FAMILIES WITH TERMINALLY ILL CHILDREN: THREE CASE STUDIES

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In the course of everyday family life, it is very easy to take things for granted. Parents carefully make plans and work towards providing a good future for their children. It is an assumption that children will finish school, find a job, settle down, perhaps provide for their parents in their old age, and have children of their own to love, nurture, raise, and provide for. Generation after generation, this cycle of loving and living is reborn.

Family life may also be deceivingly simple. Every day is filled with its share of ups and downs, pushes and pulls, sorrows and celebrations. Individual and family problems range from the trivial to grievous. When a loved one in the family is suddenly struck with a life-threatening disease, the situation has a major and drastic impact on the family life and the individual lives of its members.

Families with a terminally ill child face a unique set of problems as they attempt to adapt to the presence of a family member with a shortened lifespan. They have to contend with the same pressures and tensions of everyday family life while at the same time have to face the eventual permanent loss of a family member. They have to make provisions to make whatever is left of the child's life as normal and comfortable as possible and yet the battle of holding on versus letting go wages on. Each member of the family undergoes multiple grief experiences as a result (Raphael, 1983).

This article summarizes a multiple case study of three families with terminally ill children. It describes the experiences of the fathers, mothers, and children. This study sought to explore and describe the answers to the following questions: What is the impact of the presence of a terminally ill child on the family's dynamics? From a developmental point of view, what are the differences in the experiences of terminally ill children?

Among the points explored were the family members' perceptions of the stressor, critical family events, feelings, stress and coping experiences, perception of the impact of the stressor on individuals and family relationships, etc. For the purposes of this study, the term "family" only refers to the father, the mother, and the terminally ill child.

The Terminally Ill Child and His Family

In the last few years, family systems theories have focused on evidence that when any stress affects one family member, the other family members may also experience reactionary stress or anxiety (Andolfi, 1979; Bowen, 1978; Minuchin, 1974). Recent studies have also pointed to the possible link between emotions, biological factors, and familial situations that may contribute to the development of cancer (Achtenberg, Simonton & Matthews-Simonton, 1976; Goldberg, 1981; LeShan, 1990). To a certain degree, cancer may be indicative of an imbalance in the family emotional system.

Keeping the family systems approach in mind, we realize that the diagnosis of a child as being terminally ill has a great impact, not only on the patient alone, but also on his entire family. Families with a terminally ill member are forced to witness the progressive, and sometimes rapid, debilitation of a loved one and are at a loss as to how to control the situation. As the illness takes its toll on the patient in the up-and-down cycles of the disease, the family constantly has to readjust with every onset of every change. On some days the patient may feel very much like his old self. This allows the patient and his family to feel hopeful and feel that they have their "old" normal and healthy child again. On other days, however, the child may feel so ill that the family worries that the inevitable death is nearing. With each cycle of the disease comes a corresponding exhausting readjustment to the situation at hand (Raphael, 1983).

The child's family members suffer greatly as they watch their loved one go through this up-and-down course and they suffer additionally in their own helplessness and failure to alleviate it.

The main tasks of a dying patient's family can be synthesized into three aspects. First, the family must begin the joint process of anticipatory grief and the completion of unfinished business with the terminally ill member to prepare for the letting go that ultimately must take place. Second, the family must accomplish this while at the same time support the dying patient. The family must still find ways to continue to live with the patient as fully as possible until the moment of death. Even with the ongoing process of relinquishing of family roles and responsibilities, the patient must still be given as much control as possible. The third main task that a family has to go through is its reorganization to maintain stability following the imbalance created by the illness of the child. The survival of the remaining family members must be ensured. Family members must begin the necessary changes that should be completed after the death of the family member. This includes grieving for the death of the family as a unit as it has been known to all the family members (Rando, 1986).

The terminally ill child. A young child may not be able to fully grasp the reality of his situation. A child who is ill experiences effects on all aspects of his life. There may be a lot of things a terminally ill child may not understand. On a physical level, he may not understand the changes his body may be going through. He may not understand the numerous painful medical procedures that violate his body with needles and tubes. Chemotherapy may involve weekly injections, three to five at a time. Blood extractions are routinary. Symptoms of the disease and side effects of the medication are all new and overwhelming experiences. The child feels nauseous, loses his hair, feels weak, and loses weight.

The change in his lifestyle may be confusing to him. Whereas, once before, he was free to play and run around, now he was confined to a bed, tired quickly, and did not have the time, strength nor opportunity to be with his peers and family members.

He may find his physical appearance frightening and embarassing, and sometimes even pitiful.

The terminally ill child may become more irritable and sensitive to usual anxieties. He may feel frustrated with the restriction of his activities and may worry about his status in his peer group. The child may also become so accustomed to special attention that social adjustment problems may arise. Sometimes a terminally ill child becomes more aggressive, finicky, or irritable. Heightened emotional feelings may be those of depression, shame due to inadequacy, guilt, or even anger and frustration (Raphael, 1983).

Children grieve and react to stress according to their own social, developmental, and emotional contexts as well as their cognitive understanding of the situation (Rando, 1986). From 2 to 3 years of age, a child's grief is experienced in bewilderment. He may exhibit regressive clinging behavior. The child may fear being left alone (Rando, 1986). O'Dougherty (1983) identified this developmental stage as a time where a child may view his illness as punishment and may perhaps develop a fear of mutilation from any medical procedure.

From ages 3 to 5, children generally interpret important happenings in the family as being caused by something they did or something they are (LeShan, 1990). It would be possible then for a child to perceive his current situation as something he had brought upon himself. He may perceive his sickness as a result of his not being good, thereby, making it his own fault (O'Dougherty, 1983).

From 5 to 8 years of age, the child has a more cognitive understanding of loss (Rando, 1986). A child at this developmental stage may hide feelings and may grieve quietly and privately. At times, observed behavior may show no indications of stress and grief but deep down inside the child is actually quietly fearful, anxious, depressed, and confused. The child may engage in fantasy that the illness may not be there. He may carry the optimism of things quickly reverting back to normal. O'Dougherty (1983) identified the developmental goals of this period as industry, achievement, and task accomplishment.

An adolescent child, on the other hand, possesses an even greater cognitive understanding of illness and its implications. Shock and denial may be experienced at this developmental stage. The child at this stage is aware of and feels threatened by mortality. Developmental concerns include acceptance from peers and establishment of a self-identity capable of independent action. Issues that may arise at this stage include a need for privacy, confidentiality, participation in decision-making, and consent for treatment (O'Dougherty, 1983). The child's illness may also interfere with a child's sense of masculinity or femininity (depending on the child's gender) and how the illness may affect the child's relationships with peers and members of the opposite sex.

The parental experience. Parents may initially blame themselves and feel guilty for not having paid more attention to early nonspecific manifestations of the disease (Hipol, 1980). Parents denied anxieties through extreme involvement in the case of their child (Richmond, 1953).

Codden (1977) recognized that the parents' feeling of competence and control are affected when a child becomes terminally ill. The child changes right before their eyes on both the physical and psychological aspects. The child is no longer happy, active, or predictable. The role of the parents as primary caretakers is relinquished to the medical staff. Parents feel threatened and helpless and wish to gain back control over the child and the situation.

Although family members continue with their lives, when a family member dies, part of them dies with him. These are parts of the self that have been constituted by the interactive relationship with that dying person. A mother will grieve for the loss of that part of her that is a mother to the child now dying. A father will grieve for the loss of that part of him that is a father to his child. Parents (and other family members as well) mourn not only for the dying member but also for themselves. Along with this comes the mourning over the loss of whatever plans and dreams the family may have had for the child. Family members undergo multiple grief experiences in such a situation (Herz, 1980; LeShan, 1990; Raphael, 1983).

Among the biggest difficulties the family has to face is having to strike a delicate balance between coping with the loved one's terminal illness while at the same time taking care of the other family members. Guilt feelings often revolve around taking care of the child in the hospital and wondering how the other children at home are (Hipol, 1980). Parents who stay at home to take care of the others feel guilty for not being present for the dying patient at the hospital.

Case Study Data

Following are summarized case profiles of three families with children afflicted with cancer. Data was gathered over a three month period with regular visits to the hospitals where the children were confined. Data gathered through clinical interviews, projective techniques, and clinical observations and counseling and therapy sessions supported earlier research and presented patterns that formed the basis of interesting new hypotheses.

Case #1: The Barrios Family

Carmina (7 years old) came from a very poor family. Her father, Jose, was only a farmer and was the sole breadwinner of a family of eight children. Rosa, her mother, was a housewife and the family caretaker and homemaker. Carmina was reported to be the father's favorite child.

Even prior to Carmina's diagnosis, the family was already deep in debt. Her father had suffered a near-fatal heart attack and had been confined for weeks. A few months later, Carmina was diagnosed as having Wilm's tumor (cancer of the kidney) and needed immediate medical attention. Her parents borrowed money from friends and relatives to be able to afford treatment for their child. Shortly after, the youngest sibling was born which further compounded the family's financial crisis.

The mass in Carmina's belly had grown to be as large as a basketball and made walking very difficult. The mass had to be shrunk in size even before surgery could be attempted. Several attempts were made to schedule an operation but all were cancelled due to varied reasons. Soon, the family could no longer afford all the expenses at the hospital. Carmina was discharged and she went home. By then the family was hopelessly in debt. As Carmina's condition worsened, in a desperate attempt to find a cure, a folk healer was consulted but there was no improvement. Carmina stopped schooling and stayed at home. Due to financial constraints, even the eldest child had to stop schooling to help look after the siblings.

Another lump on Carmina's back was later discovered and was observed to grow rapidly. Carmina complained of severe pain, and could no longer walk. She was confined once more and her chemotherapy was resumed. Christmas and New Year were spent in the hospital away from the family. Because of depleted financial resources, her scheduled operation was cancelled once more and Carmina went home. She later became even more irregular in her out-patient visits and eventually stopped coming for treatment.

Rose reported that they were never visited by family or friends anymore. Jose only visited in the evening every 2 to 3 days to bring money and food. If Rose needed something at home or missed the other children, she would go home and Jose would sleep at the hospital overnight. Rose would come back the next day and Jose would go off to work. During these visits, Jose and Rose would often end up fighting. Jose often boxed the walls and threw things in anger. The usual bone of contention was Jose's drinking and smoking and the need for additional money for a variety of needs.

The other children at home were left unattended most of the time and this was a common source of worry. Because of marital and financial difficulties that compounded the problems of caring for Carmina, Rose spoke of how she had thought on occasion that she wanted to leave her husband but never did for the sake of the children.

The tension definitely started to show in the marital relationship. Jose focused his attention on his Carmina so as not to have to deal with his marital problems. To avoid marital squabbles, the parents often spent time apart. Both parents focused their attention on their children to avoid having to discuss family matters. Rose complained that she found it difficult to be patient but she was the wife, and therefore, it was her duty to be patient, not to say anything, and accommodate her husband. She rarely spoke out her dislike over Jose's spoiling of Carmina. Afraid of embarrassing herself and her family, Rose kept things to herself. She felt that God was the only friend she had left. She often found herself crying all alone.

Carmina felt frightened and sad about the state of her parents' relationship. Her father forbade her to cry whenever she felt bad for herself or for the times she saw her parents fight. Although she was very charming and popular with the medical staff, Carmina was ashamed of her condition and she never showed her sorrow to anyone. She would only quietly cry by herself.

Carmina reacted to the situation by becoming whining and becoming demanding. She asked for a television and the parents gave in to her request despite their poverty because they claimed it gave them a sense of control over the situation.

Both parents explained how the future looked uncertain and how they were forced to live and make decisions only on a daily basis. They were helpless in their poverty and could not grasp the true nature of the disease and its implications. Even their understanding of the disease was inaccurate. Rose thought the tumor was in the uterus. Jose believed that the growth was in the stomach. Carmina just accepted that the growth was somewhere inside her belly. They did not seek information to understand the disease and its implications. It seemed that they had more important things to concern themselves with. How was the family to survive this ordeal?

Both parents wondered why God was punishing them. Carmina's illness was not the only problem that the family faced. The family poverty, Jose's poor health, heart condition, drinking, and overfatigue were all serious concerns as well. If anything happened to Jose, what would happen to the family? Who would provide for the needs of Carmina? It was difficult to identify which problem compounded which, which was more serious than which. Because of the family's complex problems, the marital relationship worsened but the parent-child relationships remained close. But even in their marital conflict, Carmina remained as the center of their parental concerns. Being the favorite child, they tried to do everything in their power to help her.

Case # 2: The Campos Family

Benedicto (13 years old) was the only son and the favorite child in a low-middle income family with five children. Symptoms were first noticed by a school teacher who reported that Benedicto looked very weak and sickly. His mother took Benedicto to see a doctor and when blood test results were not normal, he was advised to see a hematologist. Test results showed that Benedicto had leukemia.

The family sought a second opinion and Benedicto underwent another battery of tests at another hospital. The diagnosis confirmed that he had acute lymphositic leukemia. Both parents, Ruben and Tessa, were present when the doctor discussed their son's case. Both parents were unaware that Benedicto was outside the room within hearing range. Unknown to them, Benedicto heard everything that was being discussed.

Benedicto was immediately confined at a suite in the hospital. He was given blood transfusions and his first chemotherapy treatment was started. Benedicto's treatment was very expensive so Ruben took money out of his insurance to be able to afford all the expenses. For the next 4 years, Benedicto's condition would continually improve and then he would relapse. Each relapse was always worse than the previous one. Each time, the family thought that he was on the road to full recovery, only to be set back financially and emotionally by the relapses.

Adjustments had to be made. Both parents used to be income earners. But now, Tessa was forced to resign from work to be able to look after her son, even if this meant a large cut from the family earnings. The eldest child had to stop schooling. The financial impact of the medical needs was no worry to the family at first because Ruben had his insurance. But that soon ran out and left the family in deep debt. Ruben felt pressured to find ways to carry the family through the financial burden. Tessa felt frustrated that she could not contribute to the family earnings. The shift from working mother to housewife was difficult and frustrating.

Tessa and Ruben had serious marital problems because of Ruben's womanizing and drinking. These vices even became worse after the first relapse. Ruben chose to focus his affection on his favorite son, which effectively derailed attention from their marital concerns. Tessa felt helpless in her situation and felt that the best way she could deal with her problems was to give in to her husband all the time.

Things were becoming too difficult for Tessa that she even thought of ending her life to escape her problems. But when she thought of her children's future, she decided against it. It was around this time that a hospital nurse invited Tessa to join the Catholic Charismatic Movement to help her cope with her problems. As it proved to be helpful to Tessa, soon Ruben and the rest of the family joined the movement too. Ruben became a Born-Again Christian and he put an end to his vices. He even became pastor of his church. He stopped drinking and stopped seeing other women. He became more of a family-centered man and often preached about how God touched there lives with this trial.

Shortly after his spiritual renewal, Ruben was mugged and was so severely beaten up that the doctors only gave him a 50% chance of surviving. One week after Ruben had his accident, his mother fell ill and was taken to the hospital where she died a week later. During this time, Tessa had to shuttle back and forth between hospitals to settle wake and funeral arrangements and to look after the needs of her husband and son. Fortunately, Ruben was discharged after a few weeks. The family viewed this experience as a test of their renewed faith.

Ruben and Tessa described their crisis as a "spanking" from God, which was also a sign of God's love for them. They used the analogy of a parent spanking and scolding a child when he did something wrong because the parent loves the child and wants him to improve.

Both parents first saw their child's illness as a punishment from God. Ruben saw it as a punishment for his vices while Tessa saw it as a punishment for her greed. Later on, after their spiritual renewal, there was a perception shift. They believed that through Benedicto, they were taught that they should prioritize their children over work and over their selfish wants. Now, they saw Benedicto's condition as a blessing that brought their family closer together and a sign for them to be more family-oriented. Now that they had changed their ways, they could not understand why Benedicto's condition did not improve.

Benedicto was brought to many healing masses and pray-overs. Improvements in his condition were noted but they did not last very long. More potent drugs were administered but nothing seemed to help. In desperation, Ruben tried feeding his son boiled shark and other unconventional food since he had heard that they could help.

The family members' coping styles were different form each other. Benedicto seemed to accept his mortality and Tessa seemed to be nearing acceptance as well and began the process of letting go. Ruben felt that it was his role to carry on the hope and optimism for the family. His optimism, however, already seemed unrealistic as

Benedicto's condition took a drastic turn for the worse. Ruben still believed that the right cure only had to be found.

Benedicto asserted himself by demanding for his favorite food, rejecting his medicine, and asking for certain favors. The parents gave in to his requests because it gave them a sense of control over the situation. Tessa described that being able to give him what he wanted gave her a sense of satisfaction that at least there was something concrete that she could do for her son.

On his third relapse, Benedicto complained that he was tired already and began to refuse all medication and he asked to be brought home. His parents respected his request. Even if the doctors disagreed with them, they could not be convinced and Benedicto was discharged.

Benedicto felt ashamed of how he looked and he worried about his relationships with his peers. He felt guilty about the suffering the family had to go through just to take care of him. He understood the implications of his disease and was afraid. He prayed a lot and remained hopeful through the first two relapses. But Benedicto slowly started to lose his hope and his drive to live. He was very moody and irritable. He was very aware that his body was not responding to the medication and felt his body slowly breaking down. He understood what he heard the doctors discuss with his parents. He seemed to sense that he was losing the battle with cancer and he felt guilty and worried about how his family would survive. He said he felt very tired and didn't want to fight anymore.

Benedicto spent one last week at home with his family. He was described as having felt happy and seemed to have a relatively painless week. At the end of the week, however, Benedicto became very ill and he was rushed to the hospital. His condition rapidly deteriorated. Benedicto died in the hospital after battling his leukemia for years. His last words expressed that he was tired and he didn't want to try anymore. Looking back, the parents spoke of how Benedicto's ailment taught the family to work together and how the parents became more responsible. They did not understand fully the reasons that God had for taking away their favorite child and only boy but they were confident that they would reap their rewards in heaven when their turn came.

Case #3 : The Florentino Family

Rica, 4 years old, came from a low-middle income family and was the eldest and favorite among the two children of Mavic and Ted. Rica first developed fever for one week and began to limp. The pain became so severe that Rica could no longer walk and only crawled on the floor. On the suspicion that she had polio, Rica was brought from the province to a Quezon City hospital for a series of tests but the test results revealed nothing. A second opinion was sought at a different hospital. Tests results were positive for a tumor in Rica's left femur. The options given to the family were amputation, chemotherapy, or "willful neglect". After difficult deliberations, they decided on chemotherapy.

A battery of tests were undertaken to explore the extent of the disease. A biopsy was made and Rica was found to have Ewing's Sarcoma, with evidence of metastasis in her head. Rica was very much traumatized by all the medical procedures.

The parents first blamed themselves for Rica's illness and at one point even wondered why God was punishing them. It was during this time that Mavic and Ted sought spiritual strength and guidance from Couples for Christ, a Catholic Movement. After their spiritual renewal, there was a perception shift where now, things were viewed as "trials." All suffering was now an offering to the Lord as a living testimony of their faith and trust in God. Perhaps God was trying to tell them something. Every little development was seen as a miracle. Because of their faith, they felt that they could survive their crisis, no matter what the outcome.

Rica underwent her first chemotherapy treatment and was described as having been traumatized even more by the chemotherapy and its side effects. Ted and Mavic saw how Rica was getting physically and emotionally affected by the treatment and decided to discontinue with the chemotherapy. They decided to "submit Rica to the Lord" instead. Over the next 8 months, Rica's condition slowly improved. She gained weight, ate well, and everything about her seemed normal. Due to financial reasons, later that year, Ted left for Brunei to seek a higher paying job.

A month later, Rica developed on-and-off fever and began to limp again. More lumps were discovered on her head. Rica complained of body pains. Medical tests were taken and results showed that Rica developed primary tuberculosis and her cancer started to get worse. Mavic called Ted overseas at Brunei and discussed the developments. They decided to resume Rica's chemotherapy treatment immediately. Because of this new development, Rica developed a phobia for strangers, medical personnel, blood, and needles. She experienced more painful side effects and developed urinary tract infection.

During Rica's hospitalization, Both Mavic and Ted tried to be present during Rica's entire hospitalization. The only times Ted was unable to stay with them was when he was in Brunei. Whenever Ted was abroad, Mavic stayed with Rica in the hospital, together with a relative. Ina, the youngest child, stayed with the grandparents in Lipa, Batangas. This imbalance in attention and time spent was sometimes a source of guilt.

Both parents took turns playing with Rica or reading to her, depending on whose attention she demanded. Each time she felt pain spasms in her belly (which was periodic due to her urinary tract infection), she would scream to her father to massage her. Her cries and screams could be heard all the way to the end of the corridor. She wore disposable diapers instead of regular underwear and demanded that her father (when present) change her when necessary. Otherwise, only Mavic was permitted to change her. When around, Ted was always the person Rica demanded to attend to her.

Rica would scream and cry in fear everytime a nurse, doctor, or stranger entered her room. She called out to her parents to hold her hand because of the pain, even if the nurse or doctor was still standing at the door and was in no way near her at all. She had to be bribed with candy to take her vitamins.

Rica constantly needed to know if she was a "good girl." This may have stemmed from her developmental need of knowing right from wrong. Her phobia and her regressive clinging behavior were consistent with behavior expected of a child under stress at her age. She constantly feared being left alone. Other regressive behavior was exhibited in her preference for diapers and in her babytalk tone of voice as she aired her demands. The presence of her parents seemed to provide the needed comfort. When she experienced or anticipated pain, she sought to cling to her parents. She regressed to a stage where she could feel babied and pampered for the comfort and security she needed.

Rica became manipulative and would whine or "baby talk" or throw tantrums whenever she wanted something done or given to her. She would pretend to cry and begin a tantrum to get what she wanted, even if they were very simple requests such as changing the television channel or getting the book on the table.

The parents gave in to what she requested because they felt sorry for the child. Giving in to the child also gave them a sense of control over the situation. The parents were torn between disciplining the child and doing what the child wanted, even at the risk of spoiling her. In the end, both parents admitted to giving in to what she wanted and spoiling her. Rica always was Ted's favorite child and because of the situation, he focused even greater attention on the child.

Prior to the onset of Rica's illness, Ted described his relationship with Mavic as being close. Of course, like any normal married couple they had their share of fights but there never was a serious rift. After Rica became ill, which occurred at about the time they joined Couples for Christ as a married couple, their relationship improved, in spite of the crisis. Ted reported that their communication lines became even more effective. As a result, he felt that they are closer as a married couple now. Mavic shared the same views as her husband. She added that she felt they became even more mature and responsible. She said she found it amazing that in spite of the family crisis, or perhaps even because of it, they had grown closer.

Both parents also found it helpful that they understood the disease and its implications. Because of the knowledge they sought, they were able to accept that their child was not going to live a long, normal life and so they tried to help Rica live each day to the fullest. Rica, on the other hand, understood her hospitalization and the medicine only as necessary things to "melt the bumps" on her head and to take her limp away.

Anxiety-binding mechanisms that seemed to be in effect were Ted's focused attention on his favorite child and Mavic's usual agreeing with Ted's decisions. Ted and Mavic would discuss family issues but Ted always made the final decision which Mavic quietly accepted. Both parents seemed undisturbed by this arrangement which maintained the equilibrium in the family.

The family found great support in faith and assistance from friends and relatives. Ted, however, preferred to rely on himself and sought a higher paying job overseas that would allow him to bring his family with him. Both parents looked forward to offering their children new and exciting experiences abroad. Perhaps living in Brunei would provide them with special memories as a complete family while still possible.

Rica returned to the hospital every month for chemotherapy. This continued for several months until the time came that visas were granted for Rica and her entire family to live in Brunei with Ted. It was expected that her chemotherapy treatment would continue in Brunei.

Interesting Findings: Family Patterns

Looking at the data obtained, the following patterns were noted.

1. *Role and personality of the child.* All three children were found to be the favorite children of the fathers in their families. They were described as being *"mabait"* or kind, which in Filipino culture implies a quiet, affectionate, and sometimes even shy and introverted personality.
2. *Intrafamilial stressor.* A family stressor already existed at least 6 months prior to the diagnosis of the child's cancer. This preexisting stressor is what Carandang (1987) refers to as an intrafamilial stressor. The father of the Barrios family had a drinking problem. The father of the Campos family not only drank but also womanized. The father of the Florentino family was very often absent from the home because of work. The father's absence was as a stressor, although not as severe as the other two families in this study's sample.
3. *Marital stress.* Two out of the three families studied reported marital problems caused by the father. Only the Florentino family did not report marital difficulties, but they did identify that the father's absence put a strain on the family relationships.
4. *Family alliances.* Prior to the diagnosis of the child's illness, there already existed an alliance between the father and the child because the child was the

father's favorite. Both parents strengthened their alliances with the child upon the diagnosis of the disease. The child became the focus of both parents.

After the child was diagnosed as being ill, it seemed that there was a change in marital alliances. Benedicto's and Rica's parents reported improvements in their marital alliances. Carmina's parents, however, reported a further breakdown in their relationship due to a number of compounding problems.

5. *Cancer history.* All three families reported that they had no history of cancer in both sides of the family.
6. *Mothers as compromised spouses.* All three mothers acted as compromised spouses. Two wives were victims of emotional conflict. They gave in to the father and kept quiet about the situation. In their understanding, as the wife of the husband and the woman in the relationship, they were expected to keep quiet and to submit to their husbands. Two out of the three families chose not to do anything about the situation because of "*pakikisama*," or the Filipino value of smooth-interpersonal-relationship (SIR). One mother said she would rather suffer than create a scene that would be embarrassing. This is also reflective of the Filipino value of "*amor propio*" or the value of "saving face." To a certain extent, it would seem that the manner in which the wives dealt with their problems were dictated by cultural values.
7. *Overinvolved fathers.* The fathers seemed overinvolved with their favorite children who were demanding of their attention and time. Perhaps by focusing on their children, they were able to avoid having to deal with their marital tension.
8. *Attempts at maintaining equilibrium.* Certain anxiety-binding mechanisms were triggered in each family as it tried to regain and maintain lost stability.

Carmina's father avoided having to deal with his drinking and marital problems by blaming his wife for a number of deficiencies, real or unreal. By using emotional conflict, he succeeded in redirecting the attention away from his own faults to his wife. His wife on the other hand just took everything in and suffered in silence. This is how balance in the family was obtained. The father focused his affection on his favorite child more than on his wife.

In Benedicto's family, balance in the family emotional system was achieved with the mother's silence over her husband's drinking and womanizing. On occasion there would be a confrontation about the situation. The husband was fully aware that his wife knew of his vices. In the end, however, the wife would lose the argument because it would be directed at her and she would be blamed of certain deficiencies. She was made to feel that she was the cause for his drinking and infidelity. Being the authority in the family, the father would automatically "win" all the arguments. The father admittedly spoiled his only son and showed greater affection towards his son than his wife.

Rica's family differed from the others in the sense that the father's absence was the greatest marital strain that they experienced. However, although the parents always discussed things, the wife's behavior of giving in to what the husband said was manifested in the manner in which decisions were made. The father always had the final say in any decision. Whatever the husband would say, the wife quietly accepted. Discussions typically ran with the wife's presentation of options and the father's choosing from the options. The final decision was always his and the wife always honored his word.

Bearing all these points in mind, it will be recalled that family members respond to stressors not only on an individual basis but also as members of an interactive network. In times of stress, the family will struggle to maintain equilibrium and balance among relationships (Andolfi, 1979). The family emotional system reacts to keep a balance between the togetherness force and the individuality force by triggering certain anxiety-binding mechanisms. When this attempt to maintain balance becomes too exaggerated, this contributes to the type of symptom developed in the family system (Gurman & Kniskern, 1980; Kerr, 1980; Stachowiak, 1968).

All the three families reported that there was no family history of cancer. The children's personalities were described as being of the kinder and more introverted type. This was the personality type that research found to be vulnerable to the development of cancer (LeShan, 1990; Locke & Colligan, 1986).

The systemic view of terminal illness presented a theory of multiple causes of cancer (Cassel, 1965). This approach identified the balance of a biological predisposition to cancer, particular personality characteristics, and the balance of the emotional system of the togetherness and individuality forces as being influential to the development of cancer. The harmony of these elements within an individual is greatly tied to the balance of the person's significant relationships. When significant relationships of a person are disturbed, then he becomes highly vulnerable to the development of disturbances within the self (Kerr, 1981). Psychologists identified that the symptom could emerge as a physical, emotional, social, or behavioral problem (Gurman & Kniskern, 1980; Kerr, 1980).

An analysis of the patterns noted would lead one to question, could the child's cancer be a symptom of the imbalance in the family emotional system caused by marital conflict? Based on the findings of this research, a hypothesis on the child's development of cancer emerges. Considering the following key points : (a) the absence of a family history of cancer, (b) the preexisting stress involving the father, (c) the resultant marital stress, and (d) the terminal ill child as being the favorite child even prior to the diagnosis, an analysis of the relationship of these points can be made.

If the stress of the marital relationship became redirected and transformed into the father's overinvolvement with the child, it may be explained that the child may have absorbed all the stress through the father's seemingly exaggerated attention. Instead of emotional and behavioral acting out, because of the child's inherent personality characteristics, the stress took on a somatized form instead. Could the child's cancer be a somatized form of the imbalance in the family emotional system? As the favorite child, was the child in a position that made him/her highly vulnerable to the stress?

It must be emphasized that the data gathered in this research are exploratory and the analysis and questions presented here are only tentative and can be considered as hypotheses to be tested by further research. This researcher is cognizant of the limitations imposed by the size of the sample surveyed. Results do, however, suggest exciting possibilities in further research on cancer and the family emotional system.

A number of observations seem to be related to the parents' ability to cope with the situation. These are results of descriptive exploration and are not conclusions in themselves. These serve as hypotheses-generating statements that can be explored in further research.

It seemed that parents of higher educational levels seemed to have a greater ability to cope. It was observed that more educated parents sought information that would help them understand the illness and its implications. The more the individual understood the disease, the more he seemed to be able to cope. Perhaps this greater understanding of the situation helped the parents feel less anxious because certain events seemed less unpredictable.

Parents from a higher socioeconomic level seemed to have a greater ability to cope. It was observed that the higher the family's socioeconomic level, the better the quality of service, hospitalization, facilities, and medical requirements that could be availed of. Incurred debts were lower compared to lower socioeconomic level families. This may account for less stress and, therefore, less problems to deal and cope with.

Couples with more similar coping styles and free communication styles seemed to have a greater ability to cope. Families that communicated openly about the illness seemed to cope better. In situations such as this, grief could be shared and the couples could derive mutual support from each other.

Coping seemed easier when the family support system was more extensive. Those who felt they only had God left to turn to clearly had a more difficult time dealing with their stress. Those who could rely on friends and family reported higher levels of being able to cope with the situation.

Summary

From the moment that each family found out that their child was afflicted with a disease that was life-threatening, an intense emotional drama unfolded. Whether on a conscious level or not, the real meaning of cancer was the threat of pain, death, physical mutilation, permanent disfigurement, feelings of helplessness and hopelessness, disruption of personal relationships, and economic disaster.

The presence of the terminally ill child meant the following to the family: pain, shock, grief, frustration, confusion, guilt, a need to seek help and solve problems, reliance on religion, role reassignments, general improvements in parent-child and marital relationships, and financial burden. The children themselves exhibited a need for acceptance and security. Stress and coping experiences were greatly influenced by the person's stages of development on cognitive, emotional, and physical levels.

The initial reaction of the parents was shock and disbelief. As the reality set in, the parents immediately sought assistance from family, friends, and professionals to do what they could to help their child. As finances and moral support from family and friends diminished, faith served as a reservoir for hope and strength. Coping came in the form of reliance on religion, problem-solving, help-seeking, information-seeking, and for the few, optimism and acceptance. Role adjustments were made, family budgets were tightened, routines were revised. Strength and survival was rooted in God, family, and friends.

The families immediately undertook the necessary instrumental tasks of medical assessment of needs and appropriate intervention and treatment. They took their chances with chemotherapy. Parents found themselves away from home for long periods during hospitalizations. While the mothers stayed with the child, the fathers were out, working and finding ways to help their child. The other siblings were left to themselves during these times.

The families found themselves in a situation they were absolutely unprepared for. As each member individually reeled under this overpowering stress, other members suffered from their own stresses as well as reactionary stress. They had to face their own reactions to the child's illness. They had to deal with the reactions of other members as well. With the doctors, friends, and family, the shared goal was to assure that the child would conquer the disease and live a normal happy life. Their only choices were amputation (if possible), willful neglect, or an attempt to add 6 years of life (or more) with chemotherapy. If lucky, remission was possible. However, there always was the awareness that the child's survival could not be guaranteed no matter what measures would be taken. This awareness of the child's possible, or perhaps even probable, death was a reality that was difficult to face.

The more difficult task of the family, however, was more on an emotional level. Parents wondered if this ordeal was a punishment from God. Why them? Why their family? Why their child? Intense helplessness and worry for the child and the need to let go constantly battled with the feelings of wanting to hold on to the child and the hope that the crisis would soon be over. Guilt from perceived imbalances in attention given to family members arose. Feelings of frustration and helplessness in their failure to ease the child's burden were prominent. The burden of being a breadwinner for the fathers was never heavier. Mothers grieved their failure as caretakers to save their child from all his suffering.

Spiritual renewal served as turning points for errant fathers who saw their child's illness as a sign for them to repent and focus on their family life. But even as they mended their ways, their children's health continued to deteriorate.

As for the children, there were differences in levels of understanding the stress but the experiences were basically of the same nature. Much of the stress was on a physical level. Physical pain and discomfort, changes in appearance, chemotherapy side effects, fatigue, physical limitations—these only fired frustration, anxiety, anger, fear, and worry for the child. Their emotional concerns mostly stemmed from experiences related to their physical state. The experiences with the medical procedures traumatized the children.

Stresses experienced by the children from the time of diagnosis included physical and emotional concerns. On a physical level, the pain of the disease, the medical procedures and tests and the chemotherapy side effects were very traumatic for the children. Limitations on their physical activity were frustrating. Physical appearance changes were embarrassing. Emotional concerns involved fear and/or dislike of medical personnel, depression, loneliness, self-pity, and anxiety. They missed being with family and friends. The change in the family lifestyle, the changes in their physical appearance, and the changes in the way family and friends treated them served as additional stressors. They seemed to have a pronounced need to feel secure in their world which had suddenly turned unpredictable. They seemed to need to be affirmed if they were still accepted by others. There seemed to be a heightened need for acceptance and security.

The children exhibited regressive behavior in the way they talked, or in the way they behaved. A certain level of manipulativeness was observed in their demands for particular things. They made demands for particular food, toys, a television, or other material things. This manipulativeness and regressive behavior served as ways in which they could cope with their situation. The granting of the attention they demanded gave them a sense of acceptance and security.

With all attention focused on the child, parent-child relationships were reported as having improved or remained unchanged. Relationships that were reported as having remained unchanged were those that were already close prior to the child's diagnosis. For the majority of the parents, working together in shared concern for the child was reported as an improvement in their marital relations.

The poverty of the lower income families aggravated the family situation. They could not afford all the best facilities and services for their child. Sending the children to school, having many mouths to feed, domestic bills, day-to-day expenses—these were ends that the family constantly worked on to meet. Now that the care for their child involved thousands of pesos way beyond their means, the family was thrown deep into debt, even as the battle was far from being won. The parents wondered how they would possibly stand up and rise again from this ordeal.

The family system in crisis from a child's threatened life suffers from a complex myriad of stresses and reactions to this stress. The atmosphere is generally of grief, worry, anxiety, guilt, frustration and helplessness. Perhaps it is this shared experience of pain, grief, and courage that draws the family to stick together even more closely than ever before.

The need for togetherness kept the family balanced. Now, more than ever, the family had to stick together and support each other. Although relationships managed to remain intact, many other aspects of family life were thrown into chaos. Circumstances were unpredictable and were controllable only to a certain extent. This created an atmosphere of powerlessness and dependence on God and hope. In the end, the family had to cope with much more than medical bills.

The family dynamics described in this study are testaments of an admirable display of heroism — in the children who struggled to fight for their lives, in the parents who did anything in their power to help their child, in each family member who struggled to keep the family together. All stops were pulled to give the child a future, even if a future was not assured. These families showed what living in faith and hope is all about. In the darkness and chaos of their lives, hope still springs eternal.

Implications for Psychologists

There is a growing awareness and acceptance that in situations when families are under stress, the referred client may not be the only victim. In instances such as cancer afflicting a child in the family, parents and siblings become second victims as well. Bearing in mind the unique characteristics of the Filipino family, extended family members may perhaps be hidden victims as well. If indeed there is a relation between individual and familial psychological factors to one's vulnerability to (and possibly even the causation of) cancer, then, the best intervention package should address these psychological factors as well.

The significance of this study lies in the deeper understanding of family experiences under a crisis. The findings of this study provide many possible avenues for understanding cancer, for therapy and counseling with cancer-stricken children and their family members. This study supports family theories in the belief that the stress experienced by one is experienced by all. Perhaps any assistance or intervention that helps one member will also positively affect the others as well. Studies for needs assessment and the development of multi-disciplinary intervention packages involving physicians, psychologists, therapists, and the religious could provide more efficient, holistic, and helpful strategies in helping families of terminally ill children survive their agonizing experience from diagnosis to after-death.

Further research that would lead to the designing and implementation of multidisciplinary family intervention programs are strongly encouraged. Further research that would lead into the development of appropriate and effective training for people in the helping profession are just as strongly encouraged.

(NOTE: Carmina passed away due to hemmorhaging during an attempt to surgically remove her tumor. Rica passed away because of complications brought about by her illness. Both children passed away in 1994. All names have been changed to protect the privacy of the children and their families.)

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