl, that I need to go to the hospital and the day comes
F.- For the test
M.- For the test and there's nothing, there isn't money. I tell him look I, I'm telling him from the first day, since Sunday, tomorrow you have to... look I have to go to the hospital. It doesn't matter if it's Friday that I need to go, I tell him don't forget to get [the money]. Then, during those days ... and it's already Thursday, Wedsneday and he has got nothing so I get desperate.
F.- I asked people, right? And they go ah! because of me bothering them too much, it seems they get somehow upset, right? It's shameful to ask them so many favors
M.- // Sometimes, I feel angry with everybody, with my mother. I would like to run away and to forget that I had family, even like forgetting that I have daughters. I like to go away and to be able to be born again. Sometimes, I get desperate because I said to myself if I could work but my mother isn't here to be with the girls.

Francisco does not support Cristina's efforts to make money from selling food. Cristina thinks he is embarrassed of what she does to get money. Cristina wants to work outside the

home to make more money but she can not do that since nobody helps her with the girls' care.

Besides struggling with the financial difficulties, Cristina has to endure solitariness in dealing with Laura's illness. She feels that neither her partner nor her parents are helping her the way she expects. Francisco is not emotionally or physically available to Cristina; he is only concerned about getting the money to pay his debts and he helps Cristina very little at home.

> **M.-** Si él es mas tranquilo él .... como que no ..... o sea a veces problemas no que tiene uno comúnmente no, como que se me da mas duro a mí como que me, me da mas este a mi que a él. Yo le digo a él ay! pero vea que está pasando esto y esto y como que hum! (ella hace un movimiento con los hombros que significa que a él no le importa) , como que el mundo sigue y sigue.
> **P.-** Pero es que pa' que uno se va a poner a este cierto? a matarse también uno, porque mas se jode uno también, hay que llevar la vida.
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> **M.-** Yes, he's more tranquil, he ... it's like ... sometimes one has usual problems, right? It's like is harder for me [than for him], it's [harder] for me than for him. I tell him ' Hey, look this and that is happening! and he like hum! (she makes a movement with the shoulders that means he doesn't care) like the world is going and going
> **F.-** Why is one going to kill oneself; if one does that one gets bugged up more too, it's better to take it easy.

In the last interview, Cristina talked at length about the reasons for wanting to leave Francisco: "*he does not have any aspiration, he wants to be poor all his life but I do not*". He does not care about what Cristina considers important in life; he does not help her in the house and with Laura's care, he just criticizes how she runs the house and cares for the girls. Twice, he spent the money other people gave for Laura's treatment on something else. He does not support her in the small business she does to make money; he has become a burden more than help, and recently he does not want her relatives in the house with them while Laura is ill. So she believes she has plenty of good reasons to leave him. Only the fact the girls will miss him is making have second thoughts about leaving him. Cristina does not think that Francisco's relative uninvolvement is because Laura is not his biologic daughter; she thinks he would act the same if his biologic daughter were ill.

Cristina also feels alone in her battle against Laura's illness because her parents are not physically with her all the time. Her parents are far away and they can not come to live with her; they have their own lives there. However, they have been with her during the more critical moments. Sometimes, Cristina resents her mother for not coming to live with her. But Cristina understands she has to take care of her younger sister and father. The mother-in-law does not have a good relationship with Cristina either; she only watches the younger girl when Cristina goes out with Laura.

Cristina's urgent sense of needing support from her family and partner creates tension in her relationship yet it is understandable given the hideous situation she has lived with during the year. Besides, Cristina, as a very young woman and a young mother, feels the need to have somebody more experienced and knowledgeable about life to share the experience with her. She has dealt with multiple critical moments and difficult decisions during the first year of treatment: rescue treatment, radiotherapy, relapse, and rescue treatment again because Laura's illness course has been very unpredictable. In Colombian culture it is expected that family members, especially parents support emotionally and financially any family member having a catastrophic situation. Therefore, Cristina feels she is entitled to have her family next to her despite the fact that it is not practical for them to be continuously present. Cristina is very scared that Laura might die while her parents are not with her. Laura is very attached to the grandparents; this could be another reason for Cristina wanting her parents with them all the time.

> Mi mamá me acompañó al hospital y llegamos del hospital y al rato se fueron. Yo Quería que se quedarán porque yo en realidad me siento muy sola aquí y me siento muy mal acá, pero pues ellos no pueden quedarse …La niña lloró mucho ayer porque el papito se fue, lo quiere mucho a él. Ella la adoración de ella son ellos dos y ya ella dice cuando se acuesta, yo le digo rece y lo primero que le pide a papito Dios es que ella se alivie porque ella se quiere ir a vivir con papito y mamita. Entonces yo veo que la obsesión de ella es ellos. Entonces yo digo que lo mejor yo sería estar con ellos si algo va a pasar.
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> My mother came with me to the hospital and we got back from the hospital and minutes later they left. I wanted them to stay because I really feel alone here and I feel very bad here but they can't stay … The girl cried a lot yesterday because grandpa left, she loves him very much. She adores both of them [maternal grandparents]. When she goes to bed at night and I remind her to pray, the first thing she asks God is to get well because she wants to go to live with grandpa and grandma. So I see her obsession is both of them. That's why I say that's better if I would stay with them if something is going to happen.

At the time of the relapse, Cristina felt that everybody, including her partner and her parents wanted her to be patient and to have resignation regarding Laura's illness. Cristina's father believes crying and despair do not help Cristina, on the contrary she could get sick from that. He also believes Laura could get well again if she is lucky as she did the first time. But if Laura dies it would be because God needs her or because all human beings die. So he tries to convince Cristina to think and feel the way he does.

> **Ao.-** Yo pues como he sido mas pasivo pa'esas cuestiones, yo he tenido resignación. Yo no me preocupo por eso, estoy muy pendiente de ella y todo pero como <u>preocuparme</u> no. Pues si es pa'que se alivie es porque tiene suerte y si se muere será que mi Diosita la necesita. Uno no debeponerse a renegar si o no? Tener paciencia … Yo le dije en estos días que me llamó que esto que lo otro. No, tenga paciencia, no se ponga a llorar, tenga fe en que la niña se va aliviar y si no se alivia pues qué le vamos a hacer? Usted sabe que todo mundo nacimos con ese, con ese como la mata de plátano que nace, produce, reproduce y muere, así somos nosotros. Si ella es pa'este mundo pues bien si no ahí la gozamos hasta que .. hasta nueva orden
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> **Gf.-** It seems like I've been more passive for these things, I've have resignation. I worry about that, I'm very attentive and all that but like <u>worry too much,</u> no. If she is going to get well it's because she's lucky but if she dies maybe it's because God needs her. One shouldn't grumble, right? One should have patience … I told her, the day

> that she called me, "have patience, don't cry, have faith that the girl is going to get well and if she doesn't get well to accept because there's nothing else we can do". You know that everybody is born with that, like the plantain plant that grows, produces, reproduces, and dies. We're like that. If she is for this world good! but if she isn't then we'll enjoy her until ... until something new happens.

Cristina agrees with her parents about having patience for some time while they see how Laura reacts to the rescue chemotherapy but she can not have resignation if the treatment fails.

> Mi mamá ayer que estuvo acá y mi papá me dijeron que eso era algo como .. si que ya nosotros sabemos que podemos esperar, no? Que no me desespere que .. de pronto las cosas .. de pronto que nadie sabe lo que mi Diosito tiene para nosotros, no? De pronto le sale la medula buena y sigue el tratamiento, que no me desespere todavía que no me han dado a mi un .. algo definitivo, no? Que espere siquiera que pase la aplicación de la droga. Entonces yo en ese momento me tranquilicé y estoy tranquila ahora porque yo se que es verdad, tengo que esperar qué pasa con la droga, si va a reaccionar, si le va a servir, de pronto un milagro de Dios. Sin embargo yo no creo que esto viene de Dios ni nada, cosas del destino que tienen que pasar, tenemos que superarlo.

> My mother and my father were here yesterday and they told me it's something like ...that we know what to wait for, right? That I shouldn't get desperate that ... maybe things ...maybe that nobody knows what God wants for us, no? Maybe the bone marrow is going to be good and they continue the treatment. They told me I shouldn't get desperate since they haven't given me any final decision, right? That I should wait to finish the drug treatment. So, at that moment, I became calmed and I'm more tranquil now because I know it's true, I have to wait to see what happens with the drug, if she is goint to react to it?, if it's going to help her, maybe a miracle from God. However, I don't believe that this comes from God or anything, those are things that come from fate, things that should happen and we have to overcome them.

It seems that Cristina interprets her parents' request to be patient and have resignation as giving up on fighting for her daughter. But that is not a possibility that she can consider, not even in her thoughts. She also feels that her parents want her to pretend nothing is going to happen and to control her emotional suffering.

> **E.-** O sea sientes que la gente no es solidaria con tu pena, con tu dolor
> **M.-** Si, inclusive ayer lo sentí con mi papá y mi mamá porque pues no sentí como que a ellos les hubiera dolido, no los sentí muy tranquilos y los senti muy pues si

> dándome a mi, queriéndome dar a mi como resignación. Que vea que no llore, que vea que no se desespere que eso le hace daño a la niña, que le hace daño a usted pero si yo quiero llorar y si yo quiero desahogarme porque yo lo quiero asi.
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> **I.-** Do you feel that people don't feel your sorrow, your pain?
> **M.-** Yes, even yesterday I felt that with my father and my mother because I didn't sense that they were suffering, no I saw them quite tranquil and I perceived them like wanting to give me resignation. Look don't cry, look don't get desperate because that's bad for the girl and for you but if I want to cry and if I want to get it out of my system because that's what I want to.

Cristina's partner seems to have realized there is nothing they could do to help Laura. When he learned about the diagnosis, he thought Laura would die from the disease and it seems he has been thinking the same all the time.

> Ya cuando vine ya él (Francisco) me preguntó y entonces yo le dije. Pero él en el momento también lo tomó pues .. cierto? Muy doloroso y todo pero pues .. y él me dijo que qué ibamos a hacer, que .. esto teniamos que esperar desde el primer momento que nos dijeron que la niña estaba enferma de eso, hay que esperar cualquier cosa.
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> When I came home, he (Francisco) asked me and then I told him. At that moment he also took it … right? Very painful and all that but he said to me there wasn't anything we could do, that this was something we should be waiting for since the first moment they told us that the girl was sick from that, anything could happen.

Later, Francisco told Cristina he did not have more money for the rescue treatment. Cristina perceives him as a person who does not get concerned about things that really matter in life.

> **E.-** Pero siempre ha sido asi o es ahora?
> **M.-** No el siempre ha sido asi de simple, lo que pasa es que yo la otra vez pues vivia en mi casa. Yo a veces ni le decia nada a él porque tenía a mi mamá, mi papá, en cambio a quien le comunico yo las cosas? A el porque yo es con él sola y … vamos a ver que pasa.
> I.- Entonces es una costumbre que él ha tenido siempre?
> M.- Si es una costumbre que él ha tenido siempre siempre, siempre ha sido asi, él es muy simple pa'todo, el no … como que todo se le da lo mismo.
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> **I.-** Has he always been like that? Or is it something new ?
> **M.-** No, he's been simple always (meaning he doesn't show feelings or emotions). What happens is that before I was at home living with my parents. Sometimes, I didn't say anything to him because I had my mother, my father but now to whom I tell my things? To him because I'm here alone with him so we would see what happen
> **I.-** So, it's a habit that he's had always
> **M.-** Yes, it's a habit that he's had always, always; he's been like that always; he's very simple for everything, he doesn't ... like everything means the same for him.

Cristina also thinks that the only way that she can get money or anything from Francisco is fighting and insulting him. She believes he responds primarily to harsh treatment.

> Entonces, yo con la insultada porque es que el .. si el me dice no tal cosa y yo me quedo callada asi son pero si yo le digo hasta lo que no tengo que decirle ahi el se pone pilas, o sea el es una persona yo creo que el es una persona masoquista como esas mujeres que les estan dando y que ahi siguen, yo creo pues yo lo siento asi.

> So, with me insulting him .. it's that he ... if he says no to something and I stay quiet that's the way it's going to be but if I tell him everything I want to tell him, then he does what he should. That's, he's somebody I think, somebody masochist like those women who are getting hit and they stay there, I belief he's like that, that's how I perceive him.

During the first interview, Francisco expressed it was very hard to satisfy all the family's needs with his salary, which is the minimum wage. I did not talk more with Francisco about this issue because he did not continue the interviews. My understanding is that Francisco believes they are probably wasting money they do not have in an ineffective treatment for Laura.

Cristina's way of being is quite opposite to her partner's way of being. He is very tranquil but she is not. Cristina acknowledges she is very impatient and Francisco's way of being makes her even more impatient. She gets angry at him because she sees in his actions a lack of concern about what is happening with Laura. She acknowledges that he does not like to do fun things or to show affection or any positive emotions to the girls and Cristina. Before the illness, Cristina felt fine with Francisco's calmness and inaction but after the illness he drives her crazy because he does not do anything to help her with Laura's care. They disagree on the priority to spend the little money they have. He is supposed to give her some money for the treatment and other expenses but he does not. Instead he prefers to pay the rent and the refrigerator they bought to keep Laura's medicines. He told Cristina clearly that he would not give her the money for the rescue chemotherapy. Cristina does not perceive support from Francisco and sometimes perceives him more as a burden. So Cristina perceives that she is alone in dealing with the illness situation since the only person, who is physically close to her, does not share the demands of the illness situation.

<u>Fighting the Disease with Possibilities Outside of the Medical System</u>

Despite the ordeal caused by the relapse, Cristina found time and energy to find out about a folk remedy for her daughter. It was her last hope because she did not trust very much the rescue treatment since it was the second time her daughter had it.

> **E.-** En este momento en que tiene mas fe Cristina? En el remedio del animal o en la droga
> **M.-** En el remedio del animal. Si porque yo ya se esa droga se la han puesto
> **Ao.-** Desde que la señora dijo
> **M.-** Si porque ya tiene 20 años ese muchacho y pues yo creo y tiene disque ya un hijo de el. Ella me dijo que ella le habia cogido <u>mucha fe</u>
> **Ao.-** En todo caso yo digo que la fe es la mas sirve, si o no? uno coge una fe supongamos de que se va aliviar ligero y se alivia pero si uno se pone a decir ay! Yo me voy a morir, entonces se muere.

> **I.-** Right now, in which of the two treatments Cristina has more faith? The remedy with the animal or the drugs?
> **M.-** In the remedy with the animal, yes; because she has had already that drug.
> **Gf.-** Since the lady says that
> **M.-** Yes, because that guy [the child who had the remedy before] is 20 years old so I think and he has a child also. She [the woman who made the remedy] told me that she has <u>lots of faith</u> in it.
> **Gf.-** However, I think that faith is what is most useful, right? One has faith that one is going to get well quickly and one gets well quickly but if one says oh! I'm going to die, then one dies.

The remedy was done to Laura before she began the second round of the rescue treatment. A mother whose child had leukemia 14 years ago did the remedy. Cristina believes the remedy cured the child who is now a married young man and has a son. The remedy consists in giving the fresh blood of a scavenger bird mixed with a little bit of white wine and soup made of vegetables and the scavenger bird viscera.

My only concern after realizing I could not stop Cristina's intention of giving the folk remedy to Laura was that Laura would aspirate the blood if they force her to drink it. When I came to the house for the last interview, the first thing I was told was they were going to give Laura the remedy that afternoon. I was very happy for being there at the right time to make sure Laura would not aspirate the blood and also to witness the event as a researcher. The woman in charge of the remedy did not come while I could stay at Laura's home so I went home quite unhappy. However, during the interview I encouraged them to be very careful and not force Laura to drink the blood. I had the grandfather's help in doing this. He said "I*t would be much better if Laura drinks herself the blood from a small cup*". I reinforced what he said and we all agreed the remedy would be more effective if she took it herself. Next day, I went to the Chemotherapy Unit to finish the interview but mainly to find out what happened. With relief I learned that Laura drank the blood without incident "*like a juice or milk*". Cristina was very happy with Laura's recovery, which she was pretty sure was the result of the folk remedy. Laura was eating and playing; "S*he was normal again*".

> **E.-** Si tu comparas la semana la primera semana que ella tuvo de quimioterapia y esta semana que diferencia hay entre las dos?
> **M.-** Hum! Hay tanta diferencia porque la niña la otra semana de quimio era acostada, no quería que uno la cogiera, maluca, llegaba a la casa era a acostarse, como que no se queria parar de esa cama, no quería que la bañaran, no recibía nada, se sostenía con mero gatorade. En cambio esta vez no, una diferencia ...
> **E.-** O sea ahora fue casi como la primera vez
> **M.-** Ahora fue como casi la primera vez y creo que la primera vez tambien le fue muy

> bien puede que sea porque yo la primer vez le di mucho palomo. En esos dias yo le habia dado jum! como cuatro palomos, o sea que no la cogio débil. Es que esta droga hace mucho efecto es cuando los coge muy débiles. Y esta semana le dio muchas energías ese animal y yo se lo voy a seguir dando hasta que ... si de prooonto Dios no lo quiera, no lo permita, de pronto la niña pues no se me va a mejorar como yo creo y como tengo la certeza, tampoco le voy a echar la culpa al remedio porque yo se lo hice con mucha fe y creyendo en que se me iba a curar
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> ________
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> **I.-** If you compare the week, the first week that she had chemotherapy with this week, what difference do you see between the two weeks?
> **M.-** Hum! There is so much difference because the girl, the other week of chemo, she was laying in bed, she didn't want me to pick her up, she felt awful; as soon as we got to the house she went straight to lay down in bed, she didn't want to be bathed, she didn't eat or drink anything, she only drank Gatorade. But this time, no, there is difference ...
> **I.-** That's now, it's almost like the first time?
> **M.-** Now, it's like the first time and I think the first time also was very good for her maybe because the first time I gave her lots of pigeons. During those days, I gave her hum! Like four pigeons, that's she wasn't weak. It's that this drug produces lots of effects when they're very weak. And this week, that animal gave her lots of energy and I'm going to give it to her until ... maaaybe God forbid, maybe the girl isn't going to get well as I think and as I'm sure, I won't blame it on the remedy because I did it with great faith and believing it would cure her.

Cristina felt guardedly hopeful that the remedy was going to save Laura; she even was hoping that Laura would not need all the medical treatment. However, she would continue fighting for her daughter and doing whatever the oncologists told her. She was hoping there would be a miracle and Laura's next bone marrow would be normal. She felt very happy because she had done something for her daughter; the folk remedy was her idea and Laura was showing much improvement after it.

> **E.-** Cristina en este momento tu tienes mas esperanzas que hace una semana, dos semanas?
> **M.-** Si! Lo que hace que le di ese remedio como que vino el alma al cuerpo, como que dije yo, no es que mi niña no, es imposible, yo se que este remedio me la va sacar adelante
> **E.-** Que te hace sentir tanta fe en el remedio?
> **M.-** No se, no se desde que mejor dicho desde que esa señora llegó, entró a mi casa. Ella llegó con ese señor, yo como que algo me decia acá (en su corazón) ay mi niña por fin se va a aliviar! Como que algo me decía.. Cuando ella me dijo échele la

> bendición al remedio, yo se la eché con.. mejor dicho como si se la hubiera echado quien sabe quien. En todo caso yo se que Dios dentró en ese remedio, ahí. Y yo en estos días que la niña le salió el exámen de sangre malo, yo estaba pensando mucho en que de pronto la Navidad sin mi niña pero no, yo se que no, nunca va a suceder, yo se que nunca. Yo se que con este remedio, mejor dicho es que sólo con hablar de ese remedio me da como una alegría como de saber que pude hacer algo por mi hija, de que yo luché y luché y voy a seguir luchando y con ese remedio yo se que de pronto no tenga ni que terminar tanto el tratamiento. Pero si le toca yo lo termino, claro pero de proonto Dios lo puede querer así que salga la médula y diga no la niña ya no tiene nada. Dios puede hacerme un milagro, yo se y tengo la esperanza pero si no es asi y me dicen tiene que terminar con tratamiento, pero se que la médula le va a salir buena.

> **I.-** Cristina, in this moment, are you more hopeful than one week, two weeks ago?
> **M.-** Yes! Since I gave her that remedy it's like my soul came back to my body ("me vino el alma al cuerpo" it's an expression that means to feel a great relief) as I told you. No, no my girl no, it's impossible, I know this remedy is going to save her.
> **I.-** What is it that gives you such a great faith in the remedy?
> **M.-** I don't know, I don't know, from the moment that lady arrived and entered into my house. She came with that man and it was like somebody was telling me .. when she asked me to bless the remedy, I did that with .. like who knows whom did it for me. Anyway, I know that God entered into that remedy at that moment. When the girl had an abnormal blood test, I thought a lot about maybe this Christmas would be without my girl. But I know it isn't, never it's going to happen, I know that never is going to happen with this remedy. In other words, just to talk about this remedy gives me joy , to know that I was able to do something for my daughter; that I fought, fought, and I'm going to continue fighting and with this remedy I know maybe she won't have to finish the treatment. But if that's the case I would finish it, of course but maybe God could want that the bone marrow comes out and they would say she doesn't have anything. God can make that miracle. I know it and I hope it but if it isn't like that and they tell me that she has to finish the treatment but I know the bone marrow is going to be good.

It was kind of exhilarating and at the same time sad for me to see Cristina so confident about the effect of the folk remedy on Laura's recovery and how proud she felt about herself for doing that for her daughter. Many people (including me) may think she had done something that might hurt Laura. Others would think Cristina was crazy for doing that. I understand she was desperate and did what she thought it was best for her daughter. Cristina's only concern before giving the remedy to Laura was that the scavenger bird would have eating some human remains contaminated with AIDS.

The remedy was done in the last week of November/98. In January/99, I heard from the nurses that Laura was having chemotherapy and was doing fine. Today when I am writing her mother's story she is still having chemotherapy, which means she went into remission again and has continued the treatment. Cristina is still struggling to get the medicines for Laura; the chemotherapy was delayed because Cristina did not have all the drugs for the treatment session. So she continues with the same struggle in getting the funding for her daughter's treatment but she had succeeded in keeping her daughter alive and with her at home.

Fighting her Fate or Fighting Against her Daughter's Death

Doing what she has to do to keep Laura alive and well is the foremost obligation for Cristina. The length of time she needs to do it does not matter to Cristina as long as it means her daughter is with her at home and doing fine.

> **E.-** O sea, no sabes por cúanto tiempo mas va a seguir ella en tratamiento?
> **M.-** No, no se por cuanto tiempo aunque al muchacho que esta ahi me dijo que le habian aumentado un año mas.
> **E.-** A Juan
> **M.-** Que le habían aumentado un año, si pero como él recayó fue ahorita a los dos años, ya casi terminando. O sea, que yo no se a mi que me irá a decir la doctora pero yo le pido a Dios que asi sean 20 (años) con tal de que mi niña yo sepa que esta viva y que la sienta yo en mi casa pero pues yo confío en que de pronto me digan que no, que ya tiene la niña cura, que ya está curada. Ay tan rico! [lo dice con mucha esperanza y alegría].

> **I.-** That's you don't know for how long is she going to be in treatment ?
> **M.-** No, I don't know for how long. However, the guy who was there told me that he got another year.
> **I.-** Juan ?
> **M.-** Yes, that they have increased one year but it's that he had the relapse at the two years, almost finishing the treatment. In other words, I don't know what the doctor is going to tell me but I pray God that even if it's going to be for 20 [years] I don't care as long as I know that my girl is alive and I can feel her at home, but I hope that

maybe they would tell that the girl is cured. Oh, that sounds great!

The thought of Laura dying because of the illness is something Cristina can not accept but at the same time, she can not accept her daughter's prolonged suffering. She would rather Laura die quickly, despite her grief, if the illness brought prolonged pain and weakness. Imagining her daughter suffering and laying very ill in bed is something unbearable for Cristina. It is only to relieve her daughter of this, not to relieve herself from the struggle that makes it possible to imagine her daughter's death.

> **E.-** Entiendo que lo mas dificil para una mamá es ver a su hijo/a que no … porque un/a niño/a que no se para de la cama y no come
> **M.-** // Es señas de que estáa mal pues para mi es señas de que está mal y para uno de madre es muy duro no crea, uno uno cree mejor dicho uno cree ..uno de madre yo pongámosle yo decía, yo le pedí mucho a Dios que si niña se iba a poner <u>mas mal de lo que estaba</u> que mejor se acordara de ella, que me diera ese valor de pedírselo, que se acordara de que ella que yo a mi niña no, yo dije si mi niña va a seguir así, o se va a poner peor, mejor Diosito dame valor pero que mi niña no sufra mas. Usted cree que mi niña no querer nada ni que la carguen y llega una enfermera y tenerla que chuzar, nooo! Yo le pido mucho a Dios que si ese dia va a llegar mejor … ahi esta la Virgen que sabe que es perder un hijo ((M3, p. 21, 619-632).

> **I.-** I understand it's very difficult for a mother to see her daughter/son like … because a child who doesn't get up from bed and doesn't eat
> **M.-** It shows that she/he is feeling very ill, for me it shows she/he is feeling bad and that's is very hard for a mother; one thinks, as a mother, one thinks .. I tell myself that and I pray God a lot to remember her if my girl is going to get sicker than what she already is; it would be better for her. I pray God to give me the courage to ask Him that if my girl would continue like that or if she would get worse because I don't want her to suffer more. To see that my girl didn't want anything, nor even to be held by me and a nurse would come to stick a needle on her, nooo! I pray God a lot if that day comes it would be better … there is Virgin Mary who knows how is to lose a child.

When people tell her to trust and have faith in God if He wants Laura to die she feels uneasy and thinks those people are dumb. They say that because is not their child who is going to die. She also feels people are not genuine in what they tell her because they can not feel her pain and suffering. It is easy to ask for resignation when one is not emotionally

involved in the situation, Cristina believes. However, Cristina acknowledges it is impossible for others to feel her pain in the same way they can not feel the joy of having her daughter.

> **M.-** No pues yo creo que por las palabras que me dicen, no? Ay! que hay que tener mucha fe pues que si va a pasar (la muerte de Laura) pues que se va a hacer, pues ya Diosito hizo fue lo que El quiso, la voluntad de El. A mi no me parece correcto una respuesta de esas, no? Yo quisiera que alguien sintiera lo que yo estoy sintiendo, el mismo dolor. Saber yo de que .. pues yo me he puesto a pensar pero por qué pienso que la gente tiene que sentir lo que yo estoy sintiendo? si sólo yo supe qué fue el dolor de tener a mi hija, y la felicidad de saber que nació y que tan linda y tan bella y contenta y feliz porque nació mi hija. Pero entonces me ha parecido tonta la gente o me ha parecido tonta la gente decirme que tenemos que esperar la voluntad del Señor, es que no puedo creer que esa sea la voluntad de El.
> **E.-** Es muy importante para mi como enfermera lo que me estás diciendo. Qué te gustaría que la gente hiciera o te dijera?
> **M.-** Pues no se como que .. ay! yo no se como que me dieran.. como que me dijeran estoy con usted y siento lo que le está pasando a la niña pero pues .. no se, como que me respondieran algo como más.. no cierto? como más positivo, como más correcto. Pero una cosa que me contestan ah! que tenemos que esperar la vountad del Señor y esto pero como no lo <u>están viviendo</u>, ya? Por eso van a esperar la voluntad del Señor que sea esa, por qué tiene que ser esa?
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> **M.-** I think that because of what they tell me, right? Oh! that one should have lots of faith because if that's going to happen [Laura's death] there's nothing that one could do because God did whatever He wanted, His will. For me that isn't correct, an answer like that, right? I would like that somebody could feel what I'm feeling, the same pain. To know that .. but I've thought why I expect that people can feel what I'm feeling? Only me knows the pain of giving birth to her, the joy of knowing that she was born so beatiful and pretty, I was the only one happy and joyful because she was born. But at the same time, it seems to me that people are dumb or that it's dumb that people tell me that we have to wait for God's will; it's that I can't believe that is the Lord's will, I can't believe that is His will.
> **I.-** It's very important for me as a nurse what you are telling me now. What would you like that people do or tell you?
> **M.-** I don't know like … Oh! I don't know like they would tell me .. like they would tell me I'm with you and I'm sad for what is happening to the girl, I don't know, like they would answer something more .. right? Like more positive, more appropriate. But it's that they answer me Oh! We got to wait for the Lord's will but they aren't going through what I'm going through, they aren't living with it, right? That's why they are going to wait for the Lord's will to be like that. Why it has to be that way?

Given that Cristina's entire response to her daughter's illness is to take action, to do anything that might further her possibilities for health, the advice of others to accept God's fate sounds illogical and quite impossible for her.

Cristina is very afraid of the consequences that Laura's death might have on her life. She is concerned that she might become crazy, an alcoholic or a bad person; she wonders if she would want to disappear and end the relationship with Francisco. She considers the possibility of talking with another mother, whose child died recently. She expects this mother would be a role model for her in coping with Laura's death. She also expect the mother would tell her about the child's dying process so she can know how it might be for her daughter.

> **E.-** Qué esperas de la llamada, de hablar con ella? (de la madrecuyo hijo murió recientemente)
> **M.-** O sea, yo no se, yo la he querido llamar como para .. en una parte quiero saber qué pasó con el niño cuando pues los últimos días. Por eso me he retenido de llamarla porque yo digo que yo se me va a dar la inquietud de preguntarle y de pronto ella se va a sentir mal y por otra parte para saber cómo está ella. O sea, si lo ha tomado con resignación. Cómo lo debo tomar yo si llega a pasar, que ella me de como un <u>ejemplo</u> de cómo debo lo debo yo tomar, si lo debo tomar muy a pecho.. porque yo muchas veces he pensado .. yo he dicho bueno pero uno dice ay! cuando llegue el mo.. que le llegue a pasar algo a tal persona, pues a un ser <u>muy querido</u> que yo me enloquezco, yo me muero, yo me desaparezco, yo me vuelvo alcohólica, piensa uno todas esas cosas.

> **I.-** What do you expect from the call, from talking with her?
> **M.-** I don't know, I've wanted to call her for .. on one hand, I want to know what happened to the boy the last days. That's the reason for me to avoid calling her because I say to myself I'm going to want to ask her and maybe she's going to feel bad. And on the other hand, I want to know how she's doing. That's, if she has taken it with resignation. How should I take it if it's going to happen? That she gives me an <u>example</u> (be a role model for her) of the way I should take it, if I should take by heart .. Many times, I've thought .. I've said all right! but I say oh! when the moment .. when that happens to somebody, to a very <u>dear person</u> or a loved one I'm going to get crazy, I'm going to die, I disappear, I become alcoholic; one thinks all those things.

Cristina wants to be able to accept Laura's death before it actually happens. However, that is not a possibility available to her way of being. She is eager to get over the terrible moment she is facing due to illness relapse. She suffers because the loss is real. The only way not to suffer would be to disappear.

> Yo quiero aceptar lo que le va a pasar a la niña, o lo que le puede pasar porque no le ha pasado nada, lo que le pueda pasar yo lo quiero aceptar y le he pedido mucho a Dios que me de mucho valor para aceptarlo pero en estos momentos quiero como.. como salir de lo que .. en lo que estoy no? lo que yo me siento como acorralada no se. En este momento y en realidad quisiera como desaparecerme y olvidarme de que algún día fui mamá.
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> I want to accept what is going to happen to the girl or what can happen because nothing has happened so far, I want to accept what's going to happen, I pray God to give me lots of courage to accept it but at this moment, I want like .. like to get out of where I'm now, right? I feel cornered, I don't know. At this moment, I really would like to disappear and forget that I was a mother.

Mothering in the Midst of Illness

Cristina, as a young mother, is learning her way in parenting and guiding her children. Prior to the move to Cali, she lived with her parents who coaxed and coached her to parent in certain ways, even though she sometimes disagreed. Now, for the first time she is fairly independent in her efforts, with some input from her partner. There are several aspects of her parenting that may be problematic, both from my observation and from the narratives she provides. Her strong will, somewhat adamant manner, which serves her well in struggling to do all that is required in her daughter's illness, may make learning the skills of parenting more difficult for Cristina. Two examples of this difficulty are the manner in which she feeds and disciplines her daughters.

Cristina has difficulty in getting her daughters to eat well. I observed Cristina and the girls' interaction during dinner. After having the food ready in a bowl, Cristina sits them on the floor and feeds them herself. Cristina takes a belt and puts it on her neck to use it in case the girls will not eat. I am not sure for how long Cristina has had this feeding practice. It seems with Laura it has been all her life and more recent with Nancy. Nancy learned to play with the food and spend a lot of time eating. So Cristina spoons the food to both at the same time. Cristina acknowledges she has difficulties in feeding the girls but she does not recognize her practice as inappropriate. According to Cristina, she has this practice because she does not like her daughters making a mess with the food and it is the only way to get Laura to eat. Besides, Cristina wants them to eat quickly all the food she prepared for them. Cristina feels her responsibility is that the girls eat all the food they should regardless they cry or that she has to hit them with the belt sometimes. Most of the times just seeing the belt on her neck is enough. Cristina behaves the same with both girls. She even feels Laura needs more the food than her sister does. Both parents agree on the method to make them to eat and on the fact that food is very important for both children but mainly for Laura.

> **M.-** Yo le digo a la gente pero es que, ustedes no están allí conmigo, ustedes no están luchando con …. como estoy luchando yo con mi niña del hospital pa'ca, para el hospital pa'ca, ustedes no están haciendo eso, yo se lo que a la niña le hace bien y lo que le hace mal. Como voy a dejar yo que porque ella está enferma como dicen muchos, ay! es que a mí no, no me, me gusta insistirle a la niña porque pues está enferma y que pesar uno hacerla llorar sólo porque no quiera comerse algo. Entonces, qué pasa, que pues entonces se van, se van a enfermar mas,
> **P.-** Si no come y recibiendo una droga tan fuerte.
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> **M.-** I tell people it's that you aren't here with me, you aren't fighting with .. as I'm fighting for my girl, from the hospital to here, you aren't doing that. I know what's good and bad for her. How am I going to allow her that because she is ill as many say Oh, to make her crying because she doesn't want to eat something! Then, what is going to happen? That she's to get sicker
> **F.-** If she doesn't eat now that she's getting the strong drug.

Cristina uses fruit juice and vegetables to increase Laura's immune system. She learned from a friend who learned from a well-known doctor in town that fruit juices mixed with vegetables are very good to increase body defenses. The juices Cristina gives Laura are made from blackberry mixed with spinach, grapes with spinach, carrots and bananas. She also gives Laura onion before breakfast, red peppers, lentils, soymilk, and Aloe Vera with cachaza (from the sugar cane) and bees honey. So she is very committed to the daughters' good nutrition. The difficulty arises because she delivers the food in such a harsh manner that meals have a tone of confrontation.

A second indication that her parenting is outside acceptable limits, at least in her community, is that her method of setting limits on the children is via loud, verbal commands which lead the children to cry loudly as well. On several occasions neighbors have responded to her as if she were abusive, and in one instance called the police to protect the children.

Cristina is concerned about being perceived by the neighbors as a mother who abuses her daughters. But that is not true according to her perspective; she is used to speaking loudly. Sometimes she screams at the girls when they do not obey her, and the girls cry loudly a lot, especially Laura. So she fears the neighbors think she is hitting them; "T*hey just heard but do not see what is happening in the house"* but from her perspective, it does not means she is abusing them. Once, somebody called the police; they came but they did nothing because they did not believe she was abusing the girls. She has explained to some of her neighbors the girls' crying behavior.

> **P.-** De la comida porque como ella está recibiendo droga fuerte tiene que alimentarse mas
> **M.-** Alimentarse, y por eso yo no dejo que a ella le falte la comida así ella no se la quiere comer. Por acá me critican mucho, yo soy una persona que yo hablo muy duro, no? Yo no, no soy capaz de hablar pasito pues, creo que en eso salí a mi papá porque mi papá huh, cuando alega mejor dicho se le oye en el barrio. Bueno, ellos me dicen ay! que no hable tan duro. Pero pues si yo hablo así, qué puedo hacer? Y mas cuando me da rabia, como que yo, parece que como que la gente no me escucha. Entonces ella a veces no me quiere comer, y yo alego y alego, y alego y cojo la correa, yo a veces ni le pego, sino que ella es muy escandalosa, yo a veces no le pego sino que cojo la correa, y ya con solo coger la correa ya ella está llorando, y toda la gente por acá cree que yo la estoy matando aqui. Cuando ya uno sale ya le están haciendo mala cara a uno, y de pronto una arrimadita que uno pegue donde alguien, ay usted trata muy, usted maltrata mucho a la niña eso tiene yo no se que, eso tiene causa, eso, pero nadie sabe por qué yo lo hago

> **F.**- About the food because she's getting a very strong drug so she has to eat more
> **M.**- To eat and that's why I don't let her go without the food regardless if she doesn't want to eat it. People around here criticize me a lot but I'm a person who talks very loudly, right? I'm not, I'm not able to talk softly, I think I'm like my father in that regard because when my father argues everybody in the neighborhood can hear him. O.K, they tell me "Hey, don't talk so loudly! But that' the way I talk, what can I do? Especially when I'm angry because I feel like people don't hear me. So, sometimes she doesn't want to eat and I argue, argue, and argue with her and I get the belt, sometimes I don't hit her but she is also very loud, sometimes I don't hit her. As soon as I get the belt she starts crying and everybody around here thinks that I'm killing her here. When I go out, they look at me with an unfriendly face and if I go to somebody's house "Oh, you treat her very badly! You abuse the girl and that is .. it's out of the law .. " but nobody knows why I do that.

My understanding is that Cristina does not abuse the girls in the way the neighbors might think. During time 2 interview, Laura had a tantrum because Cristina was talking with me for too long. She cried and screamed intermittently until I ended the interview. It is reasonable for a person to assume Cristina is hitting her or doing something terrible to her if the person is not in the house with them. It seems to me that Cristina has handled the girls' crying behavior in a way that has reinforced their behavior. It might also be that Cristina's way of being predetermines the mother-daughters interaction and vice versa. Cristina has not yet learned another way of controlling Laura's behavior. At present, she can not stand Laura's screaming and crying, and she is not patient enough to tolerate that without becoming upset and chastising her loudly.

Cristina struggles with her parenting and how to accept the advice and counsel of others. In some ways her struggle has a quality of adolescent ambivalence. She wants and rejects the advice of others. This occurs with her partner as well with others. For example, Cristina and Francisco disagree on the things that are good and bad for Laura. Cristina does not accept Francisco telling her what is good or not because he does not know. "*He does not talk with the nurses and the physicians in the hospital",* she said. During the interview, they did argue about the sun exposure, being with other kids, and eating candy. Francisco believed those things are bad for Laura. Cristina did not agree about being with other children and eating candy. Being exposed to the sun is true but "*only if it is excessive*". Eating candy is a habit Cristina and her parents have; Laura learned that from them. So for Cristina what is bad is to eat lots of candy instead of regular food. However, she makes sure Laura eats before giving her candy. Cristina perceived that only canned food, acids, and sodas are bad for Laura according to the oncologists' advice.

Cristina also gets confused and angry by the fact that almost everybody wants to advise her about what to do or not with Laura. Sometimes, she perceives the advice from her parents, Francisco, the physicians, and the booklets as contradictory so she sees others' input about Laura's care as a source of more stress. Cristina's perception about others' advice reinforces her aloneness and her battle in dealing with her daughter's illness.

There are many aspects of Cristina's parenting that evidence her strength as well. Cristina is very committed to guide Laura and her sister. She is very aware that her daughters need good nutrition and to do fun things like going to the park or the shopping mall. She stays with them most of the time she is not at the hospital. She is able to maintain this pattern at times when Laura is doing fine. I did not explore how Laura's recent relapse changed Cristina's way of taking care of both girls but I assume Cristina was very focused on Laura's care. Probable, her younger daughter was less attended to by Cristina and her paternal grandmother watched her while Cristina was out.

In summary, Cristina's efforts at parenting demonstrate strong willed direction, yearning for guidance and yet confusion about and some rejection of others' input. As a pediatric nurse, I had concerns about some of her practices, especially regarding feeding and discipline. However, her habits are not uncommon in Colombia, and will be difficult to alter, particularly during the period of intense stress from the illness. With time, with increased maturity, and perhaps with loving input from her own parents and other persons she trusts, Cristina may learn to soften her approach to her children and use a less confrontational mode of relating to them.

Acknowledging Some Help from Others

Cristina concedes that she and her family have had support from diverse sources. Francisco's coworkers did a raffle at work and gave the money to Francisco. Francisco's mother watches the little girl while Cristina is at the hospital with Laura. Cristina's parents and maternal aunts have given Cristina emotional and financial support. Nurses, physicians, and a woman from the SSI office at the hospital have helped Cristina with advice, information and some money. Neighbors and Cristina's relatives have bought the tamales she makes. A female neighbor helped Cristina with the girl dresses by teaching her how to make them nicer and providing some of the needed materials. Cristina's mother sells the dresses in their town. People from Catholic Church also helped them by providing food and praying for Laura.

Cristina's faith in God and Virgin Mary has been a great source of emotional support for her. A woman from a Christian Church wants Cristina to become one of them but Cristina does not want to be in that religion because it would be an abdication of her family's faith. Two mothers whose children also have leukemia and are treated in the teaching hospital give advice about food and drinks good for Laura. They also share their fears and concerns with Cristina during the time she is in the chemotherapy unit.

It was very important for Cristina to receive genuine sympathy and solidarity from people around her. She felt very strongly about people, who seem to tell her to give up on Laura and about people who told her things without really understanding her pain.

> **E.-** En en un momento como el que estás viviendo uno quiere es oir cosas positivas y que le demuestren a uno que tambien les está doliendo, si no lo mismo que por menos sientan algún dolor
> **M.-** Si, si siente algo por esa persona, no? porque siente algo y que le den a uno aliento, de que lo que está sucediendo no es por culpa de uno, ni porque.. ni porque Dios.. que muchos ay no! es por culpa de Dios, ni nada sino que antes.. o sea, que lo que va a suceder es evitando algo malo, como me dijo ayer el señor
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> **I.-** In a time like the one that you're going through now, one wants to hear positive things and also wants people to show they are feeling some pain, if not the same pain one's feeling at least that they're feeling some
> **M.-** Yes, if they feel something for that person, right? Because they feel something and also to encourage you, to tell you what's happening isn't because of you, neither because of God .. many [people] Oh, no it's God's responsibility! No, nothing instead they can say that's that what's going to happen is to avoid something bad, like the gentleman told me yesterday.

This paradigm case is about Cristina, the youngest mother in the study, who demonstrates how lonely the struggle can be for a parent dealing with leukemia. Cristina's central mode of coping with the disease is to be a fighter who tries to overcome obstacles at home and with the health system in order to obtain the care her daughter needs. She fights against a health system that does not pay all the treatment and care expenses. She fights a partner who does not provide financial support for the treatment, especially after the illness relapse, and does not help her with the family's care. She fights an unsupportive family context. Cristina is away from her original family; the relationship with her mother-in-law is not good from Cristina's perspective and she does not help Cristina with her daughter's care probably because the girl is not her son's biologic daughter. Cristina also is fighting against her fate, which she can not accept since it means her daughter may die. She believes the medical treatment may not be effective so she fights that by finding new treatment possibilities for her daughter outside of the medical system. In all of this, as a mother and caretaker, she is quite successful in keeping her child alive. Although her love for her daughter is delivered in the form of intense and harsh parenting, it is clear that the daughter is bonded to her mother. It is equally clear that the mother adores Laura and finds great joy in her life and continued relationship.

Cristina struggles with the threat and risk of her daughter's suffering and possible death. She seeks solace and consolation from the church and is relieved to hear that God is neither punishing her nor seeking out her daughter. She experiences faith as something more integrated and real to her embodied sense of meaning. Her statement "my soul came back to my body" is more than an explicit or formal belief, she is able to embody the sense of possibility given in the folk remedy. As a researcher and clinician, accustomed to finding faith in science, I perceived the folk remedy as something that would not contribute to Laura's recovery. But as one who bore witness to Cristina's faith, the folk remedy was Cristina's strongest possibility to avoid her daughter's death, her way to fulfill her role as Laura's mother and have the sense she had done everything she could for her. So I did respect her choice and never discouraged her from doing it.

Commonalties and Distinctions between Cristina and Fernando's Stories

Children's illness and death are extremely disturbing for all and especially for the parents. Suffering challenges our understanding of God mainly when it seems pointless like it is in a child's case (Hauerwas, 1990). A child's death implies discontinuity of the parents' lives and it is a reminder of their own mortality and fragility. A community capable of absorbing the parents' grief is needed when facing a child's illness and death according to Hauerwas. Both Cristina and Fernando struggled in understanding the suffering due to their child's illness. Cristina and Fernando had similar theodicies to understand the child's and their own suffering. Cristina struggled more intensely with this issue than Fernando because she faced it twice, at the time of the disease diagnosis and a year later at the time of the disease relapse. But most of all, Cristina's wrestling in explaining her daughter's illness was greater because she did not have a community to share her suffering like Fernando did. Cristina could not accept there was a God who did not love them enough or was powerless to protect her and her daughter from the suffering they were going through. Fernando perceived the illness as a challenge to his religious faith so he became more engaged in public and private religious rituals. He also took up the illness as a way to become a better person since he had the sense that God had punished him for something he had done wrong. So he was committed to become a more patient father and a more tolerant and thoughtful human being.

The availability of resources and support in dealing everyday with the illness is another distinction between Cristina and Fernando experiences. Fernando had a generational nest to which he could come during time of crisis but Cristina lacked this generational nest in her everyday life. Cristina's poverty and her non-supportive partner made her struggles even greater. Both Cristina and Fernando were very engaged with their children's care and they invested all they had in their children. Fernando with the help of his mother was more successful than Cristina in keeping his daughter alive and healthy. Fernando also had more space and energy to find possibilities in his life while Cristina was entirely focused on keeping her daughter alive and in being a good mother for her two daughters.

CHAPTER 7: IMPLICATIONS

The findings from this interpretive study about the parents' concerns, habits, and practices when caring and raising their child with cancer have implications for the care of parents and children in the Colombian context. However, some implications also can apply to parents with similar cultural background in other contexts. In this chapter, first I will summarize the findings that I consider more important for Nursing practice and research. Then, I will describe some of the implications for structuring nursing care as well as for re-orienting the health care system to be more attuned to the parents' concerns, habits, and practices. Also I will discuss some implications for conducting research with parents and how the crisis process described by Bolund (1990) and some constructs from the FAAR model could be expanded using the study findings.

Parents' Concerns, Caring Practices and Skills.

This interpretive study illustrates how parents are capable caring for their children despite the lack of formal counseling and support from the health care providers. Parents developed the knowledge and skills needed to care for the children by trial and error and by learning from other parents of children with cancer, friends, relatives, neighbors, radio and TV programs, and health care providers. Some parents use their own creativity in building the skills and knowledge needed to care for the ill child. Thus, parents relied on both health professionals and other persons around them to gain the practical knowledge and skills required for the child's care at home. Parents' reliance on other sources of information and counseling partially came from the lack of access to health care professionals' advice. They did not have enough opportunity to meet with the physicians and nurses to discuss their concerns and information needs nor did they have the kind of relationship that would allow them to ask important but minor questions about how to handle the child's behavior, emotions, and care. Parents were also very concerned with doing everything they could for their child so they used all the available sources for counseling and guidance.

The notion that the parents' understanding of the biomedical aspects of the disease and its treatment is essential for the proper care of the child at home is not supported by this study findings. Most parents did not understand the biomedical aspects of the disease and the treatment. Some of them expressed that an understanding of the biomedical aspects of the disease was not useful for them. Mothers wanted to understand and learn the practical aspects of the children's care. Fathers were more interested in learning the biomedical aspects of the disease than the mothers. Pyke-Grimm et al. (1999) reported similar findings regarding parents' informational needs. Regardless if there was a good grasp or understanding of the biomedical aspects of the disease and the treatment, parents developed detailed and effortful caring practices for their children that, for the most part, supported or did not hinder the biomedical treatment. Parents developed practices and skills for attending to their children that combined an appreciation of the scientific and technical treatments with lay, practical, and traditional treatments for their children. Cure and care were distinct for these parents even though it tended to be taken for granted by both the family members and health care workers.

Parents' main concern was to protect the child and to help her/him to recover from the disease, which would also protect them from losing the child. The parents' caring practices involved a) protecting the child from further illness and physical harm and b) protecting the child from psychological harm. The practices to protect the child from physical harm involve protecting the child from 1) infection and other diseases, 2) bleeding, and 3) sun and

chemicals. The practices to protect the child from psychological harm include activities to decrease suffering from 1) painful and scaring procedures, 2) having a fatal illness, and 3) changes in physical appearance. The parents' everyday practices and concerns in caring for the child were attuned to the parents perceived role as the main protectors of the child's life and well being and also to the parents' strong need of keeping the child alive. Therefore, parents had a dual goal for their protective practices; they were protecting the child but they also were protecting themselves from losing the child. These protective practices parallel those pointed to by Plager (1995) among families of healthy children but were heightened and focused by the child's cancer.

Parents' Ways of Taking up the Illness

These study findings show that despite the ordeal parents go through during the illness experience, they find possibilities within the multiple losses that they encounter. From the time of the diagnosis, parents began a process of learning to live with the illness. When they were told the diagnosis, they felt they had lost their world but soon they were capable of getting out of the chaos created by the diagnosis to fight for their child's life. Parents perceived a sense of normalcy in their lives after the child's clinical condition stabilized and improved. This sense of normalcy was disrupted by other illness and by very low blood counts in the child that required hospitalization and special medical treatments.

The parents' emotional responses to the illness situation, their concerns and expectations toward the ill child, and their caring practices were culturally grounded and varied with the illness trajectory. Parents underwent periods of increased physical and psychological strain but they found the means to cope in such a way they could continue with their role as parents with the ill and healthy children. They also were capable of carrying out their roles in other areas of their lives such as work, family life, and community activities. They were capable of keeping the family and their emotional stability as well as their everyday lives even in the presence of minimum resources and formal support. Cristina's paradigm case is one of the most compelling examples of how parents were capable of facing all the challenges and struggles with scarce social support and financial resources. Mothers were more likely than fathers to acknowledge they were physically and psychologically drained. This difference is understandable in a context where it is taken for granted that mothers are the primary caregivers of the children and the family. Lack of help with the child's and family's care seemed to be the cause of the increase in the mothers' strain. Fathers struggled mainly with finding the financial means to cover the illness expenses. They also were concerned about being at distance in the child's care because of their work. The economic recession in the country had an effect on the parents' income and also on the treatment funding from the health system. These contextual conditions increased the financial concerns and difficulties that parents faced during the child's illness. However, health care providers need to be sensitive to the parents' financial burden. Health professionals along with parents and other community members should get involved in finding solutions to decrease the parents' financial difficulties. Here, even in a developing country where poverty is a national problem, the society might decide that in a "good" society no parents should be faced with the lack of funds to offer life saving treatment.

The illness took a central place in the parents' lives but the parents perceived it did not interfere with their everyday lives after finishing the induction phase of the treatment. Parents learned to live on the edge with a treacherous but familiar disease. Any illness or hospitalization in the child was a set back for the parents' sense of normalcy but they worked to recover the sense of normalcy.

The study shows the cultural possibilities for coping, grieving, and expression of feelings and emotions for women and men in Colombia. Although some attention has been paid to gender differences in the literature about parents' coping with their children's cancer (Cornman, 1993; Larson, et al., 1994), it is necessary to explore more these gender differences in other cultural contexts. Role differentiation in parents' responses to childhood cancer and their involvement in the child's care is an important issue to consider when counseling parents since there are positive and negative possibilities for both mothers and fathers as it was found among the parents in the study.

Although the literature on the impact of childhood cancer on couples' relationships probes for stress and difficulties, the effect of the child's illness on the parents' relationship varied in this sample of parents and within the illness trajectory. The illness experience improved the relationship among most parents. Couples with previous difficulties in their relationships had a positive but temporary improvement in their relationship. This was possible because of the closeness the parents experienced when they saw their mutual pain and suffering. The parents' fear of causing additional suffering to the child with their fights and disagreements was another reason for the improvement in their relationship. So the child's illness had a temporary palliative effect on these parents' relationships. The difficulties resumed when the child's clinical condition improved and the parents got a sense of normality in their lives. Since the causes of the difficulties in their relationship had not been eliminated it was understandable that the difficulties showed up after the crisis caused by the child's illness was over. This was what happened to the couples in families #2 and #4, whose difficulties were originated by extramarital affairs of the husband. However, the relationship among other parents was improved by the illness experience. For example, the young couple from family # 11, who had difficulties in their relationship before the diagnosis due to their way of dealing with disagreements, actually benefited from the illness situation. They realized they needed to change their problem-solving approach for the good of the ill daughter and the stability of their marriage, which would also be beneficial to the entire family. The father learned to avoid conflict when the mother was upset. So this couple's relationship improved after the diagnosis not only as a consequence of the child's cancer but also as an outcome of the learning and adjustment process that young couples go through.

Couples who demonstrated the most strife in their relationship were those in which the father did not support the mother in meeting the demands of the ill child and family's care. As it happened to the couple from family #10, among these couples the mother became emotionally and physically more taxed with the child and family's care, she resented the father for his lack of support so a vicious cycle of disaffection and resentment was set between the couple. Therefore, if the father does not get involved in supporting the mother the relationship between the couple becomes increasingly difficult.

Reasons to Abandon Treatment

The health care providers' belief that the lack of knowledge and understanding of the disease and its treatment among the parents usually is the main cause for abandoning the medical treatment is not confirmed by this study. Parents had multiple and complex reasons for abandoning the medical treatment in the study. Parents abandoned the treatment for financial reasons, to protect the child from more suffering, and because they felt there was not hope in saving the child's life. Biomedical understanding of the disease and its treatment was not a guarantee that parents would follow or adhere to the treatment as it was for the

parents in the first paradigm case (family # 1) in which the maternal grandparents were physicians. Parents' concerns in causing unnecessary suffering to the child as well as the parents' desire to keep the child at home with the family when they perceived there is no hope for the child's recovery plus the lack of health insurance to cover the illness expenses were the main reasons parents had to stop or interrupt medical treatment. The parents who abandoned or stopped the treatment did not have the opportunity to express and discuss their concerns with the health care providers in the hospital or to have financial support for the treatment.

Setting Limits and Reestablishing Discipline for the Ill Child

Parents struggled with these issues because they perceived the need to set limits and discipline the child and at the same time they were afraid of causing the child psychological suffering by restraining them from the pleasure of having all they wanted and having a life without limits. Parents were also concerned with the child becoming spoiled and rejected by others because of the inappropriate behavior. Parents were equally concerned the child's behavior would get out of the parents' control in the future. The advice from physicians, nurses, and psychologist to treat the child "as normal" also increased the parents' conflict. The first few months after the diagnosis, parents indulged and overprotected the child because they believed the child would die soon and also because the child was very ill. Later, when the child did not show signs of the disease and parents understood the child would survive, they were able to perceive and treat the child "as normal" which included resuming the use of corporal punishment to discipline the child. Although, most parents understood corporal or physical punishment could cause bleeding in the child and also psychological suffering.

Religion and Illness Meaning

The potential death of an innocent child creates both a crisis in faith and a stimulus for faith

Religion and faith helped parents to find the illness meaningful. However, the need for religious support varied among the parents even within the same family. According to this study, spiritual support from faith and religion is an important source of comfort for parents in coping with the child's illness. This could be a culturally based difference between Colombian parents and parents from USA. It might also be possible that the role of religion and faith in coping with children's cancer has been insufficiently examined in USA and other contexts. Religion is not always a comfort; it can cause more discomfort and anxiety among the parents, as happened to the mother in the second paradigm case and the father from family #4. These parents interpreted the illness as punishment because of the religious belief that children's illness is a consequence of the parents' wrongdoing. So parents' religious beliefs need to be assessed and attended to. Theodicy, a theological account for the problem of evil or the answers to the question about how a Good God can allow evil and suffering, has much to offer to the parents of gravely ill children in a religious society.

Other important aspects regarding the child's care can be learned from this interpretive study. For example, parents were not concerned about most of the immediate side effects of chemotherapy because the symptoms were mild, short lasting, and caused by the medications. However, parents were very concerned about low blood counts since it meant the child could bleed or get an infection. Irritability from high doses of steroids was very problematic for the parents to handle at the beginning when parents had not developed the skills to cope with it effectively. This study illustrates the need for nurses and physicians to

be concerned about the practicalities of the lived experience of the illness.

Implications for Nursing Practice

The mentioned findings from the study imply that nurses and other health care professionals involved in the care of the children and parents in the setting where the study was conducted and similar settings need to broaden their understanding of the parents' experience in caring for their ill child. Nurses and other health care providers need also to develop new skills and practices to provide the most appropriate care for the parents based on the understanding of the parents' concerns, habits, and practices described in this study. According to the study, counseling and support for parents, changes in the funding system of the children's care, and changes in the hospital environment are some of the aspects in which nurses and other health care providers can work to help parents in their illness experience.

Counseling and Support for Parents

It is well accepted that parents of children with cancer need counseling and support from health care providers, particularly at the time of the diagnosis and the induction phase as well as during crisis like hospitalization, relapse of the disease, and death of the child. The findings from this study support the above idea about counseling and support for the parents. However, the parents can be very resourceful in gaining the knowledge and skills to care for the child and to cope with the illness from many sources. Therefore, health care providers but especially nurses need to be aware and respectful of the parents' expertise and wisdom. This study also indicates that the parents' responses and needs vary with the child's illness trajectory. So the care and support that health care professionals provide to the parents should be adapted to the parents' specific needs.

In Colombia, as in other places, psychologists claim their role in providing

psychological support to the parents and children. Professional nurses are in an advantageous position to provide the continuous counseling and support required by the parents. Nurses are physically closer to the parents, have the technical understanding of the illness and the child's care, have the background skills to assess the parents' needs, and most importantly are committed to maintain the well-being of the children and their families. Therefore, regardless of the availability of psychologist's counseling for the parents, nurses must assume their role in supporting the parents through the entire illness experience. Nurses should provide counseling and support to the parents using individual and group approaches. The counseling and support should be provided continuously to parents so they have the opportunity to express their concerns and needs on a regular basis. Since for most parents lack of time is a constraint in their everyday lives, it is necessary for the nurse to be available to the parents when parents come to the hospital for their child's treatment, tests, and follow-up appointments. It should be the same nurse for the same parents to establish continuity and rapport between the parents and the nurse. To accomplish this, the Nursing Department from the hospital needs to assign at least two professional nurses to the Chemotherapy Unit. One of these nurses should be the nurse with a Master Degree in Oncology Nursing. But most importantly the Nursing Department must avoid moving the nurses from the Chemotherapy Unit to other units so the nurses have the opportunity to develop the skills and knowledge to care for the children and their families. The children and the parents would also benefit from having the same nursing staff over the whole illness experience since the relationship between them and the nurses will be closer.

The counseling and support should be tailored to the parents' expressed concerns and needs. The idea that all parents need and want the same information regarding the disease

and the treatment must be reexamined. At the time of the diagnosis, parents need and want to be reassured there is hope, the child could survive, the disease can be treated, and they have not done anything to cause the child's disease. Parents who had a pre-understanding that a cancer diagnosis was equivalent to death did not want to be told this at the time of diagnosis. Although honest expression of risk is the responsibility of health care providers, sensitivity to the parents' understanding of the diagnosis and appropriate timing of risk communication are necessary in compassionate care.

Parents also need time to express their sadness, anger, and frustration in private or without the child witnessing the expressions of these emotions. Parents need this space and time before they face the child and other family members upon knowing the child's diagnosis. Nurses and other health care providers should be aware of the gender differences in the parents' expression of emotions and reassure the fathers it is appropriate for them to express their sadness.

Parents in this study preferred to hear the bad news about the diagnosis from the Oncologist; they perceived the Oncologist as the expert in their child's disease so they feel more comfortable in getting the bad news and also the treatment options and prognosis from the expert. So nurses need to make sure the Oncologist meets with the parents at the time of diagnosis so the expert specialist gives the parents or the child the definite diagnosis.

Nurses also must be aware that parents' support and counseling needs regarding the child's care and the parents' well being change according to the illness trajectory. During the induction phase and immediately before and after any change in the treatment protocols, parents require information about the medications and the effects on the child's health and behavior. On a regular basis, parents also need time to express their particular concerns,

fears, and needs. Single parents and parents without a supportive partner like Cristina would require special time from the nurse. They may benefit more from having somebody that can listen to them, comfort them, and give them appropriate advice. Hospitalizations of the ill child, relapse of the disease, and death of the child are also special situations during which nurses should be closer to the parents to provide the needed support.

Nurses need to develop ways to provide support and counseling to the parents as a group. The group approach will aid the nurse to reach more parents with the same resources. But most importantly, the group approach will allow the parents to share their practical wisdom and expertise in caring and raising the ill child and it will also empower the parents individually and collectively (Chesler & Chesney, 1995). The parents' individual empowerment may be represented in the parents' feelings of control and personal efficacy, their efforts to exert control over their lives, and their participation in the self-support group (Schultz, Israel, Checkoway & Zimmerman, 1993) as cited by Chesler and Chesney (1995). Parents' empowerment as a group implies sharing leadership, skill development, and impact of the community. Participation in self-support groups helps the parents to recover and strengthen their identity as parents. Even though the parents from the study did not have the opportunity to be in a formal self-support group, they behaved like a group sharing their concerns, skills, knowledge, and practices. Some mothers were recognized as more experienced and knowledgeable by other mothers so their advice was very important, especially at the beginning of the illness trajectory. Parents also talked about having good friends among the parents whose children were in treatment; some mothers visit and talk over the telephone often as means of support and exchange useful information.

Self- support groups are not common among Colombians like in the United States. So

nurses and parents need to learn the skills to develop and participate in self-support groups. Nurses need to assume a more active role in the parents' self-support groups, especially at the early stages of the group development. For example, collaborating with the Parents' Association in Cali would provide an opportunity for the nurses. This group of parents is in its early stages of development and can benefit from the involvement of concerned and empathetic health care providers. The chair of the Parents' Association was disappointed at the lack of attendance of the parents to the meetings. So it is evident this parents' group needs support and guidance from others to become a self-support group recognized by the parents as such.

Nurses also need to join efforts with priests or religious leaders in helping the parents to find ways to explain the child's and their own suffering in order to provide parents with possibilities that decrease their sense of guilt and wondering in finding the illness meaningful.

The parents' identification of demands and their experiential wisdom in providing the care for their children provide the ground for developing a program of guidance and support for parents of children with cancer. For example, the content of the information given to the parents either orally or written about the child's care at home could be structured using the categories of caring practices developed by the parents in this study. Parents can benefit from information about ways to protect the child from physical and psychological harm. Parents might be concerned about infection, bleeding, the sun, chemicals in the food and water, and other illness as the main threats to the child's recovery and survival. So parents may want to know how to protect the child from those threats and also to strengthen the child's immune system. Parents also need information about how to protect the child from psychological

harm due to the suffering from knowing they have a disease that is life-threatening, from feeling and looking different, and from the pain and fear caused by the treatment. However, the key point in providing counseling and information to the parents is to acknowledge and rely upon the parents' concerns and needs.

Most parents in the study struggled in incorporating the advice given by the health care providers about treating the ill child as a "normal child". At the beginning of the illness experience, parents did not follow the advice because the child's condition was not normal for the child or for them. Instead, they indulged the child, tolerated all the child did, and avoided setting limits for the child's behavior. Later, when the child's condition improved, parents were more willing to follow the advice about treating the child as normal. However, even at this time it could not possible that the child be "normal". The child's life is disrupted by the weekly testing and treatment procedures and by the body sensations and feelings caused by the medications and the disease itself. Toddlers and preschoolers do not have the mental or intellectual skills to do fully understand what is happening to them. School age children and preadolescent children may have better intellectual abilities but still they do not understand some aspects of the illness experience. These older children may actually perceive a greater threat to their identity and life than the younger children in addition to resenting the limitations imposed on them by the illness and their parents. Children's aggressive behavior usually indicates their confusion and lack of understanding about what is happening to them. Our understanding of the child's illness experience is very limited, especially in Colombia, we do not have the knowledge base to claim the child is normal and should be treated as normal during the cancer experience. On the contrary, based on the understanding about children's responses to illness, hospitalizations, and other stressful

events as well on the understanding about children's normal development one can assume that children with cancer can not be considered "normal" in the sense that they may not behave the same way healthy children will behave. Children with cancer can not behave as if they would not have the cancer because they are coping with the different events or demands determined by the illness. Most of these demands are threatening and frightening for the child regardless of his/her age. So it is unrealistic to expect their behavior to be the same behavior of healthy children.

Nurses need to reexamine the way they interpret the child's behavior for themselves and for the parents. Nurses can help the parents to understand the children's behavior by providing them with information about the child's expected behavior based on the developmental stage and the impact of the illness experience. Parents also need counseling and support in making the transition from indulging and tolerating to limit setting and disciplining the child since parents' overprotective and indulgent behaviors are their ways to cope with the threat of losing the child. Equally important, parents need counseling about approaches to discipline the children without the use of corporal punishment. Even though, the use of corporal punishment is a cultural practice in Colombia, it is necessary to modify this parenting practice not only for the ill children but also for all children.

Nurses should always acknowledge and explore the parents' expertise and practical knowledge about the child's care before giving them any advice. Parents are the experts about their child and possess a wealth of knowledge and skills that nurses can learn. Parents gladly would share their knowledge and expertise with other parents and the nurses. Recognition of the parents' role and expertise by the nurses and other health care providers will protect the parents' identity and sense of mastery during the illness experience.

Parents who stop or interrupt treatment merit special attention from the health care providers. Specific and more intense follow-up activities need to be set up for these parents. Telephone calls by the nurses or physicians, home visits by volunteers or nurses from the local health institutions can be ways to reach out to these parents. Having a relationship with a nurse during the early phases of treatment might prevent the parents from dropping out the treatment precipitously. In the three instances in which the parents in the study abandoned or stopped the treatment, in only one case a nurse from the chemotherapy unit call the mother. In the other two cases, nobody from the treating hospital or the local hospital contacted the parents to find out why they abandoned or interrupted the treatment.

Changes in the Health System

Two aspects in the health system deserve serious attention in order to make the parents' illness experience less difficult. The first aspect is the children's health care funding. All parents in the study, regardless of their income, experienced the financial burden caused by the illness expenses. The chemotherapy medications, tests, and traveling to the hospital were the main reasons of the parents' financial burden. The burden was greater for the parents from the SSI, who had been in the system less than two years, and for the parents in the subsidized system. These parents usually are the ones more in need of having a complete coverage for their children's care since most of them are working people and from the lower social class, which means low income to begin with. Thus, the SSI coverage policy and the funding for the children in the subsidized system must be redefined. The latest Colombian constitution defines health care as a fundamental right for all Colombians and especially for children. The government should find the means to make this a reality for the children with cancer. Also within the structure of the health system in Colombia there is a special fund to provide health

care and insurance to persons with catastrophic illness. So there are legal bases for claiming free health care for children from low-income families and complete coverage for children in the SSI. However, it is necessary combine the efforts from the parents, health care professionals, media, and community leaders to accomplish the goal of funded care for children with cancer. In the mean time, nurses and other health professionals involved with the children's care need to be conscious and sensitive to the families' needs in this regard and to advocate for the parents to the SSI and hospital authorities. Nurses can provide information to the parents about the local resources that can help them with the treatment expenses.

There are also some changes in the hospital environment that need improvement in order to make it more attuned to the parents' concerns and needs. For example, the rule about having only one parent with the child while she or he is in the ER should be relaxed to allow multiple visitors to be with the child at this time. It is very taxing and difficult for one parent to do all the activities over the different areas in the hospital in order to get the child's diagnosis and at the same time watch and care for the child in the midst of the chaos of the ER and the anxiety from the child's situation. Allowing the two parents or a relative to be in the ER area, to help the parent in the ER, would make a huge difference for the parents and children's comfort since it would facilitate things for the them besides keeping them together at this critical time in the illness experience.

The inpatient rooms for the children with cancer in the Pediatric ward need to have at least a comfortable chair for the parents to rest. A paid telephone should be installed inside the unit so the parents do not have to go outside to call their homes and leave the child alone.

Implications for Research

The findings from this study also have implications for conducting research among the parents of children with cancer. For example, the variability in the parents' ways of taking up the illness during the different phases of the treatment or disease trajectory indicates the need for researchers to study parents and families in each of the phases. It is important to consider the treatment or disease phase designing the studies of families of children with cancer since the parents' responses to the child's cancer changes over time. The induction, remission, and survival stages of the disease are tied to time as well as the treatment phases. Reaching and getting over each step of the disease or illness trajectory involves changes in the parents' emotional responses, concerns, and caring practices. At the time of diagnosis, parents perceived great losses: the child, their taken for granted everyday, and their future. Accordingly, they experienced intense emotions and a great chaos. By the end of the induction phase of the treatment if the child went into remission, they had great hopes so they started to recover their familiar world, as they perceived they were recovering their child. During the maintenance phase of treatment, parents felt their everyday lives were almost back to "normal". Given the extreme variability in parents’ demands and responses during these phases, it seems imperative that they be studied separately. Sandelowski (1999) suggests that time should be taken into consideration in sampling the participants, collecting and analyzing the data, and reporting the study findings regardless of the research methodology used but especially in qualitative studies where changes over time become are relevant.

Sometimes researchers report or interpret some of the research findings about the effect of the illness on the parents are conflictive, contradictory, and inconsistent but that is not the case. As it has been described for the parents in this study, the illness impact and the responses of the parents varies since human beings interpret and cope with the events present in their lives in a variety of ways. So the researchers need to explore and acknowledge the differences as well as the similarities in the parents' ways of coping and living with the illness experience. For example, the role differentiation in parents' concerns, practices, and skills when caring for the children need to be explored in different contexts and cultural settings.

Another salient aspect of the findings from this interpretative study, in relation to our understanding of parents facing cancer in their child, is the wealth of knowledge about the positive, healthy or "normal" ways parents use to cope and live with the illness situation despite all the struggles and suffering imposed by the illness. This does not mean that life is easy for these parents or that they can go through the illness experience without experiencing major difficulties. Instead it shows the need for researchers to explore more this aspect of the parents without pathologyzing or medicalizing the parents' experience. Parents as well as clinicians would mutually benefit from the knowledge about parents' everyday concerns and practices in raising and caring for a child with cancer. Parents of newly diagnosed children can get more courage, support, and comfort from knowing how other parents live and cope with the child's cancer in their everyday. On the other hand, clinicians would be able to identify parents at risk of having difficulties and focus more in helping these parents to overcome the difficulties.

Implications Regarding the Conceptualization of Parents' Responses to Childhood Cancer

The trajectory that parents went through in learning to live everyday with the child's illness is similar to the crisis process described by Bolund (1990) for adults having cancer. So

it seems that parents living with their children's cancer follow a trajectory similar to the process that adult cancer patients go through in learning to live with the illness. It is important to understand that parents of children with cancer live with their child's cancer as if it were their own illness. However, the terms used to describe the phases in the crisis process seem to be derived from a psychiatric perspective and do not represent the patients' everydayness. People living the cancer experience may not be able to identify what happens to them when using Bolund's labeling of the process phases. The shock phase in Bolund's crisis process is similar to what the parents described as "the world had ended" at the time of the disease diagnosis. The work through and reorientation phases can be assimilated to "Coming out of the labyrinth" and "Remission opened up the possibility of normalcy". Similar crisis and reorientation processes have been described for families as a whole (Rolland, 1994).

The FAAR model about the family adaptation to chronic illness includes religion as one of the many resources families use to cope with the illness. For the parents in the study, religion was more than just a resource in coping with the child's cancer. Religion was central to the parents' process in learning to live with the illness. Religion helped the parents to reorient their everyday lives around the child's illness in a very meaningful and useful way. So it is fundamental to consider religion as a key resource for the parents living in a context or culture in which religion has a predominant place. If the FAAR model were to be used to conceptualize Colombian families experience with childhood cancer, religion as a coping resource would have to figure more prominently in the model.

Coping is an important construct in the FAAR model and it refers to the family capabilities to deal with the illness. The way coping is considered in the FAAR model falls short in describing all what parents do in living with the child's illness. For example, the protective practices that parents developed to care for the children and the different ways they used to create and establish those practices. As it is currently conceptualized, coping refers most to the reactive patterns parents make to stress. In order to address the parents' proactive, creative efforts at protecting many aspects of the child's health and existence, additional conceptualization about protective practices would warranted.

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Appendix A: Composition of the Study Families

Family #1: Elena, 35, housewife; Felipe, 42, industrial engineer; 9 year-old girl, 4 year- old Pablo who is the ill child, and 2 year old boy. Felipe also has a 17 years old daughter. They live in a city 30 minutes driving from Cali.

Family #2: Gloria, 28, housewife; Enrique, 36, school teacher; Carlos, 6 (ill child), girl, 8, and 10 year- old boy. Enrique has another 14 year-old daughter from a previous relationship but she does not live with them. They live in a small town about 50 miles from Cali.

Family #3: Enrique, 40 and Marta, 43 are the parents of 3 boys: 21, 18 and 12. Alejandro, the youngest is the ill child. Enrique works in a recycling company and Marta runs a store in the house.

Family #4: Gustavo, 43 and Nubia, 33 are the parents of Lorena, 12 (ill child), and two girls, age 6 and 3. She is a housewife; he is a taxi driver. Gustavo has another daughter, 15 year old who he has not seen since she was a baby.

Family #5: Patricia, age 5 is Fernando's only child. Fernando is 27 years old, divorced, and with no stable job. Patricia and Fernando live with Fernando's parents, two brothers, and one 11 year-old nephew. They live in a city, 30 minutes driving from Cali. Lucia, 56 is the paternal grandmother.

Family #6: Marina, 29 and her only son Juan, 8 years old. They lived with Marina's mother. Marina works selling lottery tickets.

Family #7: Rosa, grandmother, 62; Carmen, mother, 38, and Luis, 12. They lived in the rural area of a small town about 1 hour driving from Cali.

Family #8: Blanca, 29; Arturo, 36; Gabriel (ill child), age 4 died 7 months after the diagnosis; his sister, 11 and brother 6. They live with Blanca's parents in Cali, in a neighborhood that is considered unsafe.

Family #9: Silvia, 21; Carlos, 34, and their only child Camilo, 3½ years. They live with Carlos's parents and brother who is a physician.

Family #10: Cristina, 19; Francisco, 29, and Laura (ill child), age 4; Nancy, age 2. Before the diagnosis, they lived in a small town north of Cali with Cristina's parents. They moved to Cali to live with Francisco's mother and brother in a neighborhood quite far from the hospital, about 1 hour by bus.

Family #11: Constanza, 24; Gonzalo, 27, and 2 girls: Dora, 4 (ill child) and Nancy, 2. They live with Constanza's parents and siblings. The house is located in a neighborhood that is known as dangerous for robbery and violence.

Appendix B: Interview Guidelines

Interview #1

1. Please tell me about the time when you first noticed your child was ill or that there was a problem. Please, think about specific times or instances and tell me what happened. (Obtain narratives and history of events using the following probes)

What led up to the situation?

How did you feel at that time?

What did you do? What did other around you do? Were there any conflict between what you did and what the others did? How was the conflict resolved?

How did what you did change the situation?

Did your action change the way you felt about the situation?

What else did you consider doing?

Looking back on it now, would you do anything differently?

Is there anything that has changed as a result of that situation you experienced?

2. Can you tell me about the first time you heard what was wrong (a diagnosis) with your child? Please tell me about this experience.

3. Can you tell me about the experience of having your child in treatment? (Obtain narratives and history of events using the above probes)

4. How do you understand your child's illness?

What do you think caused your child's illness?

How did you see the illness at the time of diagnosis?

Have your ideas about the illness change now that she/he is in treatment?

What is your understanding of the illness treatment? How do you think it works?

What are the benefits you see from the treatment?

What are the negative effects you see from the treatment?

Can you talk about what you think will happen to your child in the future?

4. How is for you to raise your child knowing the illness he/she has?

Please, talk about the changes you notice in your interaction with your child since the time of diagnosis. (Probe for changes in feelings, expectations, and concerns about the child)

Have your ways of disciplining your child changed since your child was diagnosed with the leukemia?

Have you noticed changes in your feelings, concerns, expectations, and ways of disciplining your other children? (Probe for changes in feelings, concerns, expectations, and ways of disciplining other children).

5. Please, think about specific times, since the diagnosis, when you have had difficult times in raising your child and tell me what happened. (Use probes to get the full narrative and history of the events).

6. Please also think about meaningful moments you have had with your child, since the diagnosis and tell me what happened. (Use probes to get the full narrative).

Interview #2

1. How has it been for your child and you since our last conversation?

    What changes have you seen in the child's health and behavior?

    What changes have you seen in your feelings and expectations about the ill child and other children you have?

    What changes have you seen in the treatment your child is having?

2. How is it for you to be involved in the care of your child's needs due to the illness that he/she has?

3. What are the most difficult things that have arisen for you in the care of the child? Please, think about a specific difficulty you have had and tell me what happened. (Use the probes to get the full narrative).

4. What are the less difficult things for you in the care of the child? Please, think about a specific time you felt capable of doing what your child needed and tell me what happened. (Use the probes to get the full narrative).

5. What are the changes you have in your everyday life due to the child's illness? In an ordinary day, for example yesterday, how were you aware of your child's illness? Please, tell me about a specific change you have seen. (Use probes to get full narrative).

6. Who and what has made it easier for you to face the situation with your child?

    What persons in your family, the hospital, and the community have been helpful to you?

    What things have they done that are helpful to you?

7. Who and what has made it more difficult for you to face the situation with your child.

What persons and things in your family, the hospital, and the community have been helpful to you?

What have they done that have been helpful to you?

Interview #3

1. How has it been for your child and you since our last conversation?

    What changes have you seen in the child's health and behavior?

    What changes have you seen in your feelings and expectations about the ill child and other children you have?

    What changes have you seen in the treatment your child is having?

2. Have you changed your ideas about the illness and its treatment?

3. Have you changed your ideas about how you see your child now and later?

4. Can you tell me about a difficult time that arose in the past month regarding the care of your child. Please, tell me the story of what happened.

5. Please, think about something special or memorable that happened between you and your child since our last conversation and tell me what happened. (Use the probes to obtain full narrative)

Appendix C: Informational Flier for the Participants

The parents who face the experience of having a child with leukemia need a lot of support from the health care providers to deal with this situation. To be able to give the care and support needed by the ill child and the parents, health care providers should understand the parents' situation. Most of the information that we as health care providers have about this issue is based on the experiences of parents in others countries with different ways of living, feeling and seen what happen to them. We need to know how the parents in our country deal and live when they have a child who has leukemia, and how is for them to raise a child in this situation. This is why, as nurses teaching other nurses in the School of Nursing at the University of California, San Francisco and the Universidad del Valle, we are very interested in doing a research that could help us to obtain the necessary information to take better care of the families and their children when they have leukemia.

You will be interviewed three times in your home or wherever you want to. The first interview will be done individually, the second interview will be done together with your spouse/partner, and the third interview will be done individually. The interviews will be tape-recorded and then transcribed by a typist.

The information given by you will be used only for the purpose of the study. Your name will not appear in the interview transcripts. A fictitious name and a number will be used to identify you as participant in the study. Some of the data may be used to teach nursing students in the future. However, only data without the participants' identity will be available to students. During the interview, you might be disturbed by the questions as by the researcher. You can end the interview whenever you want to. You also can decide about answering or not the questions asked by the researcher until you feel you are ready to answer them.

You also are given a photo-camera to take pictures of situations or moments that are important for you and you want to share with the researchers. One set of the pictures will be given to you. If you agree, another set of the pictures will be kept by the researchers and it will be used as data.

Your participation in the research is voluntary, you may refuse to participate for any reason without any negative effect on the medical care of you or your family. You can leave the study at any moment that you want to do so. The care of your child will not be affected in any way by your decision to participate or leave the study.

Your participation in this study is very important to understand the parents' situation in raising and caring for a child with leukemia. It is also important to develop ways of helping other parents to go through this experience with appropriate support and help from the health care providers.

If you have any question you can contact Edelmira Castillo at 5521220 in Cali, or Dr. Catherine Chesla (415) 476-4433 or the Committee on Human Research, UCSF at (415) 476-1814 in San Francisco. You can call collect to the United States.

Appendix D: Demographic Data from the Participants

Demographic data from the parents

	Mother	Father
Age	__________	__________
Ethnic group	________________	______________________
Social class	__________________	______________________
Occupation	__________________	______________________
Monthly income	______________	______________________
Place of Origin	_______________	_______________________
Religion	_____________________	_______________________
Marital status	________________	________________________
Number of children	___________	

Demographic data from the child

Age _______ Sex ________ Order of birth _____________

Time since diagnosis _________________ Phase of the treatment ________


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