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# The Grief Experience of Caregivers When the Child Has a Life Threatening Illness

Avigail Ward

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School of Science and Technology  
in conjunction with the  
Faculty of Graduate Studies

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The Grief Experience of Caregivers  
When the Child Has a Life Threatening Illness

by

Avigail Ward

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A Dissertation submitted in partial satisfaction of  
the requirements for the degree of  
Doctor of Philosophy in Marriage and Family Therapy

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September 2011

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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## ABSTRACT OF THE DISSERTATION

The Grief Experience of Caregivers  
When the Child Has a Life Threatening Illness

by

Avigail Ward

Doctor of Philosophy, Graduate Program in Marriage and Family Therapy  
Loma Linda University, September 2011  
Dr. Barbara C. Hernandez, Chairperson

Using a mixed method approach, this study explored the impact of attachment styles on the grief experience of parents and guardians of a child who has a hematological or oncological illness. The grief experience was evaluated through the lenses of Chronic Sorrow, Ambiguous Loss and Anticipatory Grief. This study was conducted at the Loma Linda University Medical Center Hematology Oncology Pediatric Clinic and was completed by 106 participants who responded to a quantitative survey with open-ended questions. An open-ended questionnaire regarding the impact of the child's illness on the couple relationship was completed by six couples. The results indicated that experienced grief is significantly lower for parents or guardians with a Secure attachment style. The degree of grief experienced by parents could be predicted by whether or not the child was currently receiving treatment, whether the child was considered cured and the time elapsed since the diagnosis was given. Healthy and unhealthy coping skills were identified within the couple relationships, which provided richness to the understanding of the experience of parents and guardians with a child who has a life threatening illness.

## INTRODUCTION

Survival rate for childhood cancer currently exceeds 70% (Mitchell, Clarke & Sloper, 2005), but the process of the treatment and dealing with such a crisis is recognized as a traumatic experience both for the patient and their family. Part of the difficulty involves the adjustment to continuous uncertainty, the potential for losing the child and the looming possibility of reappearance of the disease, to name just a few of the concerns families face.

The core emotional issue that families both on the individual and systemic level deal with, when a child is suffering with cancer, is loss. The world as the family once knew it is no longer the same safe or secure place (Woodgate, 2006). According to McDaniel, Hepworth and Doherty (1992) loss does not only occur in the situations of a child passing, or the strong potential of the loss of a child looming, but also at the time a child is diagnosed with a potentially life threatening illness. Primary caregivers suffer the loss of the normal healthy child they thought they had. They grieve the image, dreams, hopes and plans they once had for their child. They mourn the loss of who they thought their child would grow up to be. The caregivers deal with the loss of innocence, which is the loss of their belief, “nothing will happen to my child”.

The proposed study will examine the experience of grief that primary caregivers go through when their child is diagnosed with a hematological or oncological disorder. The goal is to examine specifically the manifestation of loss that are experienced while the child is alive and may or may not have a terminal prognosis.

This unique grief experience, which is referred to in the literature by a variety of names such as *chronic sorrow* (Olshansky, 1962), and *anticipatory grief* (Parkes &

Weiss, 1983), is examined from the lens of *Ambiguous Loss* (Boss, 1999). While other terminology describes aspects of the loss, the term Ambiguous Loss seems to be far more encompassing, like an umbrella concept that adds depth and richness that other theories and concepts tend to omit.

The uniqueness of this research is that it uses Ambiguous Loss theory to describe the experience of primary caregivers when their child is diagnosed with a hematological or oncological illness. While Ambiguous Loss has been used to describe the experience of chronic illness (Couden & Boss, 2002) this study extends the theory further in specifying how the family subsystems, specifically the primary caregivers with a child who has a potential life threatening illness is impacted by Ambiguous Loss.

Another unique feature of the study is the examination of Ambiguous Loss through the lens of attachment theory. In particular it is hypothesized that each caregiver's attachment style will impact their grief experience. This idea offers a new dimension in understanding people experiencing Ambiguous Loss in the context of the attachment style they experience.

The dissertation contributes to the scholarly literature as it looks to fill a gap in which there is minimal research pertaining to the loss and grief experienced by primary caregivers of living children who have been diagnosed with some of the most common hematological and oncological illnesses, further examining the experience described from an attachment style perspective.

The research question therefore is: Does attachment style impact the experience of Ambiguous Loss in primary caregivers of children with potentially terminal hematological and oncological diagnoses?



## **CHAPTER ONE**

### **LITERATURE REVIEW**

The study proposed will examine whether attachment styles impact the experience of Ambiguous Loss in primary caregivers of children with hematological and oncological diagnoses. The first chapter of the literature review is divided into four main sections: (1) A Description of hematological and oncological illnesses, such diagnoses as leukemia, brain tumors and others. This is followed by (2) a discussion of the current mental health treatment provided in the hospital settings (3) a discussion of the impact terminal illness has on the family system, specifically the parental dyad (4) terminal illness and grief, which includes the different types of grief associated with a child's illness and (5) a discussion of attachment, which includes the topic of Attachment Style and grief and Attachment Styles and illness.

#### **Hematological and Oncological Illnesses**

Hematology refers to internal medicine that is concerned with blood disease, while oncology refers to the branch of medicine that focuses on cancer. A large number of the illnesses that fall under the category of hematology and oncology are terminal.

In the following section, pediatric hematological and oncological illnesses are discussed. A descriptive overview of illnesses included in the study will be provided by Hay, Levin, Sondheimer and Deterding (2009), with some additional references. A short description of the illness, its prevalence, symptoms, treatment and prognosis are given.

### *Acute Lymphoblastic Leukemia (ALL)*

The most common malignancy seen in childhood is ALL. It comprises approximately 25% of all cancer diagnoses in patients 15 years or younger. In the United States, roughly 3000 children are diagnosed each year (Acute Lymphocytic Leukemia, 2009). The majority (85%) of patients are diagnosed between the ages of 2 and 10. The cause for ALL is still unknown, however genetic factors are thought to play a role in the etiology of the disease.

Presenting symptoms include decreased bone marrow production of platelets, red and white blood cells, fevers, fatigue, pale skin, bruising and bone pain (Acute Lymphocytic Leukemia, 2009). Treatment of ALL is lengthy and complex. The first month of therapy is called *Induction*, which includes the use of oral chemotherapy. With this treatment over 95% of patients go into remission. The second phase includes several months of chemotherapy and radiation. Maintenance therapy follows, which includes daily, weekly and monthly medication administration. The length of treatment varies between 2.2 years on average for girls and 3.2 years on average for boys.

The prognosis for ALL is an 85% survival rate for children aged 1-9 years. Infants age 6 months or younger have a lower chance of cure with conventional chemotherapy alone. It is important to note that according to Reismuller, et al., (2008) approximately 20% of all children with ALL suffer with some form of recurrent disease. The prognosis for relapsed ALL is substantially worse with a 30-35% long term survival rate (Einsiedel, et al., 2005)

### ***Acute Myeloid Leukemia (AML)***

Each year there are 500 new cases of AML diagnosed in children and adolescents in the US (Hay, et al., 2009). While AML accounts for only 25% of all types of leukemia, it is responsible for a third of deaths from leukemia in children and teenagers. The majority of patients have no particular risk factors.

Symptoms of AML usually include low hemoglobin and platelet levels that are discovered through routine blood tests. AML is less responsive to treatment compared to ALL and requires more aggressive chemotherapy treatment. For AML, due to the high doses, toxicities from chemotherapy are common and are often life-threatening. After remission is gained patients with a matched sibling donor may receive transplantation of blood stem cells (Cheung, Chow, Liang & Leung, 2008), and those without a suitable related donor are treated with extra rounds of aggressive chemotherapy for approximately 6-9 months.

The prognosis of AML is currently at 75-85% for complete remission rate. Long term survival, however, is at approximately 50%. For patients who do not have siblings who are a match for hematopoietic stem cells, there is a 50-60% survival rate at the five year mark from the first remission. According to Ravandi, Burnett, Agura, and Kantarjian (2007), this particular type of Leukemia tends to relapse, and in such cases only 30-40% of the patients experience long term remission.

### ***Brain Tumors***

In the United States, between 1500-2000 brain tumors are diagnosed in children each year, which account for 25-30% of all childhood cancer (Hutchinson, Willard,

Hardy & Bonner, 2009). It is interesting to note that children have a better prognosis compared to adults with brain tumors. Headache and vomiting is observed in less than 30% of children with brain tumors. In young children irritability, failure to thrive and delayed cognitive development are common. In older children, noticeable school difficulties as well as personality changes are common.

At this time the cause of childhood brain tumors are unknown. Some childhood brain tumors seem to happen in families with higher genetic vulnerability. The objective of treatment is to get rid of the tumor with minimal complications. Careful surgical removal of as much tumor as possible is the preferred initial approach (Hutchinson, et al., 2009). Systemic chemotherapy and radiation are used as well.

The prognosis for children who received radiation and chemotherapy is a 45% survival rate. For children whose tumors return, high doses of chemotherapy are used. For patients receiving partial or subtotal resection, the survival rate is between 29 and 32%. The 5 - 10 year survival rate is 60-90%. Prognosis in all cases depends on both location and the original size of the tumor.

### ***Lymphomas and Lymphoproliferative Disorders***

Lymphoma refers to a malignant production of lymphoid cells, which are part of the immune system and that help the body defend against infections through the production of antibodies. Lymphoma is a common childhood cancer diagnosis and accounts for roughly 10-15% of all malignancies. Approximately 50% of all lymphomas are Hodgkin disease. The other subtypes are referred to as non-Hodgkin lymphoma (Non Hodgkin Lymphoma, 2009). Lymphoproliferative disorders occur due to a buildup of

lymphocytes that take place when the immune system does not control viral transformed lymphocytes. Lymphoproliferative disorders are considered to be rare and most are nonmalignant. However they are often life threatening.

### **Hodgkin Disease**

This disease represents approximately 4-5% of all cancers in children under the age of 15 and about 16% of cancers in adolescents. In teenagers ages 15 and up, Hodgkin Disease is the most common malignancy (Bleyer, O'Leary, Barr and Ries, 2006). Compared to adults, children with Hodgkin disease tend to respond better to treatment. At 20 years past diagnosis, they have a 75% overall survival rate. Of the cases of Hodgkin disease, 85% of people diagnosed are above the age of 16.

The presenting complaints for children with Hodgkin disease are often firm lymph nodes, fever, weight loss and night sweats. For diagnosis, a thorough examination of all nodal sites is required as Hodgkin disease in the majority of cases, starts in lymph nodes and spreads to neighboring nodal groups. A systemic search for the manifestation of the disease in other parts of the body often includes chest x-rays, a CT scan of the chest, abdomen and pelvis, as well as a bone marrow biopsy.

This disease is typically treated with chemotherapy alone in order to promote long term survival. Compared with protocols for leukemia, treatment time is reasonably shorter (less than two years). About two thirds of all relapses take place within two years of diagnosis and few relapses take place beyond the four year mark. There is a potential risk of developing leukemias and tumors, however this seems to be associated with treatment by radiation therapy.

## **Non-Hodgkin Lymphoma (NHL)**

NHLs are a different group of cancers accounting for 5-10% of malignancies in children under the age of 15. Approximately 500 new cases are seen each year in the United States. This type disease is the fourth most common malignancy diagnosed in adolescents in the United States (Hockberg, Waxman, Kelly, Morris, Cairo, 2008). The occurrence of NHLs goes up with age. During adolescence, males are more affected than females (Bleyer, et al., 2006). The NHL tumors are aggressive in nature, however they are responsive to treatment.

Symptoms of childhood NHLs can be seen in any location of lymphoid tissue which includes the lymph nodes, thymus, liver and spleen. Initially, a comprehensive physical examination, blood test, and liver function are required in order to diagnose NHLs. Chest radiography, CT scan, abdominal ultrasounds and bone marrow examination are performed as needed for differential diagnosis.

When treatment is considered, patients whose tumor impinges on their airway need immediate treatment. Systemic chemotherapy is the standard practice for NHLs. Use of steroids and radiation therapy usually takes place within 12 to 24 hours from time of diagnosis (Non Hodgkin Lymphoma, 2009). The length of treatment is approximately two years and involves a weekly regimen of chemotherapy treatment. Surgery is not recommended, unless the whole tumor can be removed in a successful manner. A significant factor related to the prognosis of the disease is the level of the disease at the time of initial diagnosis. It is expected that 90% of patients with an extractable tumor can expect long term survival.

### ***Neuroblastoma***

Among pediatric malignancies, 7-10% are diagnosed as neuroblastoma. This type of cancer is frequently diagnosed in preschool aged children (Paolo Tonini, 2009). Fifty percent of neuroblastomas are diagnosed before the age of two, and 90% are diagnosed before the age of five. The presenting symptoms in most children include fever, weight loss, irritability, and bone pain. Neuroblastoma is diagnosed through X-rays of the tumor as well as Computed Tomography (CT) scanning and Magnetic Resonance Imaging (MRI).

The treatment of choice is usually surgical removal (Paolo Tonini, 2009), followed by radiation and chemotherapy. Approximately 80% of patients reach either complete or partial remission, except in cases when first diagnosis occurred at a stage of advanced disease in which the overall survival rate is less than 15%.

### ***Wilms' Tumor (Nephroblastoma)***

In the United States roughly 460 new cases of Wilms tumor are diagnosed each year in children between the ages of two to five years. This represents 5-6% of total cancers in children under the age of 15. This is the second most common abdominal tumor in children (after neuroblastoma) and is associated with a genetic predisposition for the disease (Ohata, et al., 2009).

The symptoms for Wilms' tumor include an increased size of the abdomen. Diagnosis is performed through the use of ultrasonography or CT scan of the abdomen. The liver is imaged to check for the presence of metastatic disease as well.

The treatment protocol for Wilms tumor begins with surgical exploration (Gratiassi & Dome, 2008) of the abdomen to inspect the liver and lymph nodes. Any suspicious areas are biopsied or removed. Chemotherapy is usually started five days after surgery. The overall cure rate of Wilms tumors is approximately 90%. Patients with a recurrence have a cure rate of roughly 50% with surgery, radiation therapy and chemotherapy.

### *Osteosarcoma*

Osteosarcoma is a type of bone tumor that is the sixth most common malignancy in childhood, and third among adolescents (Kansara, et al., 2009). The high occurrence during adolescence is attributed to the bone proliferation that occurs during their “growth spurts”. Patients usually have symptoms for several months before diagnosis, which commonly includes pain in the involved area.

X-rays and MRI are used to define the location of the primary tumor. Lung and bone are the most common sites of metastases. Therefore a CT scan of the chest and bone are essential. In addition, a biopsy is required in order verify the diagnosis.

Radiation is not effective for Osteosarcoma since these lesions are radio resistant. Prior to surgery, chemotherapy is administered. In extreme cases, amputation and limb salvage are used to achieve local control. Chemotherapy is usually continued for approximately one year after surgery.

Chemotherapy has resulted in substantially improved survival rates (55-85%) between in patients followed for 3-10 years (Arndt et al., 2007; Stiller, Craft, & Corazziari, 2006). Past the three year mark, relapses are rare. Patients with localized



Osteosarcoma have a 70-85% long term survival rate if they did not have metastatic disease at time of diagnosis.

### ***Retinoblastoma***

Retinoblastoma is a hereditary cancer. While present at birth, retinoblastoma is usually not diagnosed until it has grown to a substantial size. Parents often notice an unusual look of the eye or symmetry of the eyes in a photograph. To diagnose retinoblastoma a detailed ophthalmologic examination, under general anesthesia, is needed and a CT scan is used to detect the tumor.

Between 200 and 300 new cases of Retinoblastoma are diagnosed each year in the United States. Retinoblastoma is diagnosed in 3% of malignant disease in children 15 years and younger and is diagnosed most often by the age of five (Canty, 2009) causing 5% of childhood blindness.

Each eye is treated as an attempt to preserve vision. The choice of therapy depends on the size, location and number of lesions. Patients with metastatic disease receive chemotherapy. Patients with retinoblastoma limited to the retina, have an excellent prognosis of a 90% survival rate past five years (Melamud, Palekar & Singh, 2006).

### ***Congenital Hemolytic Anemias: Hemoglobinopathies***

The hemoglobinopathies, are diseases that involve defects that occur to a fetus, which could be due to genetic abnormalities, the uterus environment or chromosomal abnormalities. Such disorders are seen among several ethnic groups. The high occurrence

of these genetic variants seems to be correlated with malaria protection. The hemoglobinopathies are separated into two major groups which include the thalassemias and Sickle Cell disease.

### **$\alpha$ -Thalassemia**

The majority of the  $\alpha$ -thalassemia syndromes, are the result of reduction of one or more of the  $\alpha$ -globin genes on the 16<sup>th</sup> chromosome (Harteveld, Losekoot, Fodde, Giodano & Bernini, 1997). Generally there are no signs or symptoms for this disorder. Among different ethnic groups, there is a variance in regards to the severity of the illness. In the African population individuals are silent carriers. In Asians the most common  $\alpha$ -thalassemia type is seen (Fucharoes, Fucharoes, Wanhakit & Srithong, 1995). Individuals in this population either have traits of the illness or are silent carriers.

People with  $\alpha$ -thalassemia trait receive no treatment. Those with hemoglobin H disease usually receive supplemental folic acid. Times of infection may exacerbate the anemia. In such an occurrence a blood transfusions may be required.

### **$\beta$ -Thalassemia**

$\beta$ -Thalassemia is a hereditary disorder (Orkin & Nathan, 1998), in which only two  $\beta$ -globin genes are present. In diagnosis there are two types of  $\beta$ -thalassemia: major and minor.  $\beta$ -thalassemia major (Cooley anemia) is a severe transfusion-dependent anemia, which is more severe than thalassemia minor, but is not transfusion-dependent.  $\beta$ -thalassemia major is the most common cause of transfusion dependent anemia in childhood.

People with  $\beta$ -Thalassemia minor are for the most part asymptomatic. The main concern with  $\beta$ -thalassemia minor is the unnecessary use of iron therapy. Those with  $\beta$ -thalassemia major appear to be normal at birth yet develop significant anemia in their first year of life. If the disorder is not diagnosed or treated with blood transfusions, children with the disorder grow poorly and have thinning of the bony cortex. The skeletal changes are the cause for facial deformities and potential recurring fractures. Without treatment, most children die in their first 10 years of life.

In regards to treatment,  $\beta$ -thalassemia minor requires no specific therapy. For those with  $\beta$ -thalassemia major, two treatments are available; chronic transfusions (Smolkin, et al., 2008), and stem cell transplantation. Bone marrow or umbilical cord blood transplantation is another therapeutic option for children with such a disease. When transplantation takes place, a 90% probability of cure is expected.

### **Sickle Cell Disease**

High occurrence of sickle hemoglobin is identified in people of central African descent. Other ethnic groups that occurrence has been observed is Italy, Greece, Turkey, Saudi Arabia, and India. Sickle cell anemia is the most common type of sickle cell disease. The prevalence of Sickle cell disease is 1 in 400 infant African Americans, which translates to 250,000 children who are affected each year (Weatherall & clegg, 2001).

Neonatal screening identifies most infants that are born with sickle disease in the United States. Symptoms of sickle cell disease are usually not manifested before the age of three or four. During childhood and adolescence exhaustion, acute and unpredictable

pain (Barakat, Patterson, Daniel & Dampier, 2008) and jaundice, as well as predisposition to the growth of gallstones are of great concern. At these ages, there is a great risk for systemic infection. Strokes take place in approximately 8% of children and tend to be recurrent. Fever and chest pain is another symptom seen often. By adulthood, multiple organ dysfunctions are common. In order to diagnose sickle cell disease, extensive blood work is done to confirm such diagnosis.

The typical treatment, for sickle cell disease is enrollment in a program that involves education of patients and their families, and complete outpatient care, as well as treatment of severe complications as needed. The success of such programs is determined by the blood bank services provided and psychosocial support. Routine immunizations such as vaccination against influenza are recommended. Fever higher than 38.5C requires immediate evaluation. Transfusions are used to avoid symptoms of anemia.

The cure for sickle cell disease is stem cell transplantation. However, such treatment is limited due to the risks associated with such a procedure. Mortality has been reduced through the early screening of infants with sickle cell. As of today, the majority of patients live well into adulthood, at some point deal with complications that may include damage to the majority of organ systems. In addition, patients who need many transfusions are considered to be at risk of having transfusion-related issues.

### **Germ Cell Tumor**

Germ Cell Tumors are both malignant and non malignant tumors composed mainly from germ cells. These are cells that are developed in an unborn child and are the

cells that develop into one's reproductive system in both males and in females. The cells go through the body and land in the pelvis areas as ovarian or as testicular cells.

Tumors that are located outside of the gonad are called extragonadal sites. They can be found in the head, chest, stomach and lower back area. Germ Cell Tumors can also spread throughout the body and are often seen in the lungs, liver, lymph nodes and the central nervous system. Germ cells tumors are seen in approximately 3% of all childhood cancers.

Diagnosis and treatment of hematological and oncological diseases is often a traumatic experience for both patients and their families. There is often difficulty in learning to live with the uncertainty and fear of recurrence of the disease (McGrath, 2001). Therefore we will examine next the resources medical facilities provide, that addresses the emotional toll on the patient and family members.

### ***Standard Mental Health Treatment in Hospital Settings***

It was suggested by Kinrade, Jackson and Tomnay (2009) that families have basic needs that must be met in order for them to cope better with the hospital stay of a child. Many hospitals offer spiritual services, temporary living arrangements close to the hospital, referrals to various support groups and other services (Hebert, Copeland, Schulz, Amato & Arnold, 2008). Doctors, nurses, social workers, Child Life Specialists and other hospital staff, are hard at work trying to fulfill the needs presented by patients and their families (Mitchell, Clarke & Sloper, 2005). In examining the mental health support offered in hospital settings, McGrath (2001) recommended a psychosocial support approach as an established part of practice, when dealing with childhood cancer.

Patients and their families reported satisfaction during time of treatment in the areas of medical information provided, as well as support from the nurses and social workers.

### **The Role of Hospital Staff**

Psychological and social work services have a key role to play in conjunction with nursing and medical staff to address the needs of family members of ill children. Of parents of children at all ages and stages of the illness, the majority seem satisfied with support given by hospital staff, specifically by social workers and nurses (Herbert et al., 2008). Children and adults further reported appreciation for the fact that hospital staff carves out time to talk to them as well as listened to their needs and experiences. Patients take advantage of the social worker services provided at the hospital and report feeling heard.

### **Child Life Services**

Part of the support offered by St. Jude Children's Hospital (2007) as well as other hospitals across the country, is provided by Child Life specialists. This service is geared toward minimizing the stress associated with a lengthy hospital stay. Child Life Specialists assist the patients through play, learning, education and other activities as a way for the child to express his or her experiences in the hospital, their fears and concerns. Education is provided as a tool for the patient and the family to learn more about the illness and be as informed as possible.

## **Support Groups**

Cancer support groups are offered across the nation at various locations both in and outside the hospital setting. According to Mitchell and colleagues (2005), less than a fifth of patients and families attend an organized support group. However, among the participants who attend a group, the majority reported that they were pleased with the support offered.

## **Counseling for Parents, Siblings and Grandparents**

Mitchell and colleagues (2005), reported that mental health support emerged as an area of poor satisfaction and greater need in their sample of parents. Furthermore, 44% reported a need for couples counseling, specifically parents of older children. Support services for siblings or grandparents were identified as low. It was reported by 48% of the participants that there was a great need for information to be provided to grandparents regarding the child's illness and treatment. Parents of teenagers between the ages of 12 and 18 requested age appropriate information regarding cancer and the treatment. Overall, the need for greater emotional support through the difficult experience of the child's illness was expressed.

## **Illness and the Impact on the Family System**

The following section will focus on the impact that illness and loss has on the family system. Specifically this section will examine the grief that is experienced by family members, with the focus placed on the role of parents as the protectors of their children. In addition the gender roles that manifest through the grief experience, and the

impact on the couple's relationship when their child is suffering from a potentially life threatening illness, will be discussed.

### *Grief in the Family System*

In examining the family system when dealing with life threatening illness, normal stages of grief, such as guilt, anger and denial are seen (McDaniel et al., 1992). Different members of the family suffer loss and may be processing it in different ways and may be experiencing loss at different stages and at different times. This too can impact family dynamics and can add to potential friction. It is common for one person in the family to accept the illness, while the others may view such an adjustment as a form of betrayal. While the focus of the study is on Ambiguous Loss, which will be elaborated on shortly, the focus of this section is on the impact of the death of the child, on the family and the parental dyad.

According to Smeding (1996) losing a child is a life shattering occurrence for the family. The death of a child goes against the law of nature whereby the parents are supposed to protect their child (Rando, 1985). Rosenblatt (2000), examined grief among couples, and stated that grief manifested within the family system context. Such manifestation was seen during the early stages of bereavement, the parents are not completely available to their other children when such manifestation was seen. Their attention is focused on the death that occurred and the grief they are experiencing. When a child dies, a large portion of the parents' energy seems to die with the child (Rubing & Malkinson, 2001).



The parents seem to lack the energy and motivation to provide normal attentiveness and availability to the surviving children. In his study, Rosenblatt (2000) discovered that after the death of a child, parents engaged in overprotection of their other children. Such overprotection seemed to be due to the parents learning how vulnerable children are (Powell, 1995).

Looking at the overprotection parents exhibited, from a family systems lens, the dynamics of parental protectiveness included the child agreement in the process. In other words, it was not only the parents who were doing something to their children, but the children were allowing it to be done. The children went along with it, and at times supported and encourage it (Rosenblatt, 2000).

In regards to grief expression, parents seemed to limit the child's exposure to the parental grief. While parents did not hide their grief completely, the expression of intense grief was done when the children were not around (Rosenblatt, 2000).

Surviving children tended to have developed an understanding that death is a reality. They often feared that they or their parents could die. Some parents were aware of this and tried to reassure their children. The feeling of vulnerability led children to act in ways in which they protected themselves both emotionally and physically (Rosenblatt, 2000).

### **Parents and their Role as Protectors**

Parents with a terminally ill child experienced great guilt and denial. Denial can be an obstacle for families in adjusting to their new reality and limitations the illness provides (McDaniel et al., 1992).

Loss is the core emotional issue that families both on the individual and systemic level deal with, when a child is suffering with oncological and hematological illness. The world as these families once knew it is no longer the same safe secure place (Woodgate, 2006). According to McDaniel, Hepworth and Doherty (1992), loss does not only occur in the situations of a child dying, or with the strong potential of a death of a child looming, but also at the time a child is diagnosed with a horrific illness. Parents suffer the loss of the normal healthy child they thought they had (Almeida, 1995: Gordon, 2009). They grieve the image, dreams, hopes and plans they once had for their child. They mourn the loss of the individual they thought their child would grow up to be (Griffin & Kearney, 2001). Parents deal with the loss of the belief that their child will grow up to be healthy and strong and that nothing will happen to their child (McDaniel et al., 1992).

Normal stages of grief, such as guilt, anger and denial are seen in such families. The guilt seen in parents is often due to parents feeling they are their child's protector and they failed in that role. Parents feel they hold a form of personal responsibility for the child's illness. The anger, which at times is due to guilt, is often aimed at the medical professionals or other family members.

Parents receive the diagnosis of the illness with great fear and seriousness as though it is a confrontation with death. As they begin treatment, they often experience great shock and grief, which is made worse by an overwhelming sense of uncertainty. According to Coles (1996), parents have greater reactions of guilt and blame in situations which they are responsible for the illness in some way such as with  $\alpha$ -Thalassemia, which has genetic and ethnic factors. Parents are seen to experience negative emotions in addition to sorrow. Some of the emotions are: anger, fear, frustration, and a sense of

helplessness (Lowes & Lynee, 2000; Parkes, 1996; Worden, 1995). Parents often worry about issues such as maturation, reproduction, and eventual marriage of their child (Moyer, 1989).

The grief process experienced by parents whose children are afflicted with cancer has received minimal attention in the mental health literature. Although the survival rate for pediatric oncology currently exceeds 70%, the medical treatment intervention and psychological cost of coping with such a crisis can be highly traumatic, both for the patient as well as the family (Mitchell, Clarke & Sloper, 2005). Part of the difficulty involves the adjustment to continuous uncertainty, the looming possibility of reappearance of the disease, learning to cope and adjust to new medical treatments and procedures. In short, the family faces a new and very changing reality of continual adaptation (Lavee & Mey-Dan, 2003).

In the study conducted by Rosenblatt (2000), examining parents who have lost a child, vulnerability of the child as well as the vulnerability of the parent came to light. The parents were very much aware of the pain that occurs when a child dies, which lead them to overprotect their surviving children. Overprotection was seen in parents' actions such as checking if the child was breathing at night or rushing to get medical attention sooner than they usually would with any suspicious symptom. Some parents stated that they were especially attuned to symptoms similar to those of the child who died.

### **Gender Differences in Grief**

According to Roos (2000), men and women experience loss differently. Her perspective on grief is related to male and female identity development. In general, men

typically separate and individuate easier than women. Male identity is embedded in values and attributes of individualism. However, female identity is rooted in connectedness, affiliation and attachment to others (Josselson, 1992). The grief experienced by parents due to their child's illness therefore has different meaning, which leads to different responses among men and women.

As stated by Cacciatore, DeFrain, Jones, and Jones (2008), mothers and fathers grieve individually and collectively, while struggling to find meaning in their loss. The parent's reaction to a child's death may depend on parent's gender as well as the level of attachment to the child.

When learning of their child's diagnosis, mothers and fathers both experienced sorrow but they differed in their expression of grief. The mother's experience is often manifested in a greater intensity of sorrow than did fathers (Roos, 2000). For mothers, recurrence of sorrow was related to the management of a health care crisis, which meant going to the doctor more often and preoccupation with physical symptoms. On the other hand, for fathers, the recurrence was related to conflicts and frustrations with social norms of expression of grief. Mothers usually experienced grater symptoms of depression, yearning, guilt, anxiety, shame and trauma (Barr, 2004) while fathers, on the other hand, experienced anger and frustration (Bohannon, 1990). In addition, fathers struggle with feeling powerless in protecting their loved ones (Armstrong, 2002).

In terms of depression, bereaved mothers and fathers showed higher levels of depression compared to control groups. Pertaining to thoughts of suicide, 28% mothers and 17% of fathers seriously considered such actions. Depression seemed to be longer

lasting in mothers, with intense sorrow lasting up to 30 months after the death of the child (Boyle, Vance, Najman & Thearle, 1996).

As gender is related to caretaking of their chronically ill child, mothers tend to experience an unequal sharing of care-giving responsibilities. Even when mothers are employed outside the home, care-giving continues to be disproportionately the women's responsibility (Roos, 2000). Therefore, women often interpreted the experience of loss as a heavy burden, and lack of freedom. The author adds that men on the other hand focused on instrumental concerns such as financial issues that occur due to the illness. Fathers often returned to work earlier with less challenges compared to mothers, which led women to often accuse their husbands of seeking an escape in their work (Laasko & Paunonen-Ilmonen, 2002).

Socially, women benefit from the support given after the loss (Barr, 2004). They tend to need to discuss their loss in great detail, in a repeated manner (Laasko & Paunonen-Ilmonen, 2002). However, fathers typically deal with guilt regarding their powerlessness to alleviate their partner's distress. Despite their own pain, fathers have a sense they have to be strong, and they feel that they are not allowed to show their emotions, as that would upset their partner (Cacciatore et al., 2008; Roos, 2002). It is interesting to note however that according to Cacciatore and colleagues (2008) mothers reported that they wanted their partners to be more emotionally expressive.

While in some cases mothers and fathers may have similar grieving styles, the way they express their grief is often different. It is also important to remember that while there are gender stereotypes and generalization, grief is unique from person to person (Cacciatore et al., 2008).

***The Impact of Pediatric Hematological and Oncological Illness on  
the Couple's Relationship***

While the ultimate loss feared by the family is the death of the sick child, another important loss that is feared at such a time is the breakup of the family unit. As reported by Woodgate (2006), families report that the struggle to keep the family intact is one of the most difficult issues when dealing with childhood cancer.

Couples with children who have a hematological or oncological illness, do not seem to be at greater risk for divorce, compared with the population at large, but rather at higher risk for marital discord. The study conducted by Lansky, Cairns and Hassanein (1978) revealed that marital disharmony was experienced by as many as 68% of the parents of children who had cancer. Some explanations for this are that the couples in such situations were dealing with issues such as feelings of hopelessness, and low self esteem. A low level of social interactions and contact, were identified as contributors to the increased spousal conflict as well. The conflict, in these cases, was assumed to be due to the social isolation that is observed in families dealing with fatal illnesses. In addition Lansky et al. (1978) suggested that marital stress is significantly higher when dealing with childhood cancer, compared with other chronic illnesses, because of the risk of death that accompanies such an illness.

Lavee and Mey-Dan (2003) studied the impact of childhood cancer on a marriage across time. The findings showed that marital relationships exhibit great deterioration in the first year and continuous deterioration, four years or longer, in long term illness. Parental high levels of ongoing stress, negatively impacts the marriage quality post

diagnosis and is compounded with additional hospitalizations and relapses leading to further deterioration within the relationship.

### **Terminal Illness and Grief**

Many parallels are observed between the grieving process that is seen in the mourning of someone who has passed away, and the grieving seen with chronic illness (Moulton, 1984). Grief is viewed as a healthy psychological reaction to bereavement (Miyabayashi & Ysuda, 2007) and a sense of loss that is followed by grief is viewed as a normal universal reaction (Chamberlain, 2006). The following section will discuss the grief experience of primary caretakers that takes place when their child is diagnosed with a potentially life threatening illness. In this section a brief example will be given as to the difference in grief response when comparing two different illnesses such as ALL and AML as well as issues dealing with brain tumors. This will be followed by a discussion regarding the difference between suffering from bereavement and depression, the traditional time bound theory of grief, the benefits and limitations of this in understanding the grief experience of such caregivers. According to George, Vickers, Wilkes and Barton (2007), the grief from chronic and potentially terminal illness is related to an ongoing situation of loss. This situation has been referred to in the literature as *Anticipatory Loss* (Green, 2006), *chronic grief* (Olshansky, 1962) and at times *chronic sorrow* (Lichtenstein, Laska & Clair, 2002) which allows us to understand the grief phenomenon of primary caregivers when dealing with a pediatric hematological and oncological diagnosis

## *Illness and Grief*

Chronic illness is often a trigger for further events to take place, which can lead to a sense of loss. Both loss and grief are viewed as being related to each other. Grief is defined as great emotional anguish caused by loss, hardship, injury or any other misfortune (Moulton, 1984). Due to this definition, grief is not restricted as a reaction solely to death and can appropriately describe the experience of many chronically ill patients as well as their families.

Chronic illness has both real and potential losses, which are on a continuum over an indefinite time. Due to the onset of a physical illness, the patient could find his or her world limited or destroyed. The patient often feels great loss of control and power. Simultaneously, the family or any significant others are faced with coping with a variety of changes in their lifestyle (Moulton, 1984).

Boss and Couden (2002), described the experience of grief due to chronic illness as a sway of emotions, in which people go back and forth between feeling hope on one hand and hopelessness on the other. At times things are the way they were prior to the illness, and at other times there is preoccupation with symptoms of the illness. The authors described the experience of Ambiguous Loss due to chronic illness as the ongoing grief that results from the loss of the person that once was. This often leads to the family system to become frozen in place, where nothing can change and decisions cannot be made.



### *Type of Illnesses and their Impact on Grief*

According to George and colleagues (2007), some parents of children with chronic illness stated that they would not be able to overcome the grief they had experienced. Other parents stated they often think about what life could have been like, had things been different. All parents however reported that their grief was triggered by multiple factors, which included hurtful comments from other people, being asked continuously of the child's medical history, facing the reality of the child's condition as well as hearing stories about death of other children in similar conditions.

As stated by McGrath, Paton and Huff (2004), there are many similarities in the parental experience of childhood cancers. However, there are some differences when dealing specifically with the experience of AML. This is due to the less favorable prognosis offered with such a disease. With AML, there is the greater confrontation with death. The higher levels of anxiety seen by all AML family members are an important point of difference to other types of leukemia. There is an apparent awareness that the odds of a good outcome are not as good as for ALL. Recall that for ALL there is a 75-85% cure rate, while for AML the cure rate is 40-50% (Loeb & Arceci, 2002).

AML families in the study conducted by McGrath and colleagues (2004), reported feeling overwhelmed by the fatigue associated with attending to the demands of the situation. Some examples of the demands included providing food, getting appropriate information, and worrying about schooling. The distress of the situation seemed to be exacerbated by fatigue and worry about poor nutrition. All families in this study were found to have a difficult time dealing with invasive procedures and aggressive drug

regimens. These issues were found to take an emotional toll on the families which was made worse by the great sense of uncertainty.

In a study conducted by Bonner, Hardy and Willard (2008), parents of children diagnosed with a brain tumor dealt with great uncertainty and experienced unresolved sorrow. This is explained specifically due to the fact that many children with cancers that impact the central nervous system have other significant effects, such as neurocognitive decline, delayed growth, and physical limitations. Therefore it seems reasonable that parents of children with brain tumors potentially have more uncertainty and distress regarding their child's future quality of life.

Given the variable remission rates of these illnesses, it is understandable that parents would struggle with grief as they attempted to monitor their child's treatment, observe the child for symptoms of relapse, endure painful procedures, imagine life without their child, and make good memories in the shadow of potential death.

### ***Bereavement vs. Depression***

When examining the grief parents experience during the time their child is sick with a severe hematological or oncological illness, it is important to identify if the parent is presenting with symptoms of grief or if they are experiencing depression. It is also important to identify if depression was a preexisting condition. In other words, one must differentiate what parents are truly experiencing.

The DSM IV-TR (2000) described bereavement as a normal reaction to the passing of a loved one. Normal grief has traits of a Major Depressive Episode, which includes feelings of sadness insomnia, poor appetite, and weight loss. The bereaved

individual usually views their depressed mood as normative given their circumstances. The length of grief as well as the manifestation of what is considered to be normal bereavement varies across cultural groups. The diagnosis for Major Depressive Disorder (MDD) is usually not assigned unless the symptoms are severe and are observed two months after loss.

In order to differentiate between bereavement and MDD, identification of symptoms that are not characteristic of a “normal” grief reaction are examined. These symptoms include:

(1) guilt regarding issues other than actions taken or not taken by the survivor at the time of the loss. (2) Thoughts of death besides the survivor feeling that he or she would be better off dead with the deceased person. (3) Preoccupation with worthlessness that is morbid in nature. (4) psychomotor retardation. (5) Long term functional impairment and (6) Hallucinations that do not relate to the deceased person (DSM IV-TR, 2000, p. 741).

The grief experience of parents whose children have a potentially terminal illness, includes these symptoms, yet have their own nuances, as the child in the study is still alive.

In the following sections, a discussion of the various types of grief are presented, which include the traditional *Time Bound Theory of Grief*, *Chronic Sorrow*, *Anticipatory Loss*, *Complicated Grief*, and will conclude with a brief description of *Ambiguous Loss*, which will be expanded upon in the following theory chapter.

### ***Time Bound Theory of Grief***

The *Time Bound Theory of Grief* (Kubler-Ross, 1971) is a long standing accepted linear grief process that names specific stages that take place in a specific order when a

person experiences a loss. The five stages of this grieving process include (1) denial, (2) anger, (3) bargaining, (4) depression, and (5) acceptance. These stages define grief as being a dynamic process, as the mourning person may move back and forth through the stages (Moulton, 1984). These stages are seen as steps the bereaved goes through in their journey toward recovery, in order to gain resolution and acceptance of the new reality of the loss at hand (Chamberlain, 2006). In contrast to Kubler-Ross, Lowes and Lyne (2000) stated that each person will go through these stages of grief in their own unique way and in no predetermined order. Successful grieving is jeopardized by the presence of strong ambivalent feelings regarding the death of the person, among family members.

### ***Chronic Sorrow***

*Chronic Sorrow* is described as a pathological state of prolonged grief, which may appear to be similar to depression (Gordon, 2009). Chronic sorrow however, is a normal grief response which is related to a loss that takes place when a child is alive, yet diagnosed with a life threatening illness. When adaptation does not take place, prolonged chronic grief is considered to be an abnormal response (Teel, 1991). Teel (1991) defined chronic sorrow as a persistent pain and sadness, which is stimulated by a specific event. It is interesting to note that in the study of Chronic Sorrow, conducted by Hobdell (2004) 86% of participants experienced such a phenomenon, with mothers experiencing greater chronic sorrow than did fathers.

## **Olshansky's Concept of Chronic Sorrow**

Olshansky's (1962) initial idea of chronic sorrow was used to conceptualize the connection between depression and reduced social support. Chronic Sorrow at first was used to portray the sadness observed in parents of children who were mentally ill. The parents seemed to mourn the loss of the healthy child (Olshansky, 1962; Lichtenstein, Laska & Clair, 2002). Since then, Chronic Sorrow has been used to describe chronic depression and grief observed due to a disability, ill health or any other impairment (Gordon, 2009). Chronic Sorrow refers to a loss that cannot be ignored. It is considered to be a natural response in situations that create chronic stress to either the patient or caregiver. Unlike *Time Bound Grief Theory*, Olshansky's idea of Chronic Sorrow as being cyclical, invasive and progressive, has been viewed in the context of infertility (Lichtenstein, et al., 2002) and cancer (George, et al., 2007).

In the study conducted by Lichtenstein, et al., (2002), most of the participants described feeling loss of control over their lives in major ways. There seemed to be a realization that control was an illusion, rather than reality. They concluded that life is fragile and one never knows what is going to happen. The idea of living in limbo is what intensified the experience of the chronic sorrow.

## **Chronic Sorrow as an Alternative Theory of Grief**

In contrast to the Time Bound Theories of grief, when dealing with chronic illness it is suggested that it could be too difficult to follow this pattern and reach the acceptance stage (Tinlin, 1996). Grief may be perpetuated with times of reappearance of the illness and strengthening of the grief symptoms. In dealing with such an illness, failure to reach

acceptance should not be viewed as abnormal. Parents of children with mental disabilities, with myelomeningocele, parents of children with Down Syndrome and the chronically ill, experience chronic sorrow (Lowes & Lyne, 2000). Olshansky (1962) suggested that parents never actually recover from feeling grief. Instead they adapt to the situation. This adaptation is not considered acceptance. According to Chamberlain (2006) in a study which examined traumatic brain injury, healing and resolution of the grief was still considered an issue years past the injury.

Chronic sorrow is described as chronic sadness, interwoven with times of neutrality and happiness (Teel, 1991). A parent's reaction to chronic illness implies functional adaptation to the child's condition, but not acceptance of it. When adaptation takes place, the literature demonstrates that it is inappropriate to expect acceptance as one would in traditional grief, when a person passes away (Lowes & Lyne, 2000).

When dealing with Chronic Sorrow, there are two phases seen as a reaction to loss: the first is *emotional turmoil* and the second *acceptance and adaptation* (Gordon, 2009). The emotional turmoil stage includes impact, denial and grief, which is experienced as a cycle of peaks and valleys (McGrath, Paton & Huff, 2004). Parents use appropriate coping strategies which systematically resolve the crises they are in, leading to adaptation to their new life situation. During the stage of acceptance and adaptation, emotional turmoil continues, but is seen as being less intense. While the level of sorrow is observed to fade with time, it does not seem to end. Due to the ongoing nature of the loss, many parents of children with disabilities never progress to the acceptance phase, which means they stay in the phase of emotional turmoil (Lowes & Lyne, 2000).

### *Anticipatory Grief*

Rando (2000) discussed Anticipatory Grief as a response to an upcoming loss of a loved one. Such a loss requires a delicate balance between the simultaneous demands to hold on to the person, while letting go. Moulton (1984) added that anticipatory grief manifests the steps of mourning before the actual death takes place. Family members, in such cases, may go through a grief reaction and reach acceptance before the death actually occurs (Parkes & Weiss, 1983). While this is often a healthy protective device, it could cause family members to disengage prematurely from the ill child. If anticipatory grief is not managed, the family members may withdraw from the sick child as a protection of their own emotions, which could result in abandonment of the ill person.

Fulton (2003) discussed hope as an important coping tool for parents when their child was sick. As the disease progressed and hope diminished hope was supplemented with anticipatory grief. The four month mark prior to a child's death was identified as the time the parents went through the most intense grief, leading to a calm acceptance after this time period.

According to Saldinger and Cain (2004), people often cope worse after the death of a loved one that was anticipated, rather than after a sudden death. This was measured in terms of one's general adjustment, grief behaviors and overall parental functioning. On the other hand, Fulton (2003) reported that some families actually experienced some relief at the time of death of their child, when the death was foreseen. It is important for the family members to be aware of their experience so they can process the grief, without letting go of the child prematurely.

### ***Complicated Grief***

Another type of grief that could impact parents of children with hematological and oncological illness is *Complicated Grief*. Complicated Grief is described by Chamberline (2006) as grief that has been intensified or compounded through the experience of extreme life events, such as a child being diagnosed with a terminal illness. The grief does not lead to absorption of the loss but becomes exacerbated resulting in impaired functioning. The risk factors associated with complicated grief include traumatic experiences connected to death or loss. Such losses may lead to depression, anxiety and even Post Traumatic Stress Disorder (PTSD).

Complicated grief is unique in that it is intensified by the loss due to an extreme life event. Primary caregivers of a child with a potentially terminal illness may experience complicated grief, as a result of the shock of losing their child at a young age, in an unexpected way. This grief is significant as it can be exacerbated and can last longer than grief due to more traditional, acceptable deaths, such as a death of a loved one who was very old and who lived a full life.

### ***Ambiguous Loss***

An issue in coping with grief is ambiguity surrounding the loss. *Ambiguous Loss* is the resulting grief that occurs when a “person is physically present and psychologically unavailable, or psychologically present, yet physically unavailable” (Boss, 1999, p. 11). According to Boss and Couden (2002), the most traumatic losses are the ambiguous ones due to the lack of clarity that surrounds the family members about whether the person is dying, or in remission. Ambiguous Loss is experienced by the sick person as well. The



sick person is present, but no longer can be the way he or she was (Boss & Couden, 2002). Boss (1999) described Ambiguous Loss as being the most devastating, due to the fact that it is unclear and undefined. It is the constant nature of Ambiguous Loss, uncertainty, the lack of societal recognition, as well as the preoccupation with the potential final outcome that leads people to feel paralyzed and at times demoralized while trying to cope with their situation. This type of distress can easily be overlooked by health professionals given their usual focus on the physical aspects of the disease.

The idea behind Ambiguous Loss theory is that when people understand their situation, they have the ability to cope with stressors life offers (Boss & Couden, 2002). Ambiguous Loss is a situation in which some aspect of the loss remains unclear (Boss, 2007) or does not make sense. “When illness cannot be cured, people must simultaneously hold two opposing ideas in their minds: The person as she or he was is gone; but that person is still here and in my life” (Boss & Couden, 2002, p. 1353). The theory of Ambiguous Loss (Boss, 1999) assists one to understand the stress a family endures when caring for a sick family member. Ill people may not look any different, which leads family members to not realize that the sick person may be in pain, or be anxious about their prognosis. As patients become preoccupied with their symptoms, they slowly withdraw or are excluded from activities at work or with family and friends (Boss & Couden, 2002). There is a sense of hanging on to hope that things will return to be the way they used to be. Problem solving is difficult given the problems resulting from the illness can be either final or temporary but it is unclear which it is (Boss, 1999). Due to these issues, the relentless uncertainty experienced through Ambiguous Loss can lead to physical and emotional exhaustion and negative relationship consequences.

## **The Impact of Ambiguous Loss in the Family System**

The ambiguity of the illness leads the patient as well as their family members to swing between hope and hopelessness. Families are in limbo. Ambiguous Loss, according to Boss (1999), can cause both personal as well as family issues. This is due to the fact that the situation at hand is beyond the control of the system. For example, roles within the family system may change prematurely, or may stay stagnant due to the immobilization that takes place with Ambiguous Loss. Family rituals are often placed on hold, putting the family at higher risk of feeling in limbo.

It is important to realize that different members of the family suffer loss and may process it in different ways. They may be experiencing loss at different stages at different times. This too can impact family dynamics, and can add to potential friction.

The family stress perspective (Boss, 1992) is relevant to Ambiguous Loss as it explains the stress placed on the family system due to a loss that pertains to an illness. The family stress perspective offers the notion that the ambiguity created due to the illness, maintains confusion (Boss & Couden, 2002). This leads family members to either maintain distance from the patient and act as if he or she has passed away, or deny that the illness even exists by ignoring it altogether. While there often needs to be a change in roles within the family system, the ambiguity related to the prognosis of the illness, puts the reorganization of family roles, on hold. In essence, the family is put on *pause*. In addition, members of the family often question justice in their world view feeling that what has happened to their loved one or themselves is not fair. Ambiguous Loss, over long periods of time, has a negative physical and psychological effect on various members of the family (Boss, 1999). Ambiguous Loss provides a unique lens that allows

us to understand the experience parents go through when their child has a potentially life threatening illness. The uniqueness of this theory provides us with the understanding that primary caregivers often feel in limbo for long expanses of time, suffering a loss that may not be apparent to others.

### **Do Primary Caregivers Suffer from Post Traumatic Stress Disorder or Ambiguous Loss**

The literature on the impact of pediatric life threatening illnesses on the parents, has examined the possibility that parents suffer with Post Traumatic Stress Disorder (PTSD) and Post Traumatic Stress Syndrome (PTSS) as a reaction to the child's illness. This was examined in a study where hematopoietic stem cell transplantation (HSCT) was used as treatment for life threatening hematological and oncological illnesses. PTSD as well as depression and anxiety, were found in high rates among parents and other members of the family, dealing with childhood cancer, reported on mothers of children who survived HSCT and the impact such a procedure has on them (Manne et al., 2004). It appeared that right before and after the procedure, was an especially difficult time for parents to deal with the child's illness. Over 66% of mothers tested for depression, and 52% tested for anxiety, with symptoms within clinical range (Nelson, Miles & Belyea, 1997).

PTSD was discussed in relation to parents of children who survived HSCT. Learning that the child has a potentially life threatening illness is viewed as a traumatic event, qualifying for PTSD (American Psychiatric Association, 2000). Other symptoms comprise invasive fears or re-experiencing aspect of the upsetting event, avoidance of

situations which reminds a person of the event or a numbing of emotions, and hyper vigilance or increased physiological arousal all can indicate that a person is suffering with PTSD (Manne et al., 2004).

While primary caregivers of children with a potentially life threatening illness may qualify for a diagnosis of PTSD, Boss (2006) distinguishes Ambiguous Loss from PTSD as in PTSD the event is over and flashbacks are what the person is suffering from. With Ambiguous Loss “the loss is an ongoing trauma. The assault never lets up” (p. 41). The outcomes of both PTSD and Ambiguous Loss have the ability to greatly impact relationships (Boss, Beaulieu, Wieling, Turner & LaCruz, 2003).

The current section focused on the grief experienced by primary caregivers when their child is suffering from a hematological or oncological illness. The next section moves to a different aspect, in which we will discuss the aspect of how attachment impacts illness and loss. The study will examine the different types of attachment styles, as they impact one’s experience of grief.

### **Attachment**

Attachment theory has gained renewed interest in recent years in the field of Marriage and Family Therapy. Attachment styles have been examined in the literature as related to illness and grief. In the current study, Ambiguous Loss associated with a gravely ill child is examined through the lens of the primary caregivers’ attachment style. It is this author’s hypothesis that primary caregivers with different attachment styles will experience Ambiguous Loss due to their child’s illness in various unique ways. In this section the literature as it pertains to attachment styles and illness, as well as attachment

styles and grief are examined. This will provide the foundation for the development of ideas that support the current study.

### ***Definition of Attachment***

Considerable literature points to the importance of the attachment between parents and children (Feeney, 2000). Attachment describes the nature of the relationship between infants and their caregivers. It is also an important indicator for relationships throughout one's life. Early attachment relationships influence one's social experiences (Berry, Shah, Cook, Geater, Barrowclough & Wearden, 2008). Attachment styles in adults are seen as good predictors of one's relational interactions (Crowell, Fraley & Shaver, 1999). According to Ainsworth (1973), attachment is an affectionate tie that is developed between two people. Bowlby (1969) hypothesized that infants develop a lasting and affectionate bond with key caregivers, which is rooted biologically and operates as protection from danger. Children learn what to expect from other important figures and learn how to feel about themselves. According to Bowlby (1969), almost all healthy infants develop attachments to their caregivers. However, some infants are more secure in their attachment compared to others. Attachment research points out that a mother's sensitivity toward her child is an accurate predictor of the child's secure or insecure level of attachment (Minde, 1999). In this study, an examination of attachment styles and the way they impact the Ambiguous Loss experienced by parents who have children with a potentially life threatening illness, will be provided.

### *Types of Attachment*

The literature refers to three types of adult attachment styles. These include (1) Secure attachment (2) Preoccupied attachment, which is referred to in the infant literature as Anxious or Insecure-Resistant (3) Fearful attachment style, which is referred to in the infant attachment literature as Avoidant (4) Dismissive attachment style. *Secure Attachment* is defined as a relationship of trust and confidence between a person and their caregiver (Bowlby, 1969). It is marked by comfort with intimacy together with autonomy. During infancy, this relationship gives the child enough comfort and reassurance which promotes confidence for independent exploration of the environment (Ainsworth, Blehar, Waters & Wall, 1978). This allows the child to have a secure base from which she slowly gains distance during exploration, yet with a safe place where she is welcomed to return (Randolph, Brown Smart & Nelson, 1997). In this type of attachment people are content depending on others (Shaver & Brennan, 1992).

*Fearful Attachment* is the situation in which a person tries to avoid connection with another (Bowlby, 1969). It refers to distrust and fear of rejection (Feeney, 2000) as well as the fear of relying on others (Randolph et al., 1997). As an infant, the child is uninterested in their caregiver's presence as well as their departure. At reunion, the child ignores the caregiver (Ainsworth, Blehar, Waters & Wall, 1978). Individuals with such attachment styles are often uncomfortable being emotionally close to others (Shaver & Brennan, 1992).

*Preoccupied Attachment* refers to a pattern of attachment in which anxiety and ambiguity keep one person clinging to another (Bowlby, 1969). It is often observed when the child has a fear of the caregiver abandoning them (Randolph, et al., 1997). It is

identified by over dependence and desire for great closeness (Feeney, 2000). This is often seen in an infant who resists active exploration. Such a baby tends to be very upset at separation, however he both resists and seeks connection at time of a reunion (Ainsworth, Blehar, Waters & Wall, 1978). With this attachment style the adult person could be insecure and “clingy” to others (Shaver & Brennan, 1992).

*Dismissive attachment* style refers to people who have a positive view of themselves, yet a negative evaluation of others. People with such an attachment style have high self esteem, low anxiety levels and find relationships to be unimportant. Such people find it difficult to trust others, and focus on independence and self reliance (Fiori, Consedine & Magai, 2009).

The same caretaking patterns that are developed in the quality of the attachment to the child are influenced by social and psychological variables, which go back to the patterns of the mother’s relationship with her mother (van Ijzendoon, 1995). Mothers who are preoccupied or dismissive with their own past life and relationships seem to lack appropriate sensitivity needed towards their children (Lyons-Ruth, Connell, Grunebaum, & Botein, 1990). It is important to note that across generations, secure attachment patterns are more stable than insecure ones (Benoit & Parker, 1994) meaning that secure attachments are more likely to self perpetuate from one generation to the next than other forms of attachment styles.

### ***Attachment and Grief***

As articulated by Shaver & Tancredy (2001), attachment theory suggests that infants are biologically inclined to bond with primary caregivers, most commonly their

parents, and adults tend to connect with other important people. Even in adulthood, people experience distress at times which they are separated from the attachment figure unexpectedly or when ill. The way infants interact and experience the connection with their primary caregiver will impact how they experience relationships and hence, grief in the future (Bowlby, 1969).

### **Attachment Styles and the Experience of Grief**

Mourning due to a death or loss has great implications as to the way the grief is constructed and understood. People with specific attachment styles are more vulnerable to grief related difficulties, compared with others. Individuals who have a preoccupied attachment style, tend to have a clinging character to their relationships, and may be more inclined to experience chronic or long-term grief (Neria & Litz, 2003; Servaty-Seib, 2004). On the other hand, people with a fearful style of attachment, and who tend to be guarded in relationships, are more likely to experience either inhibited or no grief responses (Stroebe, 2002). Finally, securely attached people are expected to respond to death of an important person in the characteristic manner in which they experience emotions without becoming overwhelmed by the experience (Shaver & Tancredy, 2001).

The way people cope with death and loss is similar to the way they cope with other losses in relationships. The process of reorganization after loss is comparable to other transitions in which an individual is expected to remain connected to his or her living primary caregivers, while being able to create new connections. Some people are able to maintain connections at the same time as they develop new relationships, while others experience greater difficulty in such a transition (Servaty-Seib, 2004).



From the attachment perspective, healthy recovery in mourning, includes maintaining a secure bond with the attachment figure while coming to terms with the idea that the person is no longer physically present (Bowlby, 1980). People with a fearful style of attachment who tend to show few signs of grief may have little conscious need to maintain such a bond (Stroebe, 2002). It has been proposed that in cases in which individuals with an avoidant attachment style do avoid having intimate connections, they may be unable to maintain a connection with the deceased after an attachment figure dies. Individuals with a resistant-ambivalent style of attachment may have a great need to mourn through finding ways that reduce an excessively invested bond after the death of the loved one, rather than focusing on the maintenance of a bond (Servaty-Seib, 2004).

According to Neria and Litz (2003), a number of factors, independent of the nature of the loss, influence the course of the outcome of bereavement such as relational variables between the individual and the social network of the bereaved. Therefore not only the relationship with the deceased impacts the bereavement but other relationships and their level of security impacts it as well. In addition, issues of concern can arise by the person's lack of self esteem, which may complicate the process of grief.

There are different meanings held in regards to the relationship that are lost when losing a child, spouse, sibling, parent, close friend, or acquaintance. However, the loss of the child has been said to be most painful and long term compared with any other loss as it is against the laws of nature, in which the children are supposed to outlive their parents (Leahy, 1992). The grief is particularly difficult when the person and relationship lost is of great importance in the life of the bereaved (Weiss, 2001). In addition, losing a relationship that was an integral part of the bereaved individual's social network, identity,

social support or of particular connection causes greater pain and confusion in the process of grief (Shaver & Tancredey, 2001).

During the time of grief, the support provided by family and friends is of fundamental importance to the person's ability to cope with the loss. The significance of this support twofold: First, having someone with which the grieving individual feels comfortable to express his or her emotions, is a priceless resource. A network of support becomes necessary to ease the responsibilities such as planning death related ceremonies as well as to relieve the stress of the daily tasks that can potentially become a burden during this difficult time. Second, the loss of a significant attachment figure can leave the bereaved person feeling great emotional loneliness. At this time social supports become even more crucial (Neria & Litz, 2003).

### *Attachment and Illness*

There are two reasons for evaluating the impact of attachment style on health behavior. The first reasons include health implications for children and adults and the various parts of personal relationships (Cohen, 1988). The second reason for understanding a link between attachment style and health behaviors is seen in attachment theory. In attachment theory, Bowlby (1969) conceptualized the attachment system in childhood as one that maintains a balance between attachment and exploratory behavior of the child. Therefore, attachment style is usually made evident when the child is in a strange or threatening situation (Bowlby, 1969), such as dealing with a life threatening illness. Ill health is likely to activate the attachment system, and therefore individuals

with various attachment styles are expected to differ in their responses to unusual or distressing physical symptoms (Feeney, 2000).

### ***Grieving a Medical Diagnosis from an Attachment Theory Lens***

As discussed earlier, a difficult time for families to deal with childhood illness is when the parents first receive their child's diagnosis. Marvin and Pianta (1996) have looked specifically at the diagnosis of cerebral palsy. Receiving such a diagnosis is considered a crisis for most parents causing them to go through a period of mourning.

Marvin and Pianta (1996) pointed out the importance of primary caregivers going through the process of grief, by stating that if caregivers are not given the opportunity to grieve and process the shock created by receiving such a diagnosis, their care giving could potentially be compromised and lead to the development of an insecure attachment with the child. An additional risk seems to be the result of parents' loss of their child. It seems to be the parents' lack of resolution of the situation rather than the trauma itself that is related to problems of attachment (Bowlby, 1980).

The loss of an attachment figure can be overwhelming, which can lead to the disbelief that the loss is permanent. When the loss is not processed, there seems to be a direct link between unresolved trauma and being at an increased risk that the person's child will develop insecure patterns of attachment. Marvin and Pianta (1996) suggested that the parent, who experienced unresolved loss will be distressed in other attachment interactions and will either show caregiving behaviors that do not make sense to the child or will have a tendency to avoid the child and opportunities to develop a secure

attachment. In such situations it is of great difficulty for the parents to serve as a secure base for the child (Main & Hesse, 1990).

### **Preoccupied Attachment and Fearful Attachment**

Pain and illness can be seen as risk factors for preoccupied attachment. In regards to different attachment styles, some studies report little difference between healthy children compared with those dealing chronic illness (Goldberg, Washington, Morris, Fisher-Fay & Simmons, 1990). Other studies have found that insecure styles of attachment are overrepresented in the pediatric samples (Goldberg, Gotowiec & Simmons, 1995). These mixed results may be attributed to the fact that attachment style is impacted not only by the child's health status, but also by the parents' reaction to the child's illness. For example, overindulgent parents were positively associated with the child's preoccupied attachment and negatively associated with fearful attachment (Feeney & Ryan, 1994). In addition, it was observed that children with avoidant attachment style learned to suppress their distress in order to avoid the risk of distancing from the caregivers (Feeney, 2000).

Thomson, Connell and Bridges (1988), discussed the fact that insecure attachment is associated with the child's tendency to reflect negative emotional expression. Young children with medical conditions such as cystic fibrosis and congenital heart disease were found to be less secure in infancy and more disorganized in their attachment style compared with a control group of healthy children (Goldberg, Gotowiec & Simmons, 1995). It is suggested that this is because of fear and insecurities they felt during their young years and possible overprotection by their parents.

In a study conducted by Mikulincer and Florian (1998), people dealing with a variety of serious stressors, such as chronic pain, were examined. Findings indicated that individuals with avoidant attachment styles reported higher levels of stress. When facing chronic illness, fearful attachment is related to negative outcomes. People with fearful attachment styles are seen as avoiding intimacy as well as negative emotions. Such individuals focus on self reliance and reject the need to be close to others. On the other hand Turan, Osar, Turan, Ilkova and Demci (2002) suggested that those who are fearful want intimacy, but at the same time avoid getting close to others due to their fear of rejection. The authors further stated that fearful attachment style is correlated with fear of death. This suggests that fearful attachment style could lead to a defensive suppression of feelings of distress and weakness.

### **Attachment Style as Predictor of Care**

According to Feeney (2000), the style of attachment between the primary caregivers and child, predicts the way the family responds to the child's illness. This is also reported by Robinson, Rankin & Drotar (1996) who observed the link between attachment styles and the parents' number of visits of the child in the hospital, as well as the family's involvement in understanding of the illness. Maternal visitation was further investigated and found that the mother-child attachment style was the variable that predicted the amount of visitation. For children with mothers who had insecure attachments, visitation rates were lower, which many indicate that insecure attachment could be associated with less accommodating parental behavior when the child was ill.

Preoccupied and fearful attachment styles show different ways of one responding to their attachment figures as well as to difficult situations. With this knowledge, medical professionals who understand these differences may be able to adjust their own interactions with both parents and children according to the parent and child levels of attachment. This could promote positive responses to the child's care while minimizing difficulties associated with compliance (Feeney, 2000).

### *The Mother's Role*

It has been speculated that the relationship between the mother and child is influenced by the child's early behavior and the association with the mother's thoughts, fears and concerns (Goldberg, Gotowiec, & Simmons, 1995). The pattern of the relationship seems to continue even if the cause for concern has changed or improved.

A study conducted by Minde, Whitelaw, Brown and Fitzharding (1983) examined parental interaction in the neonatal intensive care unit (NICU) and found that the degree of the mother's interaction with the child (both at the hospital and at home), was often associated with the mother's reflection about past life experiences, such as present pregnancy and psychological events in her life. It seemed that such parents with seriously sick children interacted with the child minimally, even after their recovery.

In a later study, Minde (1999) reported that parents with babies in the neonatal intensive care unit changed their interactions with their baby for the worse, as the severity of the situation got worse due to medical complications. When the infant's illness improved, mothers returned to their initial interactive style which was typically better for the child. However, this only took place when the illness lasted less than two weeks. In

cases where the baby was sick for 4-10 weeks, mothers still behaved as if their children were dangerously ill after six months.

Further it was observed by Minde et al. (1983) that when the baby was less than one month old; the mothers of the more severely ill children spent greater amounts of time in caretaking and engaged in verbally stimulating activities with the baby. However, past this age point, mothers of the sick infants interacted with their child significantly less compared to mothers with healthy infants. This could be attributed to the mother's overwhelmed feeling, due to the instability of the infant's prognosis for survival. This could possibly lead to a level of emotional withdrawal from the child, which was seen by the lack of interaction.

The behaviors discussed seem to be indicative as to how attachment impacts ill children. However, such attachment varies according to the age of the child, as well as past and present experiences of the mother.

### *Attachment Styles and Stress Management*

Securely attached people have been reported to be able to rationally evaluate stressful situations and see themselves as able to cope with the events effectively (Mikulincer & Florian, 1995). Such people tend to use supportive coping strategies in order to maintain psychological well being during stressful times (Birnbaum, Mikulincer & Florian, 1997). On the other hand, people who are fearful in their attachment style have been found to see the stressful events in more threatening terms and tend to divert attention from the stressful situation (Mikulincer & Florian, 1998). They report doubt regarding their ability to cope and they suffer great levels of distress. People, who have

an anxious attachment style, tend to be distracted and ruminate on their negative thoughts (Fraley & Shaver, 1997). St. Clair (2000) highlighted that through loss, separation, and more specifically terminal illness, pathological attachment bonds have the opportunity to be addressed.

The severity of the child's illness seems to be an indicator of the mother's level of distress, specifically at the beginning stages of the illness (Berant, Mikulincer and Florians, 2003). This is in the context of connection between the mothers' attachment style and adjustment to stress. For example, when raising an infant with congenital heart disease, there is a visible increase in the demands and stress on mothers. This is due to the physical demands, as well as the additional caregiving requirements, which could result in the mother's psychological distress, the triggering of her attachment style and other emotional issues (Cohn, 1996).

The person with a secure attachment has the belief that the attachment figure will be accessible and supportive. This is due to the belief that the person is worthy of such support. On the other hand, the dismissing person believes that the attachment figure is neither available, supportive nor trustworthy (Fraley, Davis & Shaver, 1998). Such thinking leads the person to believe that the only way to handle situations is by taking care of their needs themselves. In addition, their main goal is to avoid distress and anxiety (Fraley & Shaver, 1997). This is accomplished by diverting their attention from sources of distress and any discomfort, especially regarding stressful situations such as potentially life threatening illnesses. Such avoidance could prevent the person from focusing on the issue at hand in order to come up with positive coping strategies. Fearful people tend to rely on strategies such as avoidance, wishful thinking and self blame when



compared to people with other attachment styles. Avoidance coping is especially harmful when dealing with chronic illness (Turan, Osar, Turan, Ilkova & Damci, 2002) as people in such predicament will not receive the physical and emotional care they need.

Both the child and the adult seek closeness with attachment figures in stress of threat conditions (Bowlby, 1969). Illness can be a factor to activate the attachment system (Mikulincer, Birnbaum, Woddis & Nachmias, 2000). Turan and colleagues (2002), hypothesized that dealing with a disease such as insulin dependent diabetes mellitus, could activate the attachment system and impact the way patients and families cope and deal with the disease. Avoidance coping was defined as the distraction of oneself from the issues that related to the diabetes, and important responsibilities associated with diabetes management. It was further reported that when dealing with chronic disease, avoidance coping was associated together with lower focus of attention, processing less amounts of information as well as have less knowledge regarding one's medication.

### **Conclusion**

It is through the interconnectedness of attachment and illness that the experience of hematological and oncological illness is examined from the perspective of primary caregivers grief and attachment. In examining this issue from a systems lens, it is noted that caregivers experience grief differently as individuals and together as a unit. When a child is diagnosed with a potentially terminal illness, great grief impacts both primary caregivers. In addition, it appears that caregivers with different attachment styles handle illness and grief in a variety of distinct ways. This study will allow greater understanding

of the impact that such grave illnesses have on the caregivers, through the lens of their attachment styles, and therefore how they experience the phenomenon of Ambiguous Loss.

## CHAPTER TWO

### THEORY

When considering the grief primary caregivers experience when their child has a hematological or an oncological diagnosis two theories inform the research: Ambiguous Loss theory and Attachment Theory. The author hypothesizes that attachment styles impact the experience of Ambiguous Loss in primary caregivers whose children have a potentially life threatening illness. This research paper examines two theories separately as they pertain to the experience of the population described. The chapter begins with a summary of Attachment theory and the ways in which attachment styles impact grief. A discussion follows regarding the ways Ambiguous Loss connects to a variety of phenomena, specifically the Ambiguous Loss experienced by the caregivers of children with a potentially life threatening illness.

#### Attachment Theory

In the development of attachment theory, John Bolby (1973) focused on the relationships between children and caregivers, specifically mothers, in order to examine maternal nurturance and importance, which allowed for development of an *Attachment Bond*. The theory focuses on the attachment bonds developed early in a person's life and are the foundation for the sense of security and one's survival. He identified different styles of interaction with caregivers and how each style affects one's connections in other relationships. According to Bowlby, attachment behavior is instinctual and mediates proximity, affection and connectedness to another individual. Attachment is first

developed between a child and a parent, and is carried over to relationships between adults later in life.

To feel attached, is to feel safe and secure. Equally, a threat of loss, such as a child being terminally ill, creates high levels of anxiety and actual loss leads to great sorrow. An attachment relationship is described by the presence of proximity and the secure base effect. *Secure Base* is the support of a relationship which allows for one's autonomous exploration of the environment (Feeney & Thrush, 2010). The secure base allows one to return to the secure relationship for comfort as well as reassurance that may be needed (Feeney, 2004). *Proximity* is the condition in which the child seeks a preferred figure with whom they feel safe, and the secure base effect is observed when danger is perceived as near, which allows one to return to the attachment figure and feel safe again (Bowlby, 1973).

Bell and Ainsworth (1972) examined crying as it is manifested in relation to attachment. The act of crying signals the child's need for the parent's protection and attention. The crying allows for a response from the caregiver. Such an interaction of a cry for help and response to it develops and maintains an attachment bond. Lack of attentiveness to the crying by the parent, leads to the child feeling unprotected and results in negative impacts on the trust relationship between the child and the caregiver. Bowlby considered crying an attachment behavior which is triggered by separation, and the experience of loss later in life (Bowlby 1969). Therefore, crying both establishes and maintains attachment between infants and their caregiver. At its core, this is due to the fact that few people are actually able to ignore an infant's cry. Those cases in which the cry of a baby is ignored, or when a parent leaves and there is no consistent care for their

needs, it places the infant at risk to develop a pattern of detachment. Such children would ignore their own caregiver and at times isolate themselves (Nelson, 1998). This behavior can become a blueprint for future relationships, which will make it difficult for a child to develop healthy attachments to significant people in their future.

### *Types of Attachment*

As discussed in Chapter Two, four types of adult attachment styles have been identified, which include *Secure Attachment*, *Preoccupied*, *Fearful* and *Dismissive* styles. According to Bowlby (1969) the quality of the bond between the caregiver and the child, allows for the development of the child's emotional experience and behavior. At birth, children have a need for closeness with their caregiver, which provides them with safety as well as protection (Lydon & Sherry, 2001). For example, at infancy, a baby will feel protected by a mother who attends to its needs, such as when they cry and need to be held. At times when the child is separated from their caregiver, the bond is at risk. At such time the child demonstrates behavior that will promote reconnection, such as crying. The response of the caregiver to such behavior allows for a blueprint for the child to learn to expect similar relationships and responses in the future.

*Secure Attachment* is characterized by trust and confidence between an infant and the caregiver (Bowlby, 1969). Comfort and intimacy along with ability to develop autonomy are at the core of a securely attached relationship (Feeney, 2000). During infancy, this relationship gives the child enough comfort and reassurance to allow the child to feel confident and seek independent exploration of the environment because they know they can rely on their caregiver if they become frightened (Bowlby, 1988). Pistole

(2010) elaborated and stated that when one exhibits needs, the caregiver is motivated to fulfill those needs by providing comforting and reassurance, or a secure base which can provide an anchor for personal growth (Feeney & Collins, 2004), as well as safety from any threat, either internal or external.

*Fearful* attachment style is characterized by efforts of an individual who tries to avoid connection with another person (Bowlby, 1969). More specifically in infancy, avoid contact with their mother (Petersen & Koehler, 2006). At its core, it is rooted in distrust and fear of rejection (Feeney, 2000). This distrust develops as the result of the child having needs such as protection or closeness from the caregiver and the caregiver does not fulfill those needs. As an infant, the child appears to be uninterested in the caregiver's presence or departure since there is no comfort in their presence. At reunion, the child ignores the caregiver as well (Bowlby, 1988). When separation from the caregiver is extended, distress becomes intense (Renn, 2002).

*Preoccupied Attachment* style is observed as a pattern of attachment in which anxiety and ambiguity keep one person clinging to another (Bowlby, 1969). It is characterized by a person appearing to be over-dependent with a desire for excessive closeness (Feeney, 2000). This is often seen in an infant who resists active exploration. Such a child will tend to get very upset at separation from their caregiver, however at time of reunion they both resist and seek connection with the caregiver simultaneously. This is formed when a child needs closeness from their caregiver and the caregiver does not fulfill that need. The child then becomes clingy as they do not have the confidence that they will be received when desired. Such insecurity exhibits great ambivalence in approach and avoidance tendencies as one learns to negotiate levels of closeness

(Mikulincer, Shaver, Bar-On & Ein-Dor, 2010). The attachment while motivated by the desire and need for closeness, is filled with fear of rejection and potential abandonment (Mikulincer & Shaver, 2007).

*Dismissive Attachment* is a style of attachment that views relationships as being unimportant. While the person has a high view of themselves and great self esteem, they tend to view others in a negative light. People with Dismissive attachment style were raised feeling that they could not trust their caregiver and therefore tend to have issues with trusting others in adult life (Fiori, Consedine & Magai, 2009).

### ***Attachment and Grief***

According to Bowlby (1980) intense emotions, such as a child crying at separation, occur during formation of relationships with one's attachment figure, as this is the time that great focus is placed on the relationship. Additionally, the child's needs are met through this interaction. The same is evident in the maintenance and disruption of these relationships. Bowlby (1980) pointed out that such intense emotions are experienced during a time of serious sickness, when a child is removed from the home and sent to the hospital. In such a case there is potential disruption in the attachment relationship. This is evident especially when parents are not able to stay with their child at the hospital, or when only one parent is able to be by the child's bedside.

Bowlby (1980) defined grief as a response to the demands of adapting to a new situation. The grief response is an emotional experience in which individuals are drawn toward something that is missing (Parkes, 1993), such as the idealized concept of the healthy child the parents had or desired.

According to Dunne (2004), when a loved one dies, people still remain attached to the idea of the living person. The survivor begins to question their own value independent of the attachment figure that was lost. Healthy mourning happens when an individual is able to accept that a change has taken place as well as recognize that his or her attachment behavior must adjust accordingly (Bowlby, 1980). Healthy mourning is a process in which a person reorganizes relationships, rather than detaches completely (Field, 2006).

Regarding attachment, grief is viewed as separation anxiety due to a disruption in the attachment bond (Middleton, Raphael, Martinek, & Misso, 1993). Bowlby (1969) described parallels between the process of grieving the death of a loved one and the mourning experienced by infants when a parent is temporarily away. Thus, when an adult experiences bereavement, it is a similar emotional experience to that of a child who is left by their primary caregiver. The difference however is that adults are usually able to negotiate the grief and reorganize their attachment relationship, but they use the same attachment mechanism to do this. They are able to evaluate the relationship and the meaning it had. As adults reach grief resolution, the loss does heal and hope returns with energy to develop new attachment relationships (Nelson, 1998).

Adapting to the loss of a loved one is a slow and painful process (Field, 2006). According to Bowlby (1980), news of the death of a loved one leads to activation of the attachment system. The bereaved tries to reunite and re-experience the attachment system (Archer, 1999). This could be done through maintaining a relationship with the person who passed away, through conversations with the person, discussions with others



regarding the person who passed, or any other method that maintains closeness to the person who is no longer living.

Marris (1991) discussed that attachment and making meaning go hand in hand. The search for meaning is often seen in parents of children with hematological and oncological illnesses. Attachment arises from the most crucial relationships through which we learn to organize meaning. Furthermore, loss that disrupts the core purposes in life aggravates grief. It is a painful and ambivalent process, causing one to reflect on the meaning of what has been lost. Primary caregivers of children with hematological and oncological illnesses search for meaning, as they exist in the uncertainty regarding their child's health outcome.

### ***Types of Attachment Styles and the Impact on Grief***

When it comes to grief, securely attached individuals tend to be more resilient than those with other attachment styles (Uren & Wastell, 2002). If they have a secure base of strong attachment, they are able to put death in context and embrace the relationships they once had and enjoy the relationships that are in the present. That said, it is not uncommon, especially for women, to maintain an emotional relationship with their deceased child, even four years after death (Rubin, 1984). Field (2006) elaborated by stating that bereaved parents often keep the room of the deceased child exactly the same as it was at the time the child was alive, for long periods of time.

According to Uren and Wastell (2002), prolonged distress after the loss of a loved one is associated with higher levels of dependency in close relationships such as is typically seen in the *Preoccupied Attachment* styles. People who were greatly dependent

on the deceased, especially those who counted on the deceased for emotional support, appeared to experience greater levels of grief (Hagman, 1995). In cases of such cases, emotional turmoil seems to be more prominent in the grief process (Horowitz et al., 1984).

In the case of *Fearful Attachment* style, the individuals adopt a guarded attitude toward the relationship, which leads to a reserved style of grief or no visible grief response at all (Servaty-Seib, 2004). A Fearful style of expression is often used to keep the pain reduced when reminded of the loss (Field, 2006).

### **Attachment Styles and Ambiguous Loss**

The experience of primary caregivers whose children have hematological or oncological illnesses is examined through the lens of Ambiguous Loss theory. However, the experience of Ambiguous Loss is examined from the perspective of attachment theory. This study hypothesizes that different types of caregiver attachment styles will influence the way caregivers experience Ambiguous Loss. While the current literature on attachment discusses grief, it does not discuss Ambiguous Loss or the experience primary caregivers go through when their child is chronically ill, potentially dying, yet living.

### **Ambiguous Loss Theory**

The following section discusses Ambiguous Loss Theory. As part of the theory the concepts of Mastery, Family Stress Theory, Boundary Ambiguity and Identity Ambiguity will be discussed, in order to provide a greater understanding of the experience parents have when their child is suffering from a life threatening illness.

In 1971, Pauline Boss studied families of soldiers missing in action. The phenomenon of the grief that takes place when “a person is both physically present and psychologically unavailable, or psychologically present, yet physically unavailable” (Boss, 1999, p. 11), Boss conceptualized and referred to this phenomenon as *Ambiguous Loss*. As she was training with Carl Whitaker, in 1972, boss observed patterns in families in which the fathers seemed to be distant or absent (Boss, 2004). Such ambiguity impacted children greatly. Following the original study, a broader idea of Ambiguous Loss was developed by Boss (2004) to described situations in which a family member is present, yet not emotionally available or engaged with others. Since then, Pauline Boss together with other scholars, has advanced the theory further. Ambiguous Loss explains experiences of families with missing children (Fravel & Boss, 1992) families with foster children (Lee & Whiting, 2007), children separating from parents (Luster, Qin, Bates, Hohanson & Rana, 2009) families dealing with chronic illness (Boss & Couden, 2002) mental illness such as Alzheimer’s disease (Dupuis, 2002) autism spectrum disorders (O’Brien, 2007), mixed orientation marriages (Hernandez & Wilson, 2007) and the breakup of lesbian couple (Allen, 2007). Ambiguous Loss continues to offer a solid framework to understand phenomena that take place and impact the family system. The theory allows us to understand relationships that are ambiguous, such as the emotionally relevant but physically absent relationship families have with missing soldier.

The main difference between ordinary loss and Ambiguous Loss is that ordinary loss allows for the grief process to get resolved, while Ambiguous Loss does not (Boss, 2004). Ambiguous Loss is a loss that is unclear (Boss, 2007). It is incomplete, confusing and often uncertain (Boss, 1999). At the core of the theory is the idea that a state of

uncertainty is traumatizing for both the individual and the family as a system. The ambiguity of the situation makes closure impossible, as the natural process of grief is not allowed to take place (Vargas, 2008). As explained by Sobel and Cowan (2003) the ambiguity of the loss interferes with making meaning of what is taking place. Without meaning, there is no resolution. Blieszner, Roberto, Wilcox, Barham & Winston (2007) and Boss (1999) view Ambiguous Loss as the most stressful loss. This is due to the fact that there is no resolution and it creates a confused state in the family system regarding who is and who is not part of the family unit. In the case of an ordinary loss, having a death certificate and certain mourning rituals, provides more tangible clarity as well as an opportunity to honor the dead and provide closure for the family. With Ambiguous Loss, questions are left unanswered and these rituals do not take place. Closure is unachievable.

Ambiguous Loss is more stressful as neither the ambiguity, nor the situation ever lets up (Boss, 2006). Such grief has been referred to as *complicated grief*, which could become chronic in nature (Hernandez & Wilson, 2007).

In the case of terminal illness of a child, the ambiguity stems from the situation that the family members perceive the child as being physically present, yet psychologically different from the child they know and love. The perception of the healthy child the family once knew no longer exists. According to O'Brien (2007), parents have to adjust to the idea that the child they thought they had is not the child they now live with. Parental expectations at this time have to change. It is through Ambiguous Loss theory that one can understand the emotional stress and turmoil experienced. If the experience is highlighted the family can then understand and deal with such an ongoing loss (Dupuis, 2002).

### *Mastery and Ambiguous Loss*

When we are unable to control things in our lives, we are ill prepared to come to terms with them (Boss, 2006), such is the case with being unable to control a child being diagnosed with a life threatening illness and the Ambiguous Loss associated with such an illness. Mastery in such a case seems to be the last thing one has in their lives. Mastery according to Pearline (1995) is one's feeling of having control over their lives and a sense of agency regarding their wellbeing. We live in a society that promotes a desire for a sense of mastery, without acknowledging that some issues are out of our control and cannot be fixed. Most people have a difficult time tolerating situations that are out of their control (Boss, 1999a).

When dealing with loss, the goal is often to achieve closure, which is gained through the process of gaining mastery. Many dealing with Ambiguous Loss are not able to entertain the idea of closure. Thinking of the possibility their child may die, is often too overwhelming for parents to face. Instead Becvar (2001) suggested that people have to learn to integrate grief into their lives. Individuals require some level of mastery to have a sense of their ability to survive a crisis, but at the same time, ambiguity must also be accepted. As stated by Boss (2006), when dealing with Ambiguous Loss, closure is not an option. The ability to master some aspects of life helps people whose ambiguous circumstances defy understanding.

The issue of resiliency is relevant when dealing with trauma, stress and Ambiguous Loss. People manage such situations depending on their perception regarding how they can cope and have control in their lives (Pearlin & Schooler, 1978; Pearlin, Menaghan, Leberman & Mullan, 1981). It is important to note that the more people value

their ability to have power and control, the more troubled they are when faced with an Ambiguous Loss that has no immediate resolution or sense of closure. Pearlin (1995) discussed that mastery is extremely important when facing stress particularly in circumstances that are confusing and in which their best efforts do not make appreciable inroads. Mastery allows a person to have a sense of control and feel less helpless when dealing with a situation that is out of one's control. Another benefit of mastery is that one envisions their ability to overcome obstacles and will act accordingly with great strength and tenacity. Having a sense of mastery can help with symptoms of depression and feelings of helplessness.

It is often difficult to accept the idea that some problems cannot be solved. When dealing with Ambiguous Loss, one must accept the inability to solve the problem, while negotiating one's need for mastery. In other words, one must accept a situation as it is. As Boss (2006) stated, one must be flexible and choose to accept the ambiguity, rather than having full control or being completely helpless. The goal when dealing with Ambiguous Loss is to live with the situation, even though there is no closure.

### **The Balance of Mastery**

There is a fine balance between too much or too little mastery, as either extreme can prove to be harmful. According to Boss (2006) one must be able to live with loss and ambiguity, while maintaining the desire to get through the trauma and Ambiguous Loss and resume life as normal. Mastery must be modified when trying to handle Ambiguous Loss. As one cannot feel a great sense of control while embracing the ambiguity experienced.

The pursuit of too much mastery is often seen when people strive for perfection, which is an unattainable goal in life and especially when dealing with Ambiguous Loss. On the other hand, not striving for enough mastery is seen as one being too passive. This could be seen by someone just waiting for a miracle, rather than actively seeking avenues to make changes in a difficult situation. The ideal goal, when dealing with issues that involve mastery, is to have a healthy level of active coping, while accepting the ambiguity of the situation. For example, with a child facing a life threatening illness, it is helpful to look for potential cures, while accepting that the child may not survive. Having some mastery skills allows one to examine all options. However, as time goes on, one must reexamine the situation and potential for healing, while accepting the reality of the disease.

### **Mastery and Culture**

There is a cultural element to the need for mastery. Some cultures value mastery and control in a person's life (Zarit, Pearlin, & Schaie, 2003). In such cases, the stress of Ambiguous Loss is even greater and can be traumatizing. The more people and culture value control and mastery, the more difficult it is for them not to have clarity or closure when they are accustomed to directing their own lives.

Cultural values, religious and spiritual beliefs, as well as individual personality, all influence the degree people are able to handle ambiguity in their lives without experiencing incapacitating stress and ambivalence (Boss, 2002; Boss & Kaplan, 2004). Some cultures, that are spiritually focused, as well as emphasize social support, allow for more ambiguity in one's life, as society maintains a tight structure supporting the family

as they experience Ambiguous Loss. When it comes to one's personality, those who have a greater need and focus more on mastery and control in their lives, will have a more difficult time dealing with Ambiguous Loss, as that sense of control is taken away. In addition one's personality characteristics, their genetic makeup as well as one's ability to adjust to change impact the way one can tolerate ambiguity in their lives (Afifi & Keith, 2004).

### ***Pauline Boss's Family Stress Theory***

Ambiguous Loss has great potential to inflict stress on the family system. Pauline Boss defines family stress as "pressure or tension, disturbance in the steady state of the family" (Boss, 1988, p. 12). Hobfoll and Spielberger's (1992) stated that research on family stress has focused on stressors such as illness, which have great possibility to create ambiguity. According to Boss (1992), change in itself is not a cause for stress in the family system. Therefore change alone may not cause strain on the family. However, other changes, more specifically loss, can become an issue within the system.

Patterson (1988) discussed family resources as a determining factor in how stress impacts the family. However, according to Boss (1992) availability of family resources is not the only determining factor in predicting how families will manage a crisis. The family's definition of the event seems to have far more of an impact on the family.

Hobfoll and Spielberger (1992) stated that the demands an event places on the family is what creates stress on the family. Boss (1992) does not think that such demands alone deplete the family's resources. She stated that even through difficult times, positive



family life can be maintained. Things become problematic when there is an imbalance between the family system's stress in relation to their resources.

It is important to remember that both researchers and counselors focus on unpleasant events families go through and the negative impact these have on the family. However, according to McCubbin and Boss (1980) most families cope well with crisis and have a natural ability to recover. We therefore focus on what aspects promote the family's healthy adaptation.

According to Boss (1992), even if one member of the family is having a difficult time managing stress, the whole family is not managing the situation in the best manner. Boss therefore explored both the individual, the family as a whole system and their interactions, in order to understand family stress.

Ambiguous Loss is a major family stressor (Boss, 1992). The degree of ambiguity is what sets the stage for the impact on the family. What happens when the family cannot gain clarity regarding a loss? The family system freezes, there is no structural reorganization and the boundaries within the system cannot be kept. The individuals within the system are stuck until they are able to restructure which family members are in and which members are out of the unit. When dealing with Ambiguous Loss, perception plays a large role in the family's frozen state (Boss, 1992; Boss & Greenberg, 1984).

### **Family Stress and Mastery**

Boss (1992) suggested that family stress theory together with the concept of learned helplessness (Seligman, 1975) and the idea of mastery (Pearlin, Menaghan, Lieverman & Mullam, 1981) underlie the experience of Ambiguous Loss. She also

suggested that the individual and family perceptions impact family stress. It is through the perception of the situation, which is reported by the family members, we can understand which families will demonstrate resiliency through the event and which families will not.

To understand family stress, one must understand the family's mastery over a situation (Pearlin, et al., 1981). Families are not in a position to use their resources unless they believe their actions will have an impact on their stressor at hand.

### ***Boundary Ambiguity***

In the literature, the way family members perceive Ambiguous Loss and the confusion and change in one's membership in the family unit is referred to as *Boundary Ambiguity* (Boss, 1999; Caron, Boss & Mortimer, 1999; Kaplan & Boss, 1999).

Ambiguous Loss can lead to Boundary Ambiguity. This is a situation in which members are uncertain regarding who is in or out of the family circle (Boss, 2006). Such confusion can reduce the family's level of functioning and resilience. Parents may look at their child who is sick and be uncertain whether or not he is going to be in or out of the family unit. The shocking realization that their child may not survive the illness hits them. This begs the question for primary caregivers: Is their child dying or is he a recovering child? Is the caregiver about to become childless or are they still going to be a parent to the child?

Another aspect of Boundary Ambiguity is role change. When a child is sick with a potentially life threatening illness, roles of various family members are different. As primary caregivers are in the hospital and preoccupied with the sick child, another child

at home may take on the caretaker role and run the household leading to parentification of that child. In the relationship between the parent and the sick child, there may be Boundary Ambiguity as well. For example, when the child is under medical care, specifically in the hospital, it can often seem unclear who is responsible and who is making decision for the treatment of the child. Is it the doctor and nurses or the primary caregiver? On the one hand, the caregivers turn to the medical staff for guidance as to how the child should be treated. On the other hand, it is ultimately the caregiver's responsibility to protect the child, even though they may feel a great sense of powerlessness in relation to the medical staff.

As stated by Boss (2006), the larger the discrepancy between one's physical and psychological presence, the higher the risk for Boundary Ambiguity. The more roles are confused, family obligations tend to be placed on hold, and the whole system seems stagnant (Boss, 2006). In the case of childhood illness, this issue could become more problematic when the child is removed from the home and is hospitalized. Obligations such as paying bills, attending social functions, participating in sports activities and hobbies, all get placed on hold during such a crisis. When one thinks of "family", other children may question whether the hospitalized child has the same role power or input as they do, since that child has been removed from their daily lives (Doka & Aber, 1989). Does the sick child get more attention due to their illness? Or does the child at home gain more power as they are now running the household and have less parental supervision?

High levels of Boundary Ambiguity put individuals and families at risk for poor stress management (Boss, 2002). Due to Boundary Ambiguity, family boundaries change, roles become confused, tasks at hand do not get accomplished, important decisions are at

times postponed (Boss 1999) and the family as a whole starts to feel powerless as they become less connected and the household is more disorganized. Both the coping and grieving processes are placed on hold (Boss, 2004). The family focuses only on what has to be attended to, which is usually the illness, with little space given to thinking about the potential death of the child. The focus is on care, hope and treatment. Due to the ongoing demands of the illness and the frozen state that is created in the family system, Boundary Ambiguity can often predict depression in caregivers (Boss, Caron, Horbal, & Mortimer, 1990; Kaplan & Boss, 1999). An association has been reported between parental uncertainty of the child's illness, levels of boundary ambiguity and one's sense of depression (Carroll, Olson & Buckmiller, 2007). The confusion created by Boundary Ambiguity within the family system can become more taxing on the family than the actual illness (Blieszner et al., 2007; Dupuis, 2002).

### ***Identity Ambiguity***

A result of Ambiguous Loss can be, as referred to in the literature, *Identity Ambiguity* (O'Brien, 2007). Identity Ambiguity impacts the family relationships and is related to Boundary Ambiguity, which was previously discussed. In both Boundary Ambiguity and Identity Ambiguity family roles may have changed and may be unclear due to the illness the child is suffering. O'Brien (2007) defined Identity Ambiguity as the overlap between parental identity and the identity of their children. Identity Ambiguity is a situation that takes place when the identities of both parent and child become unclear and their relationship changes. This change in interaction happens at times as a result of the experience of Ambiguous Loss. When parents experience Ambiguous Loss due to

their child's illness, the roles of the parents and the child change. For example, parents may become more lenient when it comes to discipline; the child may be the one who dictates what is going to happen and when due to her physical needs. In addition, parents are expected to experience higher levels of distress following the child's diagnosis. In some cases parents take over the responsibility for all aspects of the child's life, which leads to a blurring of the boundaries that should exist between them and their child.

Identity ambiguity is associated with immobilization, depression symptoms, a sense of being overwhelmed, as well as difficulty adapting to change (Boss, 2006). Therefore parents who experience Identity Ambiguity due to a child's terminal illness could potentially have difficulty in making decisions regarding the child's care.

### *The Emotional Impact of Ambiguous Loss*

Ambiguous Loss is not a mental illness (Boss, 2004). It is a situation in which an untenable situation causes stress that could potentially be debilitating. Ambiguous Loss can create alternating feelings between hope and hopelessness (Boss, 2004 ;O'Brien, 2007), confusion, uncertainty (Faber et al., 2008), and ambivalence (Lee & Whiting, 2007). Such an experience could lead to feelings of guilt and anxiety, causing a sense of being in a frozen state (Boss, 2004). For example, when asked about feelings at different stages after being given the diagnosis of their child, mothers reported experiencing simultaneous contradictory emotions such as frustration and joy (O'Brien, 2007). The symptoms are the result of the ongoing stress of having to live with no answers (Boss, 2004). However, pathologizing individuals for the inability to move on, while facing ongoing uncertainty, is unhelpful. When using the Ambiguous Loss framework, such

emotions are normalized and allow for a new way of understanding the situation in which the loss is taking place (Allen, 2007). It is beneficial to remember that the ambiguity of the situation, not the psychological wellbeing of a person, is what contributes to the perception of the stress and leads to insufficient functioning.

### ***Ambiguous Loss as a Relational Theory***

Ambiguous Loss is referred to as a “relational disorder” rather than a “psychic dysfunction” (Boss, 2007, p. 106). Ambiguous Loss holds a relational perspective in that it impacts the family as a system. While the loss may be attached to a specific individual, such as the child diagnosed with a life threatening illness, the loss impacts the whole family, parents, siblings and extended family. The family as a system becomes preoccupied with the illness. There are both physical and psychological demands that are placed on family members. The family tries to predict what will happen to their loved one. In addition, due to the preoccupation of the family with the illness, there is often a dissolution of family rituals and family traditions that created unity and a sense of family identity.

Ambiguous Loss as well as Identity Ambiguity focus on the relationships that have changed due to ambiguity that suddenly exists. For example, the role of a child changes when he or she has a terminal illness. There is lack of clarity regarding whether they are in or out of the family. The child is alive, but potentially dead as well. She may appear to be well but is really deathly sick. If she is “in”, or a full member of the family, then the questions becomes, for how long? Such ambiguity impacts the direct relationship

the parents and other family members have with the child, as well as relationships within other family subsystems, as there is a shift in filling the potential void.

Ambiguous Loss is not considered to be a traditional family theory. However, it helps us conceptualize family and relational processes that are caused by the ambiguity at hand. Ambiguous Loss holds a relational perspective that unending, confusing loss impacts the family as a system (Boss, 2007). Therefore, individual and family level assessment should be conducted to understand the impact of Ambiguous Loss (Boss, 2004).

Family members experience several phases, as they deal with an ongoing loss of their loved one to illness (Dupuis, 2002). Boss (2002) suggested that a high level of confusion regarding the causes of the disease and the high level of ambiguity puts the family at risk for decline in individual as well as relational well being. It impacts the perception of relationship as well as contributes to the stress and trauma the family experiences (Blieszner et al., 2007). It is important to note that according to Faber and colleagues (2008), the stress of the illness does not act directly on the family. It is the perception of the situation that determines how well the family will cope as a unit. The preoccupation and sense of wellbeing consumed by the illness puts strain on the individuals as well as the relationships within the family. An example is when each family member accepts the illness in a different way. One may accept that the illness is terminal, while another may cling to hope. Such contradictions have a strong potential of straining family relationships (Boss, 1999).

Another aspect of Ambiguous Loss as a relational theory is that it addresses social relationships at large. As people are unable to predict what will happen with the child's

illness, they often become preoccupied with the situation, which could actually lead them to detach and reduce communication within the family. As parents often do not completely understand what is happening with their child's illness or what the future holds, they often isolate themselves and shy away from potential insensitivity of others. Society and friends fail to recognize the parental loss and emotional experience more often than not. This too contributes to the social withdrawal families experience. Therefore, due to the ambiguity created by a life threatening illness, relationships often dissolve. While friends and acquaintances may know how to support one experiencing an ordinary loss, they do not know what to do or say when the loss is ambiguous.

### *Ambiguous Loss Process*

According to Dupuis (2002), Ambiguous Loss involves a long and painful grieving process. It is an ongoing and uncertain process in which there is often confusion that takes place partially as there is no end in sight. It is an emotional rollercoaster where one attempts to predict and impact the course of the illness, experience of hopelessness followed by a glimpse of hope revived by a potential cure and improvement in the child's condition. People tend to experience difficulty with the lack of predictability and uncertainty the illness brings, while experiencing great distress wondering what is ahead for them and their child, while all along hoping for a cure, which will give back to them the healthy child they had. Some people however are able to accept the Ambiguous Loss they are experiencing. Those people are able to live without mastery or having a solution to the issue they are facing (Boss & Couden, 2002).



For example, primary caregivers experience anticipatory loss when their child is diagnosed with a potentially terminal illness such as AML, which has a high mortality rate. The caregivers wonder what the future holds for their child and whether he or she will survive this illness or not. The lack of predictability and the fear of what is ahead causes great distress for the caregivers. Slowly however, as the child's illness progresses and the caregivers experience the great suffering, they often reach the stage where they acknowledge the loss and accept it, still however they cannot give up completely and cling to hope. Such acceptance is similar to the caregiver's acceptance of a parent with Alzheimer's disease, which is described by Boss (1999) where the person is physically present yet fundamentally different in mind (Abrams, 2001). In such a case a progressive adjustment to the loss takes place while the ambiguity of the situation holds them in the experience of Ambiguous Loss.

### ***Culture and the Impact on Ambiguous Loss***

As stated by Hernandez and Wilson (2004), one's cultural context impacts Ambiguous Loss. Culture and ethnicity defines who is included the family and where their boundaries will be placed (Boss, 2004). It is the cultural beliefs as well as values that influence the level of tolerance the family has for ambiguity (Boss, 2007).

Culture often dictates the way we grieve our losses. Here in the United States, people are often judged by the way they grieve the losses they experience. An example is seen regarding criticism of people who take longer to grieve than others think they should. As stated by Boss, 1999a) "Grieving is acceptable – but we should get over it" (p.5). Grief resolution becomes very complicated with Ambiguous Loss, as stated by

Boss (2004). Indeed, resolution is not often a realistic goal in these cases. However, the more one insists on resolution, the more the families tend to resist. In the United States however, there is great desire to fix and solve situations quickly. Such an outlook contradicts the process needed to grieve a loss. When a child is sick with a long-term illness and with an unknown outcome, grief resolution is not possible. Parents are unable and do not want to grieve their loss, as they feel guilty grieving for a child who is still alive. There is the belief that is supported by society that they must think positively, and not focus on the potential death. Therefore even the grief of the healthy child the parents once had, is not processed. It is a loss that cannot be acknowledged in an open manner (Sobel & Cowan, 2003).

While society understands the severity of hematological or oncological illnesses, there seems to be a sense of confusion regarding the parents' sense of loss, as the child is still alive. As stated by Hernandez and Wilson (2007), there is often little community support and lack of validation with Ambiguous Loss which compounds one's traumatization and a sense of invisibility. Society does not recognize or validate the grief experienced by the population described (Sobel & Cowan, 2003).

This is evident in primary caregivers dealing with the potential death of their child. When the caregivers need the social support more than ever, society may not be able to provide the support they desire. This promotes isolation the family members feel from society, as they are not receiving the needed support, recognition, or understanding of their experience.

### ***How to Cope with Ambiguous Loss – Holding Two Opposing Views***

Boss (2004) discussed the term *mastery and control* as they relate to Ambiguous Loss. The idea is that most people leading a productive life enjoy a sense of mastery and control over what is going on in their lives. This could be seen in one having a routine, continuing traditions and celebrations. According to Boss (2004) and Faber et al. (2008), the stress of an ambiguous situation, seems to be more devastating and harder to cope with in families who tend to lean towards having a greater need for mastery and control. People, who are often in control, are able to fix situations, and have a history of solving problems, seem to have a difficult time tolerating the ambiguity that is caused due to the lack of predictability of the illness. It may be that the idea of such tolerance is foreign to those with power and control, while the less fortunate and less powerful have become more adaptable through life's hardships.

As we understand the impact and process of Ambiguous Loss it is important to gain insight within the theoretical context how one can best cope with such a situation. A way to strengthen the family's resiliency, which means being able to live with unanswered questions in face of the uncertainty, is to be able to tolerate all possibilities presented by the ambiguity (Boss, 2007). A resilient family is described by Abrams (2001) as one who is able to create an environment of love and support, while facing the threat of a loss.

According to Allen (2007), when suffering Ambiguous Loss, one must embrace the contradictions in the situation they face. One must learn to tolerate two contrasting ideas at the same time (Boss, 2004) which allows one to get out of the frozen state of an

either or way of conceptualization of the situation. From an attachment perspective, securely attached individuals are able to tolerate such ambiguity.

When dealing with a child's potentially terminal illness, the family must mentally hold the idea of the child being alive and present within the family system, while being prepared for possibility of their death. On the one hand the child is dying and on the other hand he or she may still be an integral member of the family and might not even appear to be ill. O'Brien (2007) described the challenge presented to parents as they try to both accept the reality of the permanent nature of their child's illness while maintaining optimism regarding improvements that can be made through medical or alternative interventions. The family must live with the unanswered questions, deal with the ongoing confusion, and face the painful emotions that result from living in such a situation. Not every member of the family has to tolerate the uncertainty in the same way in order to move forward (Boss, 2004; Dupuis, 2002). However, if the family members are not at the same level of acceptance regarding the illness, this can contribute to other difficulties within the family system.

Having a child who is diagnosed with a hematological or oncological illness can be all consuming for the primary caregivers and to the family as a whole. Families dealing with such an illness find themselves spending a great amount of time at medical facilities and attending to the illness. There is emotional taxation as well. Therefore, between the physical and emotional toll they must endure, families often skip rituals and family-bonding activities in order to focus on enhancing the survival of their child or attending to pressing household management issues. However, Boss (2004) discussed the importance of continuing family rituals and symbols. These are the core of family life

and are helpful in reconstructing family interaction and allow for family reconnection when experiencing Ambiguous Loss. Bliezner et al. (2007) recommended reclaiming daily routines, household responsibilities, and social interactions, to promote emotional stability within the family unit.

### *Application of Ambiguous Loss Theory*

In this study, the unique experience of primary caregivers when their children have been diagnosed with a hematological or oncological illness, is examined from the Ambiguous Loss perspective, more specifically Identity Ambiguity. As stated earlier, Identity Ambiguity is a result of Ambiguous Loss, in which the roles within the family become unclear due to the Ambiguous Loss created by the illness. Identity Ambiguity will be examined from the lens of Attachment Theory, in which each primary caregiver's attachment style will be determined and examined to see whether it impacts one's experience of Identity Ambiguity. Ambiguous Loss theory was chosen since anecdotally, parents whose children are diagnosed with a life threatening illness experience great ambiguity surrounding the illness. The caregivers who receive such a diagnosis feel great sadness as they mourn the loss of their healthy child, even though their child is still alive and any form of grieving is socially unacceptable. As Boss (1999) stated "It feels like a loss but it is not *really* one" (p.11). On the one hand, primary caregivers must be hopeful that their child will overcome the disease, while at the same time come to terms with such a potentially horrific life sentence. Holding these two opposing thoughts is required of parents and creates a great sense of loss, confusion, and helplessness.

## Conclusion

Having a child with a life threatening illness is the closest experience primary caregivers can have to losing a child, which is the most horrendous loss. Attachment styles impact the way one interacts within relationships, and how one responds to crisis, such as when a child has a potentially terminal illness and to grief. Attachment issues and disruption of the bond between the child and caregiver are viewed when a child is suffering with a life threatening illness, and caregivers adapt to the new reality that the child is no longer healthy.

The author hypothesizes that different styles of attachment impact grief and they influence the experience of Ambiguous Loss. Primary caregivers with different styles of attachments will perceive the illness and potential outcome in different ways. When a child has the potential to be terminally ill, those with a secure attachment style, will most likely be able to gain strength from prior and other current relationships and be able to maintain the idea that their child is with them, but in a different way than he or she once was. Such caregivers are able to put the illness in context and can embrace relationships they had with their healthy child while embracing a new relationship with their child who might either be dying or coming into remission. They will be able to hold to two opposing views where the child is present and may get better, yet may die. People with Preoccupied attachment styles are at higher risk to be unable to cope with the Ambiguous Loss and suffer a great emotional impact. Emotional turmoil seems to be a prominent outcome rather than accepting the illness and the ambiguity. Primary caregivers with a Fearful attachment style are at risk of detaching from the child, at a time in which the child needs most care and protection. Such caregivers may have a guarded attitude.

Finally, people with Dismissive attachment style, who have a difficult time trusting others will have a difficult time adapting to the ambiguity of the illness and trusting the health care professionals to be able to assist them in their crisis.

As discussed in this chapter, attachment styles impact not only overall well being and relationships, but also the way one deals with grief and illness. Grief was examined specifically through the experience of Ambiguous Loss. Ambiguous Loss demonstrated the confusion a life threatening illness of a child can cause on both the individual and systems level in the family. Through examining Ambiguous Loss we see caregivers experience significant grief even when the child is alive, and not only after the child dies from a dreadful illness. It is the hope that the application of these theoretical frameworks will contribute to the understanding of the experience primary caregivers go through when their child has a life threatening illness, as well as raise social and professional awareness.

## CHAPTER THREE

### METHOD

The current study is a mixed-method study with the purpose of gleaning a greater understanding of the relationship between attachment styles and the Ambiguous Loss phenomenon experienced by primary caregivers of children afflicted with life threatening illness. A mixed- method research design was used as it allows researchers to offset the limitations and weaknesses inherent in strictly qualitative or quantitative research designs (Ngulube, Mokwatlo & Ndwandwe, 2009). Several assessment tools were used for the quantitative analysis in conjunction with four structured, open given to couples where both partners were present for the qualitative section of the study. Using both quantitative and qualitative methods allows for a more holistic and dynamic understanding of the topic studied.

Qualitative research according to Tashakkori and Teddlie (2003), is often referred to as exploratory research while quantitative research are viewed as confirmatory research. According to Punch (1998), qualitative research has focused on generating theory and quantitative research used for theory verification. A great advantage of mixed method research is that it allows the researcher to answer confirmatory as well as exploratory questions. By doing so, the study conducted both created and verified hypotheses in one study. Combining qualitative and quantitative methods provides insights and greater understandings that otherwise might be missed when using what is referred to by Ngulube and colleagues (2009) as a “mono method” (p. 105).

Through the use of a mixed-method approach, the gap between qualitative and quantitative methods is bridged, and allows answering research questions in a more



holistic manner (Ngulube, et al., 2009). In the case of a study examining the grief experience of parents of children with a potentially life threatening illness from the lens of attachment styles, a mixed-method approach was beneficial. It allowed the researcher to simultaneously demonstrate that the two variables (grief and attachment) have a predicted relationship while at the same time allowing one to answer exploratory questions regarding the depth of the grief experience and provide greater understanding of the phenomenon (Tashakkori & Teddlie, 2003). By doing so, a mixed method design allowed confirmation of a quantitative hypothesis, while exploring in depth the process of how the relationship takes place.

### **Recruitment**

While the power analysis for this study indicated the need for 63 participants, the following mixed method study examined the experience of 106 participants to ensure a larger sample. The participants were primary caregivers of children under the age of 18 diagnosed with a hematological or oncological illness, such as Acute Lymphoblastic Leukemia, Brain Tumors, Hodgkin Disease, Neuroblastoma or Thalassemia, to name a few. While the caregivers were the subject of the study, the criteria inclusion was that their child is a patient who is treated at the Loma Linda University Medical Center Pediatric Hematology Oncology Clinic (LLUMCPHOC). The children were at various stages of the illness, which included children who were recently diagnosed, children who were currently receiving treatment, children who were considered to be in remission and those who are cured and receiving follow up care from a hematology-oncologist.

Caregivers were of various ethnic background, education level, and income. The only criteria for inclusion or exclusion for the study was the diagnosis of a child as mentioned above, and their current treatment at the LLUMCPHOC.

The data collection was obtained at the LLUMCPHOC, where the researcher recruited participants. The investigator approached parents and guardians in the waiting room of the medical office, while waiting for the physician. An informed consent, a resource sheet as well as a survey was handed to one or both parents who brought their child for treatment or physician check up. The caregiver received a brief explanation regarding the study as well as the significance of their participation. They were advised regarding the benefit of their participation in contributing to a body of knowledge, which will benefit other parents in their similar predicaments. A monetary incentive was offered to the parents who returned their complete survey package consisting of an entry into a drawing for a \$100 gift certificate to Target store.

For the qualitative portion of the study six couples out of the participants, were given a survey that included the additional four open ended questions. The couples selected were be currently married or cohabitating and were both present at the LLUMCHOPC at the time of the study.

### **Procedures**

The study was conducted at the LLUMCPHOC. Data was collected over a one month period. A survey packet was given to primary caregivers of children treated at LLUMCPHOC, during their clinic check up. Each packet included (1) an instruction letter explaining the need for the caregiver to participate in the study which included a

resource sheet providing contact information for clinical consultation in case of participant distress as a result of inclusion in the study (2) a consent form (3) and the following quantitative instruments: The Parent Experience of Child Illness (PECI), The Grief Experience Inventory (GEI), Identity Ambiguity, the Experience in Close Relationship (ECR) and Demographic Information Sheet (DIS) that includes demographic questions.

Six couples were selected to participate in the qualitative portion of the study. These participants received in addition to the regular survey, four open ended questions. This was done in order to validate findings that are relevant to the couple relationship. The questions included were: “What kinds of challenges have you had as a result of having an ill child?”, “Has there been any impact on you as a couple to have a child with a serious illness?”, “What do you think is important for other couples with a child with a life threatening illness to do or to know about how to have a good relationship?” and “Is there anything else about being in an intimate relationship and having an ill child that I didn’t ask you, but that you would like to discuss?”

While the study examined sensitive issues, it is important to note that the information contained in the survey did not differ from the type of information presented to caregivers by the medical establishment, internet, media and other sources. Thus, caregivers eagerly volunteered to participate in the study. Participants were treated in accordance with the ethical guidelines stipulated by the American Association of Marriage Family Therapy (AAMFT), the Health Insurance Portability and Accountability Act (HIPAA), as well as the Institutional Review Board (IRB) of Loma Linda University.

## **Instruments**

The following section discusses the various instruments currently used in the literature that were used in the current study to measure the grief experience and attachment style of primary caregivers with ill children. The instruments measure Chronic Sorrow, Anticipatory Grief and Ambiguous Loss, as well as categorize one's attachment style. At the end of each instrument a reliability table for the current study is presented.

### ***Measuring Chronic Sorrow***

The PECEI (Bonner, Hardy, Guill, McLaughlin, Schweitzer & Carter, 2006) is a quantitative instrument that measures the experience of primary caregivers of a child dealing with oncological illnesses. The instrument was developed and tested in a division of Pediatric Neuro-Oncology and Pediatric Hematology-Oncology. The instrument uses Chronic Sorrow as the guiding theory to explain the caregiving experience relevant to a child with chronic, potentially life threatening illness. It measures significant aspects of the parental adjustment required in such a population.

This instrument is comprised of 25-items on a five point Likert scale ranging from "0" being *Never* to "4" representing *Always* (see Appendix A). Questions posed for example are: "I worry that any minute, things might take a turn for the worse" or "I think about whether or not my child will die." A high score indicates higher levels of Chronic Sorrow and implies greater difficulty managing the subjective emotions associated with their child's illness. The Cronbach-alpha of the scale is .84.

The instrument has four subscales and alphas include: (1) Guilt and Worry, with (0.89); Emotional Resources (0.72); Unresolved Sorrow and Anger (0.86), and Long term Uncertainty, (0.80).

It is the author's hypothesis that people with a Secure style of attachment, will have moderate Chronic Sorrow scores, while caregivers with a Preoccupied style of attachment, will show high levels of chronic sorrow. Finally people with Fearful styles of attachment will exhibit low levels of Chronic Sorrow.

Table 1.

*Reliability Table.*

Chronic Sorrow	Mean	SD	Cronbach's Alpha
Guilt and Worry			<b>0.832</b>
I feel guilty because my child became ill whereas I remained healthy	3.01	1.538	0.554
I worry that I may be responsible for my child's illness in some way	2.53	1.535	0.525
I worry that any minute things might take a turn for the worse	3.82	1.155	0.677
I worry about something bad happening to my child when s/he is out of my care	3.89	1.290	0.662
I think about whether or not my child will die	2.84	1.518	0.535
I am afraid of this diagnosis occurring in other members of my family	2.82	1.507	0.547
I trust myself to manage the future, whatever happens	4.25	1.155	0.040
When my child is actively playing, I find myself worried that s/he will get hurt	4.03	1.194	0.540
I wake up during the night and check on my child	4.13	1.124	0.450
When I'm not with my child, I find myself thinking about whether or not s/he is ok	4.37	0.993	0.543
I worry that my child's illness will worsen	3.84	1.231	0.515
Unresolved Anger and Sorrow			<b>0.651</b>
It is painful for me to think about what my child might have been like had s/he never gotten sick	2.92	1.405	0.596
I am at peace with the circumstances in my life	3.92	1.2	-0.282

Table 1. *Continued.*

I experience angry feelings when I think about my child's illness	3.02	1.449	0.444
I find it hard to socialize with people who do not understand what being a parent to my child means	2.72	1.485	0.560
I believe I will never be as completely happy or satisfied as I was before my child became ill	2.86	1.428	0.423
I am jealous of parents who have healthy children	1.93	1.261	0.471
Seeing healthy children doing everyday activities makes me feel sad	2.35	1.391	0.512
Long Term Uncertainty			<b>0.683</b>
I worry about my child's future	3.942	1.29	0.529
I worry about whether my child will be able to live independently as an adult	3.097	1.581	0.548
I have regrets about decisions I have made Concerning my child's illness	1.864	1.197	0.294
My hopes and dreams for my child's future are uncertain	2.456	1.467	0.537
Emotional Resources			<b>0.459</b>
I feel ready to face challenges related to my Child's well being in the future	4.25	1.123	0.356
I am aware of the specific ways I react to sadness and loss	4.07	1.027	0.306
I can get help and support when I need it	4.17	1.082	0.195

### *Measuring Anticipatory Grief*

The GEI was developed to examine the Anticipatory Grief experience of family members. Anticipatory Grief is relevant to the study as primary caregivers of children with hematological or oncological illnesses are often faced with the possibility of impending death of a child, either in the near or far future. Such a prognosis leads the parents to anticipate potential upcoming loss. A study of Anticipatory Grief, conducted by Gillian and Fleming (1998), was used to validate the GEI through spouses of both terminally ill and of chronically ill (not life threatening in near future). The illnesses included in the study were terminal cancer, Alzheimer's, stroke, Parkinson's disease and multiple sclerosis. The questions on this instrument will be adapted for parents of terminally or chronically ill children.

The GEI assessment tool is composed of two instruments: the Factors Influencing Adjustment Questionnaire (FIAQ) and the Background Information Questionnaire (BIQ) (See Appendix B).

#### **The FIAQ**

The FIAQ is a 23-item multiple choice questionnaire that examines variables that influence grief responses and that are associated with higher risk levels for complicated or nontraditional grief reactions. Lower scores on this questionnaire indicate better functioning on the participant's part. Participants are able to identify the response that most closely represents their experience. An example of questions on this instrument is: "How does your child seem to be feeling physically?" Answers for this question range from "comfortable and pain free" to "extreme pain and discomfort." Four subscales



measure Social Support the person has (Cronbach alpha, 0.80), Nature of relationship, which assesses the levels of closeness between family members (0.65), Guilt or Regret that people have in relation to the patient (0.62), and Perceived Stress and Difficulty of Coping with the illness (0.69).

### **The BIQ**

The BIQ is a six item multiple choice questionnaire, which is designed to assess one's background and information pertaining to sociodemographic data, illness information, as well acceptance and preparatory behaviors of the spouse (Gillian & Fleming, 1998). The BIQ has two subscales including Acceptance or Perception, with a Cronbach alpha (0.73) and Perception of Patient's Pain (0.73). The overall test has a moderate level of Cronbach alpha (0.60).

The author hypothesizes that people with a Secure style of attachment, will have moderate levels of Anticipatory Grief, while caregivers with a Preoccupied style of attachment, will show high levels of Anticipatory Grief and participants with Fearful styles of attachment will exhibit low levels of Anticipatory Grief.

Table 2.

*Reliability Table.*

Anticipatory Grief	Mean	SD	Cronbach's Alpha
Acceptance or Preparation			<b>0.471</b>
What have the doctor or health care staff told you to expect with regard to your child's illness	1.884	0.823	0.235
Do they think that your child will survive this illness	1.495	0.742	0.430
Do you believe that your child will survive this illness	1.337	0.694	0.292
Should your child die from this illness, how prepared do you feel for this	5.274	1.372	-0.021
How hopeful do you feel for your child's Recovery from this illness	1.337	0.766	0.136
Social Support			<b>0.759</b>
The degree of care and support shown to me by my family is	1.583	0.846	0.585
The degree of care shown to me by my friends is	1.738	0.863	0.718
The degree of care and support show to me by my medical and health care staff is	1.466	0.711	0.495
Guilt or Regret			<b>0.133</b>
How much do you feel that you are responsible for or have contributed to your child's current illness	2.214	1.535	0.110
How much do you feel you have done for your child during his or her current illness	1.092	3.543	-0.018
How many regrets do you have for things that you have said or done to your child in the past, or thing that you failed to say	2.030	1.040	0.160

Table 2. *Continued.*

Perception of Patient's Pain			<b>0.862</b>
How does your child seem to be feeling physically	1.631	1.085	0.660
How often does your child seem to be in pain	2.350	0.926	0.651
What level of pain and suffering do you think your child is feeling because of his illness	2.243	1.295	0.838
What level of emotional distress do you think your Child is feeling because of this illness	2.476	1.297	0.707
Perceived Stress			<b>0.630</b>
How well do you feel you are coping with the demands and stresses of this illness	2.094	0.907	0.437
How well do you feel you are coping with the demands and stresses of daily life	1.854	0.833	0.384
My general level of self esteem and self confidence	2.302	0.908	0.398
In addition to your child's illness, what degree of other stresses are you experiencing	3.198	1.092	0.358
How would you rate your current health	2.281	0.817	0.510
The degree of financial resources available to meet current and future daily needs is	3.031	0.934	0.234
Has anyone dear to you ever died	2.771	1.285	0.007

### *Measuring Ambiguous Loss*

According to Boss (2007), phenomena such as Ambiguous Loss cannot be measured or quantified. Therefore the term *ambiguity* will be understood through qualitative data, as reliability cannot take place when assessing a “perceptual phenomenon that is expected to change over time” (p.107). To measure the concept through a quantitative assessment, Identity Ambiguity will be examined in place of the term Ambiguous Loss as it has significant overlap with the concept. Overlap is seen in that both terms (Identity Ambiguity and Ambiguous Loss) which discuss immobilization and struggle with the inability to produce change created by the ambiguity of the situation at hand (Boss, 2006). In addition, Identity Ambiguity was described by O’Brien (2007) as a result that occurs when Ambiguous Loss takes place.

Without the certified validation of an actual loss, the ambiguity that takes place within boundaries, roles or identity is limited to the concept of perception. Instead, Ambiguous Loss stems from social construction, which is examined through qualitative assessment.

Boss (2007) concluded that it takes both qualitative and quantitative methods to advance the theory of Ambiguous Loss as it pertains to the experience of parents whose children have potentially terminal illnesses. The richness of the Ambiguous Loss experience will be overlooked if only quantitative methods are used, and at the same time, generalizability will be lost without quantitative evidence gathered through valid and reliable measures.

Identity Ambiguity, which is described as immobilization, a sense of being overwhelmed and inability to change situations, while struggling with change (Boss,

2006), can be quantified. Identity Ambiguity can be operationalized more easily than Ambiguous Loss. To measure Identity Ambiguity, O'Brien (2007) used both the *Impact on Parent* subscale of the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996) and the six item *Parent Control* subscale of the Health-Specific Locus of Control measure (HSLC) (Rau & Ware, 1981) (See Appendix C). Because there is significant overlap between Ambiguous Loss and Identity Ambiguity, scores from the IPQ will be utilized to assess Ambiguous Loss.

## **IPQ**

The IPQ scale consists of six questions that are used to assess the level of preoccupation with their child's illness that the mothers report and the impact the illness has on them. The scale ranges from "1" indicating *Strongly Disagree* to "5" being *Strongly Agree*. The higher the score on this scale, the greater the Identity Ambiguity and consequently, the more intense the Ambiguous Loss experience by implication. An example of a question on this instrument is: "My child's condition strongly affects the way I see myself as a person."

## **HSLC**

The subscale from the Health Specific Locus of Control (HSLC) includes five items that measure the parents' perception of their responsibility to control the outcome of their child's illness. The questions in this section, specifically tap into one's sense of mastery over the illness and situation at hand. While measuring Identity Ambiguity, this concept has significant overlap with Ambiguous Loss. Each item uses a five point Likert

scale that ranges from “1” being *Strongly Disagree* to “5” being *Strongly Agree*. The higher the score on this scale (indicating absent or weak sense of control over the situation), the higher the perception one has of control over situation. The higher their Identity Ambiguity scores, the higher levels of potential Ambiguous Loss, since Boss (1999) points out that inability to master a situation is inherent in Ambiguous Loss. This scale includes the following questions “There is a lot I can do to control my child’s illness” and “My child’s illness is my own fault.” The Cronbach alpha for this instrument is 0.91.

In regards to Identity Ambiguity it is the author’s hypothesis that people with a Secure style of attachment, will have moderate Identity Ambiguity scores, while caretakers with a preoccupied style of attachment, will show high levels of Identity Ambiguity. Finally people identified with Fearful and Dismissive styles of attachment will exhibit low levels on this scale.

Table 3.

*Reliability Table.*

Identity Ambiguity	Mean	SD	Cronbach's Alpha
IPQ			<b>0.80</b>
My child's condition strongly affects the way I see myself as a person	2.74	1.482	0.413
My child's illness strongly affects the way others see me	2.373	1.371	0.409
My child's illness has serious economic and financial consequences for me and my family	3.559	1.5	0.322
My child/s condition is difficult for me to live with	2.5	1.37	0.454
My child's illness does not have much effect on my life	2.108	1.258	-0.133
My child's illness will have major consequences on my life	3.314	1.4	0.530
HSLC			<b>0.247</b>
There is a lot I can do to control my child's illness	3.38	1.284	0.156
My child's illness is my own fault	1.72	1.064	-0.074
I have a lot of confidence in my ability to help my child overcome his or her problem	4.36	0.948	0.239
There is little I could have done to prevent my child from having his or her condition	3.9	1.352	-0.073
What I do can determine whether my child's illness gets better or worse	3.53	1.352	0.411

### *Measuring Attachment Style*

To measure attachment style, the ECR instrument (see Appendix D), developed by Brennan, Clark and Shaver (1998), will be used. The ECR examines one's overall style of attachment and not the characteristics of any particular relationship (Wei, Russell, Mallinckrodt, & Bogel, 2007).

This 36-item instrument uses a Likert scale ranging from "1" *Strongly Disagree* to "5" *Strongly Agree* to respond to such questions as: "I worry about being abandoned." The ECR is used to measure attachment as it pertains to a trait tendency. The instrument has an overall Cronbach alpha of 0.78 with 0.84 for the Anxiety scale and 0.84 for Avoidance the avoidance items.

According to Mikulincer, Shaver, and Pereg, (2003) the ECR included anxiety and avoidance themes, which are the two dimensions of adult attachment style. Attachment anxiety is described as fear of abandonment with a constant need for the approval of others. Attachment avoidance is described as having a fear of dependence and a high need for self reliance. Participants who score high on one or both dimensions have an Insecure attachment style, while people who score low on these constructs are considered to have a Secure attachment (Lopez & Brennan, 2000).



Table 4.

*Reliability Table.*

Attachment Style	Mean	SD	Cronbach's Alpha
Avoidant Scale			<b>0.562</b>
I prefer not to show a partner how I feel deep down	2.531	1.276	0.073
I am very comfortable being close to romantic partners	3.790	1.191	-0.090
Just when my partner starts to get close to me I find myself pulling away	2.340	1.158	0.326
I get uncomfortable when a romantic partner wants to be very close	2.482	1.226	0.292
I don't feel comfortable opening up to romantic Partners	2.444	1.173	0.243
I want to get close to my partner, but I keep pulling back	2.556	1.183	0.426
I am nervous when partners get too close to me	2.296	1.089	0.436
I feel comfortable sharing my private thoughts and feelings with my partner	3.691	1.251	0.286
I try to avoid getting too close to my partner	2.124	1.041	0.103
I find it relatively easy to get close to my partner	3.506	1.246	0.212
I find it difficult to allow myself to depend on romantic partners	2.679	1.253	0.205
I prefer not to be too close to romantic partners	2.21	1.092	0.321
I tell my partner just about everything	3.630	1.145	0.026
I usually discuss my problems and concerns with my partner	3.877	1.077	0.048

Table 4. *Continued.*

I feel comfortable depending on romantic partners	3.222	1.285	0.227
I don't mind asking romantic partners for comfort, advice, or help	3.593	1.191	0.039
It helps to turn to my romantic partner in times of need	3.938	1.038	0.191
I turn to my partner for many things, including comfort and reassurance	3.852	1.038	0.127
Anxious Scale			<b>0.897</b>
I worry about being abandoned	2.289	1.192	0.589
I worry a lot about my relationships	2.656	1.219	0.509
I worry that romantic partners won't care about me as much as I care about them	2.356	1.211	0.680
I worry a fair amount about losing my partner	2.656	1.273	0.497
I often wish that my partner's feelings for me were as strong as my feelings for him/her	2.944	1.319	0.494
I often want to merge completely with romantic partners, and this sometimes scares them away	2.189	0.993	0.423
I worry about being alone	2.611	1.443	0.534
My desire to be very close sometimes scares people away	2.211	1.044	0.466
I need a lot of reassurance that I am loved by my partner	2.778	1.364	0.619
Sometimes I feel that I force my partners to show more feeling, more commitment	2.356	1.257	0.585
I do not often worry about being abandoned	2.978	1.398	0.032
If I can't get my partner to show interest in me, I get upset or angry	2.5	1.274	0.673

Table 4. *Continued.*

I find that my partner(s) don't want to get as close as I would like	2.311	1.158	0.699
When I'm not involved in a relationship, I feel somewhat anxious and insecure	2.356	1.154	0.588
I get frustrated when my partner is not around as much as I would like	2.922	1.309	0.617
I get frustrated if romantic partners are not available when I need them	2.774	1.268	0.616
When romantic partners disapprove of me, I feel really bad about myself	2.778	1.261	0.550
I resent it when my partner spends time away from me	2.833	1.291	0.542

### *Open Ended Questions*

The qualitative portion of the study will include short open ended questions which will be analyzed using content analysis. Couples responding to this section of the study answered the following questions:

1. What kinds of challenges have you had as a result of having an ill child?
2. Has there been any impact on you as a couple to have a child with a serious illness?
3. What do you think is important for other couples with a child with a life threatening illness to do or to know about how to have a good relationship?
4. Is there anything else about being in an intimate relationship and having an ill child that I didn't ask you, but that you would like to discuss?

Through these questions the participants provided insight regarding the impact the illness of their child has had on their relationship as a couple. It was hoped that in

answering these questions the couples were given an opportunity to share information that may be otherwise overlooked and may be beneficial for future studies.

### ***Demographic Information***

The Demographic Information Sheet (DIS) (See Appendix F) is a 16- item questionnaire, which includes some general information regarding the child's illness status (such as type of illness, how long has it been since the family received the diagnosis, the child's current health status, etc.). This was followed by other demographic items such as the caregiver's age, marital status, the number of children, ethnic background and household yearly income. Several items are multiple choice, while others are short answer questions.

Table 5.

*Reliability Table.*

Demographics	Mean	SD	Cronbach's Alpha
Demographics Information			<b>0.80</b>
How long has it been since your child was diagnosed	4.667	0.577	0.990
How would you describe the stage of illness the child is in right now	5.000	1.732	0.988
How old is your sick child	3.667	1.155	0.540
Gender of sick child	0.333	0.577	0.337
How many times was your child hospitalized due to his/her illness	12.33	6.506	-0.553
Has anyone else in your family been diagnosed with the same illness	0.333	0.577	0.337
Are you currently married	0.667	0.577	0.990
If yes- are you married to the sick child's parent or primary caregiver	0.667	0.577	0.990
How long have you been married	6.667	7.638	0.285
If not married – are you living with the sick child's parent or primary caregiver?	0.667	0.577	0.990
Please provide your age	2.667	0.577	-0.423
Please provide your gender	0.333	0.577	-0.992
Number of children you have	3.000	1.000	0.044
Ethnicity	1.333	0.5774	0.577
Support from social worker	0.333	0.5774	0.577
Support from child life	0.333	0.5774	0.577

### **Data Analysis**

Data was collected from a total sample of 106 subjects to ensure a large sample size. Analysis did show however that 63 participants will achieve 81% power to detect differences among the means versus the alternative of equal means using an F test with a 0.05 significance level. Once data was collected, it was entered and analyzed using Predictive Analytic SoftWare (PASW). The relationship between attachment style, was be the independent predictor variable, and the grief, which was the dependent variable.

In order to assess the impact of Attachment styles on the grief experience of primary caregivers with a child diagnosed with hemotological or oncological illness, the analysis was performed in two steps. The first step was to run a MANOVA to examine the group differences that exist representing different attachment styles. The second step of analysis was to conduct linear regression and identify a model that shows what factors, other than attachment style, impact the parental grief.

### ***Content Analysis***

As this study deepens the understanding of the experience of couples who have a child with a potentially life threatening illness, for the qualitative portion of the study, content analysis was used for the open ended questions. Identifying patterns among couples as well as uniqueness was the goal of this portion.

### **Self of the Researcher**

In 2001 my son who was three years old at the time was diagnosed with Aplastic Anemia. This is a potentially life threatening disease, in which the bone marrow stops

producing blood. My son was sick for over a year, and thankfully recovered after that time. Through this experience I learned about the experience of parents when their child suffers from a life threatening illness. While great medical interventions were in place, it was evident that emotional support, specifically for the family, was minimal.

While my own experience as the parent of a child with a life threatening illness is beneficial for the proposed study, it creates a concern for subjectivity during data analysis. Objectivity will be addressed by having another person, who is naïve to the topic, look over some of the open ended questions and make sure that their perspective on the findings are similar to the researcher's.

In order to assure accuracy of the use of the theory of Ambiguous Loss and that it did indeed capture the experience of parents described in this study, communication with Pauline Boss, who conceptualized Ambiguous Loss, was conducted. Confirmation regarding the correct use of the theory was received.

It is the hope of the researcher to contribute to the knowledge existing in the field of Marriage and Family Therapy in dealing with parents of a child with a life threatening illness. As the body of literature on this topic is scarce, with the use of qualitative studies almost exclusively, the intention of the author, through the use of a mixed method study, is to pave the way for future quantitative studies. Finally, it is the goal with this study to contribute to the current body literature specifically in relation to Ambiguous Loss and Attachment and provide a link between the two theories as they pertain to the population described.

## CHAPTER FOUR

### RESULTS

The results section is comprised of two parts. The first section will discuss the quantitative results and the second section will present the qualitative results of the study.

#### **Quantitative Results**

This section will begin with a description of the demographics of the participants which includes information regarding the parents and guardians as well as information about the sick child and the illness. The following section will discuss the data analysis, which includes data preparation, restating the study's hypothesis, and an explanation of the process of conducting a MANOVA as well as fitting linear regression models. The final section discusses the model that was developed. It examines other factors that impact parental grief, which includes the health status of the child, whether the child is receiving treatment and whether the child is considered cured.

#### *Demographics*

##### **Parent and Guardian Demographics**

The sample consisted of 106 parents and guardians of children diagnosed with a hematological or oncological illness and were treated at Loma Linda University Medical Center Hematology Oncology Pediatric Clinic (LLUMCHOPC) located in San Bernardino County. Table 6 provides the demographics of the participants. The sample was comprised of both male (33.3%) and female (66.7%) participants. Hispanic parents



and guardians were the largest ethnic group represented in the sample (63.2%), in comparison to the Hispanic population in San Bernardino which is 44% of the population in San Bernardino being Hispanic (City of San Bernardino, 2011) and 44.7% in Riverside County (U.S. Census Bureau, 2010). Approximately two thirds (63.2%) of the respondents were English speaking, while a third of the participants used the survey translated into Spanish.

Two thirds (67%) of the participants were married. Of those 80% were married to the sick child's parent or guardian. The length of marriages ranged from less than a year, to 29 years, with a bi-modal central tendency of five years (12.9%) and fourteen years (12.9%). The participants had one to eight children, and the most frequently reported number of children reported was two (35%).

Of the parents and guardians who participated in the study 17.9% received mental health treatment from social workers, 2.8% attended support groups, 13.2% received support from Child Life Specialists and 5.7% received counseling which included individual, couple and family therapy. Eighty four percent reported that they received support from their families. Support from friends was reported by 64.2% of the participants and 24.8% reported receiving support from churches or other religious organizations.

Table 6.

*Demographics of Parents and Guardians Dealing with Illness*

Characteristic	n	%
Ethnicity		
Hispanic	67	63.2
Caucasian	19	17.9
African-American	6	5.7
Asian	3	2.8
Black non African-American	3	2.8
Other	6	5.7
Age of Parent		
18-25	8	7.8
26-35	37	35.9
36-45	35	34
46-55	19	18
56+	4	3.9
Number of Years Married		
Less than a year	3	9.7
1-2 years	1	3.2
3-5 years	7	22.6
6-10 years	6	19.4
11-15 years	7	22.5
16-20 years	3	9.7
21 years or more	4	12.8

**Child Demographics**

The demographics of the sick children are presented below in table 7 (below). The sample included 53.9% male and 46.1% female children. The largest age group (41.7%)

for children was between the ages of 4-10, which indicates a sample of relatively young families.

Table 7.

*Demographics of Patients Dealing with Illness (Children)*

Characteristics	n	%
Child's Age		
0-11 months	1	1
1-3	16	15.5
4-10	43	41.7
11-13	18	17.5
14-18	25	24.3

The illness type of the child varied as seen in table 8. The category “Other illnesses” accounted for 31.4% of the illnesses, which included the following illnesses: Aplastic Anemia, Evans Syndrome, ITP, Mast Cell Sarcoma, and Ewing Sarcoma. The majority of children in the sample (59%) were diagnosed within the last two years. Of the participants, one percent reported they “recently received the diagnosis”, and 5.7% of the parents reported that their child “is currently experiencing a relapse.” The majority, 51.4% reported they are currently “receiving treatment” and 11.4% stated their child was “off treatment.” Almost 24% reported that their child “is considered cured and is receiving follow up care.” The participants reported that their child had been hospitalized between zero and eighty times. The mode, 23.9%, were hospitalized once, and 12% were hospitalized three times.

Of the participants 13.3% reported that there was someone else in their family who was diagnosed with the same illness. The relative varied from brother, father, uncle, cousin, great uncle, grandmother, mother, and sister.

Table 8.

*Illness Information*

Category	n	%
Type of Illness		
ALL	48	45.7
Sickle Cell Disease	7	6.6
Brain Tumor	4	3.8
Non-Hodgkin Lymphoma	4	3.8
Hodgkin Disease	3	2.9
Osteosarcoma	3	2.9
Other	33	31.4
Time Since Diagnosis		
Within last 4 months	13	13.1
4-6 months	17	17.2
1-2 years	29	29.3
3-10 years	27	27.3

***Analysis***

The following section will discuss the process of the data analysis. Data preparation and cleaning will be described and will be followed by presentation and analysis of the hypotheses. For each hypothesis a linear regression with the following dependent variable was fit: Chronic Sorrow, Identity Ambiguity (used as the quantitative measure to represent Ambiguous Loss) and Anticipatory Grief. Prior to running the linear

regression models a MANOVA was performed in order to control for experiment-wise alpha.

### **Data Preparation and Cleaning**

Data preparation began by identifying what questions in the survey comprised the subscales for Chronic Sorrow: *Guilt and Worry*, *Emotional Resources*, *Unresolved Sorrow and Anger*, and *Long Term Uncertainty*. Each grouping of the questions was added for a total score for the subscale. Then subscales were added together to create a total score for each dependent variable. Prior to creating these aggregate totals, each scale was examined for missing data.

When examining Chronic Sorrow subscales *Guilt and Worry* had 8% missing data, *Emotional Resources* had 4% missing data, *Unresolved Sorrow and Anger* had 3% missing data and *Long Term Uncertainty* 2% missing data. A new variable was created that represented whether a value was missing or not for each of these variables. A series of chi square were run to determine a pattern of missing data for each variable. No significant relationships were found. This meant that there was no pattern to the missing values (such as being influenced by the gender of the child, the gender of the parent, or the age of the parent). Rather the data were missing at random. Therefore a mean imputation was used in place of the missing value.

For Identity Ambiguity the questions for the subscale *Illness Perception Questionnaire* (IPQ), had 3% of missing data. *Health Specific Locus of Control* (HSLC) had 5% missing data. A new variable was created to represent whether data was missing for that participant or not. A chi square was run, and no significance was found.

Therefore the missing data was considered to be missing at random. Given this finding a mean imputation was used to replace the missing data.

Finally, for the dependent variable Anticipatory Grief 2% of the subscale *Social Support* had missing data, 7% of the subscale *Guilty and Worry*, 9% of the *Perceived Stress and Difficulty* subscale, 10% of the *Acceptance or Preparation* subscale and 2% of the subscale Perception of Patient Pain had missing data. For each subscale a new variable was created to represent whether data were missing or not. A chi square was performed to see if the data was missing at random. The chi square showed no significance, which meant the data was missing at random. Therefore a mean imputation was used.

## **Hypotheses**

The hypotheses for this study were comprised of three parts. In each part the attachment style of the parent or guardian was examined. The independent variable (IV) is one's attachment style, which is represented by a continuum between *Secure Attachment* and *Fearful Attachment* (is referred to as an avoidant style of attachment on the ECR scale) and the continuum between *Secure Attachment* and *Preoccupied Attachment* (is represented on the Anxious style of attachment on the ECR Scale). The dependent variables are Chronic Sorrow, Identity Ambiguity and Anticipatory Grief.

A *Securely* attached participant scored low on the ECR attachment scale, while *Anxious and Avoidant* styles of attachment scored high on the ECR attachment scale. Chronic Sorrow was measured on a continuum on the Parent Experience of Child Illness (PECI) (Bonner, Hardy, Guill, McLaughlin, Schweitzer & Carter, 2006) assessment tool

Identity Ambiguity was also measured on a continuum using the assessment tool by O'Brien (2007). Finally, Anticipatory Grief is measured on a continuum on the Grief Experience Inventory (GEI) (Gillian & Fleming, 1998).

### **Hypothesis One**

It was hypothesized that participants with a *Secure* style of attachment, would exhibit moderate Chronic Sorrow scores, indicating a well balanced approach and good adaptability to the illness. This would be due to the parent's ability to cope well with grief, as those who are securely attached experience grief related emotions without becoming overwhelmed by the experience (Shaver& Tancredy, 2001). Caregivers with an *Anxious* style of attachment, were hypothesized to show high levels of Chronic Sorrow due to their lack of security and overinvolvement in their relationship with the child. This could be explained as those with an *Anxious* style of attachment tend to have a clinging characteristic and are therefore inclined to have experience chronic, long term grief. Participants with *Avoidant* styles of attachment were hypothesized to exhibit low levels of Chronic Sorrow. This is due to the fact that those with an avoidant style of attachment tend to be guarded in their relationship, and therefore experience inhibited or no grief (Stroebe, 2002).

### **Hypothesis Two**

Participants with a *Secure* style of attachment, will show moderate levels of Identity Ambiguity as they are able to cope with negative experiences in a balanced fashion. Participants with an *Anxious* style of attachment, would show high levels of

Identity Ambiguity. This is due to their inability to detach and let go, but rather cling to the person and the situation at hand. On the other end of the spectrum, people with *Avoidant* styles of attachment, who tend to be more guarded in their relationships, would display low levels of Identity Ambiguity.

### **Hypothesis Three**

Participants with a *Secure* style of attachment, who handle negative experiences in a balanced way, will show moderate levels of Anticipatory Grief, while those with an *Anxious* style of attachment, who have a difficult time letting go, would show high levels of Anticipatory grief. Those with *Avoidant* styles of attachment were hypothesized to show low levels of Anticipatory Grief, as they are often detached from the relationship to begin with.

### **MANOVA**

Prior to addressing the stated hypotheses, a multivariate analysis of variance was employed with Chronic Sorrow, Identity Ambiguity and Anticipatory Grief as the dependent variables, and the category grouping variables for each of the *Avoidant* and *Anxious* scales was created for use as the independent variables. *Avoidant* and *Anxious* scales were broken into three categories: *Secure*, *low* and *high*. The *Secure* group included individuals that scored within one standard deviation of the mean on each scale (*Avoidant* and *Anxious*). The *Low* group included individuals that were one standard deviation below the mean and the *high* group scored one standard deviation or higher above the mean.



The results of the MANOVA test suggested that there is no main effect for the Anxious scale  $F(3,87)=3.92$   $p>0.05$  but an interaction effect between the Avoidance and Anxious scales  $F(3,88)=4.27$   $p<0.05$  and a main effect for Avoidant scales  $F(3,87)=1.89$   $p<0.05$ . This means that there is a difference between the low medium and high groups for the Avoidant scale as well as the interaction between the Anxious and Avoidant scales. For the Anxious Scale there was no difference between the groups.

Given the significant MANOVA results post hoc ANOVAs were examined for each of the dependent variables. The post hoc ANOVAs showed significant group differences on the Chronic Sorrow scales, but not on Identity Ambiguity and Anticipatory Grief. Since MANOVA requires a categorical independent variable, therefore the attachment scales were broken into three categories. It was determined that this categorization process might have contributed to the null findings for Identity Ambiguity and Anticipatory Grief. Given this hypothesis and the overall significant MANOVA test a series of post hoc linear regression models were fit.

### **Models Developed**

A series of linear regression models were tested to assess the association between the independent variables, attachment styles and the following dependent variables: Chronic Sorrow, Identity Ambiguity and Anticipatory Grief. The analysis consisted of a two step process. It began by regressing the dependent variables (DVs) on to the interaction between the Avoidant and Anxiety scales (The main effect for the Avoidant scale was also tested at this step. In each case the main effect became insignificant in the presence of the interaction effect. Therefore the following hypotheses present the

interaction effect alone). Following this step, additional regression models (with each of the subscales on the Avoidant and Anxious scales as the DV) were tested. The models include the main effect for the interaction effect of the Anxious and Avoidant scales, as well as the Parent and Guardian's gender, whether the child recently received the diagnosis, whether the child was receiving treatment or not, whether child has had a relapse, if the child is considered cured, and the length of time since the diagnosis. These models will be described in three sections according to each of the dependent variables: Chronic Sorrow, Identity Ambiguity and Anticipatory Grief.

### ***Hypothesis One: Chronic Sorrow***

To test the first dependent variable, Chronic Sorrow, a linear regression was fit with Chronic Sorrow as the dependent variable. Measures on the interaction of Anxious and Avoidant were modeled as the independent variables. Overall the model was significant ( $F(1,104)=14.726, p<0.005$ ) and explained approximately 12% of the variance in Chronic Sorrow (see Table 4.4). For Chronic sorrow, the interaction effect for Anxious and Avoidant styles was significant ( $\beta=0.352, SE=0.07, p<0.005$ ). Therefore the findings show that one's attachment style predicts Chronic Sorrow levels. More specifically the more secure the attachment style, the less Chronic Sorrow they will experience.

In the next step the following covariates were included in the model: parent and guardian's gender, whether the child had recently received the diagnosis, if the child was experiencing a relapse, if the child was receiving treatment, if the child was cured and how long has it been since the child was diagnosed. Overall, the model was significant ( $F(7,76)=3.350 p<0.005$ ) and explained approximately 24% of the variance in Chronic

Sorrow (see Table 4.5). For Chronic Sorrow, the interaction effect for Anxiety and Avoidant styles was significant ( $\beta=0.263$ ,  $SE= 0.07$ ,  $p<0.05$ ). Therefore we understand that the independent variable, attachment style, accounts for 24% of the Chronic Sorrow parents and guardians experience. Additionally as the child receives treatment, lower levels of Chronic Sorrow were detected ( $\beta= -1.017$ ,  $SE=11$ ,  $p< 0.005$ ). The same was found for the cases in which the child was considered cured ( $\beta= -0.827$ ,  $SE=11.13$ ,  $p<0.05$ ) as well as the length of time that had passed since diagnosis ( $\beta= -0.227$ ,  $SE=1.07$ ,  $p<0.05$ ).

Chronic Sorrow scores were lower for parents and guardians who are securely attached as well as for those whose children are receiving treatment, and for parents and guardians with children who have been cured. Additionally, the length of time from the point of diagnosis decreased the Chronic Sorrow score.

Next, each subscale was used as a dependent variables and the same independent variable and covariates were fit into the model.

### **Chronic Sorrow Subscale Guilt and Worry**

The first step in this analysis regressed the subscale Guilt and Worry onto the interaction Anxious and Avoidant scale. In examining this model the interaction of Anxious and Avoidant scales was significant ( $F(1,104)=4.627$ ,  $p<0.05$ ) and explained 4% of the variance. For Guilt and Worry the interaction effect was significant ( $\beta=0.206$ ,  $SE=0.037$ ,  $p<0.05$ ) indicating that the attachment styles predicted the Guilt and Worry subscale. More specifically, the more securely attached a participant was, the less guilt and worry they experienced (Table 9).

The second step included the covariates in the model: the parent and guardian's gender, whether the child had recently received the diagnosis, if the child was experiencing a relapse, if the child was receiving treatment, if the child was cured and how long had it been since the child was diagnosed. Overall the model was not significant ( $F(7,76)=1.399, p>0.05$ ), which suggests that one's Guilt and Worry are not impacted by the covariates used (see Table 4.5).

### **Chronic Sorrow Subscale Emotional Resources**

In the first step, Emotional Resources was examined with the interaction of the *Anxious and Avoidant* scale. Emotional Resources refers to one's ability to cope with the hardship of the illness, which includes having a support system, one's ability to face challenges related to the illness. The model fit was significant ( $F(1,104)=8,956, p<0.005$ ) and explained approximately 8% of the variance. The interaction effect was significant ( $\beta= -0.282, SE=0.016, p<0.003$ ). These findings indicate that the more secure one's attachment is, the greater are their Emotional Resources (see Table 4.4).

The following step included looking at the subscale of Chronic Sorrow, Emotional Resources adding the covariates described above. The model fit was adequate ( $F(7,76) =2.189, p<0.05$ ) and explained approximately 17% of the variance. Within this model, the interaction for the *Anxious and Avoidant* Scales was significant ( $\beta= -0.284, SE=0.02, p<0.05$ ). Additionally, the time since diagnosis variable was found to be a significant predictor of Emotional Resources ( $\beta= -0.25, SE=0.23, p<0.05$ ). Therefore, parents with lower scores across the *Anxious and Avoidant* scales will score higher on the

Emotional Resources subscale. Also the longer the time since diagnosis the higher the emotional resources score (see Table 4.5).

### **Chronic Sorrow Subscale Unresolved Sorrow and Anger**

In examining Chronic Sorrow and its subscale *Unresolved Sorrow and Anger* the model fit ( $F(1,104)=25.264, p<0.005$ ) was significant. The interaction for the Anxious and Avoidant scales was significant ( $\beta= 0.442, SE=0.03, p<0.05$ ) and explained 20% of the variance (see Table 4.4).

In step two, when adding the covariates, the model fit was still significant ( $F(7,76)=4.141, p<0.005$ ) with 28% prediction of the variance. A significance level of  $p<0.005$  was found for the interaction of Anxious and Avoidant ( $\beta=0.389, SE=0.03, p<0.005$ ) as well as for the variable whether the child was receiving treatment ( $\beta= -0.782, SE=3.97, p<0.05$ ) and whether the child was considered cured ( $\beta= -0.669, SE=4.02, p<0.05$ ) (see Table 4.5). This means that the more secure the parents or guardians are, as the child was receiving treatment or if the child was considered cured, the unresolved sorrow and anger levels experienced by the parents and guardians were lowered.

### **Chronic Sorrow Subscale Long Term Uncertainty**

Finally, Chronic Sorrow was examined with the subscale *Long Term Uncertainty*. The interaction of *Anxious and Avoidant* scale had a model fit ( $F(1,104)=26.144, p<0.005$ ). The interaction for the *Anxious and Avoidant* scale was significant ( $\beta=0.448, SE=0.02, p<0.005$ ), which accounted for 20% of the variance (see Table 9).

In the next step, when the covariates were added, the model fit ( $F(7,76)=4.125$ ,  $p<0.005$ ) with 28% prediction of the variance. Within this model the interaction for the Anxious and Avoidant scales was found to be significant ( $\beta=0.393$ ,  $SE=0.02$ ,  $p<0.05$ ). However this model did not yield significance with any of the other variables presented (see Table 10).

Table 9.

*Model Results for Anxiety and Avoidance Interaction with Chronic Sorrow and Subscales*

	Chronic Sorrow	Guilt & Worry	Emotional Resources	Unresolved Sorrow & Anger	Long-Term Uncertainty
Anxiety & Avoidance	0.352(0.07)**	0.206(0.04)*	-0.282(0.02)**	0.442(0.03)**	0.448(0.02)**
R-Square	0.124	0.043	0.079	0.195	0.201
F(DF)	14.726(1,104)**	4.63(1,104)*	8.96(1,104)**	25.26(1,104)**	26.144(1,104)**

Note: \*=0.05; \*\*=0.005

Table 10.

*Model Results for Chronic Sorrow and Subscales*

	Chronic Sorrow	Guilt & Worry	Emotional Resources	Unresolved Sorrow & Anger	Long-Term Uncertainty
Anxiety & Avoidance	0.263(0.08)*	0.108(0.04)	-0.284(0.02)*	0.389(0.03)**	0.393(0.02)**
Parent Gender	0.042(3.55)	0.144(1.97)	0.134(0.77)	-0.08(1.28)	-0.097(1.07)
Received DX	-0.219(19.09)	-0.202(10.59)	-0.13(4.16)	-0.17(6.89)	-0.08(5.79)
Relapse	-0.176(12.81)	-0.226(7.11)	-0.021(2.79)	-0.16(4.63)	0.014(3.88)
Receiving Tx	-1.017(11.00)**	-0.898(6.10)*	-0.486(2.4)	-0.782(3.97)*	-0.523(3.34)
Child is Cured	-0.827(11.13)*	-0.771(6.17)*	-0.403(2.43)	-0.669(4.02)*	-0.314(3.37)
Time Since Diagnosis	-0.227(1.07)*	-0.168(0.6)	-0.25(0.23)*	-0.134(0.39)	-0.123(0.33)
R-Square	0.236	0.114	0.168	0.276	0.275
F(DF)	3.350(7,76)**	1.399(7,76)	2.189(7,76)*	4.141(7,76)**	4.125(7,76)**

Note: \*=0.05; \*\*=0.005

**Summary of Chronic Sorrow**

The models were significant in predicting the total score for Chronic Sorrow ( $F(7,76)=3.350, p<0.05$ ), the subscales of *Emotional Resources* ( $F(7,76)=2.189, p<0.05$ ), *Unresolved Sorrow and Anger* ( $F(7,76)=4.141, p<0.005$ ) and *Long Term Uncertainty* ( $F(7,76)=4.125, p<0.005$ ). In general for the overall Chronic Sorrow score, the more securely attached a participant was, the less Chronic Sorrow they experienced. In the

subscales Guilt and Worry, Unresolved Sorrow and Anger as well as Long Term Uncertainty the models indicated having a higher combined Avoidant and Anxious score increased the dependent variable scores. This suggested that the more securely attached a person is, the less Chronic Sorrow they experience. For *Emotional Resources* the opposite was correct: the more securely attached a person is, the more emotional resources they appear to have.

Additionally, receiving treatment reduced the dependent variable scores in overall Chronic Sorrow, Guilt and Worry as well as Unresolved Sorrow and Anger. Having a child that is considered “cured,” reduced scores in overall Chronic Sorrow, Guilt and Worry as well as Unresolved Sorrow and Anger. Finally the longer time had passed since the diagnosis was given, the less the Chronic Sorrow and the better the Emotional Resources. This allows us to conclude that except for Guilt and Worry, the more secure a person is in their attachment style, the lower their levels of Chronic Sorrow and subscales will be seen. In addition, while a child is in the process of receiving treatment or is considered cured, as well as the factor of time passing from time of diagnosis, Chronic Sorrow and the subscales for parents and guardians are lower.

### ***Hypothesis Two: Identity Ambiguity***

To test the second dependent variable, Identity Ambiguity (O’Brien, 2007), a linear regression was performed with Identity Ambiguity as the dependent variable. As discussed earlier, elements of Identity Ambiguity are also present in Ambiguous Loss, such as issues of mastery, immobilization, and the difficulty one experiences with the inability to create change. Therefore, in this study the actual measurement is of Identity



Ambiguity, with the understanding that if Identity Ambiguity exists, we may conclude that probably Ambiguous Loss takes place as well. In examining the data high scores on this variable would indicate the parents and guardians experiencing high levels of Identity Ambiguity. This means that the parent or guardian may experience immobilization, depression symptoms, a sense of being overwhelmed, a difficulty adapting to the changes presented by the illness as well as having difficulty making decisions regarding the child's medical care. In the first step the interaction of the two scales Anxious and Avoidant interaction was modeled as the independent variable. The second step, as with Chronic sorrow, the following covariates were included in the model: parent and guardian's gender, whether the child had recently receiving the diagnosis, if the child was currently experiencing a relapse, if the child was receiving treatment, if the child was cured, and length of time since diagnosis. Overall the model, examining the interaction of Anxious and Avoidance scale with Identity Ambiguity, was significant ( $F(1,94)=10.755$ ,  $p<0.005$ ). The model explained approximately 10% of the variance in Identity Ambiguity. The interaction was significant ( $\beta=0.32$ ,  $SE=0.03$ ,  $p<0.005$ ) (see table 4.6).

For the second step, where the covariates were added to the model, the overall the model was significant ( $F(7,70)=3.231$ ,  $p<0.005$ ). The model explained approximately 25% of the variance in Identity Ambiguity (see table 12). A full 25% of the variance in Identity Ambiguity scores can be explained by the model, where Identity Ambiguity is impacted by the whether the child is or is not receiving treatment and if the child was considered cured. For Identity Ambiguity the interaction effect for Anxious and Avoidant was significant ( $\beta=0.266$ ,  $SE=0.03$ ,  $p>0.05$ ). Additionally, children receiving treatment have parents and guardians with lower Identity Ambiguity scores ( $\beta= -0.742$ ,  $SE=4.17$ ,

$p < 0.05$ ) and when the child is cured ( $\beta = -0.674$ ,  $SE = 4.22$ ,  $p < 0.05$ ). Next, each subscale was used as a dependent variable and the same independent variable and covariates were fit into the model.

### **Identity Ambiguity Subscale Illness Perception Questionnaire**

#### **(IPQ)**

In examining the subscale of Identity Ambiguity IPQ, and the interaction of Anxious and Avoidant scales, the model fit was ( $F(1,100) = 13.175$ ,  $p < 0.005$ ) and explained 12% of the variance. The interaction of Anxiety and Avoidance scale was significant ( $\beta = 0.341$ ,  $SE = 0.02$ ,  $p > 0.005$ ) (see Table 11). Therefore we can state that attachment style predicts IPQ. Specifically, the more secure a person's attachment style, the less IPQ is experienced.

In the second step, when including covariates the model fit was significant ( $F(7,74) = 3.848$ ,  $p < 0.005$ ) with 25% of the variance explained and with a significant interaction of ( $\beta = 0.263$ ,  $SE = 0.02$ ,  $p < 0.05$ ). Significance was also found for *Receiving Treatment*, which decreased the IPQ score ( $\beta = -0.763$ ,  $SE = 3.29$ ,  $p < 0.05$ ) as well as whether the child was cured ( $\beta = -0.727$ ,  $SE = 3.33$ ,  $p < 0.05$ ). Therefore in addition to the parent or guardian's attachment style, as the child was receiving treatment or was considered cured, the levels of Illness Perception (IPQ) were reduced (see Table 12).

## Identity Ambiguity Subscale Health Specific Locus of Control (HSLC)

In running the subscale of Identity Ambiguity HSLC, the model fit was not significant ( $F(1,98)=1.681, p>0.05$ ) with the interaction of Anxiety and Avoidance scales (see Table 11). This was also the case when adding the covariates. The model fit was not significant ( $F(7,72)=0.64, p>0.05$ ) (see Table 12). Therefore one's attachment style does not predict HSLC.

Table 11.

*Model Results for Anxiety and Avoidance Interaction with Identity Ambiguity and Subscales*

	Identity Ambiguity	Identity Ambiguity IPQ	Identity Ambiguity HSLC
Anxiety & Avoidance	0.32(0.03)**	0.341(0.02)**	0.13(0.01)
R-Square	0.103	0.116	0.017
F(DF)	10.775(1,94)**	13.175(1,100)**	1.681(1,98)

Note: \*=0.05; \*\*=0.005

IPQ= Illness Perception Questionnaire

HSLC= Health Specific Locus of Control

Table 12.

*Model Results for Identity Ambiguity and Subscales*

	Identity Ambiguity	Identity Ambiguity IPQ	Identity Ambiguity
HSLC			
Anxiety & Avoidance	0.266(0.03)*	0.263(0.02)*	0.111(0.02)
Parent Gender	-0.075(1.38)	-0.091(1.07)	0.039(0.73)
Received DX	0.038(7.24)	-0.019(5.71)	0.085(3.84)
Relapse	-0.1(4.84)	-0.099(3.83)	-0.039(2.57)
Receiving Tx	-0.742(4.17)*	-0.763(3.29)*	-0.313(2.22)
Child is Cured	-0.674(4.22)*	-0.727(3.33)*	-0.249(2.24)
Time Since Diagnosis	0.01(0.42)	0.046(0.32)	-0.109(0.22)
R-Square	0.244	0.248	0.059
F(DF)	3.231(7,70)**	3.484(7,74)**	0.64(7,72)

Note: \*=0.05; \*\*=0.005

As seen in table 4.6, attachment style, specifically the interaction of Anxious and Avoidant, were significant in relevance to Identity Ambiguity ( $F(7,70)=3.231$ ,  $p<0.005$ ) and IPQ ( $F(7,74)=3.484$ ,  $p<0.005$ ). Levels of Identity Ambiguity and IPQ were significantly reduced when the child was receiving treatment, or when the child was considered cured for reducing levels of Identity Ambiguity and IPQ. No significance was found for the subscale HSLC when ran with the interaction of Anxious and Avoidant scale, nor when the other covariates were added. Since both the total score and IPQ score were significant, a substantive conclusion might be that it is just the IPQ scale that is

predictive by attachment styles. We can conclude that the HSLC subscale was not significant in the overall Identity ambiguity combined number.

These findings suggest that the more securely attached a person is the less Identity Ambiguity they will suffer. They will also experience less negative issues with the illness perception. Attachment style however did not show statistical significance when it came to the participants HSLC, nor did the other covariates help explain that subscale.

### ***Hypothesis Three: Anticipatory Grief***

To test the third dependent variable, Anticipatory Grief, the model was fit to predict the total Anticipatory Grief scores as well as the subscales Perceived Stress, Social Support, Guilt or Regret, Acceptance or Preparation and Perception of Patient Pain. In the first step, Anticipatory Grief was the dependent variable. The interaction of Anxious and Avoidant Scale was modeled as the independent variable. The model fit was found to be significant ( $F(1,104)=10.42, p<0.005$ ) and explained 9% of the variance in Anticipatory Grief (see table 13). For Anticipatory Grief, those with more secure attachment styles will experience less Anticipatory Grief ( $\beta=0.302, SE=0.04, p<0.005$ ).

In the second step the following covariates were included in the model: Parent or guardian's gender, whether the child had recently received the diagnosis, if the child was currently experiencing a relapse, if the child was receiving treatment, if the child was cured and how long it had been since the time of diagnosis. Overall the model was not significant ( $F(7,76)=1.317, p>0.05$ ) (see table 14). While the interaction of Anxious and Avoidant alone is significant, once the covariates are added significance is no longer found. Therefore the relationship is more complicated than that which was identified in this study.

Table 13.

*Model Results for Anxiety and Avoidance Interaction with Anticipatory Grief and Subscales*

	Anticipatory Grief	Perceived Stress	Social Support	Guilt or Regret	Acceptance or Preparation	Perception of Patient's Pain
Anxiety & Avoidance	0.302(0.04)**	0.185(0.02)	0.206(0.01)*	0.199(0.01)*	0.197(0.01)*	0.203(0.02)*
R-Square	0.091	0.034	0.042	0.04	0.039	0.041
F(DF)	10.42(1,104)**	3.669(1,104)	4.616(1,104)*	4.285(1,104)*	4.214(1,104)	4.457(1,104)*

Note: \*=0.05; \*\*=0.005

Table 14.

*Model Results for Anticipatory Grief and Subscales*

	Anticipatory Grief	Perceived Stress	Social Support	Guilt or Regret	Acceptance or Preparation	Perception of Patient's Pain
Anxiety & Avoidance	0.233(0.05)*	0.1(0.02)	0.254(0.01)*	0.243(0.01)	0.177(0.02)	0.084(0.02)
Parent Gender	-0.099(2.13)	0.1(0.85)	-0.129(0.46)	-0.13(0.48)	-0.127(0.59)	-0.112(0.88)
Received DX	-0.086(11.49)	-0.087(4.56)	0.113(2.49)	0.097(2.56)	-0.129(3.19)	-0.152(4.71)
Relapse	0.005(7.71)	-0.128(3.06)	0.16(1.67)	0.089(1.72)	-0.117(2.14)	0.08(3.16)
Receiving Tx	-0.201(6.62)	-0.717(2.63)	0.646(1.44)	0.59(1.48)	-0.526(1.84)	-0.107(2.72)
Child is Cured	-0.247(6.7)	-0.679(2.66)	0.665(1.45)	0.492(1.49)	-0.444(1.86)	-0.271(2.75)
Time Since Diagnosis	0.02(0.65)	-0.02(0.26)	0.089(0.14)	-0.018(0.14)	0.017(0.18)	-0.019(0.27)
R-Square	0.108	0.094	0.12	0.105	0.144	0.108
F(DF)	1.317(7,76)	1.132(7,76)	1.475(7,76)	1.272(7,76)	1.403(7,76)	1.317(7,76)

Note: \*=0.05; \*\*=0.005

### **Anticipatory Grief Subscale Perceived Stress**

In examining the subscale of Anticipatory Grief, Perceived Stress and the interaction of Anxious and Avoidant scales, the model fit was not significant ( $F(1,104)=3.669, p>0.05$ ) (see Table 13). Therefore the model did not predict Perceived Stress. The same was the case when adding the covariates. The model fit was not significant ( $F(7,76)=1.132, p>0.05$ ) (see Table 14). These findings indicate therefore that attachment style does not predict one's perceived stress in parents of such ill children.

### **Anticipatory Grief Subscale Social Support**

For the subscale Social Support and the interaction of Anxious and Avoidant subscale, the model fit was ( $F(1,104)=4.616, p<0.05$ ) and explained 4% of the variance in Social Support. For Social Support, the interaction effect for Anxious and Avoidant styles was significant ( $\beta=0.306, SE=0.01, p<0.05$ ) (see Table 13). Once the additional covariance were added however, the model did not fit ( $F(7,76)=1.475, p>0.05$ ) (see Table 14). Overall attachment styles were found to predict Social Support, but the covariates did not. On the basis of these findings, it appears that the covariates that indicate whether the child is receiving treatment, whether such a child is considered cured or not, and the time that has elapsed since diagnosis do not indicate one's Social Support that they experience. Social Support is, however, impacted by one's attachment style.

### **Anticipatory Grief Subscale Guilt or Regret**

In viewing the subscale of Anticipatory Grief, Guilt or Regret and the interaction of Avoidance and Anxious scale, the model fit was significant ( $F(1,104)=4.285, p<0.05$ )



and explained 4% of the variance in Guilt or Regret. For Guilt and Regret the interaction effect of Anxious and Avoidance scale was found to be significant ( $\beta=0.199$ ,  $SE=0.01$ ,  $p<0.05$ ) (see Table 13). As the covariates were added for step two, the model did not fit ( $F(7,76)=1.272$ ,  $p>0.05$ ) (see Table 14). Therefore attachment styles alone predicted Guilt or Regret. However, when adding the covariates, significance was no longer found.

### **Anticipatory Grief Subscale Acceptance Preparation**

For the subscale of Anticipatory Grief, Acceptance Preparation and the interaction of Anxious and Avoidant scales, the model fit was not significant ( $F(1,104)=4.214$ ,  $p>0.05$ ) (see Table 13). As the model was not statistically significant as it did not predict Acceptance Preparation. This was also the case when the covariates were added in step two: the model was not significant ( $F(7,76)=1.403$ ,  $p>0.05$ ) (see Table 14).

### **Anticipatory Grief Subscale Perception of Patient's Pain**

In looking at the subscale of Anticipatory Grief, Perception of Patient's Pain and the interaction of Anxious and Avoidant scales, the model fit was significant ( $F(1,104)=4.457$ ,  $p<0.05$ ). It explained 4% of the variance in Perception of Patient's Pain. For Perception of Patient's Pain the interaction effect was found to be significant ( $\beta=0.203$ ,  $SE=0.02$ ,  $p<0.05$ ) (see Table 13). As the covariates were added in step two, the model did not fit ( $F(7,76)=1.317$ ,  $p>0.05$ ) (see Table 14). Overall, when examined alone, the attachment style one has impacts the perception of the patient's pain. However, once the covariates were added, significance was no longer found.

In examining Anticipatory Grief, significance was found when looking at the dependent variable and subscales and the interaction of Anxious and Avoidant scales (except for the subscale of Perceived stress). However, no significance was found when adding the covariates, which tells us that when dealing with Anticipatory Grief, attachment style does impact the grief, it is not predicted by whether the child is receiving treatment, is considered cured, or the time that had passed since the diagnosis.

The Results section reported the process of using linear regression in order to build a model that impacts parental grief, specifically Chronic Sorrow, Identity Ambiguity and Anticipatory Grief. As the results indicated, the independent variable, attachment style, does impact the parents' level of grief. However, as shown in Tables 4.4, 4.5, 4.6, and 4.7, the model for Chronic Sorrow and Identity Ambiguity indicated there are other factors that influence grief. These factors include whether the child is currently receiving treatment, whether the child is considered cured, and the time that has elapsed since diagnosis. These impact the level of Chronic Sorrow, Identity Ambiguity and Anticipatory grief the parents and guardians experience when their child is dealing with a life threatening illness.

### **Qualitative Results**

Six couples in the mixed method study were invited to answer open ended questions as it was not possible to obtain a focus group due to logistics of assembling parents from a wide geographical area. Many of these written responses were quite short. The demographics of this population are provided in Table 15. Regarding the length of relationships, 33% had been together 5-7 years, 16.6% were together between 10 and 19

years and 50% of the participant were together for over 20 years. All couples except for one were married. The couple that was not married did live together and reported to be in the relationship a total of five years.

Table 15.

*Demographics of Parents and Guardians Participating in Qualitative Portion of Study*

Characteristic	n	%
Ethnicity		
Caucasian	6	50
Asian	3	25
African American	2	16.7
Other	1	8.3
Age		
26-35	3	25
36-45	6	50
46-55	2	16.7
56+	1	8.3
Length of Relationship		
5-7 years	2	33.
10-19 years	1	16.
20+	3	50
Type of Illness Child has		
ALL	2	33.3
Germ Cell Tumor	3	50
Aplastic Anemia	1	16.6

Note: ALL=acute lymphoblastic leukemia

### ***Couple Demographic Information***

The following section will provide descriptive information regarding each couple. Pseudonyms are used in order to protect the participants' identities.

#### **Couple One – Tina and Robert**

Tina and Robert are married and have been together as a couple for 22 years. They have three children ages three, thirteen and fifteen, of which their 13 year old daughter has been diagnosed with a Germ Cell Tumor two years ago. The daughter has not been hospitalized in the course of her treatment for this condition. She is currently considered cured and is receiving follow up care. Robert is Asian and Tina identified herself as *Other*. Both Tina and Robert are between the ages of 36 and 45. Neither reported receiving any mental health support. Robert stated that he has had support from friends and family, and Tina stated she receives support only from her family only.

#### **Couple Two – Frank and Julie**

The second couple has been married for five years. They have two children one is four months old and the other is four years old. The four year old girl was diagnosed with ALL seven months ago. She has been hospitalized once and is currently receiving chemotherapy treatment. Frank and Julie are both Asian between the ages of 26 and 35. Julie shared that she has received individual therapy and has support from family, friends, the church and co-workers. Frank has not received mental health treatment and reports receiving support from friends, family and people from the church.

### **Couple Three – Gail and Stan**

The couple has been married 21 years. They have five children, ages 37, 34, 31, 30 and 18. The son who is eighteen was diagnosed with testicular cancer three months ago. He has been hospitalized four times and is currently receiving treatment. Stan and Gail are Caucasian. Stan is over the age of 56 and Gail is between 46 and 55. Stan has not received mental health treatment, but cites family, friends and people from the church as his support system. Gail on the other hand has received mental health support from social workers and Child Life Specialists, but did not report receiving support from any other source.

### **Couple Four – Mike and Cheryl**

Mike and Cheryl have been married for 18 years. They have four children ages eight, thirteen, seventeen and twenty one. The daughter who is 17 has been diagnosed with a Germ Cell Tumor three years ago. She has been hospitalized four times during her illness, is currently considered cured and is receiving follow up care. Cheryl and Mike are African American. Cheryl is between the ages of 36 and 45. Mike is between the ages of 46 and 55. The couple has not received any mental health support, but both report friends and family to be part of their support systems.

### **Couple Five- Josh and Leslie**

Josh and Leslie are not married and have been living together five years. They have three children ages ten, eight and three. The son who is three years old was diagnosed with ALL less than three months ago. The child was hospitalized once and is

currently receiving treatment. Leslie is Caucasian between the ages of 26 and 35. Josh is Caucasian between the ages of 36 and 45. The couple has not received mental health support, but report having support from friends and family.

### **Couple Six – David and Amanda**

David and Amanda have been married for 19 years. They have two children ages eleven and thirteen. The thirteen year old son was diagnosed with Aplastic Anemia ten years ago. He has been hospitalized once for the illness and is currently considered cured and is receiving follow up care. Amanda and David are both Caucasian between the ages of 36 and 45. David has not received any mental health treatment and reports his friends to be his support system. Amanda had received individual therapy and reports friends and family as her support.

### ***Open Ended Questions***

Participants responded to four open-ended questions by writing in their responses.

The following were the questions asked:

1. What kinds of challenges have you had as a result of having an ill child?
2. Has there been any impact on you as a couple to have a child with a serious illness?
3. What do you think is important for other couples with a child with a life threatening illness to do or to know about how to have a good relationship?
4. Is there anything else about being in an intimate relationship and having an ill child that you were not asked, but that you would like to discuss?

## **What Kinds of Challenges Have You Had as a Result of Having an Ill Child?**

Tina and Robert as well as Mike, Cheryl's husband, reported they did not experience challenges as a result of having a sick child. The other participants shared a list of practical hurdles they have had to deal with. Julie and Frank reported issues of finding adequate childcare for both their sick child and their other children. Taking time off from work and having to juggle the work schedule was an issue for Julie and Frank as well as for Gail and Stan. Stan pointed out that being a truck driver on the road a lot, seemed to pose an added dimension of difficulty for the couple to contend with. Gail and Stan as well as David and Amanda reported the challenge of getting to and from the hospital and clinic for medical care, as both couples live over an hour away from LLUMCHOPC. Mike and Cheryl wrote about their challenge to keep a normally running household for their healthy children. Josh and Leslie as well as David and Amanda expressed their fear that they are neglecting their other healthy children. Leslie also wrote about the challenge of finding time together as a couple. Gail and Stan mentioned the emotional difficulties they face, specifically for Gail who is the primary caregiver. While David did not elaborate, he wrote about the stress caused by having a son that could potentially die. Josh stated having a difficult time sleeping, crying a lot and drinking more, as challenges he faces as a result of having an ill child.

## **Has There Been Any Impact on You as a Couple to Have a Child With a Serious Illness?**

Two couples stated that the illness brought them closer as a couple. Julie said: “We are closer because we have to be united in decisions for our children. We have to be strong for our child and each other.” Frank discussed a sense of isolation as a couple from friends and family. He said he and his wife did not interact with other couples and other family members as much as they used to now that their child was ill. The issue of isolation was raised by Gail and Stan as well. Stan being a truck driver and away a lot, tended to isolate them due to distance and time constraints. Not spending much time together as a couple was difficult on Gail specifically, as she stated she wished she had her husband there to lean on during the difficult times of the illness. Leslie wrote about her husband’s drinking as isolating them from each other: “My son’s father drinks a lot more, where he does not help with anything. And you don’t want him around.” Apparently not only was the lack of assistance from Jim significant, but also implied was the burden of living with someone drinking heavily.

It is interesting to note that two of the couples did not think the illness had an impact on their relationship. The common thread with these couples was that their child is now considered cured and is receiving only follow up care.



**What Do You Think is Important for Other Couples With a Child With a Life Threatening Illness to Do or to Know About How to Have a Good Relationship?**

For Tina and Robert having faith in God was something important that other couples should know. A good relationship with God was important to Gail and Stan as well. Julie and Frank emphasized the importance of spending time together. Julie reported: “Take time each day to just hold each other.” Frank wrote: “You need both parents to be on the same page... encourage each other to take things day by day and week by week.” Being there for each other was also mentioned by Stan as something the couple must maintain in face of the adversity. Maintaining a positive outlook was suggested by Cheryl and Mike. Frank and Julie also emphasized the importance of being able to communicate clearly regarding their child’s illness, while not allowing it to take over. Josh and Leslie, who dealt with a great deal of relational disconnect due to Josh’s drinking, expressed the need for family and good friends to help support the couple. “Arranging a date night to go out to dinner or movie, and trusting a family member to help watch the kids.” David stated the importance and focus on working together and the awareness of being there to support each other through the difficult times.

**Is There Anything Else About Being in an Intimate Relationship and Having an Ill Child that You Were Not Asked, But that You Would Like to Discuss?**

While Tina and Robert, Frank and Julie, Gail and Stan did not have anything to add to the discussion, Cheryl noted that “Everything comes to a halt when your child

becomes ill.” She suggested for one to stay close to family, as that really helps. Leslie noted, “You really have to put your own feelings aside and take care of your child with the best of your ability. You need “me time” and time with your partner or spouse.”

Amanda added, “Having a child seriously ill effects[sic] not just the child, but the whole family. It is important to stay together, turn to and not away from each other.”

Participants responses to the above questions provided evidence of the couples’ experience when their child is diagnosed with a potentially life threatening illness. Some participants reported that they did not experience difficulties as a couple. Some went as far as stating that their child’s illness actually has brought them closer together. On the other hand some wrote about hurdles they had to overcome both individually (such as taking time off from work and juggling schedules) and as a unit (such as finding time for the relationship).

### ***Healthy and Unhealthy Coping Skills***

In the qualitative portion of the test instruments, Open Ended Questions for Couples (Appendix F), which was given to six couples, study participants reported both healthy and unhealthy coping skills in their relationship when dealing with their child’s illness. In the following section a description of the healthy coping skills will be provided, followed by a description of the unhealthy coping skills.

#### **Healthy Couple Coping Skills**

Of the six couples four (66.6%) reported they engaged in healthy coping skills which have the potential for benefiting the couple relationship. Participants listed (1) the

power of prayer, (2) communication skills and boundaries, (3) the importance of a strong support system and (4) the need to stay positive.

### ***The Power of Prayer***

While Robert shared that he thought their child's illness brought them closer together, both he and Cheryl reported that what has helped them cope and keep them connected as a couple was praying together. Stan emphasized the importance of faith as something that has helped them as a couple through this difficult time. He wrote "Both parents need a love for Jesus which makes all the difference in the world. God is good and He is in total control and loves us so much."

### ***Communication and Boundaries***

Frank stated that their healthy way to cope with their situation was to make sure they are on the same page as a couple. He stated it is important not to assume that one person has taken care of an issue related to the illness, but rather should insist on open communication. Julie also offered practical solutions to Frank's comment on not assuming that medical concerns have been addressed. She states that it is important to "...set up a binder for medical documents for your child" in order to keep track of their child's treatment and progress. She also talked about the importance that they as a couple not be consumed by communication about medical issues constantly. She shared that it is important to have communications focused on the family, and medical issues can be looked up in the binder they prepared. This separation creates a clear boundary for them to work with.

### ***Support System***

Frank stated that the importance of having a support system so the couple can spend time together "...find time with each other while having a babysitter [watch the kids]". Julie suggested ways to connect with each other to "take time each day to just hold each other and hold your child. You don't always have to talk. Just a hug is okay." Gail also shared the importance of having a good support system. She referred to having an extended family as being important to help the couple as a unit "as otherwise the unit declines with a serious illness." This was supported by Mike who said "Everything comes to a halt when your child becomes ill. Even your relationship. Having family helping through the crisis can help not only you as a person, but us as a couple."

### ***Stay Positive***

Cheryl stated that one of their challenges as a couple has been to maintain a home that runs as normally as possible. She highlighted the importance of maintaining a balance for them as a couple and as a family, specifically for the children who are not sick. To cope with the situation she stated she had to remind herself on an ongoing basis that "[she must] stay strong and know tomorrow will be a better day."

### **Unhealthy Couple Coping Skills**

Although it is the assumption that it was not the participant's intention, two couples (33.3%) with unhealthy couple coping skills were identified, which had the potential for a negative impact on the relationship. The unhealthy coping skills included drinking, leading to lack of intimacy as well as turning away from each other.

### ***Drinking and Lack of Intimacy***

Josh and Leslie were the one couple who was living together, but who were not married. Out of all the couples they seemed to be having the hardest time relationally. Leslie shared that there were days she felt she was neglecting her kids and her relationship as she was consumed with her child's illness. "The ill child is very time consuming, [there is] no couple time at all." She talked about Josh being detached and turning to drinking due to the illness: "My son's father ... does not help with anything. And you don't want him around. He can't just deal with day to day issues. He's all about himself." Her response illustrated the sad fact that she could not rely on Josh for emotional support and highlighted her frustration in trying to find support from her partner but being confronted with his negative behaviors.

Leslie reported that as a couple they should spend more time together. She would like to be able to talk to her partner and for them to help each other emotionally. However, she states that is not currently the case. She indicated that while you need time for yourself, making couple time should be a priority.

### ***Turning Away From Each Other***

Josh who lives with Leslie described his difficulty in sleeping. He said he currently cries a lot and is drinking more than he ever used to. Rather than turning toward his partner, Josh shared that he turns away from her and isolates himself. He shared "My [significant] other wants more intimacy, but by the end of the day I just want rest." It was clear from comparing the comments from both Leslie and Josh that both were deeply affected as individuals, but also at the couple level by the illness of their child.

David and Amanda was another couple who seemed to engage in unhealthy coping skills. Amanda shared that their relationship was under great strain due to the illness of their child. She felt that David was not protecting their sick child as much as she thought he needed protection, as their child's immune system was suppressed and there was a great fear that he would get other illnesses. "Instead of turning to each other, supporting each other, we argued a lot and turned away from each other. At times I considered divorce because things were so bad."

As gathered from the qualitative portion of the study, healthy couple coping skills as well as unhealthy couple coping skills were identified. It is through the stress of the illness that couples either turned away from each other or toward the other at this great time of need. While it may not have necessarily been the couples' plan to engage in have either healthy or unhealthy coping skills, their comments reflected the fact that some couples worked well together and others did not. Turning toward each other and praying together, having good communication and boundaries, having a support system as well as staying positive was far more beneficial for the couple unit than drinking, failure to share intimate time together or turning away from each other. These coping strategies provide a useful list of intervention foci for medical family therapist at the individual and couple level.

## CHAPTER FIVE

### DISCUSSION

The following section examines how different attachment styles impact grief of parents whose children suffer with a life threatening illness. The section is followed by describing the model that was developed which discusses factors influencing grief. The final section comprises a discussion of the strengths and benefits of the study, ending with the limitations and implications of the current study.

#### **Hypothesis Evaluation for Attachment Styles and Grief**

The study examined the relationship between attachment styles and grief amongst parents and guardians of children under the age of 18 years diagnosed with potentially terminal oncological and hematological illnesses. In general, the study confirmed the hypothesis that the more secure style of attachment one has, the less Chronic Sorrow, Ambiguous Loss and Anticipatory Grief they will experience.

The following section will examine the confirmation and limitations of the hypothesis driving the above study. The hypothesis will be discussed while examining attachment styles and each of the three types of grief that were examined in the study: Chronic Sorrow, Identity Ambiguity and Anticipatory Grief.

#### ***Chronic Sorrow***

It was hypothesized that participants with a Secure style of attachment, would exhibit moderate Chronic Sorrow scores, while participants with a Preoccupied style of

attachment, would show high levels of chronic sorrow. Finally, participants with Fearful and Dismissive styles of attachment would exhibit low levels of Chronic Sorrow.

The study confirmed the hypothesis in that the more Secure the style of attachment a person has, the less Chronic Sorrow they reported. However, due the assessment tool used to measure attachment style (the ECR), the author was unable to tease out the differences between the Preoccupied and Fearful style of attachment in the findings. However, significance was found with the interaction of the Anxious attachment and Avoidant attachment questions. These findings demonstrated that the higher the levels of Anxious or Avoidant attachment a person exhibits, the higher the levels of Chronic Sorrow the participants reported in response to their child's illness. Those experiencing higher levels of Chronic Sorrow reported persistent pain and sadness. Such parents typically have a difficult time reaching a stage of acceptance regarding the illness of the child (Tinlin, 1996). While those with a Secure style of attachment may not reach a stage of acceptance either, they do appear to reach a stage of adaptation to the new reality with which they are dealing.

### *Ambiguous Loss*

Ambiguous loss was measured through using the assessment tool that examined Identity Ambiguity (O'Brian, 2007). This was done since the concept of Ambiguous Loss could not be quantified, yet has significant overlapping elements with Identity Ambiguity, such as examining the concept of mastery, impact on family relationships and roles that have changed due to the illness of the child. As with Ambiguous Loss, Identity ambiguity is associated with immobilization, depression symptoms, a sense of being



overwhelmed, as well as difficulty adapting to change (Boss, 2006). As stated by O'Brian (2007), Identity Ambiguity is viewed as the result that occurs due to the Ambiguous Loss that takes place. Boss (1999) states that when families are in a position of waiting for outcomes which they are unable to influence by their efforts, or in which some element of process or outcome is uncertain, the family experiences Ambiguous Loss. This is supported by the findings in this investigation.

It was the author's hypothesis that people with a Secure style of attachment would report moderate levels of Identity Ambiguity. Participants with a Preoccupied style of attachment, would show high levels of Identity Ambiguity and on the other end of the spectrum, and participants with Fearful and Dismissive styles of attachment would display low levels of Identity Ambiguity. .

Similar to the findings pertaining to Chronic Sorrow, the study confirmed the hypothesis that the more Secure the style of attachment the participant had, the less Identity Ambiguity they reported. Due to the use of the ECR as the measure for attachment style, it was impossible to discriminate between the various attachment styles. Therefore significance was found when examining the interaction for Anxious and Avoidant attachment styles. The higher the levels of Anxious and Avoidant attachment a person reported, the higher were the levels of Identity Ambiguity. These outcomes imply that parents with these attachment styles would have greater difficulty dealing with the Ambiguous Loss inherent in their child's illness. Preoccupation with the object of attachment is common to both Ambiguous Loss and Anxious attachment behaviors. Those with an Anxious style of attachment (a preoccupied style of attachment) are inclined to have a difficult time negotiating the ambiguity of having a potentially

terminally ill child, cling to, and even smother the child (Neria & Litz, 2003; Servaty-Seib, 2004). On the other hand those with an Avoidant attachment style appear to be more guarded and detached from the relationship with the ill child.

### *Anticipatory Grief*

The researcher hypothesized that participants with a Secure style of attachment, would show moderate levels of Anticipatory Grief as due to the severity of the situation they would have some grief and plan for the potential loss of the child, but not be overwhelmed by it. Those with a Preoccupied style of attachment, would show high levels of Anticipatory grief, which could be all consuming. The anticipation of the potential of the child dying in such a case tends to take over ones focus and emotional energy. Those with Fearful and Dismissive styles of attachment reported low levels of Anticipatory Grief. This is due to their detachment from the gravity of the situation and not being completely attuned to the grief experience they are going through.

As the results for Chronic Sorrow and Ambiguous Loss indicated, the findings confirmed the hypothesis that the more secure the style of attachment a person had, the less Anticipatory Grief they exhibited. As stated earlier, due to the way the ECR attachment scale was constructed, the author was unable to set categories for the different attachment styles. The instrument assesses for all styles of attachment, but compares Secure style of attachment with Anxious and Avoidant styles of attachment. Significance was found with the interaction of Anxious and Avoidant attachment styles, where the higher those levels, the higher the Anticipatory Grief one experienced. Anxious and

Avoidant styles, when examined separately, did not significantly indicate one's level of Anticipatory Grief.

### **Model Developed: Other Factors Influencing Grief**

In examining the data three variables were significant in reducing levels of grief in addition to one's attachment style. Those variables included (1) whether the child was currently receiving treatment, (2) if the child was considered cured and (3) the length of time since the child received the diagnosis of the hematological or oncological illness. These factors influenced the perception of the parents' control over the situation, and the length of time they have had to deal with the illness, process it and come to terms with their new reality.

### ***Child Receiving Treatment***

In examining whether the child was receiving treatment at the time of the study, we found that when the child was actively receiving treatment, the parents' and guardians' reported significantly lower levels of overall Chronic Sorrow, Guilt and Worry, Unresolved Sorrow and Anger, overall Identity Ambiguity, IPQ, and perceptions of stress and difficulty. This means that the fact that the child was receiving treatment had a positive impact on the parents' grief experience, in the categories named above.

These findings could be explained by the participant's perception and sense of mastery. When the child is receiving treatment, the participant views themselves as being proactive and had a sense of control in regards to the child's illness. Being proactive and doing something positive that has the potential of curing the child, often reduces the

parent and guardian's level of grief. However, parents of children receiving treatment did not have significantly lower levels of Anticipatory Grief. It is possible that the parents in such a case view the child receiving treatment as overwhelming and potentially anticipate the worst. In such a frame of mind, the fact that the child is receiving treatment is not comforting, but rather confirms one's fear.

### ***When Child is Considered Cured***

When a child was considered cured, the parents' and guardians' level of overall Chronic Sorrow, subcategory of Guilt and Worry, Unresolved Sorrow and Anger, Identity Ambiguity and the subcategory of IPQ, indicated statistically significant lower levels of grief.

The findings are rather obvious for the categories that showed significance. When a child is considered cured, the parents experienced reduced levels of grief. However, the fact that all types of sorrow were not significantly reduced, demonstrates that this population is a little more complex than might be apparent. When a child is considered cured, parents and guardians often become acutely aware that their child is more prone to reoccurrence and other serious illnesses, now that they had such a horrific illness. This reality can promote a sense of grief. In addition, as discussed by McDaniel and colleagues (1992) the parents' innocence of having what they perceived as a healthy child, has been taken away, and a certain level of grief regarding that reality exists even when the child is considered cured. At times, the reality of this loss can only be processed once the child is cured, as the parents and guardians are often consumed with other thoughts and concerns when the child is in the acute stages of the illness. Finally, as

stated by Lowes and Lyne (2000), such grief often does not end, and therefore the parents continue to experience some levels of grief even post recovery.

### **Time Elapsed Since the Diagnosis Was Given**

Participants reported that the longer the time past since the diagnosis was given, the lower their Chronic Sorrow and the better their Emotional Resources were.

These findings indicated that the longer time that has passed since the time of diagnosis, the lower level of Chronic Sorrow one experienced. Such findings were supported by Tinlin (1996) who stated that the grief experience takes place in relation to the phase of the treatment and diagnosis the child is in. However, the ups and downs and potential relapse that exists in the illnesses discussed, do not allow for a clear, definitive end to the grief, just due to time passing from the time the diagnosis was received. It would be important to find other ways to measure or operationalize the reduction of grief in relevance to the phase of illness, rather than the time since the diagnosis, which alone seems to reduce grief, specifically Chronic Sorrow.

### **Strength of Study**

#### ***Contribution to the Field***

As discussed in this study, the emotional impact and specifically the grief experienced by parents and guardians of children with an illness, has had minimal attention in the academic literature, not to mention parents and guardians of children dealing with a life threatening illness such as hematological and oncological disorders. This study is the first in its kind to contribute to the literature in a unique way. It

addresses the sensitive topic of potentially losing a child and the emotional impact that the ambiguity of the situation could have on the parents or guardians. The study identified and examined specifically three categories of grief: Chronic Sorrow, Ambiguous Loss and Anticipatory Grief, as they relate to one's attachment style. Therefore this study sheds light on a population that deals with great emotional impact and showed benefits from receiving mental health treatment.

This innovative study contributes to the field of Marriage and Family Therapy, specifically Medical Family Therapy, which focuses on the impact of medical issues on the family. It sheds light on the varieties of grief and issues that arise from a potentially terminal illness of a child. In addition, this study contributes to the education of medical professionals who deal with children with hematological and oncological illnesses. The application of Ambiguous Loss to the experience of families affected by potentially terminal illness provides a lens through which healthcare workers and medical family therapists can understand the impact such an illness has on the parents and guardians, as well specific interventions parents and guardians need in order to reduce their levels of grief.

### ***Translated Survey and Related Documents***

As the current study was conducted in the San-Bernardino area, and had a predominantly Hispanic sample, one of the great strengths of the study was that the instruments were translated into Spanish. By doing so, we were able to include a large Hispanic population, that otherwise would have been ignored. In the current study 36.8% of the participants did not speak English and were invited to participate in the study

through the use of a translated survey, informed consent and instruction letter. This allowed for a large population to have a voice that otherwise could be silenced.

Unlike other studies, the current study was able to examine a large Hispanic population (specifically Mexican-American). The importance of studying this population is not only to shed a cultural light on a growing population that is often silenced, but it also adds a dimension for understanding family dynamics, as Mexican-American families appear to have greater family support during a time of crisis and seem to enjoy closer family ties. Therefore, the study was able to identify the grief experience on a variety of attachment styles within a specific culture.

### *Gender*

The investigator initially expected a small number of fathers and male guardians to participate in the study, as the assumption was that mostly mothers and female guardians would be available to bring their child to their physician check-ups, and therefore would be the majority of participants. Surprisingly, a large number of fathers and male guardians 33.3% participated in the study, which allowed for input by both genders. The high number of fathers' attendance could be attributed to the severity of the child's illness. While mothers are usually the ones taking children to regular doctor visits dealing with colds, viruses, vaccinations and such, the doctor visits at the LLUMCHOPC seemed to hold a different level of importance. It could be that the severity of the illness leads the fathers to being more involved in the child's medical care. In addition, when dealing with such severe illnesses, there is a sense of the child needing an advocate to assure they are receiving the best possible treatment. It is the investigator's hypothesis

that fathers feel comfortable filling the role of the advocate and thus wanted to be at the physician's appointment to assure their child is receiving the best possible care.

### ***Variety of Participants***

Data was collected at different days and different times of day, with patients of different doctors. The goal in doing so was to include a variety of participants, those who work, those who are home, mothers, and fathers, thus increasing the potential for collecting data from those affected by a variety of illnesses. By doing so, it was the hope of the researcher to capture a representative sample and not overlook a potentially silent group of people within the population under examination. By sampling at different times of the day, more fathers participated in the study, as they brought their child for the doctor visits after their work hours.

### ***Couple Perspective***

As the study was a mixed method study, the qualitative portion examined couples and the impact of the illness experience on their relationship. The data collected was relational data, as it was collected from both husband and wife together, and then compared to each other as a unit. By collecting such data, greater richness was provided to the study, rather than asking about the relational experience from individuals, without having the ability to compare the answers of husbands and their wives. It was beneficial to use such data to forward the field of MFT which benefits from the collection of relational data by hearing the voices of both partners.



## **Limitations and Implications**

### *Limitations*

#### **Language**

While a great benefit to the study was that it was translated to Spanish and therefore included both English and Spanish speakers, the survey and accompanying materials were not translated into any other language, which eliminated participants that spoke another language (such as Arabic) and did not feel comfortable reading and completing a survey in English.

#### **Ethnic Diversity**

As stated earlier, the area in which the LLUMCHOPC is located in is a predominantly Hispanic (City of San Bernardino, 2011). This population was captured with 63% of participants of the study being of this ethnic group. Caucasians was the next large group at 18%. The surprise in study was the low number of African Americans studied (6%). The number of African American participants was expected to be larger, as children in this population suffer with Sickle-Cell disease. The study did capture however a large variety of mixed ethnicities such as those who classify themselves as Hispanic-Asian, Caucasian-Hispanic, Caucasian-Eastern Indian, Caucasian-Asian and Hispanic-African American. The sample seemed to be a reflection of the area studied, and captured the ethnic essence of the location of the study.

The predominantly Hispanic population was not captured in the qualitative portion of the study. Of the Hispanic parents that did attend the clinic as a couple, most felt they could only answer the questions presented in Spanish. Due to the language

barrier, those participants were eliminated from the qualitative portion of the study. Due to this, 50% of the participant in the open-ended questions were Caucasian, 25% Asian, 17% of African American descent and 8% reported as identifying as “other” ethnicity, but did not report the ethnicity they identified with.

### **Study Location**

The study took place at the LLUMCHOPC. Studying parents and guardians at the clinic location only and not at the hospital as well, ignored the crisis stage of the illness and focused more on the chronic stage of treatment and follow up. Due to this focus, the results provided have the potential of being substantially different than if the study was conducted at both locations. It is hypothesized that greater levels of grief would be reported by parents and guardians at the time their child is hospitalized than at follow up appointments in an outpatient clinic setting.

### **Demographics**

While the study asked extensive demographic questions regarding the child, parent / guardian and the illness, one question that was not asked was the parent or guardian’s income. By not having a question regarding income, we were unable to identify if socioeconomic status impacted one’s grief in such a population. Another issue that was not examined and would have provided greater depth of understanding of the participants was their physical distance from their family and friends. LLUMCHOPC operates as part of a large regional medical center provides services for patients from near and far. Some travel to this location from other countries, leaving their loved ones for

several weeks, months and even years. Identifying this as an issue would have allowed us to examine if those who are away from their primary support community have greater Chronic Sorrow, Ambiguous Loss and Anticipatory Grief.

### **Attachment Style Scale**

A limitation of the study was that the ECR response scale was converted from a seven point likert scale to a five point likert scale. While this was done to provide consistency and greater ease for the participants, it eliminated the ability to compare scores of the participants with prior studies that used the ECR. Finally, one of the biggest limitation of the study was not being able to categorize the various Attachment Styles people had, but rather being limited to comparisons between Securely attached individuals with those who have an Anxious or an Avoidant style of attachment as a combined unit. Future studies would benefit from using a different measure of attachment other than the ECR, which had valid questions to identify adult attachment style, but did not allow for classification of various style types.

### **Qualitative Data**

Initially for the qualitative portion of the study the plan was to conduct a focus group for five couples and ask questions regarding the impact of the child's illness on their relationship. Due to logistics such as couples living far from the clinic location and inability to set up child care for the sick child, so both partners could attend the focus group, we were unable to secure a commitment from five couples to participate in a focus

group. By not conducting a focus group, a potential for reduction in the richness of data is assumed.

### *Implications*

#### **Future Research**

The current study contributed to a foundation of research in a scarcely studied population. While significant levels of grief, specifically Chronic Sorrow, Ambiguous Loss and Anticipatory Grief were found in this study, the study was located at a clinic, in which ongoing treatment and follow up visits with physicians was provided after the crisis of the illness was resolved at the hospital location. Future studies should include parents and guardians during the time the child is hospitalized. By studying this population during hospitalization, we will be able to better understand the grief as it is influenced by the stage of the illness.

Finally, in the current study we only surveyed the parent or guardian that brought the child to the clinic. It would be of interest for future studies to compare the grief experience between the parent or guardian that brings the child to their checkups, compared to the parent or guardian who does not. Is the parent or guardian who stays behind less involved and more detached and therefore experiences less Chronic Sorrow, Ambiguous Loss and Anticipatory Grief? Is there a difference in their attachment style which influences the involvement with the child's illness? Additionally, the experience of siblings of oncology or hematology patients could provide insight into the issues that other children in these families have. These would all be interesting research questions to further understand the population studied.

## **Education**

Medical Family Therapy (MedFT) is a biopsychosocial treatment approach to the individual as well as the family who is dealing with medical issues (Burwell, Templeton, Kennedy & Zak-Hunter, 2008). MedFT appreciates the challenges of dealing with illness and is distinguished from other therapy by its conscious attention to the medical condition as well as the role it plays in both the personal and interpersonal life of the patient and the family (McDaniel, Hepworth, & Doherty, 1992). MedFT, does not aim to cure the person, but rather offers families the tools needed to help them cope better with the illness they are facing.

MedFT however is a new field within MFT, which is a relatively young field. MFTs in general practice typically do not identify or fully understand the grief experience of parents and guardian of a child who are dealing with a life threatening illness. The field is well aware of the grief experienced by caregivers when the child dies, but not the Chronic Sorrow, Ambiguous Loss and Anticipatory Grief experienced when the child is still alive when there is the fear of losing the child. Such a concept as well as its relation to one's attachment style and other factors that were identified in this study as contributors to grief would be beneficial to be taught to therapists in training as well as to those in the medical profession who come in contact with the population studied.

## **Clinical Practice**

While the main benefit of the study for clinical practice is to raise awareness of the grief experienced by parents and guardians of children with life threatening illness, it is of great importance for clinicians to understand the compounding factors of the grief.

As the study identified, securely attached people experience lower levels of Chronic Sorrow, Ambiguous Loss and Anticipatory Grief. Clinically, therefore, it is beneficial for the therapist to consider the client's attachment style and promote work for the client to heal broken bonds (Palmer, 2009) and develop a more secure style of attachment (Walker, Johnson, Manion, & Cloutier, 1996).

Finally, clinically, this study suggests the benefit of promoting mastery in cases of children with medical illnesses. This could be achieved by pursuing treatment recommended for the child, as that gives the parents and guardians a sense of control over a difficult situation. In addition, as Boss (2004) recommends, maintaining family traditions contributes to the sense of mastery, while dealing with a difficult and unpredictable situation.

Greater focus and understanding regarding the grief experience of parents and guardians who have a child with a life threatening illness, is beneficial in the clinical setting, as little attention has been given to this population in the past. It is the hope of this author that continued research, practice recommendations, and educational curricula will address issues of grief and oncological-hematological illnesses in pediatric populations.

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## APPENDIX A

### PARENT EXPERIENCE OF CHILD ILLNESS - PECCI

#### Measurement for Chronic Sorrow

1. I worry that any minute, things might take a turn for the worse
2. I think about whether or not my child will die
3. I am afraid of this diagnosis occurring in another member of my family
4. I worry that my child's illness will worsen/return.
5. I feel guilty because my child became ill, whereas I remained healthy.
6. I worry that I may be responsible for my child's illness in some way.
7. I worry about something bad happening to my child when s/he is out of my care
8. When my child is actively playing, I find myself worried that s/he will get hurt
9. I wake up during the night and check on my child
10. When I'm not with my child, I find myself thinking about whether or not s/he is ok.
11. I trust myself to manage the future, whatever happens.
12. I feel ready to face challenges related to my child's well being in the future
13. I can get help and support when I need it
14. I am aware of the specific ways I react to sadness and loss
15. I am at peace with the circumstances in my life
16. I experience angry feelings when I think about my child's illness
17. I find it hard to socialize with people who do not understand what being a parent to my child means

18. I believe I will never be as completely happy or satisfied as I was before my child became ill
19. I am jealous of parents who have healthy children
20. Seeing healthy children doing everyday activities makes me feel sad
21. It is painful for me to think about what my child might have been like had s/he never gotten sick
22. I have regrets about decisions I have made concerning my child's illness
23. My hopes and dreams for my child's future are uncertain
24. I worry about my child's future
25. I worry about whether my child will be able to live independently as an adult



## APPENDIX B

### THE GRIEF EXPERIENCE INVENTORY - GEI

#### Measurement for Anticipatory Grief

The Background Information Questionnaire (BIQ)

*Acceptance / preparation*

What have the doctor or health care staff told you to expect with regard to your child's illness:

- a. Simple diagnosis
- b. Severity of diagnosis emphasized
- c. Conditional diagnosis (may be fatal)
- d. Fatal prognosis
- e. Fatal prognosis with estimated time of death

Do they think that your child will survive this illness:

- a. Definitely
- b. Probably
- c. Uncertain / unknown
- d. Probably not
- e. Definitely not

Do you believe that your child will survive this illness

- a. Definitely
- b. Probably
- c. Uncertain / unknown
- d. Probably not
- e. Definitely not

Should your child die from this illness, how prepared do you feel for this:

- a. Totally unprepared
- b. Generally unprepared
- c. Uncertain degree of preparation
- d. Somewhat prepared for a short time
- e. Somewhat prepared for quite some time
- f. Prepared for a short time
- g. Prepared for quite some time

### Factors Influencing Adjustment Questionnaire (FIAQ)

How hopeful do you feel for your child's recovery from this illness

- a. Completely hopeful
- b. Moderately hopeful
- c. Sometimes hopeful
- d. Moderately hopeless
- e. Totally hopeless

### *Social Support*

The degree of care and support show to me by my family is:

- a. Totally caring and supportive
- b. Caring and supportive most of the time
- c. Somewhat caring and supportive
- d. Uncaring and / or unsupportive
- e. Totally uncaring and unsupportive

The degree of care shown to me by my friends is:

- a. Totally caring and supportive
- b. Caring and supportive most of the time
- c. Somewhat caring and supportive
- d. Uncaring and / or unsupportive
- e. Totally uncaring and unsupportive

The degree of care and support shown to me by my medical and health care staff is:

- a. Totally caring and supportive
- b. Caring and supportive most of the time
- c. Somewhat caring and supportive
- d. Uncaring and / or unsupportive
- e. Totally uncaring and unsupportive

### *Guilt / regret*

How much do you feel that you are responsible for, or have contributed to, your child's current illness:

- a. not at all responsible
- b. Minimally responsible
- c. Moderately responsible
- d. Largely responsible
- e. Completely responsible.

How much do you feel you have done for your child during his / her current illness:

- a. Everything that a parent could do
- b. Mos of what a parent could do
- c. Some of what a parent could do
- d. Little of what a parent could do
- e. None of what a parent could do

How many regrets do you have for things that you have said or done to your child in the past, or things that you failed to say:

- a. No regrets
- b. Few regrets
- c. Some regrets
- d. Many regrets
- e. A great deal of regrets

*Perception of Patient's Pain*

How does your child seem to be feeling physically:

- a. Comfortable and pain free
- b. Pain free but uncomfortable
- c. Mild pain and discomfort
- d. Moderate pain and discomfort
- e. Extreme pain and discomfort

How often does your child seem to be in pain:

- a. Never
- b. Rarely
- c. Occasionally
- d. Frequently
- e. Constantly

What level of pain and suffering do you think your child is feeling because of this illness:

- a. A very low level / none
- b. A low level
- c. A moderate level
- d. A high level
- e. A very high level

What level of emotional distress do you think your child is feeling because of this illness:

- a. A very low level / none
- b. A low level
- c. A moderate level
- d. A high level
- e. A very high level

*Perceived Stress and Difficulty Coping*

How well do you feel you are coping with the demands and stresses of this illness:

- a. Totally able to cope
- b. Coping well
- c. Coping, but with difficulty
- d. Coping poorly
- e. Totally unable to cope / overwhelmed

How well do you feel you are coping with the demands and stresses of daily life (family, chores, job):

- a. Totally able to cope
- b. Coping well
- c. Coping, but with difficulty
- d. Coping poorly
- e. Totally unable to cope / overwhelmed

My general level of self-esteem and self-confidence is:

- a. Very high
- b. High
- c. Moderate
- d. Low
- e. Very low.

In addition to your child's illness, what degree of other stresses are you experiencing (job changes, financial concerns, change in residence, family responsibilities):

- a. A very low degree / none
- b. A low degree
- c. A moderate degree
- d. A high degree
- e. A very high degree

How would you rate your current health:

- a. Very healthy
- b. Healthy
- c. Some symptoms / minor illness
- d. Several symptoms / moderate illness
- e. Major acute or chronic illness

The degree of financial resources available to meet current and future daily needs is:

- a. More than sufficient
- b. Sufficient to meet all needs
- c. Sufficient to meet some needs
- d. Insufficient to meet most needs
- e. Totally insufficient

Has anyone dear to you ever died:

- a. No, never
- b. Lost one person more than 5 years ago
- c. Lost two or more persons more than 5 years ago
- d. Lost one person less than 5 years ago
- e. Lost two or more persons less than 5 years ago.

**APPENDIX C**  
**IDENTITY AMBIGUITY**

**Illness Perception Questionnaire IPQ:**

My child's condition strongly affects the way I see myself as a person

My child's illness strongly affects the way others see me

My child's illness has serious economic and financial consequences for me and my family

My child's condition is difficult for me to live with

My child's illness does not have much effect on my life (reverse scored)

My child's illness will have major consequences on my life.

**Health Specific Locus of Control (HSLC):**

There is a lot I can do to control my child's illness

My child's illness is my own fault

I have a lot of confidence in my ability to help my child overcome his or her problem

There is little I could have done to prevent my child from having his or her condition (reverse scored)

What I do can determine whether my child's illness gets better or worse.

## APPENDIX D

### EXPERIENCES IN CLOSE RELATIONSHIP - ECR

#### Measure of Adult Attachment Style

1. I prefer not to show a partner how I feel deep down.
2. I worry about being abandoned.
3. I am very comfortable being close to romantic partners. (R)
4. I worry a lot about my relationships.
5. Just when my partner starts to get close to me I find myself pulling away.
6. I worry that romantic partners won't care about me as much as I care about them.
7. I get uncomfortable when a romantic partner wants to be very close.
8. I worry a fair amount about losing my partner.
9. I don't feel comfortable opening up to romantic partners.
10. I often wish that my partner's feelings for me were as strong as my feelings for him/her.
11. I want to get close to my partner, but I keep pulling back.
12. I often want to merge completely with romantic partners, and this sometimes scares them away.
13. I am nervous when partners get too close to me.
14. I worry about being alone.
15. I feel comfortable sharing my private thoughts and feelings with my partner. (R)
16. My desire to be very close sometimes scares people away.
17. I try to avoid getting too close to my partner.
18. I need a lot of reassurance that I am loved by my partner.
19. I find it relatively easy to get close to my partner. (R)
20. Sometimes I feel that I force my partners to show more feeling, more commitment.
21. I find it difficult to allow myself to depend on romantic partners.
22. I do not often worry about being abandoned. (R)
23. I prefer not to be too close to romantic partners.
24. If I can't get my partner to show interest in me, I get upset or angry.
25. I tell my partner just about everything. (R)
26. I find that my partner(s) don't want to get as close as I would like.
27. I usually discuss my problems and concerns with my partner. (R)
28. When I'm not involved in a relationship, I feel somewhat anxious and insecure.
29. I feel comfortable depending on romantic partners. (R)
30. I get frustrated when my partner is not around as much as I would like.
31. I don't mind asking romantic partners for comfort, advice, or help. (R)
32. I get frustrated if romantic partners are not available when I need them.
33. It helps to turn to my romantic partner in times of need. (R)
34. When romantic partners disapprove of me, I feel really bad about myself.
35. I turn to my partner for many things, including comfort and reassurance. (R)
36. I resent it when my partner spends time away from me.

## APPENDIX E

### DEMOGRAPHICS INFORMATION SHEET - DIS

What type of illness was your child diagnosed with?

- ALL
- AML
- Brain Tumor
- Hodgkin Disease
- Non-Hodgkin Lymphoma
- Neuroblastoma
- Willms Tumor (Nephroblastoma)
- Osteosarcoma
- Retinoblastoma
- $\alpha$ -Thalassemia
- $\beta$ -Thalassemia
- Sickle Cell Disease
- Other \_\_\_\_\_

How long has it been since your child was diagnosed?

Less than a month

1-3 months

4-6 months

7-12 months

1-2 years

3-5 years

5-10 years

Other \_\_\_\_\_

How would you describe the stage of illness you are in right now?

We recently received the diagnosis

Receiving treatment

My child is off treatment

My child is experiencing a relapse

My child is considered to be cured and is receiving followup care

How many times was your child hospitalized due to his/ her illness? \_\_\_\_\_  
times

Has anyone else in your family been diagnosed with the same illness?

Yes/No

If yes – who? \_\_\_\_\_

Are you currently married? Yes/ no  
If yes – are you married to the sick child’s parent? Yes / No  
How long have you been married for? \_\_\_\_\_  
If no – Are you living with the sick child’s parent? Yes /No

Age of parent : \_\_\_\_\_

Gender of Parent completing survey: Male/ female  
Age of child: \_\_\_\_\_

Gender of Child: Male / Female

# of children you have \_\_\_\_\_

# of children living at home with you \_\_\_\_\_

Ages of other children: \_\_\_\_\_

Ethnicity:

- White
- African American
- Black
- Asian
- Hispanic / Latino
- Native American
- Other \_\_\_\_\_

Have you received any mental health support since your child’s diagnosis?

1. I have not received Mental Health support
2. Social worker
3. Child Life Specialists
4. Support group
5. Family Therapy
6. Couple therapy
7. Individual therapy

Who have you received support from since your child’s illness?

- Family
- Friends
- People from church (or other religious organizations)
- Other \_\_\_\_\_

Would you be willing for us to contact you for further questions to help us understand your experience better? Yes / NO

If yes please provide us with the following information



Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

Best time to reach you: \_\_\_\_\_

## APPENDIX F

### OPEN ENDED QUESTIONS FOR COUPLES

1. What kinds of challenges have you had as a result of having an ill child?
2. Has there been any impact on you as a couple to have a child with a serious illness?
3. What do you think is important for other couples with a child with a life threatening illness to do or to know about how to have a good relationship?
4. Is there anything else about being in an intimate relationship and having an ill child that I didn't ask you, but that you would like to discuss?