Children living with HIV/AIDS: Variations of grief intensity as manifest in house-tree-person projective drawings

Georgina Yoshioka-Armijo

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CHILDREN LIVING WITH HIV/AIDS: VARIATIONS OF GRIEF INTENSITY AS MANIFEST IN HOUSE-TREE-PERSON PROJECTIVE DRAWINGS

A Project
Presented to the Faculty of California State University, San Bernardino

In Partial Fulfillment of the Requirements for the Degree Master of Social Work

by
Georgina Yoshioka-Armijo

June 1999
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ABSTRACT

Today in our society there is a terminal illness spreading steadily, not only among adults, but also among children. This illness is not hereditary, but rather a "careless exposure." It is called Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). The purpose for this research was to explore the understudied area of children infected with HIV/AIDS, the ramifications for those children who are diagnosed with HIV/AIDS and the "death and dying" perceptions that these children may have due to their diagnosis of a terminal illness. This study explored how these children participants manifested grief intensity, especially due to the fact that they were not aware of their terminal diagnosis. Children, six to nine years of age, were given a projective test called House-Tree-Person (H-T-P). These drawings were analyzed and then matched to a list of grief indicators. The results of this study will help educate social workers on the grief process that children who are diagnosed with HIV/AIDS children experience when they do not have knowledge of their diagnosis.
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CHAPTER ONE
INTRODUCTION

Problem Statement
The sky is blue, the grass is green, and it's a new day. For most people it's off to school and/or work. For others, it's a time to get the rest of the family off into the awakened day. The individuals at this time who are the most dependent upon this agenda are our children of tomorrow. With lunches in one hand, books in the other, off they go to a little place called the "house of education and socialization." Here is where they learn about themselves and others and begin to explore the meanings of life that adults find so fascinating. But not every child can experience this image. Some come from situations that prevent them from feeling the sensations of being a small child.

Today in our society there is a terminal illness spreading steadily, not only among adults, but among many children. It is called Acquired Immune Deficiency Syndrome (AIDS). It is different than a terminal illness such as cancer because this terminal illness can be prevented from spreading not only to adults, but children also. Whereas with cancer, an individual is born with it and/or may inherit it sometime later in life. On the other hand, this illness shares something in common with the illness such as cancer. It can affect any type of gender, age, and ethnicity.

In 1987, more than 12,000 cases and 6,000 deaths were
reported to be infected with this syndrome called AIDS (Halevie-Goldman, Potkin, & Poyourow, 1987). In 1993, 361,509 cases of AIDS in the United States had been reported to the Centers for Disease Control and Prevention (CDC). By the end of 1993, 220,871 individuals in the United States had lost their lives to this disease. At this point, these figures are most certainly an underestimate. AIDS is not identified as the cause of death in about one quarter of the deaths that are HIV-related (Geballe, Gruendel, & Andiman, 1995).

In 1982, the first case of childhood AIDS was reported to the world. In 1988, pediatric AIDS had become the ninth leading cause of death in American children ages of four and under. There were 785 cases reported in 1989 where children under the age of one were diagnosed with AIDS, along with 1210 cases where the children were between one and twelve years of age. This is an eighty percent increase since 1988 (Roth, 1992). By the end of 1993, there were 5,234 cases of AIDS reported in children under the age of thirteen years (Geballe, Gruendel, & Andiman, 1995).

Even though awareness of this illness is publicized in our society, this epidemic continues to worsen. According to the Center of Disease Control (1997), as of September 30, 1996, there were a total of 566,002 AIDS cases, including 7,472 cases among children thirteen years of age and younger. Children reported with AIDS were most
likely perinatally infected with the virus from their mothers. During 1988-1993, an estimated 6,000 to 7,000 children were born each year to HIV-infected women. An estimated 1,000 to 2,000 of these children were infected annually (Center for Disease Control, 1997). Children at this point have no control over their lives.

Children at the time of infection are literally facing death in the eyes because of its seriousness. There is no cure for this terminal illness. This means that a young life will be cut short. Because the numbers are increasing in the amount of infected children with this terminal illness, it will be important that this area be emphasized more in future studies. A clear understanding must be given to those individuals directly involved with these children on how they see their future. Will they answer the question, "What would you like to be when you grow up?" or will they say, "I'll never be a grownup."

It will also be important to understand how children perceive death and dying. These children may know something is wrong, but can they relate it to their own life coming to an end?

**Problem Focus**

There is an uncertainty about how children with HIV/AIDS perceive death and dying. They know something is wrong, but they may not fully understand the concept of why they are so ill. Whether it is a friend, family member, or even themselves who are faced with dying, they will experience grief for the loss that they may have
already encountered or will be encountering in the near future. Children experience illnesses such as chicken pox and the flu but are reassured by their parents and doctors that these illnesses are not life-threatening. However, the question remains as to when do children begin to understand what it means to have a terminal illness such as HIV/AIDS. Also, when do they begin to comprehend that currently there is no cure for it.

The rate of death in children versus adults with this illness differs due to the fact that children are usually infected in their early developmental years. There have been data collected from various institutions in the United States and Europe that confirm observations at Yale at a bimodal pattern in expression of disease and in survival. Models describing survival among childhood populations indicate that approximately ten to fifteen percent of children are likely to die before the age four years, with a median age at death of five to eleven months. Among those surviving beyond four years, the median age at death is more than sixty months (Geballe, Gruendel, & Andiman, 1995).

Taylor-Brown & Garcia (1995) indicate that most social workers study death and dying as part of their professional education but abandon that learning when the client in question is diagnosed with AIDS. AIDS is perceived differently, compared to some other life threatening illness (i.e. cancer); consequently, the people with AIDS and their families are further victimized by these biases
and ignorance. The death of a person with AIDS need not be treated any differently than other types of deaths (Taylor-Brown & Garcia, 1995). Overall, there will need to be support for the dying individuals and their families, along with the process of appropriate farewells and resolution of unfinished business. This study's findings could help educate social workers who work with this population in understanding how a child diagnosed with HIV/AIDS anticipates death versus a child who is not diagnosed with a life-threatening illness.

According to Miller & Carlton (1988), several recently published articles have attempted to cover the complex ethical and legal ramifications of the HIV/AIDS epidemic. However, most of the articles fail to address the rights of infants and children who are born infected with HIV. Dickens (1988) has grappled with this issue in order to address the question: "Does an unborn child have the right to be born free of a disease that is fatal when there is a 50-percent chance that the infant will be born infected if the virus is present in the mother and the mother knows it?" Dickens points out that some jurisdictions have introduced a new crime called "willfully and knowingly exposing another to the HIV/AIDS virus" where the offense of attempted homicide has been used. However, Dickens has noted that the doctrine of parental immunity may protect mothers against such a suit. He has summed up that "few jurisdictions, in fact, recognize wrongful life actions, and, because liability to such
action may lead to abortion, some jurisdictions have prohibited them" (Miller & Carlton, 1988).

Siporin (1982) has claimed that social work's "moral philosophy and mission have become fragmented and weakened" in its response to major social changes and even "immoral" in some instances (Miller & Carlton, 1988). Therefore, social workers, who are individuals that value human life and assume children will live to old age, must take an amoral stance in designing responses to the needs of this most vulnerable of populations. By working with the foster care system, which is probably in the best position to define and design the responses required, social workers will be able to engage in more intimate collaboration between the child welfare system and health/medical services, and other systems of care (Miller & Carlton, 1988).

Since 1982, people in the United States have been gaining more insight to the spread of this disease called HIV/AIDS. This question remains: "How much do young children know or understand about this illness?" Many children with HIV/AIDS received this diagnosis before they were even born into this world. Because of possible early minor complications, they may not have the opportunity to cognitively develop at the rate like other children who do not have a diagnosis of a terminal illness. Nevertheless, based on survival rates, children with HIV/AIDS will eventually have to be educated on why they are dying sooner than are their cohorts. Hopefully, once
children have an awareness of their illness, they will then gain an understanding about death and dying, especially if they have already lost a family member to AIDS or to another terminal illness such as cancer. Therefore, this researcher proposes the hypothesis that children who are informed that they have HIV/AIDS are more likely to show greater grief intensity in their drawings than children who have not been informed.

Overall, social workers are playing an important role in preventing the spread of HIV/AIDS. However, many children have already been infected and are living day to day with this life threatening illness. Therefore this study will help educate social workers on the grief process that HIV/AIDS children experience especially when they are not informed of their diagnosis. With this knowledge base, social workers will be able to provide more adequate advocacy for these infected children and their families.
CHAPTER TWO
LITERATURE REVIEW

Acquired Immune Deficiency Syndrome (AIDS) continues to be an expanding major public health problem since its first report in 1981. AIDS is clinically complex. The process begins with infection through the bloodstream with the Human Immunodeficiency Virus (HIV). Initially, there are no obvious symptoms. However, after about four weeks, flu-like symptoms may occur, indicating an immune reaction. This reaction is the body’s normal way of removing infections. At this point, the “helper cells” located in the immune system began to change their structure from “helping” to “infecting” cells. Therefore, every time an immune reaction occurs within the body, the virus is replicated. This is considered to be the most dangerous part of the viral activity that makes HIV so intractable to treatment (Aldridge, 1993).

At this point, the stage of AIDS is set, but its progress varies from one person to another due to individual circumstances (i.e. substance abuse, blood transfusion, sexual contact, etc.). Individuals begin to get opportunistic infections, which is often the cause of death. AIDS has the characteristics of the following symptoms: a) common infections (i.e. pneumonia), b) malignancies (i.e. rare skin cancers), and c) neurological disorders (i.e. dementia). Today, however, there is a new AIDS definition that was proposed by the Center of Disease Control in the United States. Now those individuals,
regardless of symptomatic expression, who are seropositive for HIV and have a particular white blood cell count (CD4 T-lymphocyte) of less than 200 will be defined with a diagnosis of AIDS. This decision will help define cases easier and, in practice, this decision means that the incidence of AIDS will rise sharply (Aldridge, 1993).

When this epidemic began affecting children, a large portion of these cases involved children who had received transfusions of contaminated blood. More recently, only a minority of cases are infected the same way due to advanced procedures of detecting the virus in the blood. In 1993, ninety percent of the cases among children were due to mother-to-child transmission of the virus. Transmission can occur during the pregnancy, at birth, or during breast feeding. According to various studies, between thirteen to thirty-three percent of mothers are infected themselves with the virus before pregnancy. Whether infected or not, all babies born to infected mothers will initially have a positive HIV antibody test, reflecting the presence of maternal antibodies (Geballe, Gruendel, & Andiman, 1995).

Infants or an unborn child can become infected with the HIV/AIDS virus through direct transmission, drinking an infected mother’s milk, or through indirect transmission through the placenta. An average of two infants per day are born to mothers who have the HIV/AIDS virus in New York alone. Approximately half of the children have the virus (Staff & Brubaker, 1995). Women are vulnerable to the
HIV/AIDS infection, either through sexual contact with bisexual or drug-addicted partners or through personally injecting drugs (Taylor-Brown & Garcia, 1995). Overall, pediatric AIDS is rapidly growing but almost invisible menace to our nation’s children. It is important to understand this problem because it is misunderstood, under-recognized, and under reported.

Unlike adults who are HIV positive, infected children tend to become symptomatic more quickly. Seventy percent develop symptoms within one year of age, and seventeen percent die within the first year. AIDS is the leading cause of death for children between the age of one to four years old. However, over half the children infected live to seven years of age, and those infected in early years of the epidemic are living to adolescent age. Based on ethnicity, in 1990, AIDS was the leading cause of death in Hispanic children and the second leading cause of death with African-American children, both between the ages of one to four years old (Geballe, Gruendel, & Andiman, 1995).

Young children tend not to view death as final but rather as a separation. Death to them may be that they will lie down, not die, but instead just sleep for a long time. There are no simple, foolproof answers to death, the most difficult of all questions. Adults, along with children, are more likely to differ more widely in their reactions to death than any other possible human phenomenon (Bates-Ames, 1967). The development of a perspective on death is a continuous process that begins at childhood and

Dying individuals have varying attitudes and behavior patterns based on their emotional perception of death (Oaks & Ezell, 1987). Toddlers reflect an inability to conceive of an irreversible state of lifelessness. They are likely to think that a person may be dead at one moment and "undeaded" the next. Very young children (near age two) can sense loss, but do not conceptualize death as being a temporary state, they do not understand the sadness around them when a family grieves a death.

By age three, children have the intellectual inquiry on the subject of death (Burch, 1991). Children near middle school age have a realistic concept of death but are unlikely to relate that concept to themselves or to others close to them (Newman & Newman, 1995). Children aged seven through ten transitions into the acceptance of death as final for all living things, although this may be viewed as "far away" in the future. By age eight, separation of body and spirit can be understood in fuller explanations of death because death begins to acquire a social dimension as others are observed grieving a loss (Burch, 1991).

Cognitive theories provide a conceptual framework for viewing the development of human thought. Jean Piaget has woven a complex integrative theory about the stages of mental development. Piaget saw the mind as not a blank slate on which knowledge is written, nor a mirror which
reflects what it sees. He found that in the mind, perceptions are either assimilated (they are fit into a category) or they are accommodated (the mind changes itself in order to fit the information into a category). Piaget used the word "scheme" to designate these mental structures for processing information. He found that schemes change, and they become more complex as an individual matures. This is essentially a biological model for describing the processes by which our minds adapt to the world (Specht & Craig, 1987). Individuals develop progressively complex schemes to organize information about their outside world. Piaget has divided this development into four discrete and qualitatively different stages: the sensorimotor period (birth until 18 months of age), the preoperational period (age of 2 until 7), the concrete operations (around age 8 until puberty), and the final stage called formal operations (adolescence).

The stage of preoperational intelligence consists of individuals between the age of two and seven, which will be the age range of the children who will be participating in this study. Children develop the tools for representing schemes symbolically through language, imitation, imagery, symbolic play, and symbolic drawing (Newman & Newman, 1995). Also, during this stage, children begin to derive concepts from experiences. Learning occurs through first-hand sensorimotor activities. Their thinking is very concrete in that reality is exactly what is perceived, no more and no less, and there is little ability to
consider alternatives (Longres, 1995). Deliberate behaviors and intuitive thinking emerges, enhanced by the development of language and the ability to play and pretend. Children in this stage focus on a single aspect of an object, neglect others, and cannot rearrange or reorganize information in their minds due to the fact that they are still dependent on direct sensorimotor experiences. They are also unable to understand the principle of conservation. For example, children do not comprehend that one quart of milk will pour into four glasses and will still equal one quart (Longres, 1995).

The stage of concrete operational intelligence consists of individuals who are emerging around the age of eight, continuing into puberty, which will be the age range of the children who will be participating in this study. Children begin to be able to perform logical and mathematical operations, but they cannot deal with abstract ideas, only with concrete or real objects. Children can solve problems of classification, and these skills are enhanced by the ability to understand the logic of relations (Longres, 1995). Other conceptual skills that are developed are conservation and combinatorial skills. These skills bring children in touch with the logic and order of the physical world. Children realize that they can use their enhanced capacities of reasoning to solve interpersonal problems and to arrange daily life so that it better meets their interests and needs (Newman & Newman, 1995).
Cognitive-developmental theorists have also focused on the orderly sequence of development of the child's thought about moral issues. Piaget (1932/1948), described the major transition in moral judgement as a shift from heteronomous to autonomous morality. Heteronomous morality means that rules are understood as fixed, unchangeable aspects of social reality. An act is judged as right or wrong based on the letter of the law. Autonomous morality is when children see rules as products of cooperative agreements. Give-and-take with peers highlights mutual respect and mutual benefit as rewards for holding to the terms of agreement (Newman & Newman, 1995).

Looking at how and when children grieve, especially when they are the ones who are dying was an important area of research for this study. Experts have determined that grieving children may express varied feelings as follows:

- **Shock and Denial:** "It can't be true." They may not accept the fact that death has really happened and may act like it hasn't occurred.
- **Physical Symptoms:** "I feel sick." They may have complaints such as headaches.
- **Anger:** "Why did God let it happen." They may become furious with the person who died which causes them and their family much grief.
- **Guilt:** "Why did I...?" Why didn't I...?" They possibly may feel that they may have caused the death by misbehaving.
Jealousy: "How come ....dad is still alive?" They find it difficult to witness families that are still intact.

• Anxiety and Fear: "If you die, too, who will take care of me?" They begin to think that other family members may die soon. They begin to cling to major role players in their life.

• Sadness and Loneliness: "Can't my ....come back? It is natural for them to want to talk, touch, and share with the deceased.

Overall, there is no single way for a child to grieve (Papadatou & Papadatos, 1991).

Currently, there is a dearth of studies that have examined the issue of mourning in children diagnosed with HIV/AIDS. This researcher was able to find a few studies that focused on how children view death, as well as one study on the cognitive functioning of children infected with HIV/AIDS.

HIV/AIDS is a life-threatening illness and is fairly comparable to the life-threatening illness called cancer. For example, in 1986, the Pediatric Branch of the National Cancer Institute began treating HIV-infected children. According to the authors of this study, they found that like cancer, AIDS would disrupt the equilibrium of affected families. However, unlike cancer, in most AIDS-infected families, there is frequently a tenuous equilibrium to begin with, and there is generally more than one family member who is affected or ill. Most AIDS-infected families are already burdened with poverty,
discrimination, and poor support systems and are already known to multiple social service agencies. Overall, the aim of this program is to be child centered, family focused, and comprehensive in nature (Wiener, Moss, Davidson, and Fair, 1992).

Frank & Foley (1997) conducted a study that focused on 27 HIV-positive children aged six through seventeen who were attending public schools. They present that previous studies indicate that infants and young children have shown signs that cognitive and motor functioning often declines as the disease progresses. They are also in agreement that most HIV-positive children are infected perinatally from their mothers, while ten percent acquire the virus through contaminated blood products. According to the authors the aim of this study was to evaluate the children's cognitive functioning and to examine the interrelation of cognitive functioning, disease stage, drug therapy, mode of transmission, and home situation.

The majority of the children involved in this study medically were at stage P2, which typically means that they are characterized by the failure to thrive, generalized lymphadenopathy, hepatosplenomegaly, enlarged parotid arteries, and persistent or recurrent diarrhea. The remainder of the children were at P1, which is characterized as lacking symptoms. These children have been taking antiretroviral medication for the past three years, the older children, five years. The researchers administered the Verbal Performance and Full Scale of IQ
to the participants. Their findings were that this group of HIV-positive children were within normal range on the tests that were administered (Frank & Foley, 1997).

Tamm & Granqvist (1995) conducted a study that was two-fold: to investigate the qualitative differences in children's concept of death, as reflected in their drawings and to study the gender differences in children's death concepts. They had 431 children participate in this study, ages nine to nineteen. The children were asked to make a drawing depicting what came to their minds when they heard the word "death", and then give a brief commentary explaining the content of their drawing. The major findings of this study were a range of qualitative categories and their relation to each other. These categories extended those defined by another researcher named Wenestam. Wenestam and Wass (1987) identified ten categories from children's drawings about death, whereas this study, Tamm & Granqvist (1995) found a hierarchical category system.

The researchers argue that their description system offers a systematized and meaningful way of summarizing and describing the qualitative differences in the meanings that children attribute to death. Their study also presented results that reveal that the death concept develops from a biological representation to a metaphysical representation with increasing age. In the area of gender, these researchers found that there were substantial gender differences in the children's drawings. Boys represented
death as war, murder, shooting, killing, and explosions. Girls represented death as an accident. Therefore, these researchers conclude that the darkness and emptiness in the boys' drawings may have an existential meaning, and the pictures of near-death experiences that were depicted in the girls' drawings may reflect a scientific attempt to grasp the meaning of death (Tamm & Granqvist, 1995).

The researchers Tamm & Granqvist (1995) presented other studies in this area. They discussed the study done by Schilder & Wechsler (1934) who administered a series of death-related pictures to a sample of American children, ages 5-14 years, and asked their reactions. Their findings indicated a strong relationship between children's concept of death and their belief that death is caused by aggressive or violent forces. The themes of war, murder, accidents, or other violent acts were mentioned by children ages 5-12 after they viewed projective pictures (Tamm & Granqvist, 1995).

Another study that Tamm & Granqvist (1995) presented within their own study was by a Hungarian researcher named Nagy (1948). This researcher conducted a series of studies of children's "theories" concerning death. She used three interrelated methodological approaches: children's drawings of death, children's written compositions on death, and children's verbal feelings about death. Her most distinctive finding was the child's tendency to personify death. According to Nagy (1948), most children between the age of 5 and 9 go through a period in which
they will anthropomorphize death. To these children, death is given form and will. Death becomes the bogeyman, the grim reaper, a skeleton, a ghost, or a shadow emerging nightly from graveyards and hunting people (Tamm & Granqvist, 1995).

Wenestam (1984) conducted a study in order to expand his knowledge of what death means to 112 children between the ages of 4 to 18 years. The participants were asked to draw a picture of what death meant to them and then asked to attach a comment to explain the drawing. By qualitatively analyzing the drawings, this researcher found three themes which were evident within the drawings: violence and aggression, religious and cultural symbols, and the experience of dying. This researcher concluded the themes were significantly related to age which he correlates to age-specific sociocultural contexts that provide children at each age with a certain type of information about death and dying (Wenestam, 1984).

Wenestam (1984) also described another study done by a researcher named Weininger (1979). This researcher interviewed children ranging in the age from 4 to 9 regarding their thoughts about death and dying. This researcher added an interesting feature; he had the children play with dolls that were seriously ill or dead. Weininger (1979) found that the children's play differed from what they had verbally expressed during their interviews. He found that their play sometimes indicated a more developed understanding of death. These
differences were more apparent in children aged six and seven. This lead Weininger to conclude that consistency between play and verbal expression does not appear until the age of eight or nine.

Wenestam and his co-researcher Wass (1987) followed the same guidelines that Wenestam used in his 1984 study about the meaning of death to children. Their objective in this study was two-fold. First, to investigate the qualitative differences in children's death-related thinking regardless of nationality. Secondly, they sought to discover differences between U.S. and Swedish children, ages 4-19. Their findings indicated that there are considerable similarities in the qualities of Swedish and U.S. children's depictions of death. They found that more Swedish children depicted cultural and religious practices and symbols, whereas more U.S. children depicted violent causes of death, which were made predominantly by the youngest children and the boys.

Wenestam & Wass (1987) concluded that the differences within this study can be attributed to how the children's parents place different degrees of emphasis on assertiveness for boys, as well as the different patterns of parenting in the two societies with respect to boys. Finally, they quoted the fact that U.S. children are more exposed to televised violence than the children in Sweden. Also within this study, Wenestam and Wass (1987) found that the youngest children produced immature depictions of death, accidental, and violent causes, and bodies
visible in caskets and cemeteries. They concluded that these depictions correspond to the level of preoperational understanding in the Piagetian model.

Tamm & Granqvist (1995) explained in their article why they chose to focus on children's drawings in their study. They stated that first, drawings are a well-established medium for assessing thoughts and perceptions that may not be immediately accessible at the verbal level. Secondly, drawings have been used by earlier researchers investigating children's concepts which permitted them to compare their research methods with the others'. Thirdly, children's drawings have been used to assess gender differences on different topics.

David Thomson quotes Sigmund Freud in his book called Language (1975) as follows: "He who has eyes to see and ears to hear may convince himself that no mortal can keep a secret. If his lips are silent, he chatters with his fingertips; betrayal oozes out of him at every pore." Thomson interprets this as follows: "Even if there is no speech and the face refuses to tell, the rest of the body can leak information about the person and what may be happening inside the self" (Klepsch & Logie, 1982). According to Klepsch & Logie (1982), drawing communication is elemental and basic. They also consider it universal. A drawing can capture on paper some of the drawer's thoughts and feelings. They feel that a drawing makes a portion of the inner self visible.

Drawing speaks louder than words in the early stages
of a child's development. However drawing is not the only way to get insight into personality, perception of self in relation with others, group values and attitudes. There are three main ways: self-report, observation, and projective techniques, of which drawing is but one. The unique role of drawings is that drawings add a dimension which is not tapped by self-report or observation techniques, the dimension of fantasy and imagination. Drawings are easy to obtain because they are non-threatening and children love to draw. Drawings dig deeper into whatever aspect is being measured. They seem to be able to bring out the inner depths of a person and uncover some of the otherwise inaccessible inner information (Klepsch & Logie, 1982).

According to researchers Groth-Marnat & Roberts (1998), projective drawings have consistently been rated as among the ten most frequently used assessment devices. However, despite their frequent use, there is controversy in regards to their validity. They find that one relatively neglected area of investigation is the extent to which projective drawings reflect healthy levels of adjustment. These authors feel that authors typically mention some aspects of healthy drawings but spend considerably more time describing indicators of pathology. These researchers provide a study within their own study that is an exception to the statement above. Tharinger and Stark (1990) conducted a study in which they were able to predict positive aspects of self-esteem and family functioning.
(Groth-Marnat & Roberts, 1998).

Everyday, more and more children are being infected and dying by the HIV/AIDS virus. Based on this researcher's search for previous studies done with children infected with this virus, it is clear that few studies are of avail. The studies presented show that children do think about death and can clearly depict it within their drawings. By conducting this study, the findings can bring about new information to an area which is so neglected. Knowing how children diagnosed with HIV/AIDS perceive death and dying will educate not only social workers, but also those other key players such as parents, guardians, and doctors who are involved in a child's vital time of his/her life: the last stage of death and dying.....acceptance. According to authors Ezell and Oaks (1987), they state, "Much as in teaching about death, teaching about HIV/AIDS and its transmission means confronting a host of vexing issues in which the beliefs, values, and opinions of reasonable people—not to mention a series of prejudices, unwarranted fears, and irrational ideas—vary greatly." We watch with sadness, frustration, and weariness the rising death toll on the one hand and continuing discord over AIDS/HIV education in the schools on the other (Firkaly, 1991).
CHAPTER THREE
METHODS

Design of Study

According to Rubin and Babbie (1992), exploratory research can provide a beginning familiarity with a topic, especially in the area of examining a new interest and/or when the subject of the study is relatively new and unstudied. First, this research study explored the understudied area of children infected with HIV/AIDS. Second, it explored the ramifications that effected children who were diagnosed with HIV/AIDS. Third, it explored the "death and dying" perceptions that these children had in regards to not knowing that they were diagnosed with a terminal illness.

Finally, this study explored whether children who are unaware of their illness felt the same grief intensity as children who were not exposed to the same patterns that these participants experienced on a monthly basis at the clinic. The general expectation would be that the participants would portray some certain indicators within their drawings. These indicators would be associated with grief intensity as outlined by Kubler-Ross’s (1969). The stages along with some indicators are as follows:

• First stage: Denial and Isolation: Feelings of anxiety, loneliness, “No, not me, it can’t be true”, numbness, stoicism, and shock.

• Second stage: Anger: Feelings of anger, rage, envy, and resentment.
• Third stage: Bargaining: Feelings of fantasy, postponing, setting of a self-imposed "deadline", and quiet guilt.

• Fourth stage: Depression: Feelings associated with the sense of loss, sadness, and guilt.

• Fifth stage: Acceptance: Feelings of no anger nor depressed, mourning the impending loss and contemplating the end with a certain degree of quiet expectation, void of feelings, feeling that the pain has gone, the struggle is over, tired, and weak.

The primary purpose of this research study was to explore an area which has definitely been understudied. By incorporating the five stages of death and dying in correspondence with the drawings of children who are unaware of their diagnosis with HIV/AIDS, there would be general expectations. These general expectations would be present due to the setting in which the children visit on a monthly basis. Some of these expectations are feelings associated with loneliness, anxiety, fear, frustration, anger, and inquisitive. In conclusion, the findings of this study would begin to provide valuable information to individuals working closely with these children (i.e. social workers and doctors) and who are lacking the knowledge of death and dying in relation to children.

This study encompassed both qualitative and quantitative methods. This type of research design that was used within this study was survey research. Rubin and Babbie (1992) find that survey research is a very old
research technique, and it can be used for descriptive, explanatory, and exploratory purposes. In this study, an "interview" was used as an alternative method of collecting survey data. Instead of using a standardized questionnaire, a standardized projective drawing test was administered to the children participants. Because this type of method requires face-to-face encounters, it was subject to reliability errors. However, because of the use of a standardized stimulus (Appendix B) in this study with a hypothesis that, "children who are diagnosed with HIV/AIDS, but have no knowledge of their diagnosis, may show some grief intensity in their H-T-P drawings", the unreliability will be largely eliminated because it will leave little room for this researcher to inject one's own interpretation.

Sample

A small group that consisted of eight participants from the Loma Linda University Medical Center, Pediatrics Infectious Disease Clinic (Pediatric I.D. Clinic) was selected by judgmental procedures and by a non-probability technique of convenience sampling. Also, experimental settings were also utilized because of the nature of this study. Experimental settings are not random. The participants must volunteer. The Pediatric I.D. Clinic social worker randomly chose cases that were deemed appropriate candidates for this study. All the participants were in the age range of six to nine years of age with no gender or ethnic preference. The
demographic information of the eight participants is reported in Table One (Appendix Q). All information listed on the tables was provided by the participants’ parent/guardian.

There were five male participants and three female participants. The age range of the participants were split evenly among the age group of six (2), seven (3), and eight (3) years of age. Also, there were three Caucasians, three African American, one Hispanic, and one other. Three of the participants were living with their mother or father, and the remainder of participants are living with a guardian, as is specified within Table One (Appendix Q). The participants live and attend school in the local community.

According to the clinic social worker, the participants’ fee of service was either covered by Medical, some private insurances, or by California Children Services (CCS). CCS covers costs that are not covered by Medical. All the participants were infected with the HIV/AIDS virus at birth; however, they did not immediately begin receiving services at this clinic as noted on Table One (Appendix Q). The participants have all been receiving services for at least three months prior to participating in this study. The participants also come to the clinic on a monthly basis. All participants are asymptomatic, meaning they have the virus but no symptoms (i.e. sores, liver failure) at the time of participating in this study. The services each participant received varied from drug
therapy, support network (i.e. Inland Aids Project), therapeutic groups (individual and/or family therapy), and summer camp.

All the participants in this study have no knowledge of their diagnosis with the exception of one participant. Participant G was informed of his diagnosis in March of 1999. Previous to this disclosure, he was tested by this researcher (G1) and then again (G2) at the time of disclosure. This researcher intended to select at least half of the participants to have knowledge of their HIV/AIDS diagnosis, versus the other half not having knowledge. Unfortunately, this was not possible. The clinic supports voluntary disclosure; therefore, all the participants' parents/guardians who agreed to participate in this study chose not to tell their children their diagnosis.

On Table Two (Appendix R), the participants' family members who are possibly infected with the HIV/AIDS virus are listed. All the participants' mothers are infected by the HIV/AIDS virus. This finding supports the influence of how each participant was infected by the virus. Two participant's mothers were deceased due to complications with the virus. Three participants' fathers were infected with the virus. Two were deceased due to complications with the virus also. Three participants fathers' status was unknown, with only one of them known to be living still. One participant had no knowledge of her parents and/or siblings in relation to the HIV/AIDS virus.
Overall, this sample was chosen in order to have a study with good representativeness of children experiencing a terminal illness. As cases were chosen, it was obvious that all the participants would have one common factor amongst them. This was that they had no knowledge of their diagnosis. However, this researcher was given permission by the parent/guardians to know their children’s diagnosis. This information assisted in making sure each participant was appropriate for this study.

Data Collection and Instruments

The procedure that was used for data collection was done in two parts. The first part of the study focused on the demographic background of the participants. The participants’ parents/guardians provided background information on a short data collection sheet (Appendix C) prior to the child participating in this study. The Pediatric I.D. Clinic social worker reviewed each sheet and provided additional information from the participants’ case files. The variable of interest were age, ethnicity, gender, transmission mode of HIV/AIDS, knowledge of HIV/AIDS diagnosis, current health status, and participants’ initial entry date of utilizing services at the clinic. These variables were measured at a nominal level of measurement.

The second part of the study consisted of administering to each participant a projective drawing test called a “House-Tree-Person” Test (Appendix B). John N. Buck established this test in 1948 and found that
children gave least resistance to drawing these specific objects, which were rich with symbolic meaning and stimulate spontaneous discussions (Kaufman & Wohl, 1992). This test was nonverbal, creative, and almost completely unstructured. The participants were given a minimum number of directions (Appendix C) before each of the pencil art drawings of a house, a tree, and a person were drawn. Only the drawings were used, not the interview protocols, nor the spontaneous discussions stimulated. This researcher then utilized Buck’s interpretive manual in order to set up specific nominal coded measurements of the dependent variable, which was “grief intensity in projective drawings.”

The strength of this design was its open and informal gathering of information. The data collection method was non-threatening to the participants. The participants were given three 8-1/2 x 11 blank sheets of paper which were available pre-packaged. They were then asked to draw a house, tree, and a person. For this study, this researcher did not require the participants to verbally elaborate on their drawings. Overall, this study was able to develop a lot of new insight which could be greatly utilized by practitioners who would be working closely with individuals who were facing death sooner than their cohorts.

Procedure

The data collection began in September, 1998 and ended in March, 1999. In order to keep this study on a
consistent basis, this researcher was the only individual having contact with the participant while drawing. This researcher went to the Pediatric I.D. Clinic that the participant attends for services. This researcher was required to go before the Institutional Review Board (IRB) Committee at California State University, San Bernardino first before conducting this study within the Pediatric I.D. Clinic. Upon approval from both the Loma Linda Medical Center Pediatric I.D. Clinic and the IRB Committee (Appendix F and G), demographic information was extracted from approved participants parents/guardians through a data collection sheet. Only the clinic social worker approved cases in order to assure the participants' confidentiality. At the time of the participants' medical appointment, the clinic social worker allotted time to this researcher in which the H-T-P Test was administered. The meeting place in which the test was conducted was in a safe environment for the participants to feel comfortable. The process of extracting information from the parents/guardians and/or clinic social worker took approximately five minutes for each case. The face-to-face interview, which includes only giving the projective test to the participant, took approximately four to seven minutes maximum.

**Protection of Human Subjects**

All the participants within this study remained anonymous, and any information obtained was kept confidential in a locked file box. The participants are
identified with and I.D. number, with the names locked in the file box also. The procedures on confidentiality were written into the consent form. A consent (Appendix A) form issued to each participant's parent/guardian clearly outlined the purpose of this study, emphasized that study was voluntary, and explained that all information was confidential. A verbal consent was required from the participants. The consent form was utilized in order to allow the participants to feel comfortable in withdrawing from this study. Because the participants of this study were children, this researcher did not question nor comment to these participants verbally about dying or about their terminal illness.

At the end of the "interviews," debriefing statements (Appendix D) were given to both the participants and their parent/guardian. This researcher anticipated no immediate or long-range risks to the participants. However, in case some participants began to experience either 1) slight discomfort around doing something they have never been asked to do before, 2) show any signs indicative of emotional distress and/or, 3) signs of serious distress in his/her drawings, the clinic social worker would be alerted and available.
CHAPTER FOUR
RESULTS

Indicators

John N. Buck developed a handbook called "House-Tree-Person Projective Drawing Technique: Manual and Interpretive Guide." However, that manual was revised by W.L. Warren, Ph.D (1995) in order to improve the access to generally accepted clinical interpretive concepts. The revised manual was utilized in order to interpret the H-T-P drawings each participant provided in this study.

General characteristics such as proportion, perspective, and details in a drawing can provide information about the functioning of an individual in the context of their expected level of functioning. Adequate and appropriate detailing is the first to stabilize developmentally. The ability to represent realistic proportions is second. Thirdly, is the ability to recognize and represent the need for perspective (Warren, 1995).

It must be noted that within the participant's drawings (Appendix H-P), the missing parts within the drawings indicates light lines within the actual drawing. The following are general drawing features for the House, Tree, and Person according to Warren (1995) Interpretive Concepts Checklist:

• Erasing (house, tree and person): May indicate uncertainty, conflict, indecisiveness, self-criticism, anxiety.

Proportion: (It must be noted that normal children show more
variability in drawing size than do normal adults)
• Image to form size (house, tree, and person): Large may indicate restrictive environment, tension, compensations. Small may indicate insecurity, withdrawal, discontent, regression.
• Detail to image/symmetry (house, tree, and person): Excessive symmetry may symbolize rigidity, brittleness. Distortions which are obvious may indicate psychosis and organicity. Distortions which are moderate may indicate anxiety. Asymmetry (only in the person) may indicate physical awkwardness, gender confusion.

Perspective:
• Rotation (house, tree, and person): Indicates opposition, while falling suggested shows possibly extreme distress.
• Edges of the paper (house, tree, and person): Bottom shows possibility of need of support. The side indicates feeling of constriction, and the top indicates display
fear or avoidance of environment.

• Relation to the viewer (house, tree, and person): Seen from above may be rejection, compensatory grandiosity. Seen from below could mean withdrawal, inferiority. Distance (house) may mean inaccessibility, feelings of rejection, home situation out of control. Distance (tree and person) may indicate withdrawal.

• Ground line (house, tree, and person): possibly indicates security needs, anxiety.

• Transparencies (house, tree, and person): may indicate poor reality orientation (not uncommon for young children). In the person drawing, if internal organs are displayed, it may indicate psychosis.

• Movement (tree only): may indicate environmental pressures.

Detailing:

• Excessive (house, tree, and person): obsessive-compulsiveness, anxiety.

• Lacking (house, tree, and person): withdrawal (common for young children).

• Bizarre (house, tree, and person): psychosis (common for young children).

• Line quality (house, tree, and person): Heavy may indicate tension, anxiety, forcefulness, organicity. Light: hesitance, fear, insecurity, weak ego.

• Fragmentation/difficulty with angles: organicity.

• Detail shading (house, tree and person): excessive indicates anxiety.
• Essential details (house only): one wall, roof, door, window, chimney (commonly omitted by young children).
  • Anthropomorphic: regression, organicity (not uncommon for children).
  • Chimney: emphasis may mean sexual concerns, omission may mean lack of warmth in home, excessive smoke: extreme tension in the home.
  • At an angle: regression (not uncommon in young children).
  • Door: absence may indicate absence, inaccessibility, isolation. Large size may indicate dependency, small size: reticence, inadequacy, indecision.
  • Hinged/locked may indicate defensiveness. Open door may mean need for warmth.
  • Roof: emphasis may mean introversion, fantasy.
  • Roof only: psychosis. Single line: constriction.
  • Eaves emphasized: suspiciousness.
  • Walls: thin or faint may indicate weak ego boundaries, emphasis: effortful ego control, absent: poor reality contact.
  • Windows: emphasis may mean social ambivalence, absence: withdrawal, many: exhibitionism, open: poor ego control, small: withdrawal, no panes: hostility.
• Nonessential details (house only): curtains: emphasis may mean withdrawal, evasiveness. Gutters may indicate defensiveness, suspiciousness. Shutters may indicate withdrawal.
• Irrelevant details (house only): clouds and shadows may

- Essential details (tree only): trunk and at least one branch.
  - Ground line: tree drawn in ground line depression may indicate inadequacy. Tree down on hilltop: grandiosity, isolation.
  - "Keyhole"/"Niggs": opposition, hostility.
  - Split: psychosis, organicity.
  - Type: fruit or Christmas may symbolize dependency, immaturity (common for young children). Dead: severe disturbance. Sapling: regression. Windblown: environmental pressures.

- Nonessential details (tree only): Bark emphasis may indicate anxiety, depression. Meticulous: obsessive-

• Irrelevant details (tree only): Clouds, shadows may indicate anxiety. Shrubbery-excessive: insecurity.

• Essential details (person only): head, trunk, arms, legs, facial features. (Omission of body parts common for young children).

  • Arms: emphasis may indicate high need for achievement, aggression, punishment if person drawn is not self. Spaghetti: dependency, organicity. Omitted-undersized-hidden: guilt, inadequacy, rejection if person drawn is not self. Wing-like: schizoid.


  • Eyes: emphasis may symbolize paranoia. Small-closed-omitted: introversion, voyeurism. Pupils omitted: poor reality contact (common for young
children).

- Ears: overemphasis may indicate paranoia, auditory hallucinations.
- Mouth: emphasis may show dependency (common for young children). Omitted: oral aggression, depression.
- Teeth: aggression.
- Nose: emphasis may signify sexual concerns (common for young children).
- Gender: opposite drawn first may imply gender identification conflict.

- Nonessential detail (person only):
- Clothing: over or under-clothed may indicate narcissism, sexual maladjustment. Button emphasis: immaturity (common for young children).
- Feet: omitted or chopped: helplessness, loss of autonomy, sexual concerns. Toes on clothed figure: aggression.
Hair emphasized or omitted: sexual concerns.
Irrelevant Details: Canes, swords, weapons may indicate aggression, sexual concerns.

Analysis

Child A (Appendix H): Participant A was a seven year old male. Within his drawings the following observations were made:

Erasing: house-0, tree-3x's, and person-2x's.
Interpretation: May indicate uncertainty, conflict, indecisiveness, self-criticism, anxiety.

House, tree, and person were drawn on the center of the page and on the bottom of the page.
Interpretation: Possibility need of support, rigidity (common for young children). Concreteness, depression, insecurity, inadequacy.

Hair on person is drawn with heavy lines.
Interpretation: Tension, anxiety, forcefulness, organicity.

Tree: Cloudlike, roots omitted.
Interpretation: May indicate fantasy, insecurity.

Person: Wide stance, hands are like mittens, omitted neck.
Interpretation: May indicate aggression, repressed
aggression, impulsivity.

Child B (Appendix I): Participant B was a six year old male. Within his drawings the following observations were made:

• Erasing: None.
  Interpretation: None.

• House, tree, and person were drawn on the center of the page and towards the top of the page.
  Interpretation: Possibility rigidity (common for young children). Unrealistic striving, fantasizing, frustration.

• The house appears to be smaller in size in comparison to the person and the tree.
  Interpretation: Small in size may indicate insecurity, withdrawal, discontent, regression.

• The house drawing has a ground line drawn below it.
  Interpretation: possibly indicates security needs, anxiety

• Heavy line quality on the mouth of the person.
  Interpretation: Heavy may indicate tension, anxiety, forcefulness, organicity.

• House: Large door, eaves emphasized, no panes on the windows.
  Interpretation: dependency, suspiciousness, hostility.

• Tree: Cloudlike, roots-talons.
  Interpretation: fantasy, paranoia.

• Person: Spaghetti arms, shrunken legs, omitted feet, omitted hair, spaghetti neck.
  Interpretation: May indicate dependency, organicity, helplessness, loss of autonomy, sexual concerns,
Child C (Appendix J): Participant C was a six year old male. Within his drawings the following observations were made:

- Erasing: None.
  Interpretation: None.
- Tree, and person were drawn on the center of the page and towards the middle of the page.
  Interpretation: Possibility rigidity (common for young children). Unrealistic striving, fantasizing, frustration.
- House was drawn on the left side of the pages and in the middle of the page.
  Interpretation: May symbolize withdrawal, regression, organicity, self-preoccupation, rumination over the past, impulsivity, need for immediate gratification.
- House: Large size, eaves emphasized.
  Interpretation: May indicate dependency, suspiciousness.
- Tree: Christmas tree, roots omitted.
  Interpretation: May indicate dependency, immaturity (common for young children), insecurity.
- Person: Spaghetti arms, light eyes, opposite person drawn in relation to self, shrunken leg, omitted feet, spaghetti neck.
  Interpretation: May symbolize dependency, organicity, introversion, voyeurism, gender identification conflict, helplessness, loss of autonomy, sexual concerns, psychosis.

Child D (Appendix K): Participant D was a seven year old female. Within her drawings the following
observations were made:
• Erasing: None.
Interpretation: None.
• House, tree, and person were drawn on the center of the page and towards the bottom of the page.
Interpretation: Possibility rigidity (common for young children), concreteness, depression, insecurity, inadequacy.
• Person was drawn on the edge of bottom of the page.
Interpretation: Shows possibility of need for support
• Shading of the person only.
Interpretation: May indicate anxiety.
• House: At an angle, single line, absence of windows.
Interpretation: May symbolize regression (not uncommon in young children), constriction, withdrawal.
• Tree: Broad base, cloudlike, root omitted.
Interpretation: May indicate dependency, fantasy, insecurity.
• Person: Spaghetti arms, omitted face, narrow stance, clothing, feet omitted, spaghetti neck.
Interpretation: May symbolize dependency, organicity, withdrawal, rigidity, tension, helplessness, loss of autonomy, sexual concerns, psychosis.

Child E (Appendix L): Participant E was an eight year old male. Within his drawings the following observations were made:
• Erasing: House and the person were both erased once.
Interpretation: May indicate uncertainty, conflict, indecisiveness, self-criticism, anxiety.
• House, tree, and person were drawn on the center of the page and towards the middle of the page.
Interpretation: Possibility rigidity (common for young children).
• Light line quality on the house and the top of the tree drawing.
Interpretation: May indicate hesitance, fear, insecurity, weak ego.
• House: No panes.
Interpretation: Hostility.
• Tree: Scribbled, vertical emphasis, broad base, roots omitted.
Interpretation: May indicate lability, poor reality contact, sexual concerns (common for young children), dependency, insecurity.
• Person: Spaghetti arms, one undersized arm, eyes and ears emphasized, mouth emphasized, opposite drawn gender of the drawer, feet omitted, hair emphasized, spiked hand, neck omitted.
Interpretation: dependency, organicity, guilt, inadequacy, rejection if person not drawn self, paranoia, dependency (common for young children), gender identification conflict, helplessness, loss of autonomy, sexual concerns, acting out, impulsivity.

Child F (Appendix M): Participant F was an eight year old female. Within her drawings the following observations were made:
• Erasing: House erased once.
Interpretation: May indicate uncertainty, conflict, indecisiveness, self-criticism, anxiety.

- House was drawn to the left and in the middle of the page.
  Interpretation: Possible withdrawal, regression, organicity, self-preoccupation, rumination over the past, impulsivity, need for immediate gratification.
- Person drawn in the middle of the page and located in the center of the page.
  Interpretation: May indicate rigidity (common for young children).
- Tree drawn near the left side and located near the bottom on the page.
  Interpretation: May indicate concreteness, depression, insecurity, inadequacy, shows possibility of need of support.
- Line quality on the tree is light.
  Interpretation: May symbolize hesitation, fear, insecurity, weak ego.
- House: Chimney at an angle, eaves emphasized, curtains, shrubbery.
  Interpretation: May indicate regression (not uncommon in young children), suspiciousness, may mean withdrawal, evasiveness, insecurity.
- Tree: Cloudlike, "keyhole"/"Niggs", roots omitted.
  Interpretation: May mean fantasy, opposition, hostility, insecurity.
• Person: Winglike arms, shoulders squared, spiked hand, neck emphasized.
Interpretation: May indicate schizoid, hostility, acting out, need for control.

Child G(1) (Appendix N): Participant G(1) was an year old male. Within his drawings the following observations were made:
• Erasing: None.
Interpretation: None.
• The house, tree, and person were drawn in the center of the page.
Interpretation: Rigidity (common for young children).
• The house and the tree are drawn larger in comparison of the tree.
Interpretation: Large may indicate restrictive environment, tension, compensations.
• House: Excessive smoke in the chimney, absence of the door, absence of the windows.
Interpretation: Extreme tension in the home, absence, inaccessibility, isolation, withdrawal.
• Tree: Cloudlike, roots omitted.
Interpretation: May indicate fantasy, insecurity.
• Person: Emphasis of arms, large head, emphasized eyes and ears, emphasized mouth, teeth, legs are in narrow stance, neck omitted.
Interpretation: May indicate high need for achievement, aggression, possible regression, grandiosity (common for young children), paranoia, dependency (common for young
children), rigidity, tension, impulsivity.

Child G(2) (Appendix O): Participant G(2) was an eight year old male. This is the results of his drawing after he was told of his HIV/AIDS diagnosis. Within his drawings the following observations were made:

- Erasing: None.
  Interpretation: None.
- The house, tree, and person were drawn in the center of the page.
  Interpretation: Rigidity (common for young children).
- The house and the tree are drawn larger in comparison of the tree.
  Interpretation: Large may indicate restrictive environment, tension, compensations.
- Detailed shading on the hair in the person drawing.
  Interpretation: May indicate anxiety.
- House: Lack of chimney, small door, walls thin, shutters on the windows and door.
  Interpretation: May mean lack of warmth in the home, reticence, inadequacy, indecision, weak ego boundaries, withdrawal.
- Tree: Cloudlike, broad base, omitted roots.
  Interpretation: May indicate fantasy, dependency, insecurity.
- Person: Spaghetti arms, large head, small eyes, emphasized mouth, teeth, wide stance in leg area, torso and body not fragmented, feet omitted, spiked fingers, lack of neck.
Interpretation: May indicate regression, organicity, grandiosity (common for young children), introversion, voyeurism, dependency (common for young children), aggression, severe psycho pathology, helplessness, loss of autonomy, sexual concerns, acting out, impulsivity.

Child H (Appendix P): Participant H was a seven year old female. Within her drawings the following observations were made:

- Erasing: None.
  Interpretation: None.
- The house, tree, and person are drawn near the left of the page, towards the top of the page.
  Interpretation: May symbolize withdrawal, regression, organicity, self-preoccupation, rumination over the past, impulsivity, need for immediate gratification, unrealistic striving, fantasizing, frustration (upper left placement common for young children).
- House and tree are drawn smaller in relation to the person.
  Interpretation: May indicate insecurity, withdrawal, discontent, regression.
- Line quality on tree drawing is light.
  Interpretation: May indicate hesitance, fear, insecurity, weak ego.
- House: Lack of door, lack of windows.
  Interpretation: May indicate absence, inaccessibility, isolation, withdrawal.
- Tree: Scribbled, broad base, roots omitted.
Interpretation: Lability, dependency, insecurity.

- Person: Spaghetti arms, floating stance in leg area, omitted feet.

Interpretation: Dependency, organicity, insecurity, dependency, severe psycho pathology, helplessness, loss of autonomy, sexual concerns.
CHAPTER FIVE
DISCUSSION

Children perceive the meaning of the word "death" in different ways. Because of assorted ages, they are cognitively developing at different levels. Therefore, when children are diagnosed with a terminal illness, they are more likely to be introduced to the word "death" sooner than children who are not diagnosed with a terminal illness. Healthy children, children with no diagnosis of a terminal illness, will eventually, through their developmental years, be introduced to the word "death," possibly by the death of a loved one and/or a family pet. How they perceive death likely will be different than those children diagnosed with a terminal illness, along with no knowledge of having it. "Death and dying" will be explained to terminally ill children in a "realistic" view rather than allowing them to perceive "death" like their "healthy" cohorts. Also, even though they may be in the same age range, they may eventually fall behind in their level of cognitive development. Therefore, perceiving death will become even more challenging for these terminally ill children.

The participants of this study were not aware of their HIV/AIDS diagnosis. The withholding of this piece of information changed the hypothesis of this study. The hypothesis originally stated that children who had knowledge of their diagnosis likely would show more death and dying indicators within their drawings than would
children who did not have knowledge of their diagnosis. The following hypothesis was then developed in order to gain a more thorough understanding of how children, death and dying, and HIV/AIDS possibly coincide with one another. Consequently, the hypothesis that children who are diagnosed with HIV/AIDS, but have no knowledge of their diagnosis, may show some grief intensity in their H-T-P drawings was supported by the data collected at the clinic.

First, it must be mentioned that the participants within this study appeared to look "healthy", meaning that any individual in the presence of these children probably would not know that these children were diagnosed with HIV/AIDS. These participants were smiling and engaging in conversations like many "healthy" children would be doing. Before participating in the drawing procedure of this study, one six year old male participant said, "I know, you want me to draw a house, a tree, and a person."

The most common indicators found within the nine H-T-P drawings were as follows: anxiety, insecurity, depression, tension, aggression, impulsivity, frustration, helplessness, withdrawal, loss of autonomy, fantasy, indecisiveness, fear, poor reality contact, uncertainty, conflict, regression, hostility, and isolation. These indicators are feelings that are associated with Kubler-Ross's (1969) five stages of death and dying. Consequently, the data collected in this study supports the hypothesis. However, the puzzling aspect of this
finding is that the participants in this study lacked the knowledge of their terminal diagnosis. Therefore, the question remains as to why these participants present these grief indicators within their drawings.

There is an assumption that the participants are not aware of their diagnosis. Is this really true? The participants come to the clinic located in a hospital on a monthly basis. Coming to a medical setting alone can create many feelings that are also similar to the grief indicators, such as anxiety, fear, isolation. After a few visits, the participant may begin to feel different than his/her "normal" cohorts. At the time of their visit, the participants are seen by a social worker, a doctor, a nutrition specialist, a nurse case manager, and an Inland Aids Project representative. The participants receive numerous services from these individuals that are focusing around their HIV/AIDS diagnosis.

Hence, the constant visits to a medical setting (i.e. clinic, hospital) possibly could have raised the participants' curiosity that something is different about them. Also, hospitals tend to be seen as a location where individuals go when they are sick or dying. These participants possibly may be relating themselves to those individuals, along with the fact that they are going to a place where they also are receiving drug therapy. This component plays a big role in supporting the hypothesis that children who are diagnosed with HIV/AIDS, but lack the knowledge of it, will be more likely to show grief
intensity indicators within their H-T-P drawings.

Child G was given a H-T-P pretest (Appendix N) and post-test (Appendix O). This eight year old male when first tested had no knowledge of his HIV/AIDS diagnosis. Five months later, his diagnosis was disclosed to him. There were a few notable changes and some common findings within his drawings. First, his house drawing initially indicated that possibly there was some tension in the home. In his post-test, there was possibly lack of warmth in the home. Second, possible anxiety became present after the child gained knowledge of his HIV/AIDS diagnosis. This participant’s parents both recently died of AIDS within three months of one another. The participant had knowledge of his father passing away by AIDS. He then found out he has the same illness his father had died from.

Third, the pretest drawing displays a house with no windows or doors. In the post-test drawing, the house has a small door and windows with shutters. This child may have felt very isolated and confused and consequently, may have not allowed anyone the opportunity to explore his feelings around the recent death of both his parents. After the disclosure to him, his tree drawing then indicated possible reticence, indecision and inadequacy. This possibly may have indicated that the participant began to feel insecure and more than likely would not be willing to discuss his feelings openly despite the fact that he had a rapport with the clinic.

The common findings were in the area of the position
of the drawings on the page and the common indicators that were found within the H-T-P drawings even though the drawings were drawn differently by Child G. The common placement of the drawings indicated rigidity which was common in young children’s drawings. Both tree drawings indicated insecurity. In the person drawing there were possible indications of aggression, helplessness, regression, and impulsivity. This may have indicated that this participant had unclear feelings around both his parents’ deaths and his constant visits to a medical clinic.

This participant’s pretest and a post-test showed that grief intensity indicators are capable of being projected into both sets of drawings, despite the fact that he had never been told of his own HIV/AIDS diagnosis. The fact that some of the participants may have some knowledge of their parents’ diagnosis of HIV/AIDS may bring about an awareness of his/her own well being. The medical setting possibly also brings some mystery to the table for these participants.

Limitations

The limitation of the design used within this study is that the results of this study can only be applied to the participants of this study. A major limitation within this study is the lack of interpretation in the area of death and dying within Buck’s interpretation manual. Because of this unavailable component, this researcher had to develop a list of indicators which possibly would
indicate grief intensity within the H-T-P drawings provided by the participants. Therefore, the findings presented are more of a personal opinion versus a global one.

Another limitation within this study was the lack of participants who had knowledge of their HIV/AIDS diagnosis. The original hypothesis was going to compare the drawings of children who knew their diagnosis versus children who did not have their diagnosis. This type of sample would have provided additional information on how children would portray grief intensity indicators within their drawings before and after they gained knowledge of their HIV/AIDS diagnosis. However, after reviewing Child G’s pretest and post-test H-T-P drawings, it is clear that there would have been additional limitations around comparing pretest and post-test drawings of different children. Overall, the ability to review children’s H-T-P drawings before and after their knowledge of their diagnosis, would more than likely give a more accurate understanding of how children perceive death and dying when they are diagnosed with a terminal illness.

It must be clearly noted that these findings were limited to the sample used within this study. These results could not be generalized to all children, especially children who were diagnosed with a terminal illness. This limitation attempts to dissipate the assumption that all children perceive death and dying the same way regardless if they were diagnosed with a terminal illness.
IMPLICATIONS OF SOCIAL WORK

This study has raised many questions in the area of how children really perceive death and dying. Having the opportunity to actually see pictures of a participant who lacked knowledge of his diagnosis and then gained it, was informative. It provided support to the previous studies done in the area of children's perceptions of death and dying. However, this experience also opens the door for future research in an understudied arena. Research should be expanded in the area of comparing H-T-P drawings of "healthy" children to children who have knowledge of their HIV/AIDS diagnosis.

The question also remains as to whether children should be told of their HIV/AIDS diagnosis. The clinic social worker indicated that both the children and their parents/guardians have the right to not disclose information about the presence of the HIV/AIDS diagnosis within their lives. The parents/guardians have the right to protect their children from any stress related to the disclosure of a terminal illness such as HIV/AIDS. The lack of knowledge on how HIV/AIDS can be contacted continues to not be clear to individuals in this society. Therefore, research needs to be done in the area of when children should be informed of their HIV/AIDS diagnosis. Essentially, by gaining insight on how children perceive death and dying, particularly when they have knowledge of their own HIV/AIDS diagnosis, would open the doors for practitioners in the area of equipping these children with
skills that would allow them to interact safely with uneducated individuals.

Our society holds the belief that children are our future, yet terminally ill children appear to be overlooked within this belief. These children are a significant part of the future, and their insight must be acknowledged by present and future practitioners. Ignorance and lack of knowledge must no longer go hand in hand, but rather should become empowerment and a strong body of knowledge to any practitioner working directly with HIV/AIDS diagnosed children. All practitioners must also begin to understand the dynamics of how a setting alone, such as a hospital, can cause a range of emotions to arise within a child. This study has clearly brought forward some new criteria. Children do experience a mixed array of emotions and therefore, should be supported—especially when their environment is portraying to them that something is different about them. “Am I normal” needs to be addressed with as little confusion as possible.
The study in which your child is about to participate is designed to elicit information concerning their grief process. This study is being conducted by Georgina Armijo, graduate student in Social Work at California State University, San Bernardino, under the supervision of Dr. Rosemary McCaslin (909) 880-5501. This study has been approved by the Institutional Review Board of California State University, San Bernardino.

In this study your children will be asked to participate by doing some pencil art drawings of a house, a tree, and a person. This procedure is nonverbal, creative, and almost completely unstructured. These drawings come from a standardized test that is designed to elicit information about their psychological well-being. This procedure can take anywhere from 20 to 30 minutes. The drawings will then be evaluated to detect possible signs of distress. Your child will receive a copy of their drawings.

Please be assured that any information your child provides will be held in strict confidence by this researcher. A number will be issued for each test with the names hidden in a confidential locked file. There is no evidence that indicates that children react negatively to this type of test being administered. Should your child experience any emotional distress as a consequence of this test being administered, a social worker will be available to assist.

Please understand that your child's participation in this research study is totally voluntary and you are free to withdraw your child's data at anytime during this study without penalty.

I acknowledge that I have been informed of, and understand, the nature and purpose of this study, and I freely consent to my child participating within this study. I acknowledge that I am at least 18 years of age, and I am the parent/guardian of the child participating within this study. I also give this researcher permission to know my child's HIV/AIDS status.

Parent/Guardian's Signature ___________________________ Date ____________

Researcher's Signature ___________________________ Date ____________

Child Participant's Verbal Approval □ yes □ no Date: ____________
A H-T-P Drawing Form (Pre-ordered from a catalog) was administered to each participant. Each drawing page was listed with "House", "Tree" or "Person" which indicated which direction the picture was to be drawn; horizontal versus diagonal. The name of the figure was at the top from the participant's point of view. Several No. 2 (or softer) pencils with erasers were available for each participant. The participants were instructed to choose a pencil and this researcher then gave the following statement: "I want you to draw a picture of a "house". You may draw any kind of "house" you wish, and do the best you can. You may erase as much as you like. You may take as much time as you need. Just do your best." (Tree and Person was substituted in " ".)
APPENDIX D

DATA COLLECTION SHEET

ID Number: __________

Gender: Male □ Female □

Age: __________

Ethnicity: Caucasian □ African American □ Hispanic □ Other □ __________

Grade level of participant: __________

Number of Siblings: __________

Any infected: __________ How Many: __________

Parents infected: Mother □ Father □

Still living: Mother □ Father □

Child resides with: Mother □ Father □ Both Parents □ Guardian □ Other: __________

Date participant started receiving services from this agency: __________

Is the participant aware of his/her diagnosis: Yes □ No □
APPENDIX E

DEBRIEFING STATEMENT

Thank you for giving permission for your child to participate in this study. The information I gained from you child will be used to assess possible symptoms indicative of grief. I want to assure you once more, that your child's name will be held in strict confidentiality. Should you have any questions about this research or would like to learn the results of the study, please contact Dr. Rosemary McCaslin and/or Georgina Armijo at (909) 880-5501. Results should be available by September 30, 1999. I appreciate your time and your child's time for participating in this study.
To: Georgina Armijo
From: Roberto Reid, MSW
Date: July 21, 1998
Subject: Pediatric HIV Clinic Research

This is notification that permission has been granted for you to pose your research questions to patients of the Pediatric HIV Clinic. Participation by the patient is voluntary. Parental consent must be obtained prior to any research questions being asked. Patient confidentiality will be maintained at all times.

I will, as Clinical Social Worker for the Pediatric HIV Clinic, assist you in posing the questions to the patients and collecting demographic information.
August 1, 1998

Georgina Armijo
c/o Dr. Rosemary McCaslin
Department of Social Work
California State University
5500 University Parkway
San Bernardino, California 92407

Dear Ms. Armijo:

Your application to use human subjects in research titled, "Children Living with HIV/AIDS: Variations in Grief Intensity as Manifest in H-T-P Projective Drawings" has been reviewed by the Institutional Review Board (IRB). Your application has been approved. Your informed consent statement should contain a statement that reads, "This research has been reviewed and approved by the Institutional Review Board of California State University, San Bernardino."

Please notify the IRB if any substantive changes are made in your research prospectus and/or any unanticipated risks to subjects arise. If your project lasts longer than one year, you must reapply for approval at the end of each year. You are required to keep copies of the informed consent forms and data for at least three years.

If you have any questions regarding the IRB decision, please contact Lynn Douglass, IRB Secretary. Ms. Douglass can be reached by phone at (909) 880-5027, by fax at (909) 880-7028, or by email at ldouglass@wiley.csusb.edu. Please include your application identification number (above) in all correspondence.

Best of luck with your research.

Sincerely,

Joseph Lovett, Chair
Institutional Review Board

cc: Rosemary McCaslin, Social Work

5500 University Parkway, San Bernardino, CA 92407-2597
APPENDIX H
CHILD A DRAWINGS

Figure A1

Figure A2

Figure A3
APPENDIX I

CHILD B DRAWINGS

Figure B1

Figure B2

Figure B3
APPENDIX J
CHILD C DRAWINGS

Figure C1

Figure C2

Figure C3
APPENDIX K
CHILD D DRAWINGS

Figure D1

Figure D2

Figure D3
APPENDIX L

CHILD E DRAWINGS

Figure E1

Figure E2

Figure E3
APPENDIX M

CHILD F DRAWINGS

Figure F1

Figure F2

Figure F3
APPENDIX N

CHILD G(1) DRAWINGS

Figure G(1) 1

Figure G(1) 2

Figure G(1) 3
APPENDIX O

CHILD G(2) DRAWINGS

Figure G(2)1

Figure G(2)2 Figure G(2)3

Figure G(2)2 Figure G(2)3
APPENDIX P

CHILD H DRAWINGS

Figure H1

Figure H2

Figure H3
# APPENDIX Q

## TABLE ONE

### DEMOGRAPHICS

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APPENDIX R

TABLE TWO

FAMILY MEMBERS IN RELATION TO HIV/AIDS

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REFERENCES CITED


