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**CHILDREN WITH HIV:  
HOW THEY FEEL ABOUT WHAT PARENTS SAY**

by

**Susan Pease Instone, MSN, CPNP**

**A dissertation presented to the  
FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING  
UNIVERSITY OF SAN DIEGO**

**In partial fulfillment of the  
requirements for the degree  
DOCTOR OF NURSING SCIENCE**

**July 1996**

## ABSTRACT

With improvements in diagnosis and care, children with HIV infection are living long enough to reach school age, a stage when they are capable of perceiving the stigmatizing, life-threatening nature of their illness. Many parents desire to protect them from this knowledge by avoiding an open dialogue about their disease, even though pediatric professionals advocate disclosure. Research-based guidelines about the risks and benefits of telling, however, have not been available in the literature.

Using an innovative, qualitative approach through the use of grounded theory and projective drawing techniques, this investigation sought to explore what parents said about the illness and how children responded socially and emotionally. Data were obtained from 13 parents and 12 school age children with HIV.

Although most of the children were informed about the illness by the time of the study, their drawings and conversations suggest they did not perceive that communication and support were available within their families. Instead, signs of social isolation, poor self-esteem, and severe emotional distress were found. The parents' readiness to tell determined the interval between diagnosis and disclosure, which was typically 4 years. These findings have implications for nursing practice, research, and education.

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## DEDICATION

**To Don, Ben, Mandy, Becka, and Adam  
whose patience, love, and support sustained me.**

**To my parents who endowed me with faith  
in myself and others.**

**To the memory of John B. Welsh MD  
who as my children's pediatrician first showed me  
the wisdom in children's drawings**

**To my colleagues from the UCSD Mother Child HIV Program  
who shared with me the challenge  
of caring and seeking a cure.**

**And to all the children,  
those alive and those who have died,  
and their families,  
who inspired me with their  
dignity, strength and perseverance.**

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## CHAPTER I

### INTRODUCTION

#### Background and Significance

A review of the literature reveals a paucity of information about the social and emotional experience of school age children infected with the Human Immunodeficiency Virus (HIV), an increasingly chronic, but still life-threatening illness. Today, it is estimated that over 1 million children world wide are infected with HIV (World Health Organization, 1996). With improvements in diagnosis and treatment, most children in the United States are living longer with their illness and many are surviving into middle and late childhood (Lewis, Haiken & Hoyt, 1994; Scott, 1993). By the time these children reach school-age, they may not have been informed about their diagnosis. Anecdotal evidence and preliminary reports suggest that many parents tend to conceal this information from children because of the social stigma associated with HIV. Parents also fear that children's awareness of their diagnosis causes harmful emotional distress (Hardy, Armstrong, Routh, Albrecht & Davis, 1994; Lipson, 1993, 1994; Olson, Huszti, Mason & Seibert, 1989; Sherwen & Boland, 1994; Spiegel & Mayers, 1991).

In the first decade of the HIV epidemic, many health professionals advocated informing HIV-infected children about their illness as soon as possible. This open approach evolved from childhood cancer research, involving primarily

Caucasian, middle class families, which found that school-age children discovered the life-threatening nature of their illness despite parental efforts to conceal it. This research suggested that when children were told their diagnosis, they experienced better long-term psychosocial adjustment than those who were protected from this information (Van Dongen-Melman & Sanders-Woudstra, 1986). In the last several years, however, a more cautious approach has been suggested as pediatric professionals have recognized important differences between childhood illness caused by HIV and cancer. For example, the extraordinary stigma surrounding an HIV diagnosis, the acquisition of this illness by children primarily from their parents, and the prevalence of HIV among impoverished families of color raise questions about the wisdom of applying findings from childhood cancer to families living with HIV (Lipson, 1994; Tasker, 1992).

No studies to-date have directly elicited from children with HIV how they perceive and respond to the secrecy surrounding their illness. It is clear that research is needed to better understand their social and emotional experience within the context of what parents say about HIV. Studies of other children with life-threatening illness suggest that parent-child dialogue, social stigma, and social-developmental perceptions of illness are important concepts of psychosocial health. There are two questions generated from these findings. First, are these concepts relevant to the social and emotional health of HIV-infected children? Second, what role, if any, does culture, ethnicity, dual parent-child infection, and stage of disease play in this illness? It is obvious that the magnitude of the

childhood HIV epidemic merits considerable research attention. Pediatric professionals must be prepared to offer research-based recommendations about telling to the parents of HIV-infected children.

This investigation represents a contribution to this much needed body of literature. The investigator's own experiential data and knowledge of the literature provided theoretical sensitivity to several concepts which informed this study:

1. HIV infection is a stigmatized, life-threatening illness that is often concealed from school-age children by their parents and guardians.
2. Children are aware of their diagnosis despite parental concealment and experience social and emotional distress.
3. An open parent-child dialogue about the illness relieves emotional tension within the family but has the potential to create social distress if the child discloses the diagnosis outside the family.
4. Telling children about their diagnosis should be conceptualized as a process, not a single point in time.
5. With few exceptions, parents are most qualified to make decisions about the best interest of their child.

#### Purpose

The purpose of this investigation was to describe the social and emotional response of school-age children with HIV infection to parental communication about the illness. This study was exploratory and was designed to generate hypotheses about how children respond to what parents or guardians say about a

life-threatening, stigmatized illness. Participants were recruited from the University of California, San Diego Mother-Child HIV Program. Over 80% of eligible participants were adults and children of color.

The following questions guided this investigation:

1. How and what did parents and guardians tell children about their illness, particularly those who lived in families with co-existing parental HIV infection?
2. How did sociocultural beliefs about illness in general and HIV infection in particular influence how and what children were told?
3. How did the children perceive the availability of communication about the illness within their families?
4. How did the children perceive the life-threatening and stigmatizing nature of their illness?

### Methodology

An innovative method for this qualitative investigation was needed because the investigator was interested in the perspective of parents, guardians, and children. For this reason, two interpretive techniques were utilized: grounded theory and projective drawings. The combination of these methods was necessary in order for the investigator to discover the thoughts and emotions experienced by the children, as well as those of their parents and guardians.

The methods of grounded theory were utilized to discover the adult's perspective. These methods, however, were not sufficient to elicit the children's

point of view. Among the standard procedures for information gathering in a grounded theory study (participant-observations, asking questions, and constant-comparative analysis), direct questioning of the children in this study was not feasible for two reasons.

First, the investigator could not directly ask the children about their illness if parents or guardians wanted it kept secret. The investigator encountered many adults prior to the study who resisted disclosure of the diagnosis to their children, so it was realistic to assume that they would want to maintain this secrecy throughout the course of the study.

Second, even if parents and guardians had already informed their children about the illness, it was likely for developmental reasons that most of the children would not possess sufficient cognitive or emotional capacities to discuss their understanding of their illness with the investigator in a standard interview format, like that commonly used with adults. These conditions, therefore, necessitated the use of an additional method to obtain information from the children.

Projective drawings and the stories the children told about them were utilized to understand the nature of the children's experience. This technique allowed the children to project their own thoughts and feelings onto a blank page and provide their own interpretation through the stories they told. The characteristics and symbolism of their individual drawings and stories were interpreted by standard methods described in the projective literature. All of the interpretations were then analyzed by the constant-comparative method of grounded theory in

order to find common themes among the children's experience, in the same way that the parents' interview data was analyzed.

### Structure of the Dissertation

The dissertation is divided into five chapters. Chapter I has presented the introduction to the study. A review of literature relevant to the study is provided in Chapter II. This review explores information about social stigma and childhood illness, social and emotional development in childhood, and ethical and historical aspects of talking with children about life-threatening illness.

Chapter III discusses theoretical and practical considerations in conducting qualitative research with children, including justification for the use of grounded theory and projective drawing techniques. The participants, procedures, and methods of analysis are described in detail in Chapter IV.

The findings which emerged from the interviews and drawings are presented in Chapter V. Interpretation of the data, with excerpts from the parent's and children's conversations as well as copies of the children's drawings, are provided to represent each perspective. These data explain the process by which parents and children communicated about the illness and how the children responded socially and emotionally. An integrative diagram illustrates these findings.

Chapter VI summarizes the findings and relates them to other relevant research in the literature. The strengths and limitations of the study are discussed as well as the implications for nursing research, practice, and education.

## CHAPTER II

### LITERATURE REVIEW

For over the past decade, a powerful social stigma has been associated with the Human Immunodeficiency Virus (HIV). Fear of contagion from persons infected with the virus has fueled much of the public's rejection. With the transmission of the virus to increasing numbers of women of childbearing age, children born with HIV infection are placed at risk by social disapproval that persists to the present day. Published reports in the lay press (Fisher, 1996; Hevesi, 1993) have chronicled the public stigma that is associated with an HIV diagnosis.

Until recently, no published research has described the impact of this illness and its associated stigma and secrecy upon children infected with HIV. Preliminary findings (Hardy et al., 1994; Havens, Whitaker, Feldman & Ehrhardt, 1994; Mellins & Ehrhardt, 1994; Weiner, Best & Halpern, 1994) are beginning to support anecdotal reports (Instone, 1992; Lewis et al., 1994; Lipson, 1993, 1994; Olson et al., 1989; Spiegel & Mayers, 1991) to suggest that school-age children with HIV infection are at risk for psychosocial distress.

It is reasonable to assume that the social context of family and community within which HIV-infected children receive care and attention significantly influences their sense of self and their social and emotional well-being. A major

concern, then, is the psychosocial health of children who must endure a stigmatizing, life-threatening illness that is often kept secret by parents even when children are old enough to grasp that something is wrong. This awareness parallels the developing capacity of children to understand the meaning of social interaction with parents, health care providers, and others outside the family.

With little direct evidence about how HIV-infected children respond socially and emotionally to their illness, pediatric professionals have relied upon expert opinion as a guide to telling children about their diagnosis. This opinion has been informed by research in the fields of sociology, child psychology, childhood cancer, and other chronic illnesses of childhood. In addition, an ethical perspective has been needed to sort out the conflict between the right of children to information about their illness and the right of parents to keep the diagnosis secret in order to protect their families from the social stigma of AIDS.

#### Stigma and Childhood HIV Infection

Erving Goffman (1963) identified a typology of stigma and its associated sociocultural processes that gives meaning to stigmatized conditions in general and illnesses in particular. Goffman defined stigma as "an attribute that is deeply discrediting" (p. 3) and distinguished three types: physical deformities, character or moral weaknesses, and stigma related to ethnicity, religion, or national affiliation. Childhood HIV infection simultaneously embodies all of these attributes.

First, according to Goffman (1963), individuals with a physical or external stigmatizing attribute are "discredited" by virtue of their obvious defect. Their

burden is to cope with the tension that is produced during social encounters with others who disapprove or reject them. On the other hand, individuals with stigmatizing conditions that are as yet not obvious or unknown must conceal this attribute in order to avoid discrimination. Goffman called these "discreditable" attributes. Pediatric HIV infection represents the entire spectrum of this dimension as disease progression from asymptomatic to symptomatic stages transforms it from a discreditable condition to one that is discredited.

The majority of children do not develop obvious signs of their illness until they reach school-age (Lewis et al., 1994). Stigmatizing physical manifestations in children, particularly toward the end stage of the disease, include upper and lower respiratory infections, jaundice, and dermatological problems such as severe eczema or herpetic ulcerations. These complications are often unpredictable and recurrent. In general, children frequently demonstrate growth retardation before they experience other physical signs of their illness (Duffy, 1993; Lewis et al., 1994) and may therefore be ridiculed by their peers about their diminutive stature.

Second, moral judgements are also attached to an HIV diagnosis. Findings from research in individuals with other stigmatizing conditions suggests that discrimination is directed more toward conditions for which the person is perceived to be directly responsible (Crocker & Major, 1989). For example, Albrecht, Walker and Levy (1982) found that persons expressed greater social distance from social deviants such as alcoholics and drug addicts than from

persons with physical disabilities. Several factors contribute to social distancing, including judgements about the moral weakness of the substance abuser and fears about health and safety.

While children are usually considered blameless victims of their HIV disease, parental risk behaviors such as bisexuality, injection drug use, or promiscuity are frequently laden with social disapproval or repulsion (Sherwen, Boland & Gilchrist, 1993). HIV-infected children and their siblings may experience what Goffman called "courtesy stigma" by virtue of their affiliation with their stigmatized parents (Gallo, Breitmayer, Knafl & Zoeller, 1991; Siegel & Gorey, 1994).

Third, HIV infection predominates among Latinos, Haitians, and African-American children, who are also most likely to live below the poverty level with poor access to health care (Andrews, Williams & Neil, 1993; Smeltzer & Whipple, 1991; Williams, 1991). Like other chronically-ill children, those with HIV infection may also be stigmatized because of racial stereotypes, compounding the potential for social stress (Cadman, Boyle, Szatmari & Offord, 1987; Gortmaker, Walker, Weitzman & Sobol, 1990; Lipson, 1994; Meyers & Weitzman, 1991).

#### Impact of Stigmatizing Illness

Across cultures and age groups, ample evidence suggests that adults and children hold stigmatizing views of children with chronic illnesses (Birenbaum, 1970; Gallo et al., 1991; Resnick, 1984). Potter and Roberts (1984) found that middle and lower middle-class children are more repelled by chronically-ill children with observable conditions such as epilepsy than those without obvious

signs of their disease. Moreover, like adults, children's disapproval depends upon the extent to which they judge stigmatized children to be responsible for their condition. For example, children who were obese, aggressive, or learning disabled engendered more disapproval than those in wheelchairs (Sigelman & Begley, 1987).

The effects of societal stigma upon HIV-infected children may potentiate emotional and behavioral problems found among many children with other chronic illnesses. These problems include anxiety, depression, school difficulties, and impaired self-esteem (Cadman et al., 1987; Gortmaker et al., 1990; Meyers & Weitzman, 1991). Studies among children with epilepsy suggest that the perception of stigma among low-income adolescents predicts low self-esteem (Westbrook, Bauman & Shinnar, 1992) although in an earlier study no significant long term effects were identified (Brittan, Wadsworth & Fenwich, 1984). However, Spiegel and Mayers (1991) suggest that a syndrome of apathy, social withdrawal, and anorexia that characterizes children with other chronic, debilitating illnesses also undermines the development of a sense of competence and self-esteem among HIV-infected school-age children.

If evidence from other chronic illnesses of childhood applies to HIV infection, then the physical, moral, and sociocultural stigma of the illness may adversely affect the child's internalized view of the self. Goffman (1963) proposed that a sense of shame develops if the stigmatized individual possesses the same values as the "normals" within his/her society. School-age children with HIV

infection may be devastated by the social disapproval of their peers if their stigmatizing illness or that of their parents is revealed.

### Parental Need for Secrecy

Until the development of outward signs of a stigmatizing condition, it is likely an individual will keep it secret, particularly from close family members and friends. According to Goffman, this is especially true for parents:

. . . while one parent in a family may share a dark secret about, and with, the other, the children of the house may be considered not only unsafe receptacles for the information but also of such tender nature as to be seriously damaged by the knowledge. (p. 54)

Goffman touches upon two critical dilemmas for the parents of HIV-infected children: first, whether to risk accidental disclosure by revealing the diagnosis to the child, particularly when research has been unable to predict the age at which children can reliably keep a secret (Olson et al., 1989). Second, whether children will be traumatized by learning the truth about something held secret within the family. When the secret pertains to the child's health, Goffman illuminates the delicate balance parents must maintain between concealing and revealing the illness:

Parents, knowing of their child's stigmatic condition, may encapsulate him with domestic acceptance and ignorance of what he is going to have to become. When he ventures outdoors he does so therefore as an unwitting passer, at least to the extent that his stigma is not immediately apparent.

At this point his parents are faced with a basic dilemma regarding information management, sometimes appealing to medical practitioners for strategies. If the child is informed about himself at school-age, it is felt he may not be strong enough psychologically to bear the news, and in addition may tactlessly disclose these facts about himself to those who need not know. On the other hand, if he is kept too long in the dark, then he will not be prepared for what is to happen to him and, moreover, may be informed about his condition by strangers who have no reason to take the time and care required to present the facts in a constructive, hopeful light. (pp. 90-91)

Goffman's assumptions about the capacity of school-age children for the truth reflected the protective approach generally practiced prior to the 1970s (Pernick, 1983). Today, a more open dialogue is advocated (Lipson, 1993, 1994). However, concern about accidental disclosure of a stigmatizing condition makes a strong parental argument for secrecy. Parents of HIV-infected children, therefore, are faced with a major predicament: is protection from societal stigma by concealment worth the lost opportunities for an open, hopeful dialogue with the child?

### Social and Emotional Development

Given the extraordinary social disapproval surrounding an HIV diagnosis and its life-threatening nature, it is likely that children perceive an altered emotional tone within their families and communities, even if parents and others

attempt to keep the diagnosis a secret. The ability of children to perceive the social distress associated with a stigmatizing, life-threatening condition can be understood by the qualitative-developmental model developed by Piaget (1970). He proposed that children actively construct reality in response to interaction with their environment. Cognitive growth allows the child's perspective to increasingly accommodate or cope with physical and psychological information from social experiences. For children with life-threatening illness, perception of social distress parallels developing emotional capacities and evolving concepts of illness and death.

#### Emotional Awareness

Awareness of threat to self and family depends upon emotional capacities for distress which can vary from moment to moment in childhood (Lipson, 1993). These capacities determine to what extent children perceive the process of communication, like non-verbal cues of body language or voice inflection, over the content or spoken word. These perceptual capacities, however, are regulated by defense mechanisms so that highly threatening information is assimilated at a rate that does not overwhelm the child.

Studies of children with cancer, for example, found that they often used denial as an adaptive defense to regulate emotional distress (Lazarus, 1981). More recently, Bose, Moss, Brouwers, Pizzo and Lorion (1994) found that children with hemophilia and HIV infection who knew about both diagnoses for at least 3 years reported less anxiety and depression compared to normative

scores on several measures of psychological adjustment. These findings surprised the investigators, who hypothesized that the children's use of denial as well as the availability of social supports explained their results.

Even though children use denial to filter out threatening information, studies of school-age children with cancer have also found that children were often aware of their diagnosis before they were told about it. For example, Waechter (1968) found that terminally-ill children who had not been told their diagnosis nevertheless experienced anxiety and thoughts about death. Other studies supported her findings (Bluebond-Langner, 1978; Clafin & Barbarin, 1991; Spinetta & Deasy-Spinetta, 1981; Spinetta & Maloney, 1975; Spinetta, Rigler, & Karon, 1973). Of particular interest, Bluebond-Langner also found that children who knew their diagnosis pretended they didn't by concealing their knowledge from their parents and others because they understood it was not acceptable to talk about it openly. This finding supported similar research with adults by Glaser and Strauss (1965) a decade earlier, who labeled this phenomenon 'mutual pretense.'

### Cognitive Development

Developmental stages of cognition also play an important role in children's perceptions of threat and concepts of illness and death. To illustrate, Bibace and Walsh (1980) and Walsh and Bibace (1991) demonstrated that the concepts of illness held by school-age children correspond with the prelogical and concrete-logical stages of cognition developed by Piaget (1930).

Generally, 5 to 7-year-old children explain illness through prelogical (magical) thinking with the concept of contagion: that all illness is caused when someone gets close to someone or something else without actual physical contact. For example, children this age may be afraid of another child with HIV infection, concerned they might become sick by merely being in the same room with an infected child. Older school-age children hold concrete-logical beliefs about illness. Seven and 8-year-old children believe that illness is caused by contamination from physical contact with something or someone or by engaging in some harmful activity. Nine and 10-year-olds conceptualize the cause of illness by internalization, where an external cause is taken inside the body, for example by inhaling or swallowing. While more sophisticated than the thinking of prelogical children, the idea that HIV infection is caused by something bad that should therefore be avoided still represents a vague understanding of causality by children in the concrete-logical stage of development and engenders an unrealistic fear of those who are infected. The potential for social rejection remains high if children this age become aware of the HIV diagnosis of one of their peers.

Another Piagetian dimension concerning cognitive development among children is their use of immanent justice (their belief that misbehavior will be automatically punished) to understand illness causality (Piaget, 1932). Kister and Patterson (1980) found that children use beliefs about immanent justice to explain illness, particularly when understanding about the physical mechanisms of disease are poorly developed. Their findings corresponded to other work suggesting that

sick children may feel guilty about their illness (Spinetta & Deasey-Spinetta, 1981). For HIV-infected children, it is not difficult to imagine that the perception of their illness as punishment would only be reinforced by the significant social stigma associated with their disease.

Children over the age of 6 years are also able to comprehend life-threatening diagnoses and begin to grasp the inevitability and finality of death, although their understanding may not be without profound misconceptions until they approach 10 or 11 years of age (Bluebond-Langner, 1978; Malone, 1982; Piaget, 1952, 1968). Children understand the irreversibility of death and that it may follow illness, pain, and suffering (Adams-Greenly & Moynihan, 1983). Children with life-threatening illnesses acquire this understanding at a more accelerated rate according to Spinetta (1974) and have greater awareness of their impending death as their condition deteriorates, even when they have not overtly been told about their illness (Bluebond-Langner, 1978). Given this data, it is likely that HIV-infected children understand more about their illness and its life-threatening nature than parents and others assume.

Perception of life-threatening, stigmatizing illness, then, depends upon dynamic emotional and cognitive capacities that develop throughout childhood. Lipson (1993) describes this "developing autonomy" in children with serious illness in the following way:

Not only does each child differ from every other in style and rate of development, but cognitive and emotional capacity varies from moment to moment. At times, children with life-threatening disease will regress below the threshold for disclosure; at other times, disclosure will quite properly constitute a challenge occurring at the crest of their cognitive capacity. (p. 9)

Taken together, the social stigma associated with childhood chronic illness in general may reinforce the tendency of HIV-infected school-age children to hold unrealistic beliefs about their illness and undeserved feelings of guilt and shame. Whatever understanding they have, children need reassurance about their concerns through an open, hopeful dialogue about their illness.

#### Ethical and Historical Considerations

Given the weight of evidence that suggests that chronically-ill school-age children perceive social stigma and threats to self, the pediatric professional is placed in a difficult position when parents refuse to talk openly with their HIV-infected children about the illness. An ethical and historical perspective may provide an additional context for understanding this dilemma.

Traditionally, parents have been entitled to make decisions about the best interests of their children, except where decisions involving medical care have been concerned. For centuries, physicians have been empowered by social and legal policy to determine and protect children's interests when they have required medical care, as long as those interests were within the scope of the physician's

medical knowledge (O'Brien Steinfelds, 1982). As gatekeepers, physicians advocated protecting children from information about their illness, with few exceptions, from the time of Hippocrates until the late 20th century (Pernick, 1983; Reiser, Dyck & Curran, 1977).

In the past two decades, several studies found empirical evidence that children with cancer who were told their diagnosis experienced better emotional health, closer relationships with parents, and improved self-esteem (Chesler, Paris & Barbarin, 1986; Slavin, O'Malley, Koocher & Foster, 1982; Spinetta & Maloney, 1975; Van Dongen-Melman & Sanders-Woudstra, 1986). In light of these findings, physicians and psychologists began to advocate telling the truth to children, even when parents resisted. This approach rested on the belief that pediatric providers had a moral responsibility to "establish a meaningful communication with the patient, to discuss the illness and its prognosis and thus relieve his feelings of fear, anxiety, and sense of hopelessness and loneliness" (Leikin, 1981, p. 41).

The moral imperative argued by Leikin becomes more acute if the terminally-ill child is asking for information about the illness, a behavior that represents a more mature stage in the process of the child's autonomous development described by Lipson (1993). In this situation, then, the decision by pediatric professionals to talk openly with children when parents object may be more defensible if the child has already demonstrated readiness for the truth.

But the consequences to the child and family may be devastating should the child disclose an HIV diagnosis to others outside the family who are afraid of contagion. The United Nations Convention on the Rights of the Child (1991) states that children have the right to information, but that this may be restricted by laws that protect the rights or reputations of others. What is right for the HIV-infected child may not be right for the family, given the social stigma attached to an HIV diagnosis. On the other hand, if children suffer emotionally because their illness is never openly discussed with them, it may be difficult for pediatric professionals to justify silence even when parents insist.

For these reasons, this investigation sought to describe how children respond socially and emotionally to what they have been told by their parents about their stigmatized illness. Such empirical data can only further enlighten pediatric professionals as they struggle with the conflicting needs of parents and children. What may be of greater significance, however, is whether the pediatric professional can use this knowledge in a way that validates the experience of both and assists parents to define the best interests of their child. As Lipson (1993) suggests, it will always be necessary to consider the particular circumstances of each child and family when it comes to decisions about telling.

### Summary

This discussion has considered the literature most relevant to an important clinical concern in the care of HIV-infected school-age children: their psychosocial response to what parent's have revealed or concealed about their illness. As a

variable that may influence parental decisions about telling, the social context of HIV was reviewed, with particular emphasis on the stigma and secrecy associated with this illness and other chronic diseases of childhood. Next, the capacity for children this age to perceive threats to self was discussed, even when parents and professionals deliberately protected them from information about life-threatening illness such as childhood cancer. Ample evidence was found to demonstrate that children are more perceptive than many adults assume. Finally, an ethical and historical perspective was provided as a context for understanding who should decide the best interests of children and what they should be told about their illness.

**CHAPTER III**  
**RESEARCH WITH CHILDREN:**  
**THEORETICAL AND PRACTICAL CONSIDERATIONS**

This investigation was a qualitative study designed to explore how school-age children with HIV infection responded socially and emotionally to parental communication about their diagnosis. The literature offered little empirical work about this phenomenon. Without such knowledge about the nature of the child's experience (in ontologic terms: reality), it is difficult to know what to measure by quantitative methods (Brink & Wood, 1988). According to Faux, Walsh and Deatrck (1988),

data [is] more valid when the subjects, rather than the researcher, described their world . . . accordingly, the use of open-ended questions facilitates increased credibility of data when the researcher wants to learn about the child's level of knowledge, feelings, concepts, and frame of reference. Using close-ended questions or more quantitative methods with children assumes that the researcher is aware of the child's frame of reference and can identify exclusive and exhaustive categories of response. (p. 181)

Lipson (1994) suggests that a quantitative approach to research about telling HIV-infected children about their illness will likely overlook critical aspects that should be discovered, such as the "emotional tenor and psychological complexity of the individual case" (p. S64). He and Cohen (1994) propose that a

qualitative approach is needed to resolve many of the ethical problems inherent in decisions about telling. Furthermore, a descriptive approach using psychometrically sound childhood and parental assessments, normed on mostly Caucasian, middle-class populations, is inappropriate for a population of primarily low-income families of color.

### Grounded Theory

Historically, sociologists and anthropologists have employed qualitative methods of investigation. More recently, nursing and other disciplines have used qualitative research to generate knowledge in new areas of inquiry. Qualitative research results in "rich descriptions of what it is like [for example] to be sick" (Morse, 1991, p. 21). Data is obtained through observations as well as conversations between the investigator and the participants, who are regarded as critical informants in the study. The researcher's own perspective is acknowledged and considered as data. Other sources of data may include documents such as drawings or written correspondence.

While there are several methods to guide qualitative inquiry, it was desirable to choose an approach that not only abundantly describes complex phenomena but also provides a basis for developing theory to understand and explain it. From this larger perspective, findings can be generalized to develop, apply, and evaluate interventions to benefit others who share the experience of the participants. For example, from this study it was possible to identify critical variables about if, when, how, and what parents said and how their children

responded socially and emotionally. Contextual variables such as sociocultural attitudes and beliefs and disease-related variables such as stage of illness were also considered. Correlation of these variables in future studies will permit the researcher to predict and test therapeutic approaches to communication about the illness between parents and HIV-infected school-age children.

At the core of grounded theory is the perspective of symbolic interaction which brings a social psychological focus to the dynamics between individuals within the context of families and cultures. This focus illuminates the shared meanings of a situation among individuals in the form of symbols (e.g., language and drawings) and behaviors (Maurin, 1983; Strauss, 1987).

As a qualitative technique, grounded theory analyzes data acquired primarily through informal interviews and participant-observation (Strauss, 1987). The investigator, who is an active participant in the research, brings theoretical sensitivity to the study through personal qualities and professional knowledge and experience. The researcher's assumptions and influence are acknowledged and considered in the analysis of the data, an epistemologic position that stands in sharp contrast to the relationship between investigator and subject in quantitative research.

Grounded theory is a process that poses generative questions, discovers concepts and categories in the data, interprets their meaning, and links them theoretically to form theory (Strauss & Corbin, 1991). At various points in this

process, the investigator can establish reliability and validity by returning to the participants for clarification and/or verification (Morse, 1991; Strauss, 1987).

### Issues Related to Interviewing Children

The use of qualitative methods with school-age children has been more limited than with adults. While pediatric clinicians have traditionally conducted therapeutic interviews with children, few have done qualitative analysis of these conversations. Recently, however, Mellins and Ehrhardt (1994) performed content analysis of qualitative interviews of 14 HIV-infected children ages 4 to 14 years to investigate sources of stress and coping.

Rich (1968) and Yarrow (1960) assert that most children 6 years and older can be interviewed successfully for research purposes. However, there are several critical factors that must be considered in order to enhance the validity of children's interviews (Faux et al., 1988). First, the investigator must establish rapport and gain the cooperation of the child. Second, attention should be directed toward the construction of the interview guide. Finally, the conduct of the interview should be carefully considered.

### Gaining the Child's Cooperation

School-age children may feel apprehensive about an interview and hesitate to cooperate, particularly if the researcher and setting are unfamiliar. Interviews with children for research purposes are heavily dependent upon the investigator's ability to develop rapport with the child. Lipson (1994) proposes that the researcher who also has a therapeutic relationship with the child has an advan-

tage, despite the potential for conflicts inherent in this approach. Sherwen and Boland (1994) also suggest that research with HIV-infected children, who most likely are also enrolled in medical protocols and clinical trials, may be more feasible if the researcher is already well known to the child and family.

Every effort should be made by the investigator to offer reassurance to children participating in research in order to elicit as much information as possible (Kanfer, Eyberg & Krahn, 1992). It is often helpful to first meet with the parent and child together in the waiting room to exchange introductions and initiate conversation with the child. For example, a comment about something the child is wearing: "I like that neat dinosaur on your shirt," help to break the ice. At this time, it is important to give the child a clear explanation of what will happen during the session, where he/she will be going, and where the parent will be during the interview with the child.

Placement of play objects in a visible location in the interview room will further reduce the child's anxiety. If the investigator wants the child to sit in a specific place, a comment like "here is a special chair just for you" helps the child to know what is expected. At this point, it may be helpful again for the investigator to introduce him/herself and to explain the purpose of the session. At the beginning of the interview, children should be advised in advance that there is no right or wrong answer and that, for example, "all of us get angry [or sad] sometimes" (Rich, 1968). If the interview is audiotaped, it is often helpful to allow

children to insert the tape and practice talking and listening to their voice before the actual interview begins.

Additional measures should be employed by the investigator to establish rapport and gain the child's cooperation. Frequent use of praise for staying on task is likely to maintain cooperation. A warm, empathetic approach that communicates the investigator's interest in the child and concern for his/her welfare and safety is crucial. In general, discussion about the child's right to confidentiality is appropriate for older preadolescent and adolescent child (Melton & Ehrenreich, 1992). Kanfer et al. (1992) suggest that confidentiality with the younger child be addressed in general terms: "we will be talking about a lot of things today. Then you and I will talk to your parents about the things that are important. This way we can all work together" (p. 58).

### Interview Guide

The second factor involves the construction of an interview guide for school-age children. The guide should be designed to elicit information about the thoughts and feelings of the child, beginning with topics that are least threatening, like friends, school or hobbies. More sensitive topics, such as concerns or fears, should be approached once the investigator has gained the child's trust.

The investigator should use simple terminology when interviewing school-age children. Faux et al. (1988), Rich (1968), and Yarrow (1960) emphasize the need to use concrete language with school-age children given their concrete-logical stage of development. The interviewer should focus upon what the child

"would do" in a given situation rather than what the child "would feel or say." Interviews should last 30 to 45 minutes for children this age, although the presence of fatigue, anxiety, or acting-out behavior make the duration highly variable.

The construction of interview questions for children depends upon the purpose of the investigation. Direct questions are appropriate to obtain basic information (e.g., age, grade in school, etc.), but are rarely useful to uncover thoughts and feelings about topics which are taboo or have threatening undertones (Kanfer et al., 1992). Indirect and projective questions are generally more appropriate for children who are reluctant to disclose sensitive feelings or thoughts.

Indirect questions involve asking the child what he/she would do or how he/she would feel in a hypothetical situation. Projective questions extend this idea, so that the person involved in the hypothetical situation is not the child participating in the interview, but a hypothetical child. For example, the investigator might ask a child whose parent recently died to respond to the following: "Once there was a little girl who lost her mommy in a big earthquake. I wonder what that little girl did when her mommy died?"

The underlying purpose of indirect and projective questions is to elicit from the child attitudes that are too threatening or too enmeshed in cultural inhibitions. An interpretation of the child's response to projective questions is complicated by a child's tendency to combine fantasy with reality. For this

reason, the analysis of content should take place on a symbolic level rather than at face value (Boggs & Eyberg, 1990).

### Conducting the Interview

Third, specific strategies should be considered during the actual interview. Children should be allowed to tell their story without interruption. This approach allows them to describe what is meaningful without contamination of their responses. Nonverbal behavior should be carefully observed and recorded throughout the interview. Another strategy is the use of multiple sources of data from the child to enhance the researcher's understanding of the child's perspective. As a natural medium for children to communicate, drawings are used both to reduce anxiety and to validate what the child has said.

Reflective statements about what has been said or drawn are used to produce embellishments and minimize defensiveness. Counter suggestion is an additional strategy that is used by the investigator to evaluate inconsistencies in the child's response. This technique, developed by Piaget, involves the repetition of a question or statement in an alternate or opposite way (Faux et al., 1988). For example, a researcher might say, "Well, some kids tell me that they throw their toys when they get mad" in response to a child who denies ever doing anything destructive when he/she is angry. In effect, the child is given permission to admit a behavior he/she believes is socially unacceptable to the interviewer.

Finally, it is important to separate the roles of researcher and clinician in the course of an interview so that the data is not overtly influenced by the

interviewer. Faux et al. (1988) suggest that clinical interventions such as correction of misconceptions or misunderstandings should take place at the conclusion of the interview.

### Use of Children's Drawings in Research

Researchers have used drawings, another qualitative method, both to initiate interviews (Faux et al., 1988) or as data for analysis (Barnes, 1975; Stoll, 1969). Several nursing researchers have used children's drawings as a complement to other research methods in order to enhance the validity of the data (Malkiewicz & Stember, 1994).

Considered at first as an intelligence test to be evaluated quantitatively, drawings were later discovered to possess important qualitative cues about the emotional state of the child (Hammer, 1986). In child psychology, drawings are considered a projective technique designed to elicit "the child's inner feelings, states, and attitudes" (Sigel, 1960, p. 351). Many of the studies investigating the emotional response of children to cancer used projective techniques to measure psychological distress (Malone, 1982; Spinetta & Maloney, 1975; Spinetta, et al., 1981; Spinetta et al., 1973; Waechter, 1968).

Based upon the psychoanalytic theory of human development, projective techniques involve the presentation of ambiguous stimuli, such as an ink blot, picture, story, artistic media, or toy in order to uncover thoughts and emotions the child cannot or will not verbalize. In general, projective techniques that involve processes of construction and expression, such as drawing, are likely to be

more revealing with the older child (Henry, 1960; Rabin, 1960). Drawings provide not only a means of self-expression, but also a window into the child's perception of conflicts, often on a level that surpasses the child's verbal capacities (Di Leo, 1983; Rambert, 1964). Drawings can also serve as therapeutic communication and understanding between children and adults (Winnicott, 1971).

Interpretation of children's drawings requires an understanding of the logic and symbolism of childhood. The child's stage of cognitive development provides insight into logical expression in drawings, just as the degree of repressed conflict leads to the child's use of more obscure symbols (Rambert, 1964). Children's explanations of their drawings can greatly assist in their interpretation and should be encouraged (Di Leo, 1983; Rambert, 1964; Winnicott, 1971).

In general, drawings have enjoyed widespread clinical use because they are relatively easy to elicit from children under the age of 12 years and are useful in the establishment of a therapeutic relationship with the child. However, the use of drawings in research has been criticized. Most of the criticism has centered upon the assessment and interpretation of the child's emotional state, methods which lack sufficient reliability and validity compared with quantitative psychological measures. For example, the projection of the investigator's own subjective thoughts and feelings into the interpretation of the drawing threatens the validity of the technique. In addition, the lack of normative data, with the exception of the work by Koppitz (1984), has made it problematic to interpret the findings of emotional disturbance in specific populations (Harris, 1978; Haworth, 1965).

Di Leo (1983) proposes that the value of children's drawings outweighs their failure to meet scientific statistical standards, echoing the position of Sigel (1960) two decades earlier, who suggested that projective methods provide rich information about the inner life of children that is unavailable through other more objective tests and observational approaches. Many proponents of projective drawings recognize the subjective nature of their interpretation, but recommend that interpretation take place within the context of the child's verbal and nonverbal behavior while drawing as well as the child's sociocultural circumstances to increase validity (Buck, 1964; Koppitz, 1984; Sigel, 1960; Wohl & Kaufman, 1985). It is reasonable to assume that consideration of the content of parent-child dialogue about an illness, for example, might contribute to a more valid interpretation of the child's drawing (Spinetta et al., 1981).

When children draw spontaneously, they frequently draw houses, trees, and people (Hammer, 1960). For children, houses represent relationships with parents and siblings, while trees symbolize relationships with the wider social environment. Drawings of a person indicate self-image (Buck & Warren, 1992). Family drawings, particularly those with a kinetic dimension, reveal the child's perceptions of family interaction. For these reasons, two projective drawing techniques constitute a standard battery of assessment in children: the House-Tree-Person (HTP) developed by Buck (1948), and the Kinetic Family Drawing (KFD) devised by Burns and Kaufman (1972). Human Figure Drawings (HFDs) may be obtained as part of the HTP (the Person) or as an individual measure.

In addition to their use in childhood cancer, these drawing techniques have been used to study the emotional state of several other groups of high-risk children. For example, Wohl and Kaufman (1985) found themes of helplessness, powerlessness, depression, anger, and anxiety in the HTPs and KFDs of 18 school-age children who were residents with their mothers in a shelter for battered women. A study of HFDs from sexually abused children revealed themes of anger, anxiety, helplessness, and vulnerability (Kelly, 1985). Johnson (1990) studied the HFDs and KFDs of developmentally delayed children who demonstrated emotional indicators of separation, isolation, and anxiety.

A preliminary analysis of KFDs and HFDs of 29 HIV-infected school-age children followed at the University of California, San Diego revealed emotional indicators of anxiety (as developed by Koppitz, 1984 and Burns and Kaufman, 1972) in over two-thirds of the children (Instone, 1992). Of the seven children who had been told their diagnosis prior to the time the drawings were produced, all but one of them exhibited indicators of anxiety in both drawings. No attempt was made to control for intervals between diagnosis and disclosure, stage of illness, sociocultural differences, or other variables, so that conclusions about these findings are premature.

Weiner et al. (1994) collected stories and drawings from 24 HIV-infected children who had been formally told their diagnosis. While no structured analysis was performed of this data, themes of fear, anger, sadness, and hope were expressed in the children's stories about their drawings.

Drawings can therefore provide important insight into the hidden thoughts and emotions of children who are unable or unwilling to talk directly about threats to self and family. As a projective technique, drawings are a useful clinical tool. While their use in research has been criticized, they nevertheless provide a unique window into the private world of children.

#### Cultural Considerations in the Use of Drawings

Interpretation of children's drawings, both for clinical use as well as for research, has been performed primarily on the individual and family level. Individual interpretations have focused on the child's cognitive and psychosexual development, use of defense mechanisms, and personality traits. Conflict, separation, and loss have been important family issues that have also received considerable interpretive attention. While these perspectives have been widely described in the pediatric developmental literature, comparatively few studies have examined the influence of culture upon what children reveal in their drawings.

From an historical standpoint, the relative absence of a cross-cultural perspective in the interpretative literature on children's drawings reflected a more general tendency within developmental psychology to ignore the significance of culture upon the cognitive and emotional development of children (Jahoda, 1986; Martin & Light, 1986). Childhood development was conceptualized as a universal process that applied to all children, regardless of cultural heritage.

This orthodox Piagetian position softened, however, as other researchers began to emphasize the need to consider specific sociocultural contexts in order to understand development, particularly beyond 5 years of age (Dasen, 1977; Levick, 1983). Within the past decade and a half, children's drawings have been increasingly studied among culturally diverse populations in order to understand how cultural differences influence what children draw (Cabacungan, 1985; Goodnow, Wilkins & Dawes, 1986; Ledesma, 1979; Zaidi, 1979).

Two cross-cultural studies have explored cultural differences in HFDs between American children and children from Mexico (Koppitz & de Moreau, 1968) and Argentina (Koppitz & Casullo, 1983). The children were matched by age, gender, and socioeconomic level. Both studies found that American children demonstrated more emotional indicators of anxiety, anger, and impulsivity than the Latino participants, who exhibited more signs of timidity and evasiveness.

In order to gain more knowledge about the influence of culture on the drawings of Latino children, the investigator conducted a study of 36 KFDs and HTPs produced by nine healthy Latino siblings of HIV-infected children followed in the UCSD Pediatric HIV Program (Instone, 1995). Interpretation of these drawings also suggested themes of evasiveness, like the findings of Koppitz and de Moreau (1968) and Koppitz and Casullo (1983). In addition, the drawings of the siblings suggested themes of emotional distress, diminished self-image, and closed communication within their families. It is likely that these findings were more attributed to the profound loss experienced by these children, not their cultural

identity. All of the children in this study experienced the death of a close family member. In addition, these children were living with a symptomatic HIV-infected sibling or parent at the time the drawings were produced.

No cross-cultural studies using the HTP or KFD with Latino children have been published to-date, although Burns and Kaufman have printed a Spanish version of the KFD interpretive manual (1978). It is clear that more studies are needed to interpret sociocultural influences in the drawings of Latino children.

#### Summary

In summary, the design of research involving children requires the selection of methods which will enable the investigator to establish trust, gain cooperation, and obtain reliable and valid data. When research seeks knowledge about the perspective of children, qualitative methods are appropriate modes of inquiry. For this reason, projective techniques such as drawing have been used to study the psychological adjustment of children with life-threatening illness. While issues of interpretative validity and cross cultural application have been raised, the ease with which they can be administered and their ability to illuminate the private world of children outweigh these limitations.

## CHAPTER IV

### METHOD

#### Sample

Eight parents, five guardians, and twelve HIV-infected children ages 6 through 11 years followed in the University of California, San Diego (UCSD) Mother-Child HIV Program were recruited to participate in this study. Two of the children (a 6-year-old girl and a 7-year-old boy) declined to meet with the investigator after their parents were interviewed. Children were eligible for the study if they were taking HIV-related medicines (e.g., AZT, Pneumocystis carinii pneumonia prophylaxis) and/or attending the UCSD Mother-Child HIV clinic on a monthly basis. Children were ineligible if they were too ill to participate. The UCSD program serves children from San Diego and Imperial counties in California, the states of Arizona and Nevada, and the country of Mexico. Even so, the potential pool of children this age was limited, therefore, there were no other exclusion criteria. Parents and guardians were eligible to participate if they had been the child's primary caretaker for at least 6 months prior to the study.

Seven of the children were boys, five were girls. Eight were Latino, two were African-American, one was Anglo, and one was Filipino. The mean age was 7.5 years. Based upon counts of CD4 lymphocytes (absolute number per cubic milliliter) in their peripheral blood, four of the children had mild to no

immunosuppression (CD4 > 600), four had a moderate degree (CD4 200-599), and four had severe levels of impaired immunity (CD4 < 200). All but one of the children were taking at least two medications several times a day and all required a minimum of one visit every month to the pediatric HIV clinic for evaluations. The interval since diagnosis ranged from 2 to 8 years, with a typical interval of 4 years.

Two of the parents in the study were themselves infected with HIV and the source of their children's illness. Most of the children in the study were in the care of extended family members because one or both parents had already died or were too ill to care for their children. Five children were in the care of their extended families (four with grandmothers and one with an aunt), three were with their biological mothers (two of whom were infected with HIV), and two were with their biological fathers (neither infected with HIV). In addition, two children were adopted. Table 1 illustrates the profiles of the children in the study who have been given pseudonyms. Only one child lived with both biological parents (both of whom were infected with HIV). Nine children had experienced the death of a parent (six from AIDS, three from other causes). Two children were estranged from their HIV-infected biological mothers who were unable to care for them.

### Procedures

Approval from the Human Subjects Committees of the University of San Diego and the University of California, San Diego was obtained before data was

Table 1

Demographic Data

Age & Pseudonym	Interval From Dx	Ethnic Culture	When Told	Primary Caregiver	CD4 Ct.	No. Meds.
6.4 Ana	3 years	Latina	not told	adopted	1715	0
6.4 Sara	6 years	Latina	1 mo. ago	adopted	590	2
6.5 Tanya	3 years	AA	1 mo. ago	mat.gmo	333	4
6.7 Alana	4 years	Latina	not told	father	998	2
6.9 Brisha	4 years	AA	1 mo. ago	father	591	2
7.8 Chris	7 years	Latino	1 yr. ago	mat.gmo	1064	3
7.9 Jamie	4 years	Filipino	8 mo. ago	mother	62	3
8.3 Sonia	4 years	Latina	not told	parents	839	2
8.3 David	5 years	Anglo	3 yrs. ago	mat.gmo	109	2
10.1 Carla	2 years	Latina	1 mo. ago	mat.gmo	312	4
10.7 Migel	8 years	Latino	1 yr. ago	mother	25	3
11.8 Jorge	8 years	Latino	not told	mat.aunt	38	5

AA = African American

Mat. gmo = Maternal grandmother

collected (see Appendices B and C). In addition, approval was obtained from the medical director of the UCSD Program.

The purpose and design of the study were explained individually to parents at a preliminary meeting. They were told that the investigator was interested in understanding how their children were responding socially and emotionally to information they had been given about the illness. If parents had not yet told their child about his/her HIV diagnosis, parents were assured that the investigator would not disclose this information and would only use terms about the illness with the child that had been approved in advance by the parent. For example, if parents used the term "ABC" medicine for AZT, the investigator would use this term as well (see Consent to Act as a Research Subject). The investigator also described the indirect and projective methods to be used to understand the child's perspective. Informed written consent from parents was then obtained.

The child was then invited to join the parents in the initial meeting with the investigator, who asked the child to participate in the study. The child was told that the purpose of the study was to learn more about what it is like for children who have to take medicines, come to clinic, and get shots. When feasible, informed written consent from the child was obtained.

Participation in the study took place in the offices of the Mother-Child HIV Program located at the UCSD Treatment Center, a free standing research clinic approximately three miles from the UCSD Medical Center. This location

was well known to all of the children and their families who were eligible for the study.

It was anticipated that several of the participants would be monolingual Spanish speakers, therefore these interviews were conducted in that language. The investigator utilized the services of a bilingual social worker who was affiliated with the UCSD Mother Child HIV Program and well known by all of the potential Latino participants. She had considerable experience working with Latino children and families and served as an expert consultant throughout the study. In addition, a bilingual Latina provided assistance with the translation and back-translation of the transcripts.

#### Additional Data

Demographic information about the participant's ethnicity, and household membership was obtained. Disease related information about the child such as number of visible effects of the illness, CD4+ cell count, interval since time of diagnosis, number of daily HIV-related medications, and frequency of clinic visits in the previous month was obtained from the children's clinical record.

#### Parent Interviews

With written consent, parent interviews were audiotaped and transcribed. Audiotapes were then erased. Written transcriptions were coded without the participant's name or other personal information. All research materials remained in a locked file cabinet when not in use by the investigator.

Parents were interviewed in order to discover what they had communicated to their children about their illness and what influenced them to take this approach. Initial interviews were scheduled with follow-up as needed for clarification of the data or exploration of theoretical categories until saturation was reached (Strauss & Corbin, 1990). Validity was established by clarification of the meaning of the spoken word with the participant. Interviews with parents were semi-structured and guided by the following initial questions:

1. There is a lot of public misunderstanding and fear about HIV and AIDS. Have you or your child experienced any discrimination because of your child's diagnosis or your own? How has this affected you and your child? Has this made it difficult to talk with your child? What has made it easier?
2. Describe what it was like the last time you talked with your child about his/her illness. How did your child respond?
3. What do you think your child understands about his/her illness?
4. What have you told your child about his/her illness? About your illness? What have you told other members of your family? What words or phrases do you feel comfortable using when you talk to your child about his/her illness.
5. Tell me about any religious or cultural beliefs you hold that have influenced what you have told (or not told) your child.

6. Under what circumstances, if any, do you think it would be okay for the doctors or nurses to tell your child about his/her HIV diagnosis before you have decided to do so?

#### Children's Interviews and Projective Measures

Children were interviewed separately from their parents in a quiet room with the child and investigator seated at a small table. They were told that the purpose of the study was to learn more about what it is like for them to have to take medicines, come to clinic, and get shots. Transcriptions of these data were handled in the same confidential manner as those of the parents.

All children were administered the Kinetic Family Drawings (KFD) and House-Tree-Person (HTP) test respectively. These instruments helped to reduce the child's initial anxiety and were another source of data. The standard instructions for administering these tests was followed (Buck & Warren, 1992; Burns & Kaufman, 1972).

The children were given four blank pieces of white 8" by 11" paper and a set of ten colored pencils with erasers. First, they were instructed to "draw a picture of everyone in your family, including you, doing something. Try to draw whole people, not cartoons or stick people. Remember, make everyone doing something--some kind of action" (Burns & Kaufman, 1972, p. 5).

Next, the children were instructed in the following manner: "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" (Buck & Warren, 1992, p. 117). When the children finished, they were instructed to draw a tree and person in the same manner. While the children were drawing, the investigator observed and recorded their verbal and non-verbal behavior.

Children were asked to tell a story about the drawings to clarify the content. Strategies outlined previously were utilized to engage the children in conversation. The following statements/questions guided the interview:

1. Tell me about your family drawing. Who is in the picture? What is everyone doing? What happened before? I wonder what will happen next. I wonder what everyone is thinking and feeling?
2. Tell me about this house. How many stories does it have? If it's your house, which room belongs to you? Who would you like to have live with you in this house? It looks like it's sunny (or raining, etc.). What does this house need most?
3. I wonder what kind of tree this might be. About how old is it? Is it alive? What is the weather like in this picture? Is the wind blowing? What does the tree need most?
4. Is this a boy or a girl? Tell me who this is and how old he/she is. I wonder what this child is doing. Where is she/he? I wonder how she/he feels? Is this child sick? Does this child have to take medicine or get shots? What does this child do when he/she comes to clinic? What does

he/she remind you of? What does this person need most? Describe the clothes this girl/boy is wearing.

At the conclusion of the interview, parents were invited to join the child and the investigator. The drawings were shown to the parents and the investigator praised the child for doing "such a good job." Parents were encouraged to comment on the drawings and to clarify their content should they desire. In addition, observations of parent-child interaction were made and conversations were recorded. The investigator made only general observations about the drawings and avoided in-depth interpretations at this time.

#### Data Analysis

The constant comparative method of grounded theory guided the qualitative analysis of the observations, conversations, and interpretations of the drawings in order to: (a) identify parental communication styles, (b) describe ways that children responded socially and emotionally, and (c) explore the relationship between demographic and disease data, parental communication styles, and types of children's psychosocial response. Transcriptions of conversations with the children and interpretation of their drawings were considered as a whole to represent their experience and perception of illness.

#### Analysis of interviews

Transcriptions of interviews were analyzed using the grounded theory method, which involves coding of the data. Coding represents "the operations by which data are broken down, conceptualized, and put back together in new ways"

(Strauss & Corbin, 1990, p. 57). Similar concepts were grouped under abstract categories or themes which were in turn synthesized to form a process of interaction and a conditional matrix as an analytic framework for theory development (Strauss & Corbin, 1990).

Consistent with the overall purpose of this investigation, analysis of parent conversations focused on what they communicated about their child's illness. The interview data from children underwent similar analysis, with an emphasis upon how they perceived themselves as someone who is sick, needs to take medicines, and have frequent blood tests.

#### Analysis of Projective Drawings

The HTP and KFD were interpreted qualitatively by the methods developed by Buck and Warren (1992), Burns (1982), Burns and Kaufman (1972), and Spinetta et al. (1981). A member of the investigator's dissertation committee, who has expertise in this area, reviewed and validated these interpretations, which focused upon the children's perceptions of their illness experience. Their perceptions related to three domains: (a) the quality of communication about the illness within their family, (b) image of self as ill, and (c) emotional tone.

Using the standard interpretive methods just described, the drawings were examined for specific characteristics that pertained to each domain. The quality of communication was evaluated by the presence or absence of specific drawing styles in the KFD and House drawings. These styles included the use of compartmentalization of individual human figures, barriers between individuals, and the

placement of human figures on the back of the paper. The presence of any of these styles was considered to be problematic. Other characteristics were also evaluated: the exclusion of a family member, the position of the parent or guardian (i.e., standing, sitting, or lying), and the orientation of the child's face to that of their primary caregiver. Family members who were absent, sitting or lying, or facing away from the child were interpreted by the researcher to be signs of closed communication within the family.

Self-image was evaluated qualitatively by analyzing the characteristics of the KFD and Person drawings. Specific indicators of poor self-esteem in the drawings were identified: drawing the opposite gender, disproportionate size portrayal, incompleteness, missing parts, and cross-hatching or transparencies. These were considered to be negative indications of the child's self-image if they concerned other family members as well as the child him/herself. In addition, children who did not include themselves in the drawing or drew themselves sitting, lying or drawn from the side or back were considered to have a poor self-image.

The KFD and HTP drawings were evaluated for the third domain, emotional tone, on the basis of six characteristics: (a) conditions of weather or nature, (b) use of color, (c) use of space on paper, (d) developmental level, (e) use of stick figures, and (f) facial completeness of the drawer. The depiction of threatening weather (i.e., clouds, rain, darkness, or lightning) was interpreted as a sign of a negative emotional state (i.e., anxiety, depression, loneliness, isolation, or

rejection). The use of only one or two colors and less than one-half of the paper were indications of emotional deprivation. In addition, negative emotions were attributed to drawings that were below the developmental capacity of the child, involved the use of stick figures, or omitted three important facial features (i.e., eyes, nose, and mouth).

These domains in the children's drawings were interpreted within the context of the stories they told about them and the data obtained from parents and guardians about what had been revealed or concealed about the illness. The KFD and House drawings revealed the children's perceptions of social interaction within the family, representing the extent to which dialogue and support about the illness was possible. For example, if a cohesive family was drawn without any barriers between its members, the child more than likely lived in a nurturing family that openly communicated.

Both the KFD and the HTP disclosed the children's self-image and the degree to which they were experiencing emotional distress. Extensive use of cross-hatching or shading, for example, represented anxiety. In addition, the HTP illuminated the extent to which the children perceived their wider social network as threatening or supportive.

#### Ethical Considerations

The investigator recognized several ethical concerns during the conduct of this research. First, participants may have felt coerced to enter the study. The investigator was already known to them as a member of their child's pediatric

health care team. This familiarity may have made it difficult for parents to refuse when they were approached about the study. The investigator made every effort to assure parents that their refusal to participate would in no way jeopardize their child's care.

Second, the investigator also recognized the need to separate her research role from her clinical role. When grief and loss issues surfaced during the research interviews, the investigator addressed these concerns at the end of the session whenever possible, although at times it was necessary to interrupt the interview and turn off the tape recorder while the participant cried. The investigator was qualified to manage these situations by virtue of her 6 years of experience as a pediatric nurse practitioner with the UCSD Program. In the event the investigator determined that additional professional support was needed, she referred the child and family to the appropriate resources. A bilingual Licensed Clinical Social Worker, who is a member of the UCSD Mother-Child HIV Program professional staff, was available for this purpose.

Finally, the emotional toll of these interviews and their analysis upon the investigator was also of concern, given her previous experience with other qualitative research of this nature. The investigator created a supportive network of colleagues to assist her with her own grief and loss issues.

### Summary

In summary, 23 parents, guardians, and children participated in the study. Demographic data, disease-related information, observations, and conversations

with the adult participants were analyzed using the constant-comparative method of grounded theory. In addition, the children's drawings and stories were evaluated individually using standard projective methods to discover their perceptions. The investigator next utilized the constant-comparative method of grounded theory to identify common themes in the interpretations of the children's drawings and stories, in the same way that the conversations with the parents and guardians were analyzed. The investigator's dual role as a clinician presented several ethical issues related to the recruitment of the participants and the collection of the data.

## CHAPTER V

### FINDINGS

The findings from this investigation emerged from several sources of data:

(a) the investigator's experience as a pediatric nurse practitioner involved in the clinical care of the children and their families, (b) the clinical records of the children, (c) observations of the interaction between parents or guardians and their children during the conduct of the study, (d) communication with parents, guardians, and children during the process of obtaining informed consent, (e) interviews with parents and guardians, (f) the children's drawings, and (g) interviews with the children about their drawings.

Analysis of these data led to the discovery of the process of interaction and communication about the illness between parents, guardians, and children. Dialogue about the illness was primarily dependent upon the extent to which parents and guardians were ready to reveal the stigmatizing, life-threatening nature of the illness. Parental readiness to tell was therefore identified as the core category. At the same time, the children's drawings and their stories about them illustrated how they saw themselves and how they perceived the availability of communication and support within their families. It is likely that these perceptions are important influences on psychosocial health, particularly in children with a chronic, life-threatening illness.

Eight of the 12 children in the study were told about their diagnosis by a parent or guardian before the study began: four were told approximately 6 to 12 months before they were interviewed; four were told within 1 month before their participation in the study. The typical interval between the time of diagnosis and time of disclosure was 4 years. The remaining four children had not yet been informed by their parents about their diagnosis; however one child had been accidentally told by medical personnel about 1 year before he was interviewed.

For the sake of clarification and simplicity, the children's pseudonyms will be used to identify their parents, guardians, drawings, and conversations. A descriptive profile of these participants can be found in Appendix A.

#### Parent's Readiness to Tell

The data suggest that parent's and guardian's readiness to tell depended directly upon several perceptual, cognitive, and disease-related conditions: (a) parental fears of stigma and death, (b) parental beliefs about telling children about life-threatening illness, (c) intensity with which children asked about the illness, (d) signs of the children's illness, and (e) parental illness or death. Consequences for parental readiness to tell were revealing, pretending, and concealing illness-related information. More parents and guardians revealed than concealed the diagnosis, although it was common for those who told to conceal the catastrophic nature of the illness. At times, these families vacillated between concealing and revealing information about the illness by pretending as if the children had not already been informed. Regardless of these variations in telling,

most of the children demonstrated disturbed patterns of social and emotional perceptions in their drawings and interviews.

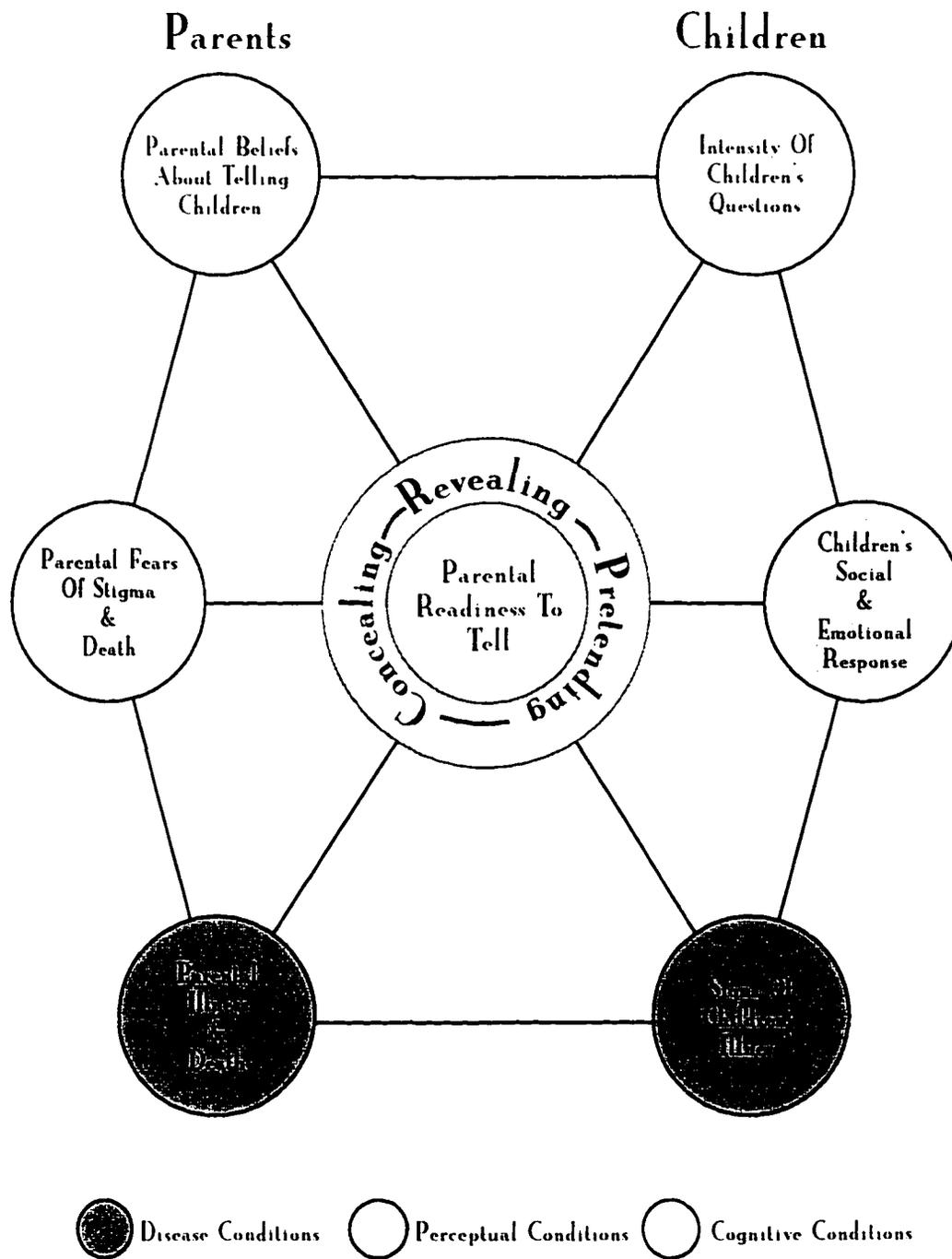
The data also suggest that parents and guardians were not directly aware of their children's distress before they informed them about the illness. The children's drawings and conversations indicated that they were anxious and worried. These concerns and their natural curiosity may have led them to ask about their illness. In this way, their perceptions indirectly influenced what parents said. At the same time, the children's response also emerged as a consequence to the patterns of concealing, pretending, and revealing found in the data.

These conditions and consequences formed the basic process of interaction between parents or guardians and their children. An interactive diagram (see Figure 1) is provided to depict this process which typically took place over a period of 4 years. This process is conceptualized as reciprocal, dynamic, and temporal. How this process is grounded in the data will be illuminated in the next section.

### Fear of Stigma and Death

An important perceptual condition for parental readiness to tell were the parents' and guardians' fears about the stigma and life-threatening nature of HIV and AIDS. These fears determined who was told about their children's HIV diagnosis. Prior to the interviews for this study, every parent and guardian had told at least one other trusted adult, although this experience met with various

# Process of Interaction Between Parents and Children



**Figure 1.** Process of interaction between parents and children.

levels of understanding or rejection. The way others responded to the news about the children's diagnosis influenced the parents' readiness to talk with their own children.

Who knows, who doesn't. Fear of social discrimination directed toward the family determined who parents and guardians told and who they didn't. In most cases, only selected adult members of the immediate family were told at first about the diagnosis. These individuals were chosen because they were identified as family members who could be trusted to keep the diagnosis a secret. The response of Ana's mother was typical:

"... the brothers . . . and my four sisters are the only ones that know. My mother and her family don't know."

Her husband went on to explain that they had learned about the unfortunate experience of another HIV-infected child who had been ridiculed by neighbors when her diagnosis became common knowledge. He stated,

"In the neighborhood where she used to live, all the people found out about her illness and they [her family] had to move from there. I think the same thing would happen to us if the people find out. We would be constantly harassed by them. This is why we have to keep it so quiet and only [let] the closest family know."

**Migel's mother agreed,**

**"We followed the recommendation of the doctors that the less people knowing the better. We talked with family members, my sister, my husband's father, and that's it. We went like that for 3 years."**

**She went on to describe what happened then,**

**"We had a reunion, like a meeting, when they found out by accident. For the whole family, I feel that one of them was afraid but the rest were very supportive."**

**She related what happened after her son's diagnosis was discovered by the family member who was afraid,**

**"He wanted to spend the night with them and she tried to find excuses not to have him at her house."**

**Jamie's HIV positive mother described who she told and how she felt about it,**

**"I talked to my best friend, she's my sister-in-law now . . . we trusted each other, so I talked to her . . . I felt ashamed, I felt ugly and stuff. I talked to my family . . . they were worried about the kids [her neices and nephews] getting it."**

**For Brisha's father, the desire to keep his daughter's diagnosis a secret from others had been difficult to achieve,**

**"I have told four people over these past years, and basically her mother (who died from AIDS in 1991) told everybody else. People have been telling people. Even the teachers at her school found out but this is**

something that even my best friend doesn't know. This is something I keep within me. It is very secret."

He went on to describe how painful this process has been,

". . . sometimes this disease gets to you . . . not so much because you know your kid is dying, but because I can't share it with anybody. Once I went to a [support] group and I told them."

In a few families, the adolescent siblings or cousins were also told about the diagnosis before it was disclosed to the children in the family who had HIV.

Carla's grandmother described who in her family knew about her granddaughter's illness,

"Yes, all my children, my daughters-in-law, my sister. All of them, they know . . . including all the grandchildren, even the ones in junior high school."

Tanya's grandmother told most of her grandchildren, including two older school-age siblings of her HIV-infected granddaughter, before revealing the diagnosis to the girl,

"He [her grandson] is 12 and he knows all about AIDS . . . and he knows he can talk about it any time he wants to and he worries about her. [The other grandson] who is 9 and her middle brother, he just doesn't acknowledge it, but he knows about it. I don't make him talk about it but I don't hide it from him."

Jorge's aunt described how her nephew's diagnosis had been shared with many members of her large extended family, even some of the adolescents, but not with Jorge's father or his family, who have been estranged for many years,

"No one knows except [our side of] the family. They know about him being hemophiliac and having the virus. But from his father's side, we are not close to them and they don't know."

In some cases, families decided to tell a wider social network that included their neighbors, friends, or church before their HIV-infected children were told.

Tanya's grandmother matter-of-factly stated,

"I'm really firm to my friends who have grandchildren, I told them about it and they had the option of wanting or not wanting to have their children around her."

Sonia's mother (also infected with HIV) agreed,

"My husband, my sister and my brothers know. My neighbors, my [apartment] manager, they know and they understand."

Sara's adoptive mother described who knew about her daughter's diagnosis,

"Our neighbors really don't know and the school doesn't know. But we were almost forced to tell the school because our principal goes to [our] church and [so do] three of the teachers from the school. And since it is a small school, it was going to get out. The board [of her church] knows . . . and some other people know. When we go for prayer, we disclose to them and other times we don't tell."

Like this mother, most other parents and guardians preferred to keep the diagnosis a secret from the children's school. This was possible because the children had no outward signs of their illness, were not absent often because of their disease, and did not have to take any of their HIV-related medications at school. Jorge was an exception to this pattern: he had both hemophilia and HIV infection and therefore had to be absent from school more often than the others. His aunt used his hemophiliac condition as an explanation for these absences.

Despite their decision not to inform their children's school, several parents reported that school personnel figured it out anyway. When asked whether she had informed her grandson's school about his illness, Chris's grandmother answered,

"No, they haven't been told. The nurse and the principal accidentally found out but I haven't talked to them . . . they hold his emergency card where I've written 'immunity deficient, please notify parent of communicable diseases.' So they put two and two together and they asked me if I wanted to talk about it. But I said no."

Carla's grandmother described how her granddaughter's school found out when her daughter's AIDS diagnosis became common knowledge in her small Mexican community,

"That came from what happened to her mom. 'If the mother has it, the child also has it.' This is what people say where I live."

Three parents decided to inform the children's school before telling them about their HIV diagnosis. These children exhibited more outward signs of their illness and required more clinic visits and blood tests. When asked if anyone at her granddaughter's school was uncomfortable about the diagnosis, Tanya's grandmother reported her experience this way,

"At school, the people who know are the principal, the teachers. I tell them they don't have to be bothered with her. I don't want them to say okay and then have her treated differently. Then I would be very upset. But, no, I haven't had any problems."

David's grandmother told the same story,

"I just told the school last week and surprisingly they were very supportive."

To summarize, fear of stigma led parents and guardians to slowly share their children's diagnosis with trustworthy adult members of their immediate and extended family. In some cases a few trusted adults outside the family were told as well as a few older siblings and cousins. In most cases, these disclosures took place long before the infected child was informed. After lengthy consideration, parents and guardians of three of the children in the study deliberately disclosed the diagnosis to their children's school. Only one of these children was informed by their parents about the illness before the school was notified.

Afraid to tell. Fear of the stigma and life-threatening nature of HIV and AIDS also influenced what the ill children were told. Parents and guardians were afraid that if told about their illness, children would somehow suffer more. All

the parents and guardians reported discriminatory social encounters because of their children's HIV diagnosis or their own, although about one-half did not believe that their children had been hurt by this criticism. Most parents and guardians believed that knowledge of the illness might make the children aware of the social stigma attached to persons with an AIDS diagnosis. For this reason, many were afraid to tell. Brisha's father commented,

"I stress out more about keeping it a secret than her getting sick . . . she is just a kid . . . to [be] treated like a virus, like a disease, like an alien, that is very difficult. AIDS is kind of like being black in a sense. You know, no one calls you an \_\_\_\_ when you're in the room, but when you leave, you know [what they say]."

Alana's father echoed the same theme,

". . . children can get sicker when they are rejected [because of their disease]. I think that if she starts being rejected it is going to be very painful for her as well as for me."

He went on to explain why he hadn't told his daughter about her HIV diagnosis,

". . . so she won't have any discrimination either from other children or from their parents, because I feel bad and the children are going to feel bad too."

Chris's grandmother offered this explanation,

"I think if they realize too early in life that people would discriminate against them, they would begin to feel that something's wrong with them as a person."

Carla's grandmother, who recently told her granddaughter about her diagnosis, remembered how much she worried before the disclosure,

"At the beginning I didn't want her to know so it wouldn't stick in her mind. I didn't want her to deal with both the rejection and the disease."

David's grandmother also expressed fear of disclosing the diagnosis. He had experienced severe social discrimination 2 years previously when he lived with his mother (who died of AIDS 4 months before the interview). The grandmother described what happened when an angry acquaintance of her daughter found out about their illness,

". . . she started to tell [the boy] that he was going to die because he had AIDS. This went on for about a year . . . . Finally I moved them [up with me]. I was really afraid that something bad was going to happen to both of them. Here, nobody knows . . . I've been wrestling to tell him for 3 years but I've been afraid [of what people would say]."

Chris's grandmother recounted how she was able to overcome her fear that if told about his diagnosis, her grandson would tell others outside the family, thereby inviting social rejection,

"I used to be really paranoid about it. I'm almost to the point where I don't care. If other people have a problem, that's too bad. I hope that they will not hurt him with feelings of discrimination and I think that if I can keep him from facing it at a very young age, he'll be able to deal with it later. But he has felt good about himself."

For parents with HIV infection or a close family member who was ill or had died from AIDS, telling represented the disclosure of other threatening information they were afraid to reveal. Alana's father was tormented over revealing the fatal nature of his wife's illness (she died of AIDS in 1993) to his children, including his HIV-infected daughter,

"I didn't want to say anything about that [his wife's HIV diagnosis] because they are children and they talk with other children. [They might ask] 'What's your Mom sick from?'. . . . Maybe if the situation were different and it [was about some] other kind of disease that isn't related to death, maybe it would be easier to tell . . . but knowing that there is no cure, it's very hard for us and for them."

Sonia's mother agonized about how she was going to some day reveal her daughter's diagnosis, as well as her own,

"The day that my daughter is old enough, it's going to be very difficult for me to confront her and tell her the truth. I don't know if I'll be able to do it . . . I don't know how she is going to react . . . . There are many things that I have to tell her . . . how I got infected . . . how can I tell her? It's

really hard . . . but I don't know how to explain [this] to her, how to tell her, where to start."

Like this parent, Migel's mother expressed remorse over how her son became infected with HIV, but for different reasons. During surgery for her son's congenital heart defect, he required blood transfusions that were later discovered to be contaminated with HIV. She and her husband had often expressed regret about allowing their son to receive blood from anonymous donors. She described why she kept her son's diagnosis secret,

"It was easier for me."

These parents and guardians believed that concealing the diagnosis would provide protection from the stigma of the illness, knowledge about its fatal outcome, as well as distress over parental decisions or behaviors that led to the children's infection. In addition, some believed that telling children too much about their illness (or their parent's) might hasten the progression of their disease and lead to death. Chris's grandmother elaborated,

"I don't want people to tell him that it's always fatal or that he will die. I don't want him to have that idea in his mind because it becomes self-fulfilling . . . I don't want to talk to him about death because I don't want him to have that fear."

David's grandmother echoed the same theme,

"I'm afraid that once that he knows [about his diagnosis] his personality is going to change. And I want to keep him happy and a little boy as long as

he can be . . . [if he was told about his diagnosis] he would connect it with 'Oh no, Mom had it, Mom died, I'm going to die.' I don't want him to get that fear in him that 'I'm going to die because Mom died.'"

These fears were expressed repeatedly by the parents and guardians interviewed for the study. By limiting the amount of information their children were given, parents and guardians may have felt a sense of control over the progression of their children's illness. Despite their fears, however, most of the parents and guardians eventually became less afraid to talk with their children about the illness. One guardian, Jorge's aunt, who had up to this point been unable to tell her nephew about his illness, nevertheless gave the investigator permission in her informed consent to disclose his disease to him during the study. She explained her decision in this way,

"As of this date, he doesn't know anything. But since we started to come to the . . . support groups, we have learned a lot and I'm not so afraid for him to know."

Miguel's mother reported how she eventually became more able to talk with her son about his HIV diagnosis. This occurred after she learned from her sister-in-law about an incident involving her son who announced that he had AIDS during a visit to the sister-in-law's home 2 years before. Up to that point, neither the mother or father had revealed their son's diagnosis to him,

"I remember once asking you, he was in the hospital on the ninth floor, and I told you about what happened with my sister-in-law and you started

to tell me how to talk to him if 1 day he asks me 'what is this?' [I was] thinking that I have to be prepared to tell him."

With the gradual acceptance of the diagnosis by close friends and relatives and encouragement to tell from the health care team, some parents and guardians were less afraid to talk about the illness with their children. Parental readiness was also influenced by other conditions which emerged from the data. These will be explored next.

### Parent Beliefs About Telling

An important cognitive condition of parental readiness to tell found in the parent and guardian interviews related to their beliefs about telling children about life-threatening illness. These beliefs can be categorized into three major themes: what children are capable of understanding about their illness, when children should be told, and who should do the telling.

### What Parents Think Children Know

The parents and guardians in the study described various levels of understanding about the illness among their children. Ana and Alana's parents were certain they had no idea they were ill. In Alana's case, her mother had already died of AIDS,

"She hasn't noticed it [her illness] yet."

"She doesn't know she's ill . . . I'm not sure if she understands anything."

Jorge's aunt, who talked openly with him about his hemophilia, was convinced that he was completely unaware of his HIV diagnosis. This assumption persisted

even after there had been an accidental disclosure of her nephew's infection during a visit to a subspecialty physician. She described what happened,

"When he started to have the rash on his head, they sent him to see that doctor and they asked him what was it that he had. They knew already but they said it out loud that he has hemophilia and HIV. That day I felt scared. I followed the nurse [out of the examining room] . . . and I told her 'you know that the child doesn't know that he has the virus and please don't mention it in front of him.'"

In another case, Brisha's father talked openly about the illness with the investigator in his daughter's presence. She had not been told previously about her diagnosis (her mother died of AIDS when she was 2). Later, when he was asked how he reconciled this disclosure, he replied,

"I don't think she understands too much."

Sonia's HIV positive mother had not told her infected daughter about their diagnoses. At first, she explained what she thought her daughter understood,

"Now she doesn't understand anything . . . when she'll be older she is going to suspect something because she is not dumb."

Later in the same interview, however, she described a different degree of understanding on the part of her daughter,

". . . because I've been going through a lot, the hospital, throwing up, crying, you know, she has been worried too much. She has gone through a lot with me and that's why she looks at me that way. Sometimes I ask her

**'don't look at me like that, you make me nervous.' But she still turns and stares at me . . . she is scared."**

**Tanya, Brisha, and Chris's parents and guardians reported a beginning understanding of the illness on the part of their children. All of these children had been told they had 'HIV' prior to their participation in the study. The parents and guardians made similar observations,**

**"Now . . . she may begin to notice or she might even know that her cuts are different, because I do handle her a lot different . . . sometimes children know more than you think."**

**"She has some knowledge of it."**

**"He knows that nobody's supposed to touch his blood . . . he knows there is some distinction with his blood."**

**In another case, Jamie had been told about AIDS by his father and a 'virus' by his mother. She described what she thought he understood,**

**"When he was getting older, about four or five, he was wondering what was going on . . . he knew something was wrong . . . now he understands a lot."**

**Chris's grandmother believed he had a fairly accurate understanding of his mother's illness (she died when he was 2),**

**"He certainly remembers how bad she looked and how much she coughed . . . he knows she had HIV the same as him . . . he knows that nobody is supposed to touch his blood."**

The guardians of two other children, Carla and David, reported that their children had a very specific understanding about HIV. They each were informed about their illness and both of their mothers died from AIDS,

"She knows about her disease but I don't know if she understands it the way we do . . . it's hard to measure how much she knows . . . the only thing she has told me is that she is having the same symptoms as her mother."

"He used to come home crying and telling me that he was going to die because he has AIDS . . . he said 'well I have AIDS 'cause I have a mediport'. . . and 'I'm the reason my Mom got sick and died'. . . now he knows that Mom is not coming back."

Migel's mother described what her child understood,

"He's angry for getting sick because of his HIV . . . it's at bedtime when we talk . . . he complains [about] feeling uncomfortable, going to the doctor, all of that. He has his own hope . . . [he says] 'I hope that someone can find the medicine to cure me.'"

A few parents and guardians were informed by other family members that their children knew about the illness, but the parents and guardians had difficulty believing it because they had not yet talked openly with them about the diagnosis.

Migel's mother recalled,

"When she told me that . . . I played the role that 'you're wrong' because I never talked to her about my son having HIV and I said to myself, 'maybe

he heard it from the TV or someone else' . . . I don't know how to explain [that he knows]. That's why I'm still . . . I don't believe that happened.

But my sister-in-law said 'he told me that, he mentioned that word.'"

In another case, David's grandmother described how she tried to find out if her daughter (who was dying of AIDS) had told him about her illness as well as his own. This episode took place, according to the grandmother, a year or so after he had been told repeatedly about his illness by an angry acquaintance of his mother,

"If she talked with him before, I don't know. But in the last year when she was right in the home, I knew . . . it's possible [she told him he has AIDS]."

These data suggest that there was considerable variation among parents and guardians as to how much they believed their children understood. Parents and guardians tended to conceal the diagnosis, even when another parent had already died of AIDS, if they were certain their children understood very little about the illness. With one exception, these children tended to be younger and have fewer physical signs of their disease. In general, parents and guardians of older children believed they knew more about their illness.

#### When Parents Should Tell

Another important theme expressed by parents and guardians had to do with their beliefs about when children should be told about their illness. Ana's mother was fairly certain there would never be a right time,

"If the illness is terminal, fatal, I wouldn't tell her. There is no reason why children should have to live with that anguish."

The fathers of Ana and Alana held similar views. Alana's mother had already died of AIDS; the other mother was ill and estranged from her child. At the time of the study, neither of the fathers wanted any information disclosed about the illness and were uncertain about when in the future they should tell,

". . . maybe when a child, 10 or 12 years old, would have a constant fever and they didn't know what it was, like with cancer. Well, I don't know if one can tell him or her or not."

"I wouldn't know what to tell you. I don't want her to be thinking about that. Because when I tell her I will have to tell her everything, even that she is going to die some day . . . well maybe when she's older and she feels well physically. If she's going out with friends or even with a boyfriend . . . I don't know what is going to happen. It's going to be difficult. It's going to be hard for me to tell her."

Brisha's father repeated this theme, although he had indirectly disclosed his daughter's diagnosis 1 month before the study,

"At some point, if she lives, I will have to tell her something . . . the longer I have to deal with this, it means that she is doing better . . . I don't think I should tell her now because she is healthy. If you're winning a race, you shouldn't stop . . . in the next few years I'm going to have to tell her, like when she's eight or nine. She's already asking me too many questions."

Sonia's mother was also uninterested in disclosure at the time of the study. When asked when she planned to talk with her daughter, she responded this way,

". . . about my sickness, not yet. About her sickness, not yet."

She went on to explain,

"When she'll be the right age to understand things, when she'll know right from wrong, when she'll be 13 or 14 years old. For me, that's the age that they are mature and they understand, because she doesn't understand anything [now]."

Several parents and guardians believed it was best to tell when children started asking about the illness. Brisha's father and Jorge's aunt had similar comments about their children,

"Whenever she asks something I try to answer it . . . so far, I haven't had to say 'well, you have the disease.' No, we are not there."

"Now he's bigger and [when] he starts asking about the illness . . . I think that with time he will learn . . . and we'll have to explain to him what it is. Until he asks questions, then we can answer them."

For Carla's grandmother, the time to tell was now,

"I knew that I had to talk to the child but I thought that she wasn't old enough. But now that the child is 10 years old, I think that it is time for her to understand what she has."

For David's grandmother, it was time to acknowledge her daughter's disease to her grandson. She was not ready, however, to discuss the nature of her grand-

son's illness with him, even though (according to the grandmother) he had already been informed by his mother before she died. The grandmother instructed the investigator in her informed consent to share the following information,

"[Say he has a] platelet problem. [Say] 'Mom had a bad disease.' If he asks, 'does my Mom have AIDS?' answer 'yes.'"

Jamie's HIV positive mother demonstrated the same kind of ambivalence about revealing her 7-year-old son's HIV diagnosis to him, even though his father had apparently discussed AIDS with him at least a year before the study. It wasn't until after her husband's death, however, that she was able to begin to talk openly with her son,

"I've explained to him and he knows that we are all sick . . . this was after [his father died] . . . because I was too afraid of talking to him [before]. I didn't know how. I wanted to get my thoughts together and make sure I had a way of talking with him and if he was old enough to understand."

At the time of the interview, Jamie's mother was not yet ready to use the term "HIV." She explained to the investigator how she planned to proceed,

"I would talk about it, I would tell him one thing at a time. I would tell him how I [already] told him . . . we are sick [with] the illness, or the virus and then I would tell him . . . in a way that we have HIV but then I wouldn't use AIDS yet. I would take it step by step with him."

She concluded by describing when she would tell him this,

**"I think when I feel that it's right, when my mind is right . . . when my mind is ready."**

**There were parents and guardians who had revealed their children's diagnosis in its entirety. Sara had been informed by both parents 3 weeks before participation in the study. Her mother explained why they told her then,**

**"My husband and I talked about it, and we talked about how we were going to tell her. We thought that if she was going to participate in the Make A Wish Foundation or Camp Hope or in anything else . . . while she is still healthy, then she needs to know . . . medical science says that she still has probably 2 years of life left . . . so we got 2 years to get her into these other activities and we would like her to be able to be part of and enjoy them. So we decided that we needed to tell."**

**In another case, Chris's grandmother, whose daughter died of AIDS 5 years before, disclosed the diagnosis in a more spontaneous manner. She described how her grandson asked 1 day while they were in the car,**

**"[He asked] what did his mother have? And what does he have in his blood? I told him HIV which is the same that his mother had."**

**Finally, Migel's mother recalled how she and her husband struggled with when to tell their son, who had acquired his infection from a blood transfusion. The father had developed a brain tumor and was ill for a couple of years before he died in 1993 when his infected son was 8. The mother describes how she decided when to tell him about his HIV infection,**

"This was our big question. It's hard to know the time . . . we knew that the time would come when his school was going to talk about HIV and that's why we made the decision to tell [then]. If nothing had happened to my husband, the illness, the dying, and everything, I think I would have talked with him before all of that. Yes, definitely. Because, as a mother, you know when a child is ready to understand."

These data suggest that the parents and guardians in this study believed that children should be told about their diagnosis at very different points in time, depending upon age, inquisitiveness, and the death of a family member. The parents' sense of urgency about involving their children in school or recreational activities was also a factor in their decision to tell. Parents and guardians tended to delay disclosure to younger children and to those whose mother or father had already died. The typical interval between the time of diagnosis and the time when children were informed about their diagnosis was 4 years.

#### Who Should Tell

Because health care professionals often espouse that children should be told about their illness, the parents and guardians were asked about who should tell, the third theme of parental beliefs about telling. Most parents and guardians said it was the parent's responsibility. Jamie and Sonia's mothers, both HIV positive, expressed similar ideas,

"I think it would be my . . . responsibility to talk to him because he would understand better that way. I should be the one talking to him." "For me, it's better if I tell her rather than other people because I'm her mother and I'm the one that lives with her."

Other parents and guardians agreed,

"I should be the one to do it. It shouldn't be somebody else."

"That's the one thing that upset me [when a doctor or nurse talked about HIV in front of her son] . . . they have to be more careful about that and that we have the right to tell . . . our kids and not anybody else."

". . . when he gets older he will ask other people and will try to verify what he has heard with me. And that will be fine if they don't contradict my beliefs of what I have already told him."

"It is very difficult with doctors because they use terms that are very . . . rude. They say the truth."

However, the guardians of Tanya, Carla, and Jorge expected to need assistance with telling,

"I may ask for help because I may have questions that I'm not . . . able to answer . . . but I feel that it needs to come from somebody that . . . [can give her] . . . the feeling of security and protection."

"She needs to be informed. This is what the psychologist at the School of Medicine told me. That we need to inform her about her disease. But he

couldn't go to our house and I cannot take her to the School of Medicine, so you have to help me discuss this with her."

"I feel uneasy that he will learn from other people . . . through his drawings we will know what he is thinking."

These data suggest that the majority of parents and guardians were uncomfortable with the idea that someone other than themselves should disclose the illness to their children. There was a distinct difference between parents and guardians on this issue: parents wanted more control over who told than guardians, a finding that may be related to a greater sense of responsibility for the children's infection on the part of parents compared with the guardians in the study.

#### Intensity of Children's Inquiry

Another significant cognitive condition to parental readiness to tell was the intensity with which children asked about their illness. According to the parents and guardians in the study, some children never asked anything, some made vague inquiries, and a few asked direct questions about their illness or their parent's.

#### He Never Asked

The parents and guardians of Ana, Alana, and Jorge, who had not yet informed their children about their illness, reported that they never asked about it,

"She never asks me anything."

"He never asked me."

"She has never told me or asked me 'what's wrong with me?' or 'why am I like this?'"

Ana's father explained why he and his wife had not told their daughter about her illness,

"She doesn't ask 'why' anymore . . . because she is not asking we are not telling."

Two parents suggested that their children probably understood something about their illness, but didn't ask about it. Migel's mother, whose husband died from a brain tumor when her son was 8, described Migel's silence about his illness this way,

"I don't know why he never asked. Maybe he understood that something was wrong but he didn't want to find out."

Jorge's aunt reported a different kind of understanding on the part of her nephew, whose mother died of leukemia when he was 6,

"He has never asked what the [HIV] medicines are for . . . he knows them by their [correct] names. He knows how to take them but he doesn't ask why he's taking them."

These data suggest that children with HIV infection were not likely to be informed about their illness if they were not asking about it. Concealment of the diagnosis on the part of parents and guardians, however, did not prevent children from making inquiries. Most of these parents reported that their children

eventually began to ask about the disease by the time they were 5 or 6 years old. This was a common finding among children whose parents had already died or were approaching the end-stage of their illness and were exhibiting outward signs of their disease.

### What's Wrong With Dad?

By the time they participated in the study, six of the children had experienced the death of a parent from AIDS. Each of these children acquired their disease from their mothers and fathers and all but one of the children asked about the nature of their parent's illness and death. Brisha's father described his daughter's interest in her mother, who died of AIDS when his daughter was 2,

"She asks about her mother all the time."

On the other hand, Chris's grandmother reported that her grandson had asked only a few times about his mother who also died of AIDS when he was 2,

"I cannot remember exactly what he said . . . [something like] what did his mother have?"

Jamie, Alana, and Sonia wanted to know about their parents who were developing serious signs of AIDS. Jamie's mother described her son's concern about his father before he died,

"He would ask me 'what's wrong with Dad?' and I told him 'your Dad's not doing good.'"

Alana's father, whose wife had already died, reported similar concern on the part of his daughter while her mother was still alive,

"Sometimes she asked why she [her mother] was ill or what she was ill from . . . she talked with other children [who would ask] 'what's your mom sick from?'"

At the time of the study, two children were witnessing the progression of their mother's illness and asking about it. Sonia's symptomatic HIV-infected mother described her daughter's inquiry,

"She asks me 'why are you losing so much weight?' and 'why are you taking so much medication?'"

A similar observation was made by Tanya's grandmother, who described her granddaughter's comments about her sick and intoxicated mother when she came to visit 1 day,

". . . she was not feeling well. I think she was depressed . . . so she stayed and [my granddaughter told me] 'I didn't know she was so sick.' She laid down, she needed to sober up and we took care of her."

According to the parents and guardians, none of the children had been informed about their parent's illness or their own at the time they were beginning to ask questions. About one-half of the children who asked about their ill parents were told the truth about them. This finding suggests that the progression of the parent's disease and/or death may have influenced some of the parents and guardians to inform their children about their illness.

**Mom, Why am I so Sick?**

Most of the parents and guardians reported that their children had been asking about their own illness. These tended to be the same children who asked about their parents,

"She asks why she's taking the medicine."

"He's starting to ask about his illness."

"She asks why she has to go to the hospital. 'Why me?'"

"She asks 'why do I have to go the doctor all the time?'"

Again, about two-thirds of the children who were asking questions were eventually informed about their illness by the time of the study. The other one-third, who tended to be younger, had not been informed. The response of Brisha's father, who had not yet been able to talk directly with her about her illness, nor that of her mother (who died of AIDS 4 years before the study), demonstrated his ambivalence about his daughter's inquiries. At first, he indicated that she hadn't asked about her illness,

"No, no, she doesn't really care [to ask] about it. She's too busy being a kid, enjoying life. And that's what I want her to do. To be thinking about things, that's for me to do basically."

Later in the same interview, however, he admitted that she had asked,

"She questions me about the medicine . . . she asks me why she isn't like other kids and why do I tell her not to bleed on people."

**On the other hand, Chris's grandmother anticipated his questions and seemed ready for them as she described the circumstances of his first inquiry about his illness,**

**"We had watched the show on television when it was about AIDS and he asked me the name of what he had and I told him it was HIV and he seemed satisfied, 'Just wanted to know the name' and he didn't ask any more questions and didn't seem to want to ask any more . . . ."**

**She elaborated about subsequent episodes when he asked about his illness, illustrating Chris's ambivalence about getting too much information in response to his questions,**

**"He'll ask the questions usually at the most inappropriate time, like when you're driving the car and merging into the freeway, 'Oh, by the way,' you know. When you're in a place when you really can't sit down and explain everything to him. When he does that, I just answer as casually as possible . . . . [he asks] what did his mother have . . . and what does he have in his blood."**

**These variations in the intensity with which children asked about their illness, as well as their parents,' and the extent to which parents and guardians were ready to disclose information about the illness represent a significant finding which emerged from these data. While most of the children wanted to know about their illness, only two-thirds of the parents and guardians interviewed in the**

study were ready to give them the information they were seeking. Parents and guardians of younger children were less likely to reveal the diagnosis.

### Signs of Children's Illness

Of particular interest, three children in the study (Sara, Carla, and Migel) were informed about their illness by their parents or guardians, even though they had not yet asked about it. They tended to be older, sicker, and more likely to require hospitalization during which accidental disclosure by hospital personnel might occur. For this reason, the health care team exerted more pressure on the parents and guardians to consider disclosure.

All of the children who were told about their illness exhibited outward signs of their HIV infection, particularly those with CD4 counts less than 600. They tended to develop poor weight gain, short stature and recurrent rash. In addition, two children (David and Jorge) required percutaneous catheters implanted in their anterior chest wall for venous access. Parents and guardians, therefore, tended to reveal the diagnosis as the children developed visible signs of their illness, with the exception of Jorge, whose aunt had not been able to tell him.

### Parental Illness and Death

Throughout this discussion, there have been several references made to the children's experience with the death of a parent and/or the suffering of a surviving parent from AIDS. The progressive physical deterioration from AIDS often transforms adults from a stage of relatively few obvious signs of the illness to a

state of emaciation, jaundice, and extreme pallor. In addition, there are often signs of mental confusion and exhaustion.

Six of the children had witnessed the end-stage illness of their parents with AIDS, four of whom died before the study. Migel and Jorge lived through the lengthy cancer illness of their parents who also died before the study began. Parents of two of the children had died of AIDS when the children were 2 years old and Tanya's father was fatally shot a year before the study. Only two children, Ana and Sara, had not lost a parent from death, but had been removed from their care when the girls were very small because they were unable to care for them.

These profound experiences of illness, death, and loss clearly had significant impact upon the surviving parents, guardians, and children and were frequently reflected throughout their conversations and drawings as well as the investigator's observations. For this reason, they provided another significant condition for interaction and communication about the illness between parents, guardians, and children.

### Summary

In summary, interviews with parents and guardians as well as other sources of data illuminated five major conditions for parental readiness to tell: fear of stigma and death, parental beliefs about telling children about life-threatening illness, the intensity of children's questions, signs of children's illness, and parental illness and death. Parents and guardians generally waited over 4 years before

they disclosed the diagnosis. They tended to tell their children about the illness if they were older, sicker, and asking about the illness. In addition, parents who told believed that their children understood more about their illness and were ready to participate in HIV-related community activities. The illness or death of the other parent, the social stigma associated with HIV and AIDS, and feelings of regret about how the child became infected were common reasons not to tell for the surviving parent or guardian. Parents and guardians agreed unanimously that only they should tell.

#### Consequences of Readiness to Tell

The data from the study suggest that the conditions of readiness to tell discussed in the preceding section led to three patterns of communication about the illness by parents, guardians, and children: concealing, pretending, and revealing. To some extent, these patterns influenced the children's perceptions of themselves as well as their perceptions of communication and support within their families. Evidence for these consequences was found in the investigator's observations, parent and guardian interviews, and the children's drawings and the stories they told about them.

#### Concealing the Illness

The illness was initially kept secret from all the children in the study. Parents and guardians explained the need for blood tests and medicines in several ways,

"I tell her that it [the medicine] is to get well or for the hair to grow or something like that. I say that to avoid telling her what she's going to die from."

A few parents and guardians were concerned about their children's appetite and used that as an explanation,

"Because you don't want to eat well."

"You have to take the medicines so you'll eat more and be stronger."

"It's a little bug that if she doesn't eat, the little bug is going to take advantage of her blood."

Several children were told their blood was different from that of other children,

"We always told her that she has special blood, always."

"I tell her don't bleed on anybody and if you do go tell them to wash their hands really good."

"He knows that nobody is supposed to touch his blood. And I've told him that nobody is supposed to touch blood period. But he did say once, 'Oh, I thought it was my blood.' He knows there is some distinction with his blood."

Other parents and guardians used co-existing diagnoses to explain the need for clinic visits, blood tests, and medicines. Migel's mother described how she used his congenital heart defect to conceal his HIV diagnosis,

"[Because of his heart surgery] it was easier for me. At one point I felt guilty because I was lying to him . . . hiding his HIV. So for me it was

easier to give the explanation that 'the doctor needs to see how your heart is doing.' He was used to going to the doctor because of his heart."

Jorge's aunt echoed the same theme as she related how she used his hemophilia medicine to explain his need for the antibiotic he was taking to prevent a life-threatening form of pneumonia, common among children with severe immunosuppression,

"He knows that he is a hemophiliac. I tell him that he has something in his blood and that's why he needs to take the factor to make him feel better. He knows that if he doesn't take the factor he may have problems with his lungs."

These data demonstrate the way that parents and guardians concealed the HIV diagnosis from their children prior to telling them about their illness.

Parents and guardians assumed that none of the children knew they were sick with HIV. Other data suggest, however, that some of the children perceived there was something wrong.

#### Pretending About the Illness

Without accurate information about their illness from parents or guardians, some of the children nevertheless suspected the truth, but were careful not to reveal their knowledge. This was illustrated by Sonia, whose mother had been quite ill from AIDS and had not yet informed her about the fact that they both had HIV infection. In a story she told about a picture she drew of her best friend, Sonia described what she thought her childhood friend knew,

"She knows because when she comes to my house, she sees that I drink medicines and she asks 'why do I have to take medicines . . .?' And I told her 'cause I don't really know about that but my mom does know. And my mom tells her but I don't know about it. She just tells her 'cause I need to eat more."

In another case, Migel, who had never been told about his HIV infection, revealed his knowledge of his diagnosis to an extended family member, but afterward never mentioned this to any one else or asked his parents about his illness. His mother described an incident that involved the boy's request to hold his newborn cousin,

"He asked her 'can I hold him?' and then she said 'no you can't because the baby is too small for you' . . . and he told her, 'no, I can't hold him because I have AIDS.'"

Jorge's aunt reported an incident involving the accidental disclosure of his diagnosis by a physician about a year before the study, when Jorge was 10. She described what happened next,

". . . I had the feeling he was going to ask me about that, but he didn't. I think that he didn't hear or that he didn't pay too much attention to what they said . . . his face didn't change [expression] at all. That's why I think that he didn't understand anything."

David's grandmother suspected that he had been told more than likely by his mother about his HIV diagnosis but would not discuss it with her,

"She used to take him in the bathroom and said 'I explained [it to] him, I talked to [her grandson].' And I tried to get [him] to tell me and he wouldn't tell me what she said."

The probability that Sara knew about her illness before she was told was illustrated by her reaction when her parents decided it was time to reveal it. They were crying when they told her,

"So we just called her to the table and asked her if she was curious why she has all the blood work and went to the doctors . . . she didn't care and then my husband told her, and then she said 'oh, okay' . . . and he said 'you know the movie that we've been watching?' And she said, 'yes, all those kids have AIDS' and he said 'that's right, and so do you.' And that was it . . . she didn't have any reaction to it. She said 'that's why my blood is special.'"

Finally, the month before Brisha was interviewed for the study, her father told the investigator in Brisha's presence that his daughter was too young to understand anything about 'HIV.' Up to that point, the father had been very careful to keep the diagnosis secret whenever he and Brisha came to the clinic. At the moment of this disclosure, Brisha, who had been coloring, stopped and looked up at the investigator with an expression of mild surprise but said nothing. She quickly lowered her head and resumed drawing. She never mentioned this episode during her interview with the investigator the next month, nor at any other subsequent encounters in the course of her clinical care.

These data suggest the probability that the children knew about their illness but pretended not to know by concealing their awareness from their parents, guardians, and other adults. This phenomenon has also been described in children with cancer (Bluebond-Langer, 1978).

### Revealing the Illness

The decision to tell the children about their illness and/or their parent's was not easy for most of the parents and guardians. As previous data suggest, they took an average of 4 years from the time of diagnosis to inform their children. Revealing the illness took place in stages, often beginning with non-specific information and the avoidance of the words 'HIV' and 'AIDS.' At times, the parents and guardians vacillated about how much information should be revealed. Tanya's grandmother described what she recently told her,

"I explained to her that when she had to be in the hospital [when she was 3] they found that she had a disease . . . in order to keep her well she needs to take the medicine. I tell her as little as possible right now, but everything she asks me, I try to give her an answer. I don't lie to her."

During the process of obtaining the grandmother's consent for the study, she did not want the investigator to use the term 'HIV' or 'AIDS' for Tanya's illness during the child's interview. She also directed the investigator to use the terms 'white medicine' and 'clear medicine' for two HIV-related medications (DDI and AZT, respectively) Tanya was taking. Despite these instructions, she reported that the term 'HIV' was openly used at home,

"Today, [she] knows that she is sick, we don't hide it. We talked about HIV and whatever comes up . . . . I don't hide it from her . . . . [but she] doesn't have an understanding of what it is."

Later in the interview, Tanya's grandmother reflected upon what more she should tell her granddaughter,

"I don't think that she has to know everything now."

David's grandmother reported similar discomfort with the use of the terms 'HIV' and 'AIDS.' She was fairly certain her daughter had openly discussed her own AIDS diagnosis with David before her death. In addition, before the interview with the investigator, the grandmother recounted two statements David made about his illness and his mother's,

"I'm the reason my mom got sick and died."

"Well I have AIDS 'cause I have a mediport."

However, she was not quite ready to use the same terminology with David, although she gave the investigator permission in her informed consent to reveal the mother's diagnosis,

"If [he] asks, 'does my mom have AIDS?' answer 'yes.'"

She called it his 'platelet problem' and told him he was born with it. She justified her approach this way,

"I know how [he] is, [he] is not mature enough yet . . . he is a very lovable, outgoing [person] and I'm also afraid that once that he knows, his personality is going to change."

Jamie's mother, whose husband had died of AIDS 8 months before the interview, was fairly certain that her husband had told him about AIDS,

"I think that my husband talked with him before about us when he was 4 or 5 . . . He had read to him about AIDS."

Despite this knowledge, she had not been able to talk openly with Jamie about her husband's illness before his death. She commented,

"I was getting worried that he would find out."

When informed consent was obtained for this study (after her husband's death), she instructed the investigator to call Jamie's HIV infection a 'sickness' and to explain to him how he became infected in this way,

"When Dad was younger, he did drugs with friends. Drugs are bad. He got sick. Later, Mom and Dad met. Mom got sick. When Mommy was pregnant with you, you got sick too. Mom and Dad felt bad. Mommy and Daddy love you very much. We want what is best for you."

For parents or guardians who were ready to reveal the term 'HIV' to their children, many wanted to avoid the use of 'AIDS.' After careful thought and discussion, Migel was informed about his 'HIV infection' by the investigator in the presence of his mother about 1 year before the study. She gave explicit instructions to avoid the term 'AIDS' (which embodies the end-stage of the illness) even though Migel was already profoundly immunosuppressed and at significant risk for life-threatening complications.

Other cases illustrated a similar approach. There were several instances in which parents, guardians, and the investigator discussed how to talk about HIV during the children's interviews. Jorge's aunt directed the investigator in the informed consent to reveal his HIV diagnosis but not the extent of his severe immunosuppression if he asked about the illness during his interview. In another case, Chris's grandmother was careful to instruct the investigator how to talk with him about his illness,

"Call it HIV unless he asks about AIDS. Say he was born with it, do not connect it to his mother's drug use unless he asks. Do not connect his [HIV] infection with her death. I don't want him to think that he will die because she did or that he will have the same symptoms or look the way she did. Do not suggest that he will die from his illness."

These data demonstrate the hesitation of parents and guardians to reveal the diagnosis, even when they acknowledged that their children had already been told. As previous data suggest, many parents and guardians questioned the capacity of their children to comprehend their disease, including its stigmatizing, life-threatening nature. In the minds of the parents and guardians, disclosure of the diagnosis meant that this threatening information might also have to be revealed. This may explain their vacillation between telling the whole truth and revealing just part of it.

### Summary

Three patterns of communication about the illness were discovered in the data. Efforts to conceal the illness were reported by several parents, guardians, and children who at times pretended not to know. Most parents and guardians eventually informed their children about their illness, but this was done in stages over many months and years in order to ameliorate the distress of disclosure. During this process, parents and guardians often vacillated about what they said, at times revealing bits of information, at other times regressing to a previous stage of concealment.

Despite efforts to control how much information the children were given, some parents and guardians realized that their children knew about their illness anyway, even that it would lead to death. This was the case with Carla, who had been informed about her HIV diagnosis just 1 month before the study. Her grandmother recounted Carla's recent conversation about her mother, who died of AIDS about 1½ years before the interview,

"She says that all of her symptoms are the same as her mother's and that she feels the same way she did. She says that everything her mother had she has. The medications are the same."

Most of the children in the study did not demonstrate this ability to verbalize their understanding of their illness. However, the stories they told about their drawings revealed recurring themes of threat, illness, and loss. In the next section, this data will be presented. These findings support the literature

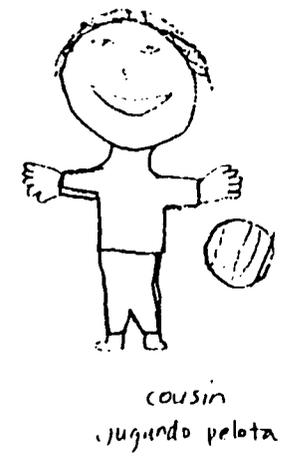
which suggests that school-age children are quite capable of comprehending the threatening nature of catastrophic illness, even when they been told very little, if anything, about it.

### Children's Perceptions

Through interpretation and analysis of the drawings and the stories the children told about them, several important domains of the children's experience were identified: communication within the family, image of self as ill, and emotional distress. These findings suggest how the children perceived and responded to what parents and guardians said about the illness.

#### Perceptions of Communication Within the Family

As the parent and guardian data indicate, the majority of the children were told about their illness, but only after a lengthy delay. Carla depicted her family as a place where an open dialogue about the illness might be possible. She was told about her diagnosis 1 month before she was interviewed (2 years after diagnosis) and drew a KFD with several positive indicators of open communication within her family (see Figure 2). These include complete faces, appropriate size of family members, no compartments, and standing, forward facing figures. The above ground pipe and water hose drawn between the girl and her grandmother may represent a weak barrier between them. It does not appear to be sufficient in size to block communication. The girl's mother is missing from the drawing, representing a realistic portrayal of the current family constellation.



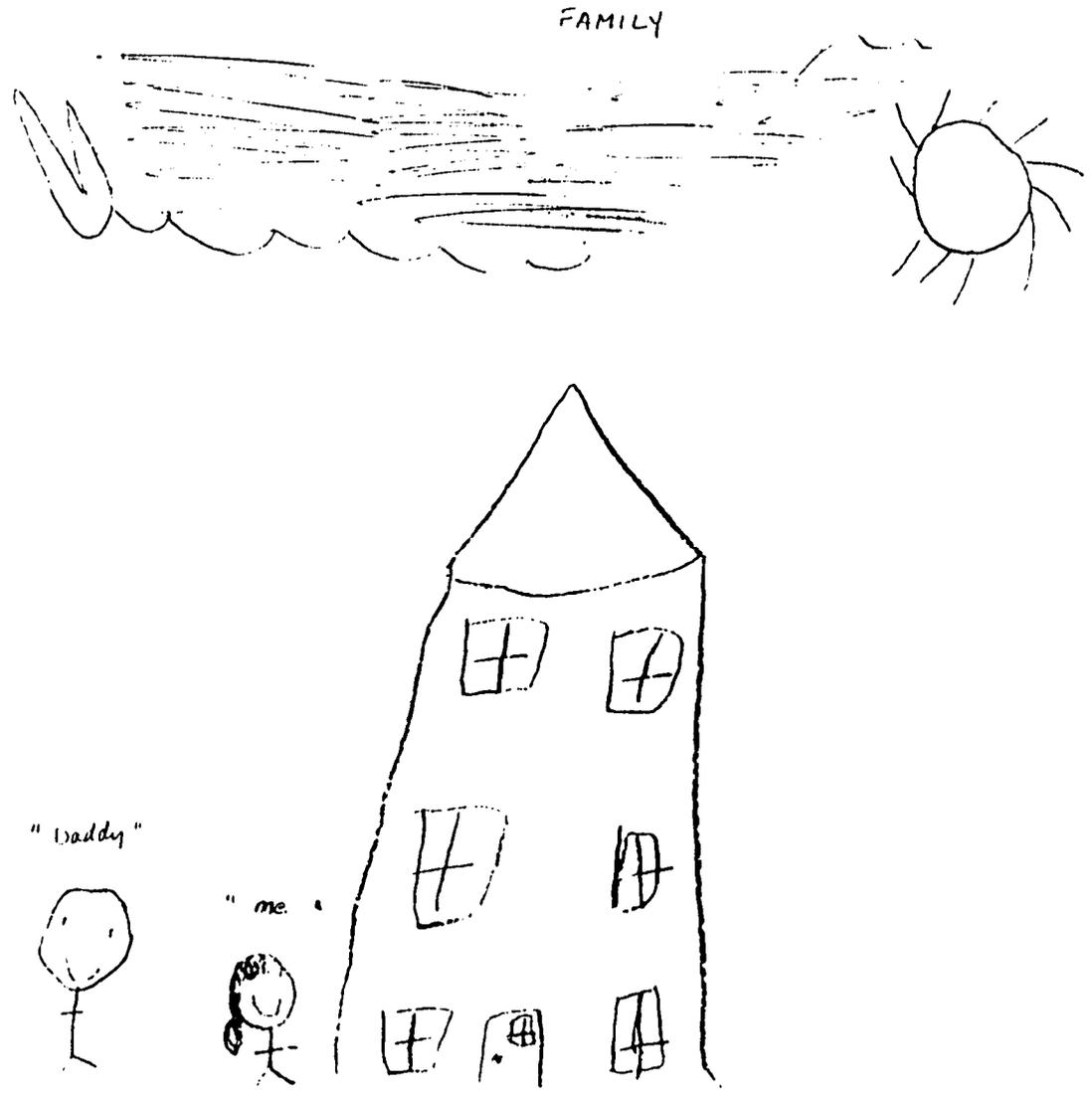
**Figure 2.** Carla's KFD.

Brisha's KFD suggested similar patterns of communication (see Figure 3). She drew herself standing next to her father facing the viewer without barriers between them. The facial features of the father are complete. However, the girl appears to be facing away from her father toward the house, which looks formidable and blocks the sun. From the child's perspective, the father seems to be available to her but she does not appear to be quite ready for any interaction with him.

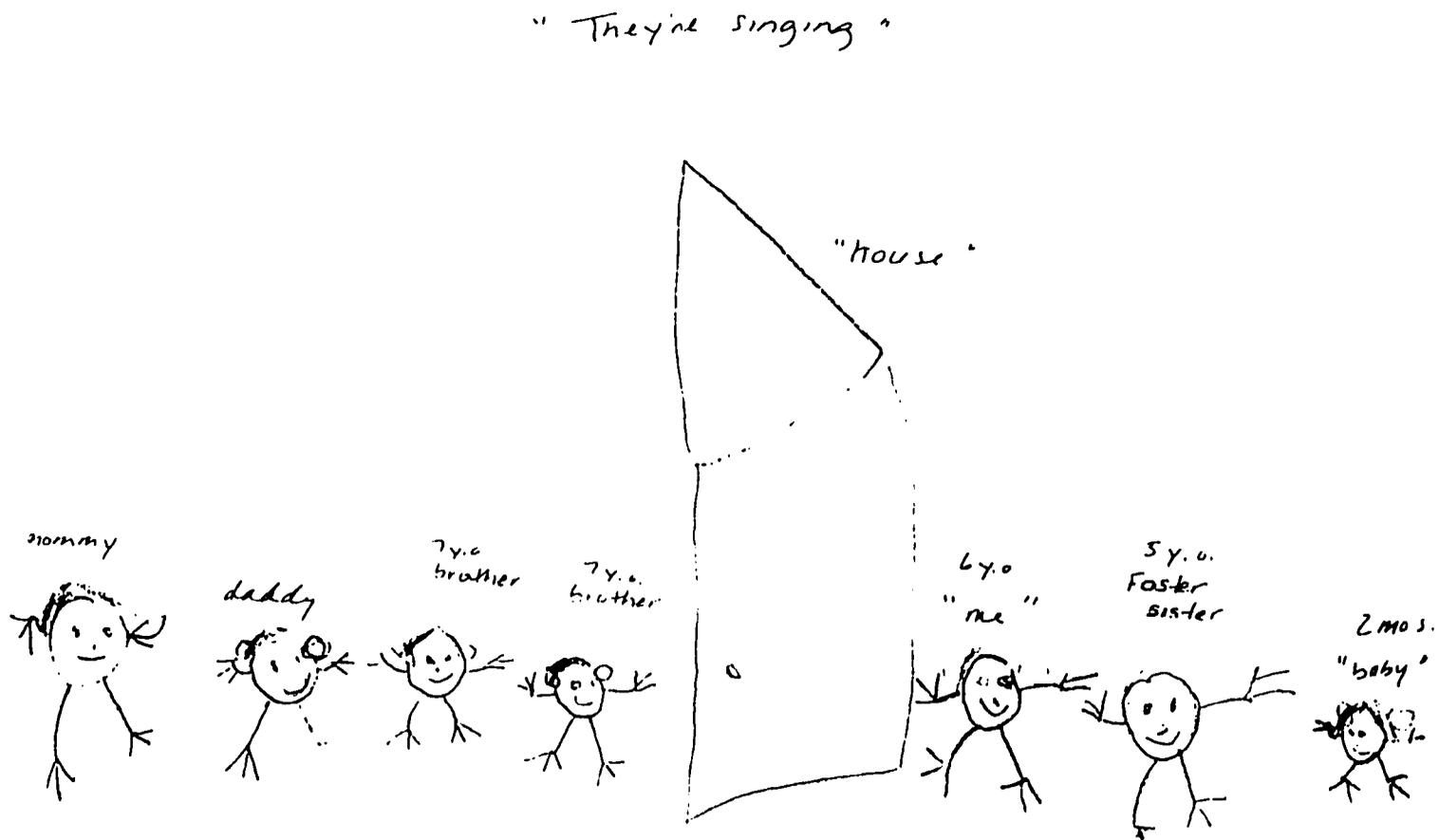
Other children who were told about their illness suggested more closed patterns of communication in their drawings. For example, Sara, told about her illness 6 years after diagnosis, drew a house between herself (next to two foster sisters) and her adopted parents and brothers (see Figure 4).

Migel, who was informed about his illness the year before (6 years after diagnosis), drew a KFD with several indicators of closed communication within his family (see Figure 5). The orientation of himself away from the viewer and the placement of the ball and younger brother between he and his mother represent subtle barriers within this family. The father, who died several years ago from cancer, is absent from the picture.

Tanya was recently told about her illness (3 years after her diagnosis) by her grandmother, who has been her guardian for the past 3 years because her mother has been too ill to care for her and her father is dead. Her KFD suggests several features of closed communication within her family (see Figure 6). For example, there are several barriers (figures and objects) between herself and her



**Figure 3.** Brisha's KFD.



**Figure 4.** Sara's KFD.

" we're playing football "



**Figure 5.** Migel's KFD.

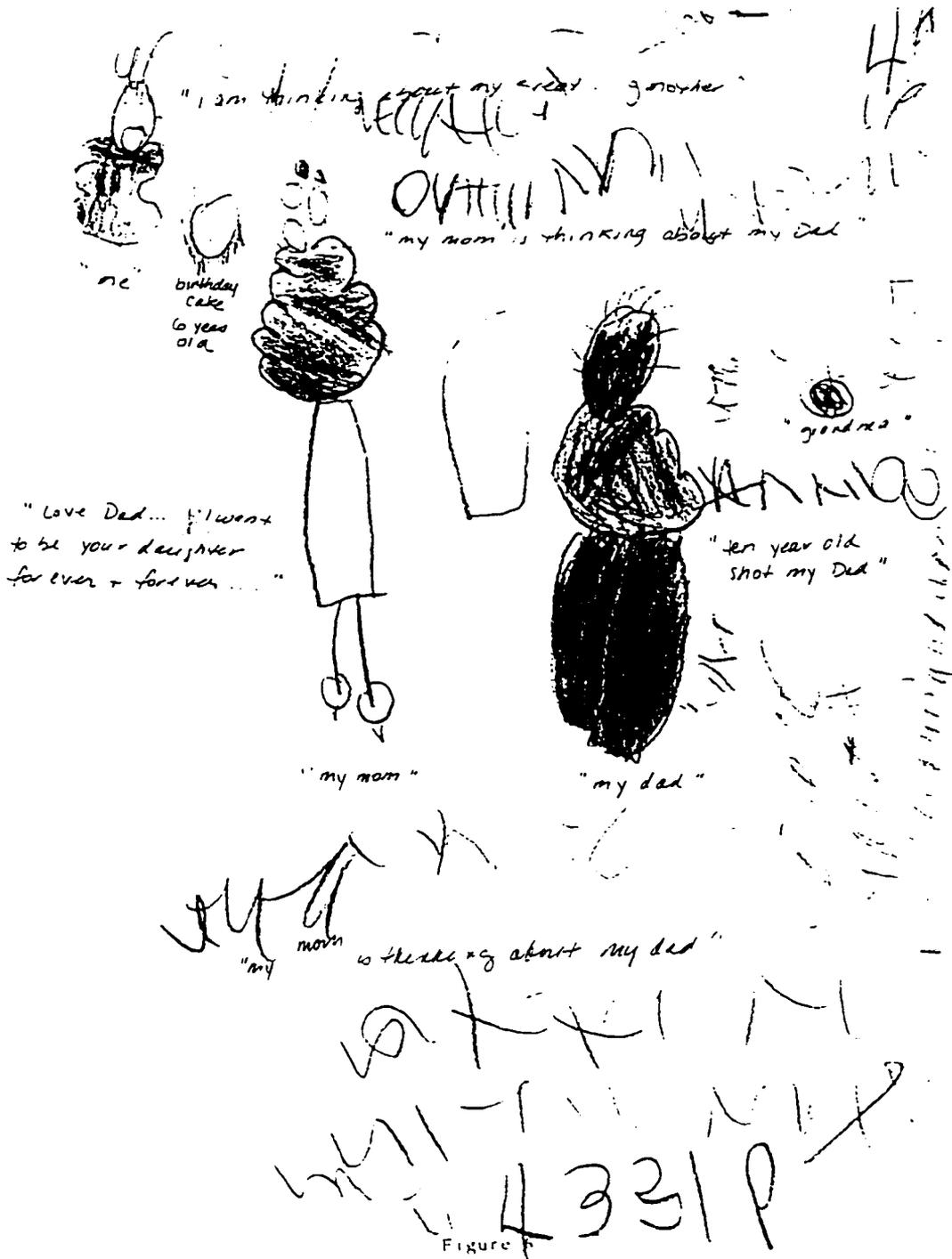


Figure 6. Tanya's KFD.

**grandmother. The grandmother is drawn without any distinct features, facial or otherwise. Finally, the drawing excludes several other close family members who lived in the same household.**

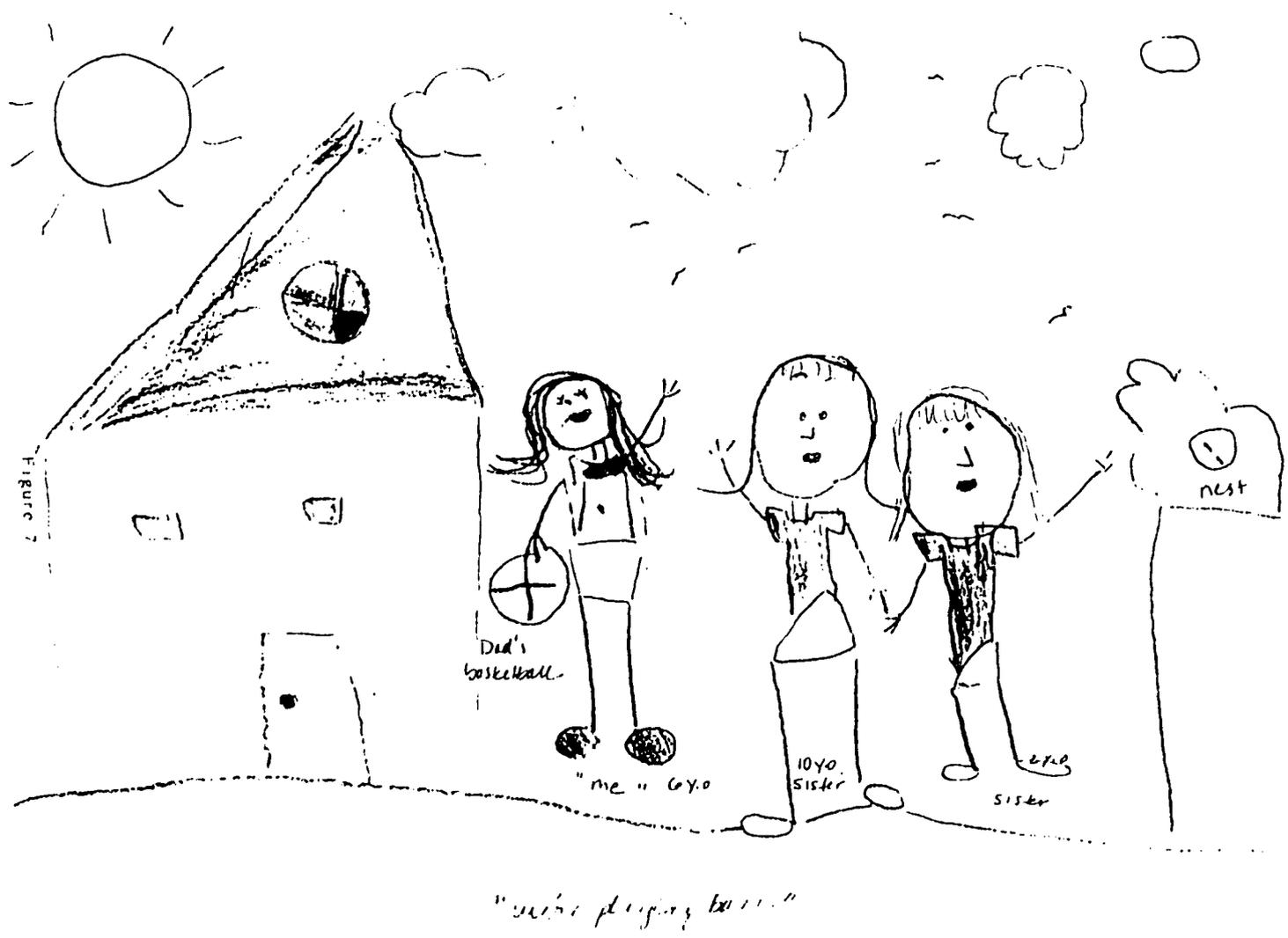
**Similar patterns of closed communication were suggested in the drawings of children who had not been informed about their illness by their parents or guardians. For example, Ana drew a KFD which excluded her parents (see Figure 7). She lived with her adoptive parents and sisters and was diagnosed 3 years ago. When asked if anyone was inside the house, the girl answered,**

**"My mommy and my daddy."**

**The absence of her parents from the drawing and their compartmentalization in the house suggest that Ana did not perceive that her parents were available for communication.**

**Another girl, Sonia (who was diagnosed 4 years before), had not been told about her diagnosis or her mother's. She drew a KFD with several barriers between herself and her mother (see Figure 8). In addition, her mother was drawn from a side view, obscuring some of her facial features. This also suggests that communication in this family, from the child's perspective, was not an open process.**

**Jorge (diagnosed 8 years before) drew a number of indicators of closed communication within his family in his KFD (see Figure 9). Several cousins (with whom he has lived since his mother died of cancer 5 years before) are compartmentalized or enclosed within the perimeter of the house. The house also serves**



**Figure 7.** Ana's KFD.



**Figure 8.** Sonia's KFD.

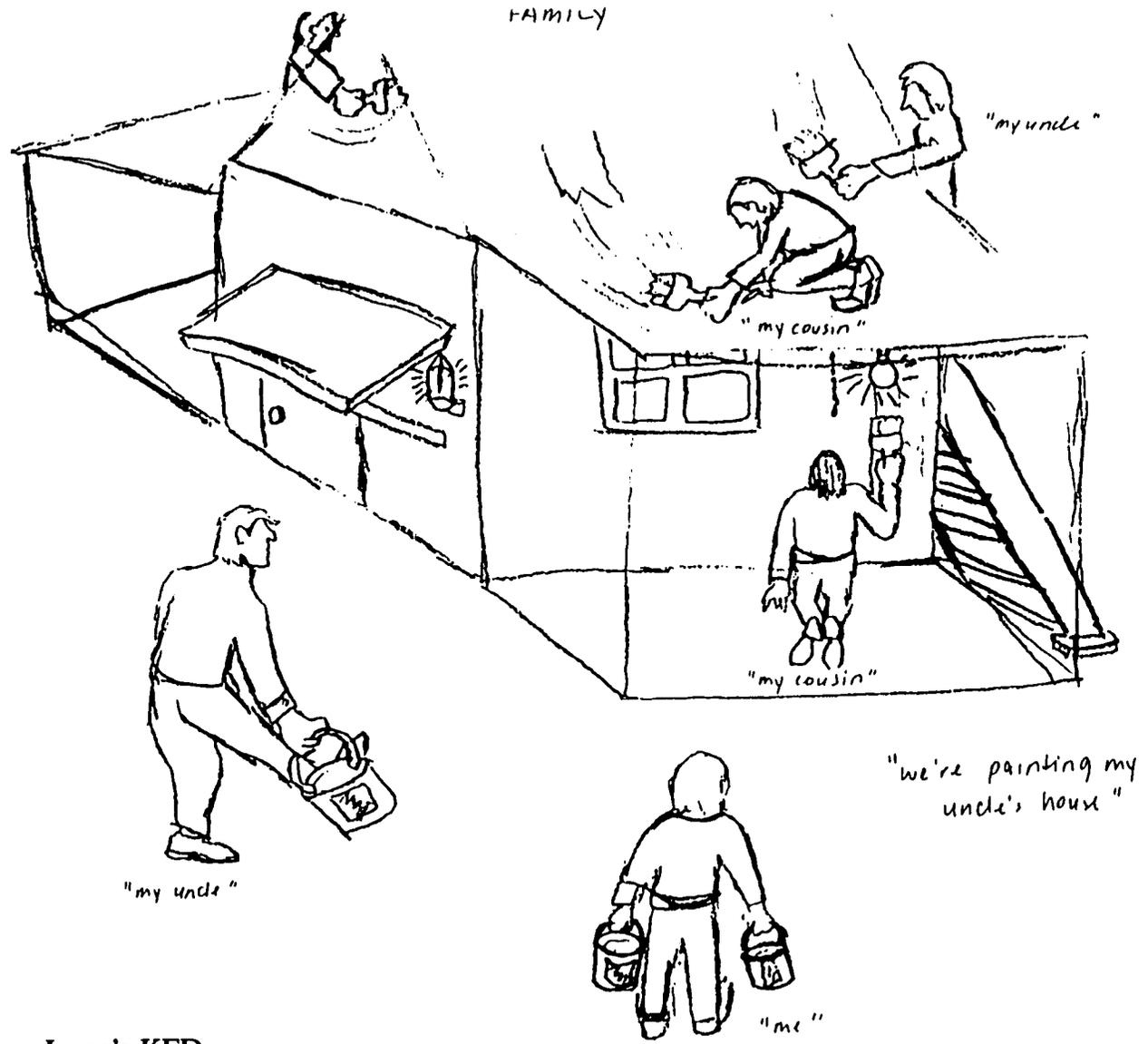


Figure 9. Jorge's KFD.

as a barrier between himself and his uncle and brother who are on the roof. The buckets carried by he and his uncle serve as subtle barriers between these two figures. There are several members missing in the drawing from his large blended family, most notably his maternal aunt who has been his primary caretaker for the past 5 years. Finally, the orientation of the boy with his back to the viewer, thereby concealing his facial features, suggests closed patterns of communication within his family.

These data suggest that children who were not informed about their illness, as well as most of those who were, did not perceive communication within their families as an open process. Instead, their drawings suggest they were isolated from information and support about the illness from the parents and guardians who otherwise had their best interests at heart. The lengthy interval during which the parents and guardians knew about the diagnosis but did not communicate it to their children probably explains this finding.

### Perceptions of Self as Ill

None of the children produced drawings which suggested a positive self-image, even if they had been informed about their illness and perceived their families as relatively open and supportive. This finding can be explained by the intensity with which HIV infection affected daily life, in contrast to that of their siblings and peers. For example, most of the children took at least two HIV-related medicines several times a day; some took four or five different drugs. All of the children required monthly clinic visits and blood tests.

Eight of the 12 children in the study had outward signs of their illness: seven had trouble gaining weight and short stature, five had recurrent rashes, and two had Mediports. When they experienced complications of their illness, the children required many more appointments, tests, and sometimes hospitalization. These factors alone could have had a detrimental effect on self-image.

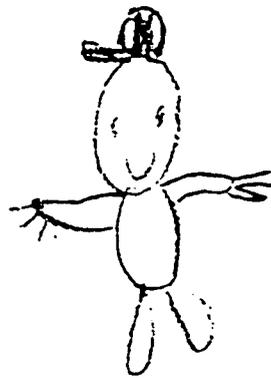
Four children produced a Person drawing of their same gender, a positive indicator of self-image. However, each drawing also contained other, more negative attributes which suggests that the experience of living with a stigmatizing, life-threatening illness adversely impacted the children's self-image.

David, who required admission to the hospital every 2 or 3 weeks to receive intravenous infusions through his Mediport, drew the person in Figure 10. He had been informed about his illness by an angry acquaintance of his mother's, who recently died. The placement of the figure low on the page, small in size, and lacking feet indicates a diminished self-image. He described this figure as an 11-year-old childhood friend who was having some difficulty in his neighborhood,

"He moved. He got kicked out of our apartment but he [still] lives close to our house."

When asked if this boy was sick or needed to take medicines, he replied,

"Sometimes. No, not like me . . . because you see, something in me, something like my platelets and that's why they go like 'puff' and then hit the ground. I have to go in there [the hospital] for three bags [of intravenous gamma globulin]."



**Figure 10.** David's Person Drawing.

Migel was informed about his HIV infection when he was 9. He had a large scar on his chest from the surgical correction of a congenital heart defect when he was an infant. Over the past year, he had been hospitalized several times for high fevers and severe dermatological infections. He drew an incomplete person who he identified as a 17-year-old boy (see Figure 11). The drawing illustrates several indicators of poor self-esteem: complete absence of the body below the head and incomplete facial features. He was very reluctant to talk about his drawing at first, but eventually described the person he drew this way,

"[He is] just standing. He doesn't have a body . . . . I didn't draw it. [He has a] skinny body . . . . tall . . . [he's wearing] regular clothes . . . blue and black . . . he broke his arm . . . he fell from a tree or something . . . the arm is still broken."

Brisha drew a person who she identified as herself (see Figure 12). The girl and her father traveled from another state every month to visit the UCSD Mother-Child HIV clinic. She had been having difficulty gaining weight and suffered from recurrent upper respiratory infections, but had not yet developed serious complications of her illness.

At first, she drew the figure without hair or clothing, adding them while she talked about her drawing. The absence of hands and feet and the diminished size of the figure are indicators of poor self-esteem. She described the girl she drew this way,



Figure 11. Migel's Person Drawing.



Figure 12. Brisha's Person Drawing.

"I don't know how to draw my hair. Okay, I'll just make it curly . . . .  
 She's 6. That's how old I am. That's me and I'm 6 . . . . [She's feeling]  
 real good, but she has a cough . . . . I have to get shots . . . and I have to  
 take medicine at night at 10:00 o'clock . . . . I don't want to take the  
 medicine anymore. [If I don't take the medicine] I'll get sick."

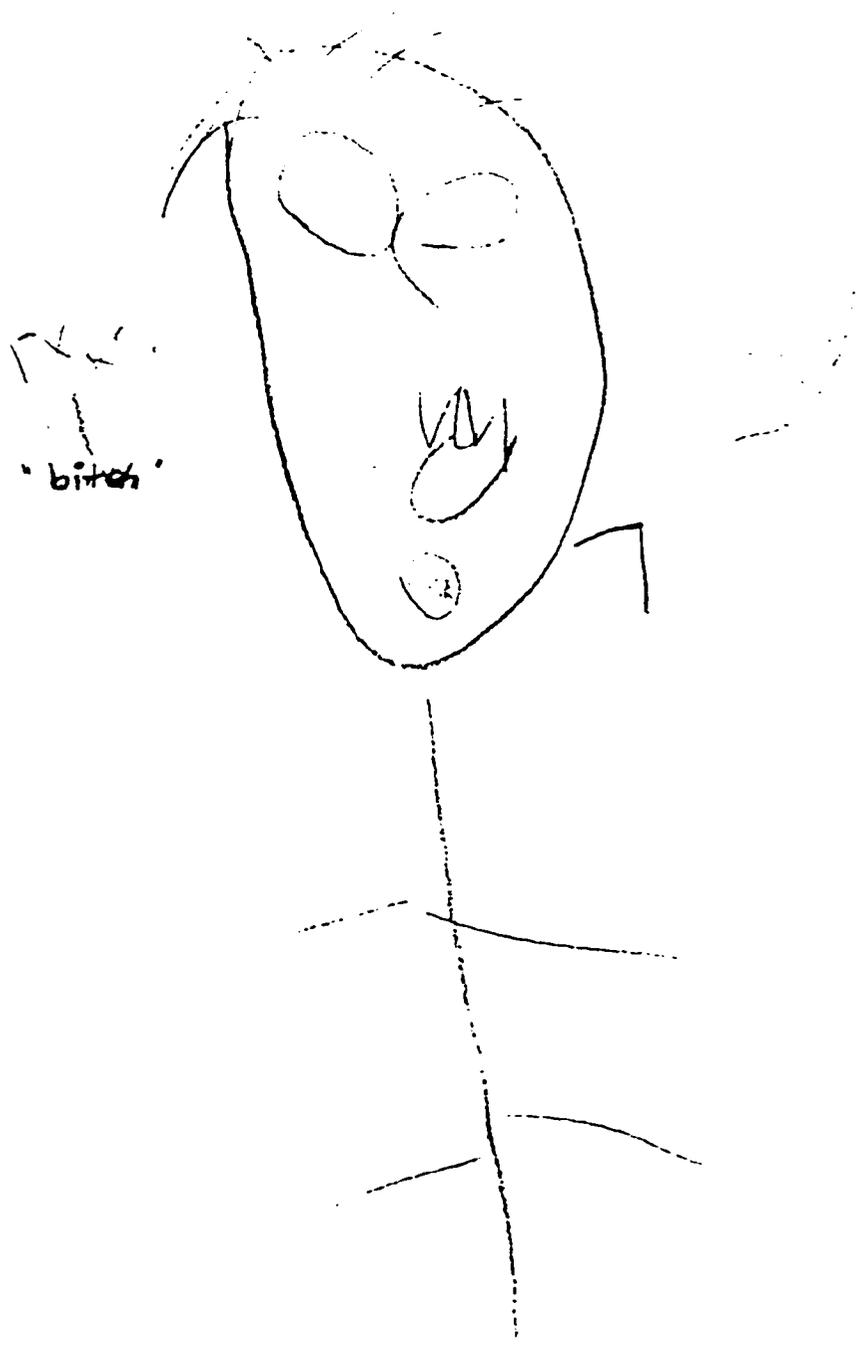
When asked what she does when she comes to the clinic, she answered,

"First they take a shot here and then they see how much I weigh and then  
 you do stuff with me and then I go home."

Tanya, whose father was dead and whose mother was unable to care for  
 her because of her illness, drew a picture of a 7-year-old child. She had been  
 informed about her diagnosis the month before by her maternal grandmother,  
 who has been her guardian for the past 3 years. The girl was hospitalized several  
 times in the past year for high fevers and severe infections.

At first she identified the figure as a boy but then changed her mind and  
 called it a girl (see Figure 13). The drawing demonstrates several indicators of  
 poor self-image: absence of hands and feet, lines drawn across the leg, and  
 disproportionate size of the head relative to the rest of the body. Her description  
 of the figure suggested a disturbed self-image,

"This is ugly . . . he has ugly teeth . . . it's a boy, it's a girl . . . she is  
 dancing, doing a butterfly . . . she is [sick] but she is feeling good . . . she  
 got sick . . . she said . . . 'bitch' . . . she came up and said 'dick.' [She] said  
 that to me. I didn't like that so I said I'm going to tell her mother."



**Figure 13.** Tanya's Person Drawing.

When asked whether the girl in the drawing had to take medicines or get shots, she answered,

"Get shots. That's why I like her to get shots . . . she don't like people to mess with her. One boy socked her in her eye and she punched him in his face. [She reminds me of] my friends. Because my friends sticked a pencil into her eye and put french fries in her mouth sticking up from her mouth and put inside her nose."

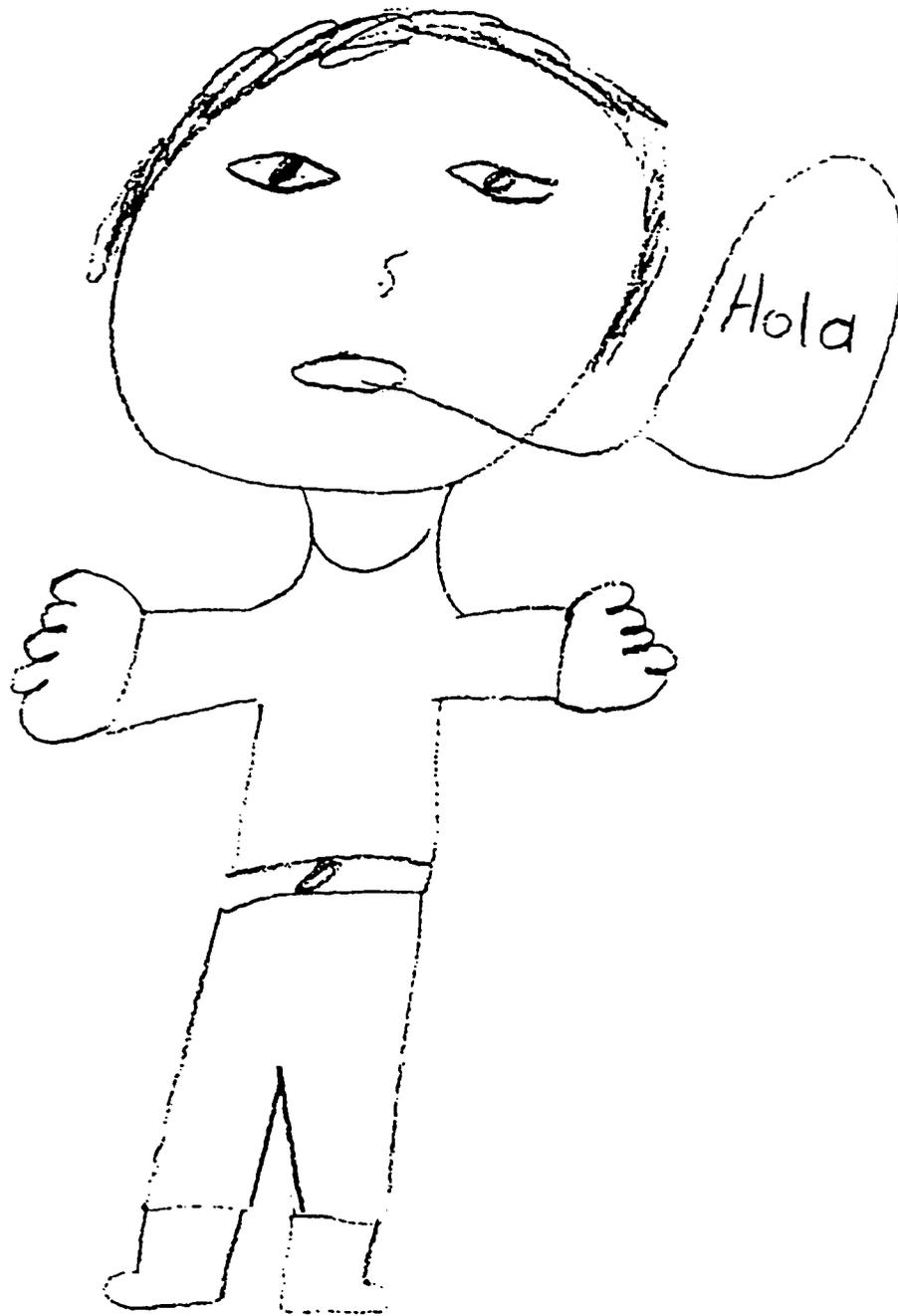
When asked what happened next, she replied,

"That's how people die."

Another child, Carla, who had been informed the month before and viewed her family as relatively open to communication, drew a Person of the opposite gender, a significant sign of poor self-image. She drew a large figure who she identified as her healthy 18 month old nephew (see Figure 14). She had been hospitalized during the past year for a severe gastrointestinal infection and had difficulty gaining weight. However, she had been feeling much better in the month preceding her participation in the study. Her mother died of AIDS 1½ years before. When asked how the boy in the drawing was feeling, Carla replied,

"I don't know. I think he is O.K. He is not sick . . . [but he has to get] shots."

Ana, who had not been informed about her illness, also drew a Person of the opposite gender. She had been relatively asymptomatic until she developed a severe infection in her blood that fortunately did not require hospitalization.



**Figure 14.** Carla's Person Drawing.

Described by her parents as a very 'picky' eater, she frequently had to spend up to an hour at the kitchen table until she finished her meal. She was a very physically attractive child who did not appear underweight and liked to perform by singing and dancing. Nevertheless, her Person drawing (see Figure 15) suggests signs of diminished self-image because of it's gender and small size.

Two other Latino children whose HIV diagnosis was kept secret by their families produced Person drawings of an idealized friend of the same gender (see Figures 16 & 17). On the surface, both drawings could be interpreted to represent a positive self-image. Careful study of each case, however, suggests the children's serious concerns about their health and the extent to which they viewed themselves in a positive way.

Jorge, who had hemophilia and HIV infection, drew the Person in Figure 16. He was severely immunosuppressed and at high risk for developing life-threatening complications. During the past year, he had not been hospitalized, but had developed several serious infections that were managed with intravenous medications he received through the Mediport in his chest, where he also received daily injections to manage his hemophilia. He had developed several painful dermatological infections and was having difficulty gaining weight, a problem which made him appear 3 or 4 years younger than his chronological age.



"papa"

**Figure 15.** Ana's Person Drawing.

PERSON

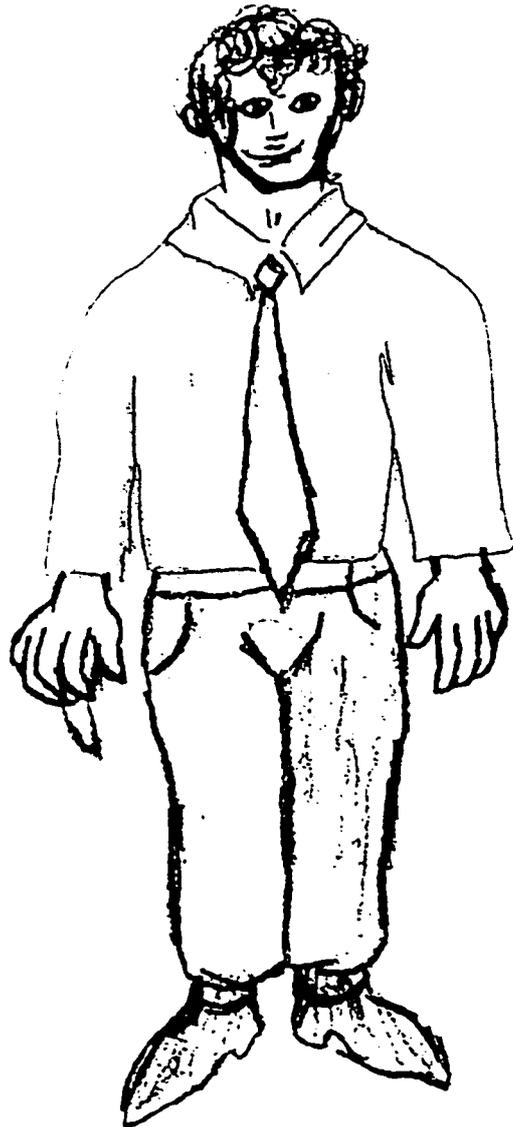
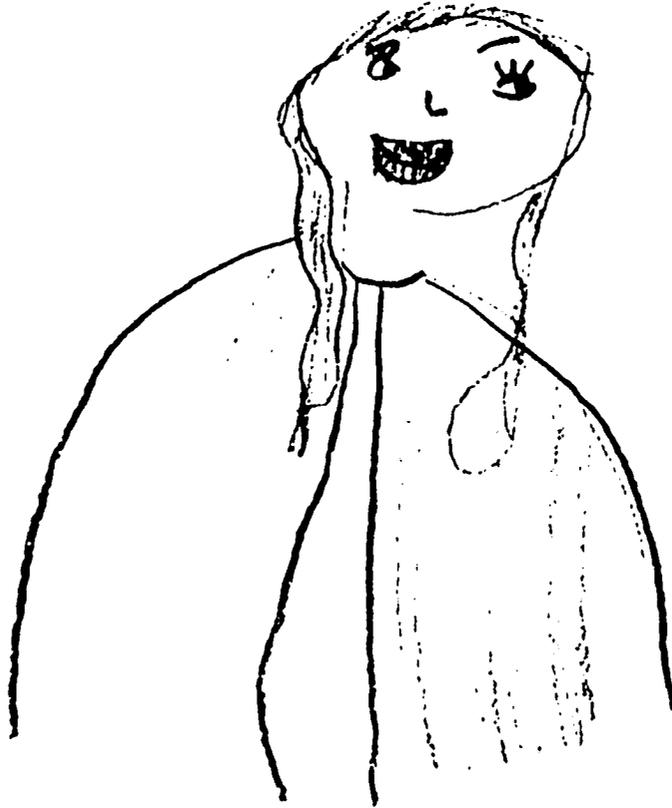


Figure 16. Jorge's Person Drawing.

"my friend"



**Figure 17.** Sonia's Person Drawing.

Jorge's mother died of cancer 5 years before. He was estranged from his father, who lived in another part of the state and had infrequent contact with him. He has lived with his siblings and maternal aunt, uncle, and cousins since his mother's death.

He identified the figure as his 'best friend,' a young man in his early twenties who had volunteered to be the boy's 'big buddy' through a local community AIDS volunteer program. He described the figure he drew this way,

"[He's] my best friend . . . [he's thinking] about me . . . [and] that he wants to take me out and buy me things and take me out to eat . . . because he loves me. [He reminds me of] my father."

The drawing suggests an idealized image which contrasts sharply with the self-esteem he projected in his KFD (see Figure 9). In that drawing, he drew his body with his back turned from the viewer, an indicator of a poor self-image.

The second case involves Sonia who was relatively asymptomatic but required several daily medicines and monthly clinic visits to monitor her health. Her mother, who took the same medicines, was exhibiting serious signs of her illness including wasting (severe vomiting and weight loss), jaundice, and intermittent dementia. The mother had required multiple hospitalizations in the past year. Her father was also ill with HIV. She lived with both parents and her younger brother and drew the person in Figure 17. She offered this explanation of the drawing,

"It's a girl. This is my friend . . . she always helps me and if I fall down or something happens to me, she helps me out. Like she wants to know what happened or if sometimes when I feel sick she takes me to the office [at school]. She is like a mother for me. She takes care of me. She is the same age as me, eight."

Despite the lively appearance of this figure, the absence of arms, hands, legs and feet reveal the girl's poor self-image, a finding that does not seem obvious upon a cursory assessment of the drawing. When considered in the context of her mother's declining health, the drawing's interpretation takes on a more worrisome meaning.

The data from these drawings and the stories the children told about them suggest that concealing or revealing the diagnosis did not protect the children from experiencing a disturbed self-image. The drawings indicate poor self-image even when the children perceived their families as open to the process of communication and therefore potentially more available for support. It is likely that the degree to which the children and their parents felt sick, experienced unpleasant procedures, and were hospitalized were more salient predictors of the poor self-image they portrayed in their drawings.

#### Perception of Emotional Distress

Several themes of emotional distress emerged from the stories the children told about their drawings. Themes included: (a) threatening conditions of nature or weather, (b) loneliness and loss, (c) bodily threats by humans, plants, and

animals, (d) escape and evasion, and (e) use of color. Every child in the study displayed multiple indicators of emotional distress, regardless of the information they were given by parents and guardians about their illness.

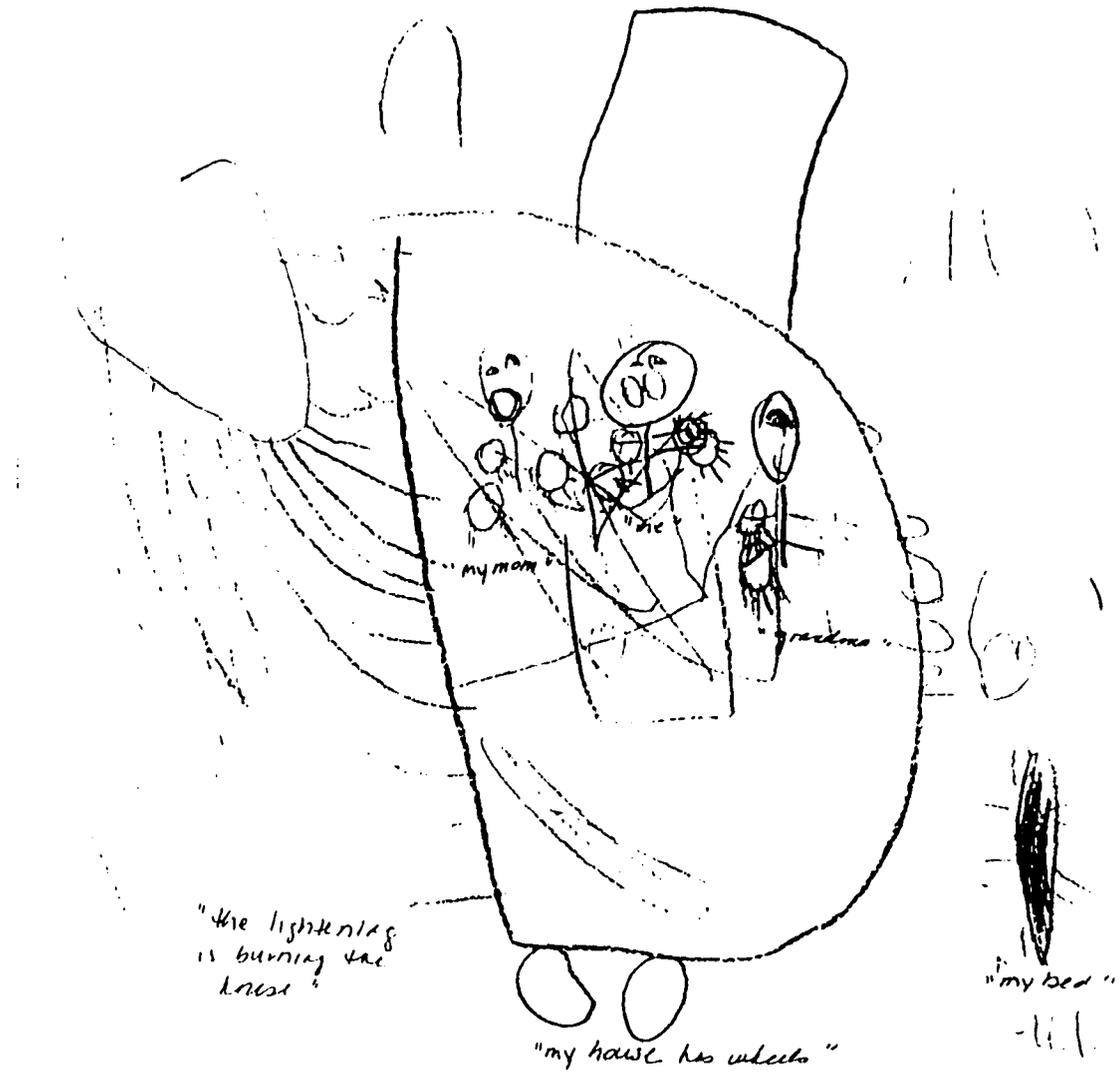
Threatening conditions of nature or weather. A number of threatening conditions of nature and weather were found in the data. This theme reflects perceptions of environmental pressures (such as the social stigma or life-threatening nature of HIV and AIDS) that become internalized as negative emotions like fear, anxiety, loneliness, isolation, and rejection. Children who had been told about their illness, as well as those who had not, often drew houses under extreme weather conditions. Houses symbolize the child's adjustment to home and intimate relationships within the family, particularly the mother.

Tanya, told about her diagnosis the month before, produced a drawing of a house (see Figure 18). Her mother was ill and her father died the year before. She described the weather in her drawing,

"The weather is lightning . . . [it's] burning the house . . . it hit the door. It is trying to get in . . . and it shot me because I was in bed with grandma and mama was downstairs, so it shot mom in the leg. It shot everybody and the house burnt."

The severity of the weather may represent the extent to which Tanya perceived the life-threatening nature of her illness, as well as her mother's.

Ana, who had not been informed about her illness and had not yet experienced many symptoms of her disease, also described lightning in the story



**Figure 18.** Tanya's House Drawing.

she told about her house (see Figure 19). She was adopted by relatives after her mother became too ill to care for her. She had not seen her mother in several years,

"Here is some lightning and I got very scared and I said 'damn lightning' because I can't sleep. I kept sleeping and I saw a lightning and I said 'I don't care' but I got scared again. The lightning scared everybody . . . it is raining and there is lightning. [The rain is] strong and it broke a little bit of my house and my dad fixed it."

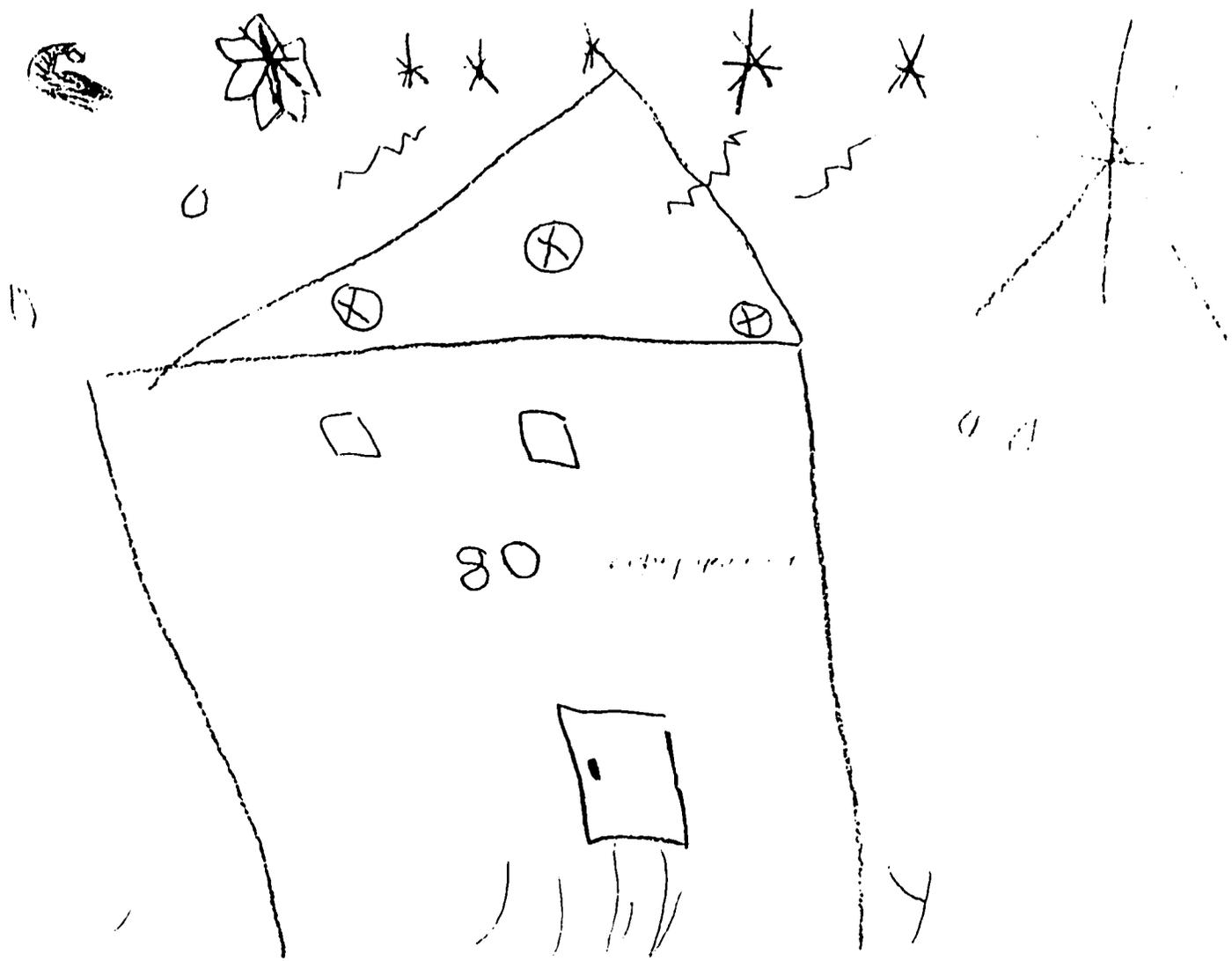
David told an elaborate story about the house he drew with a similar threatening theme (see Figure 20). The story involved a woman who used to live in the apartment above him. She played her music so loud that it disturbed everyone in his household,

"There is the lady upstairs that has a boom box and the window was busted up because the boom box broke the glass . . . we are jumping up and down because the boom box is making us . . . we're ready to call the cops."

When asked about the weather in the drawing, he said,

"Cold. Sometimes it has those tornadoes, baby tornadoes."

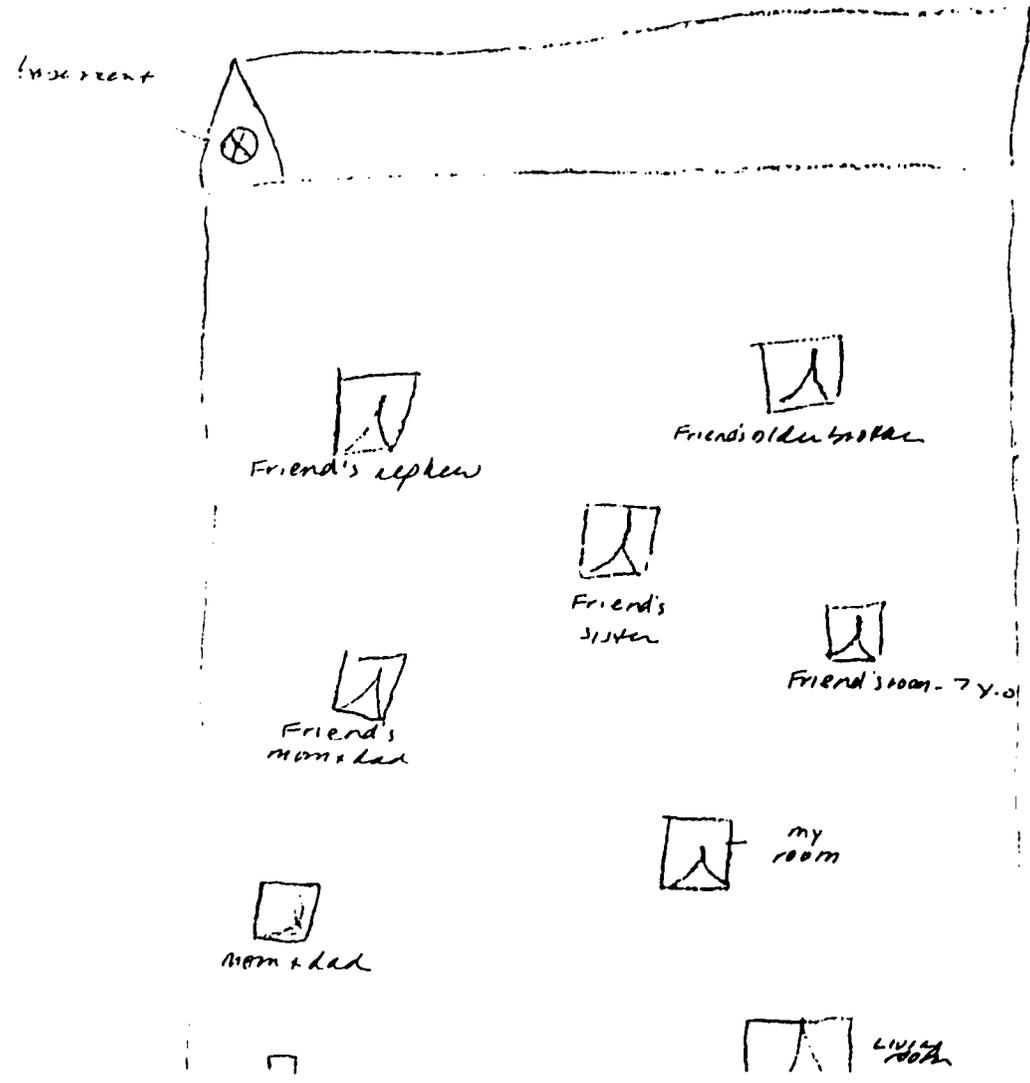
Sonia, who was relatively asymptomatic, had not been told about her diagnosis. However, her mother was severely debilitated from her disease. The girl described unpleasant weather conditions in her drawing as she talked about her house (see Figure 21),



**Figure 19.** Ana's House Drawing.



**Figure 20.** David's House Drawing.



**Figure 21.** Sonia's House Drawing.

"It's big. Our neighbors live in there. We live downstairs and they live upstairs and then we pay rent to the owner of the house. I play with my friend . . . we play a lot together and sometimes when my mom gets sick, I go to her house and spend the night . . . [The weather is] kind of rainy . . . [the temperature is] zero, like snowy."

Other children described windy weather conditions in their drawings and the stories they told, suggesting less threatening environmental forces than the lightning, tornadoes, and freezing rain already mentioned. Nevertheless, the description of wind in any story about a drawing generally indicates environmental pressure and negative internal emotions.

This type of weather is illustrated in the story Carla told about a tree she drew (see Figure 22). She had been forced out of her neighborhood school a few years before when her mother's diagnosis and her own were discovered by neighbors. The trauma she experienced as a result of this discrimination was intensified when her mother died of AIDS and she began to develop serious complications from her own illness resulting in hospitalizations and weight loss. She was informed about her illness the month before she produced this drawing.

The tree is drawn with a skinny trunk and sparse network of branches making it vulnerable to environmental forces, suggesting the child's inability to cope with her environment. She described the weather in her drawing this way,

"[The wind is blowing] strong. Yesterday it was blowing strong. Tomorrow I don't know."

ARBOL

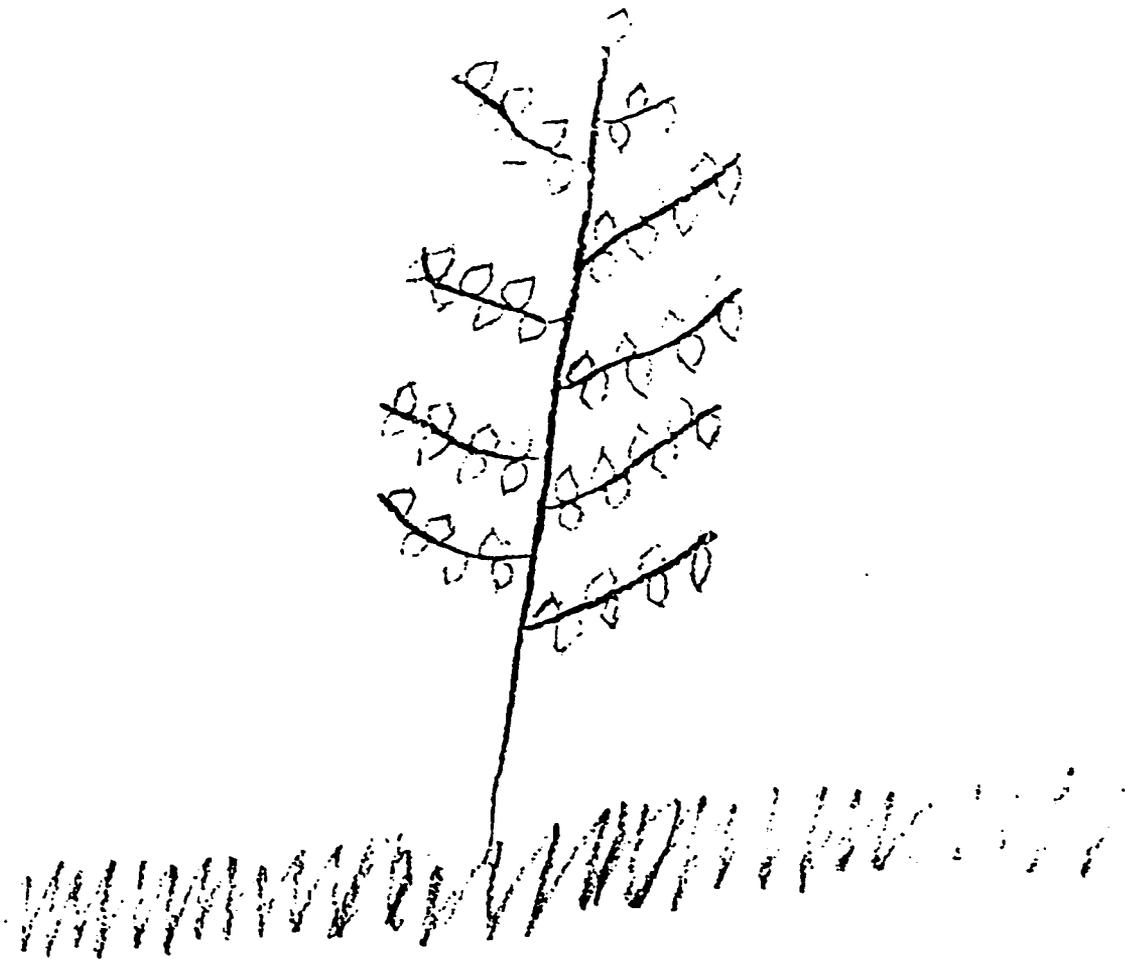


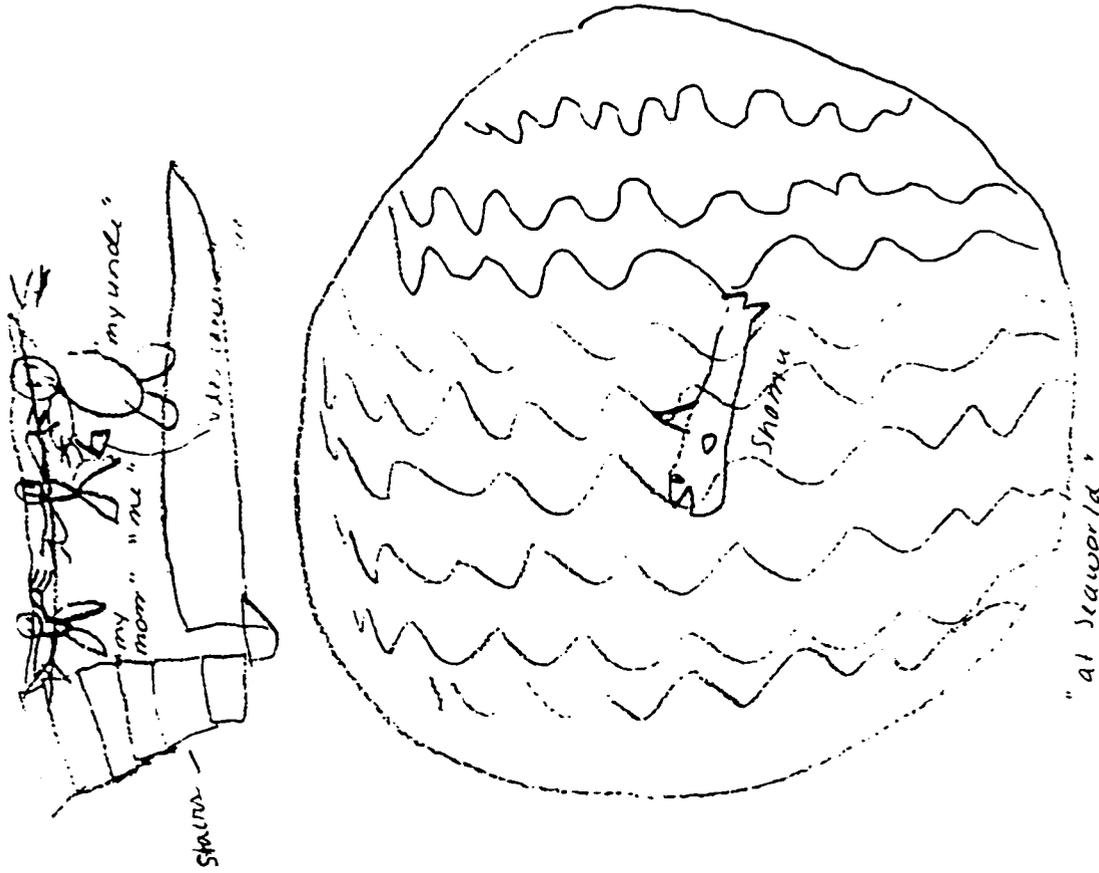
Figure 22. Carla's Tree Drawing.

The drawings and stories just depicted illustrate the extent to which these children perceived themselves to be threatened by forces they could not control. In some cases, threats came from outside the family resulting in feelings of stigmatization and social rejection. For other children, the illness and deaths of parents were devastating threats to the children's emotional health, as was their awareness of the life-threatening nature of their own disease. These perceptions led to expressions of fear and loneliness in the drawings and stories whether the children's diagnosis was concealed or revealed by their parents and guardians.

Loss and loneliness. Several children told very poignant stories of loss and loneliness despite having surviving parents or guardians to care for them. For example, as David described his KFD (see Figure 23), he talked about how much he missed his mother who told him about AIDS before her death 4 months before,

"This is about Sea World and there is me and my family on the top . . . my mom is in the first and uncle is in the last seat . . . . My mom thinks she was a little kid, a little girl again . . . [then] I still would be a little baby to start all over again . . . . Because I want my mom back. She passed away and that's why I want to go back to the beginning. I wish my mom could come back alive and not be sick again."

When asked if there was anything more he wanted to say about his drawing, he responded,



**Figure 23.** David's KFD.

"Okay, it has a lot of people . . . and kids could get lost real easy."

Later, after drawing a picture of a house (see Figure 20), he repeated the theme of loss when asked who he would like to have live with him there,

"I would like that my mom would come back to life . . . and all my pets I used to have, that would be cool . . . they are not coming back."

Another child, Tanya, echoed themes of loss as she pointed to the inventive spelling she wrote in green on her KFD (see Figure 6),

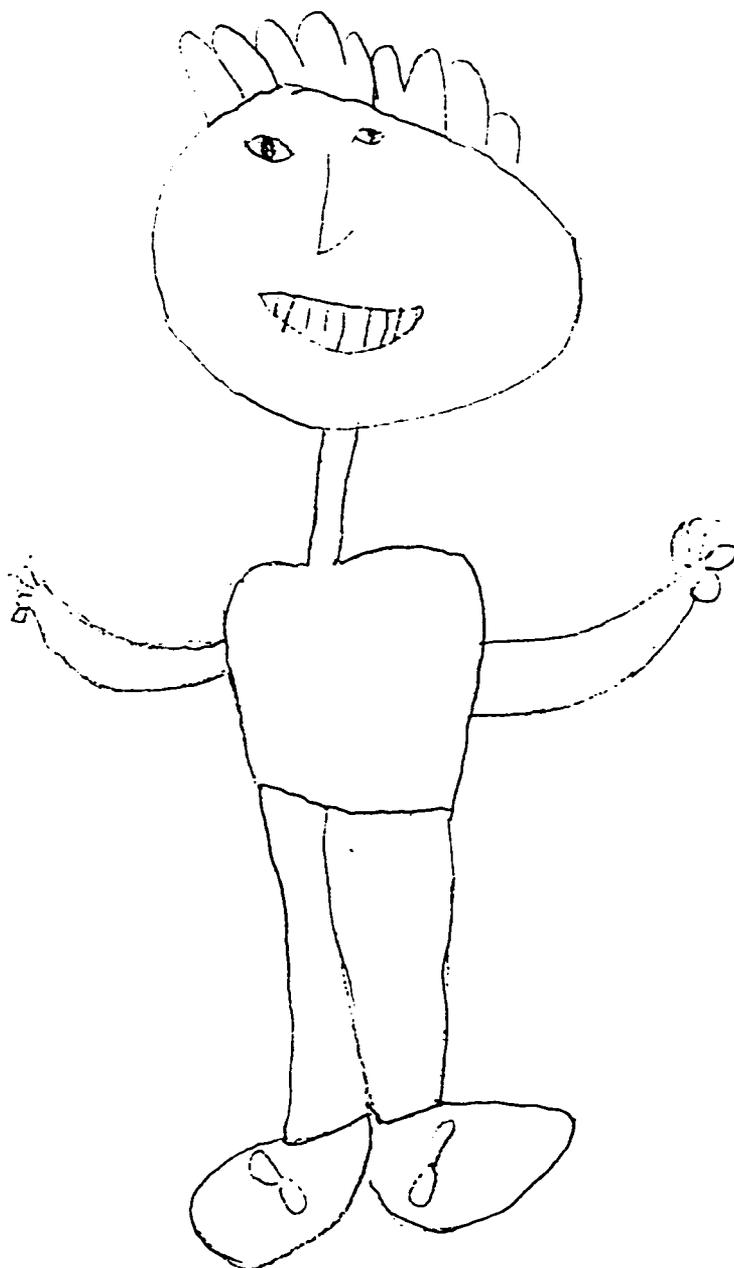
"That says, 'love daddy. I want to be your daughter forever and ever. I love my daddy. I want to be with you, that 10-year-old kill you. I love you daddy. Bye daddy. You are in heaven and you love heaven. I don't like heaven. I don't want to die.'"

She related a similar story of loss when she talked about her mother, who for the past 3 years had not been able to care for her,

". . . my mom goes to the hospital . . . because she got a stomach ache and her brain is hurting."

In another case, Jamie, whose father died of AIDS 8 months before the study and whose mother was ill as well, alluded to the theme of loss when he talked about his Person drawing (see Figure 24). He had been told by his mother that he was 'sick' with the same illness his parents had. He identified the figure as an 8-year-old boyhood friend and said the following when asked what the boy was doing,

"He is waving good bye to his mom."



"It's a boy ... he's my friend"

**Figure 24.** Jamie's Person Drawing.

Two children who had not been informed about their diagnosis also told stories about their drawings which contained themes of loss. Sonia described how she felt when she talked about the Person she drew in Figure 17, a girlfriend at school who had been sick and needed to be hospitalized. As Sonia talked, she began to cry,

"She just got into the hospital, cause she couldn't breathe at her house and they called 911 and they took her . . . . I was crying because I missed her a lot . . . sometimes she feels sad . . . [she reminds me of] a friend of mine that a long time ago she died."

Jorge, who was estranged from his father and whose mother died of cancer 5 years before, made recurring references to feelings of loneliness and sadness in his drawings. He and his siblings had been living with his maternal aunt and her family since his mother's death. He had not been told about his diagnosis by his guardians, although it had accidentally been disclosed by someone outside the family the previous year. When asked to describe his drawing of a Tree (see Figure 25), he said the following,

"The tree is in a park . . . . What does it need? I think [it needs] persons to look at it and take pictures with it and [give it] a little bit of love, that's all . . . [if it didn't have these things] it would get sad and die . . . [you could tell if the tree was sad if it was] alone . . . [if someone wrote their name on the tree] it would still be alone."

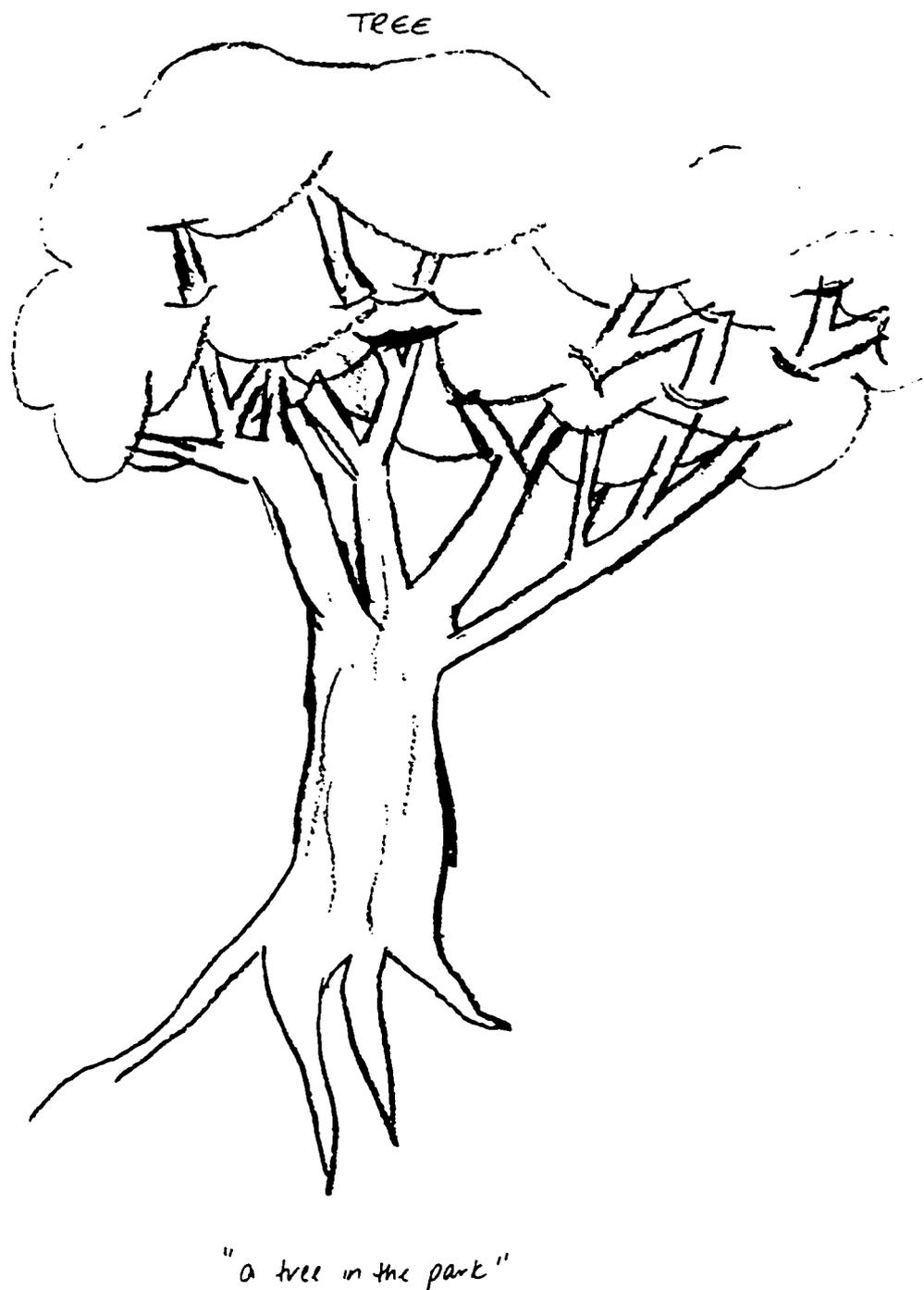


Figure 25. Jorge's Tree Drawing.

After he drew his House drawing (see Figure 26), he was asked what it needed.

He answered,

"It needs more family."

When he was asked if there was anything else he wanted to say about the house, he stated,

" . . . I wish that all my family could be in my house and live together . . .

sometimes me and sometimes my brothers and cousins [feel lonely] . . .

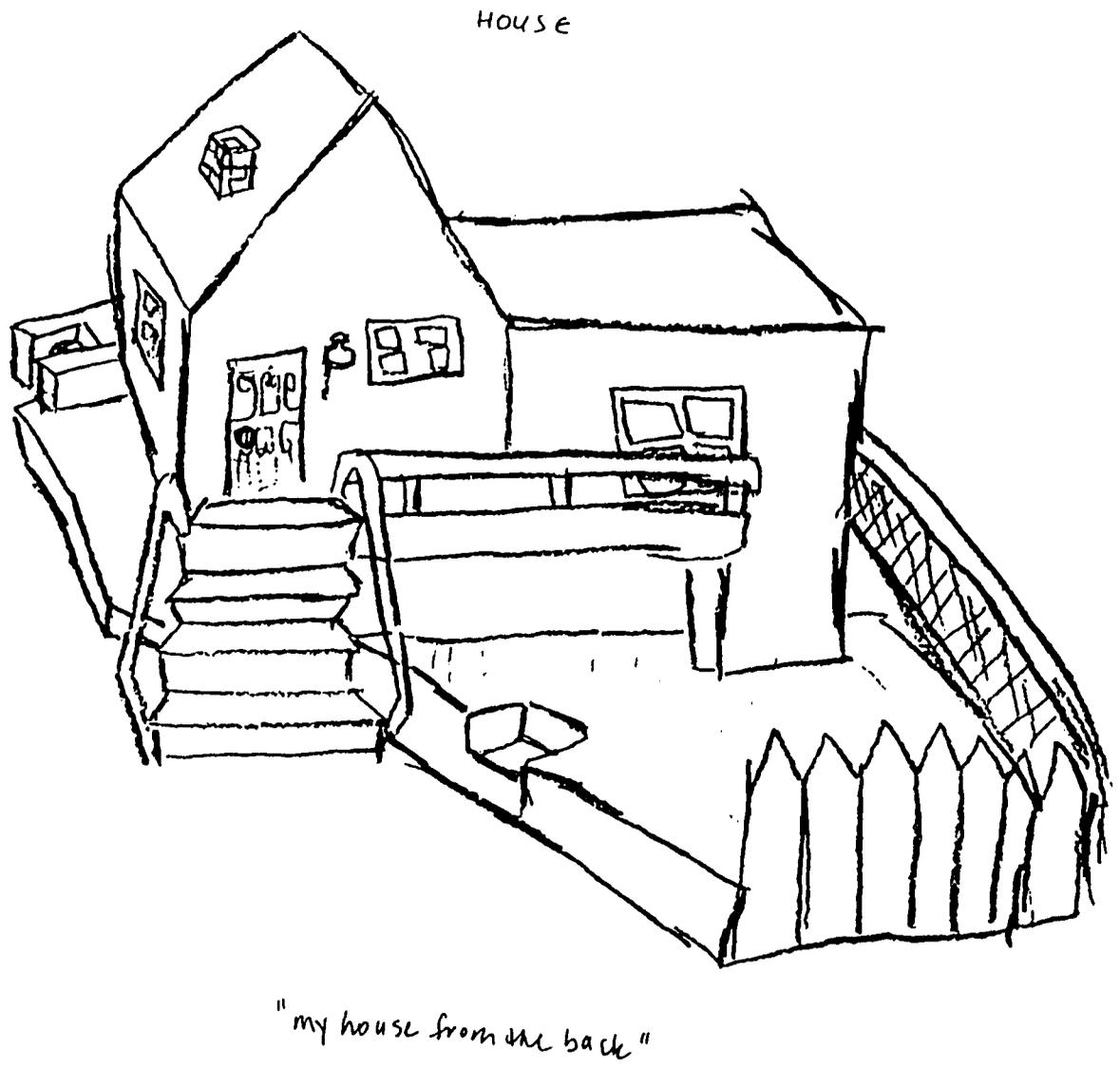
When they are sad, sometimes they say 'I'm lonely' . . . [when they are sad]

sometimes they lay on the bed or sleep . . . [if they don't fall asleep] they

get sad and lonely."

These data illustrate how the experience of life-threatening illness and the loss of parents and friends contributed to profound feelings of loss. Previous data cited in the findings from this study suggested that none of these children perceived their families as open to the process of communication, even if they had been informed about their diagnosis. Without a sense that parents and guardians were available to listen to their concerns, the children may have felt reluctant to speak up and therefore suffered their losses alone without sufficient support.

Bodily threats. Many children exhibited themes of bodily threat in their drawings and stories whether they were told about their diagnosis or not. Sara, who had been informed about her illness for the first time 3 weeks before the study, asked her adopted mother a few days later if she was going to die from



**Figure 26.** Jorge's House Drawing.

**AIDS. At first her mother said no, then qualified her answer by adding that she might get**

**". . . really sick and need to go the hospital, but we don't know if you are going to die from it or not."**

**When asked to describe the figure in her Person drawing (see Figure 27), she said,**

**"She's wearing a dress and she works in a hospital . . . [the people she takes care of have to take shots] little ones for little kids. Little needles but they don't hurt."**

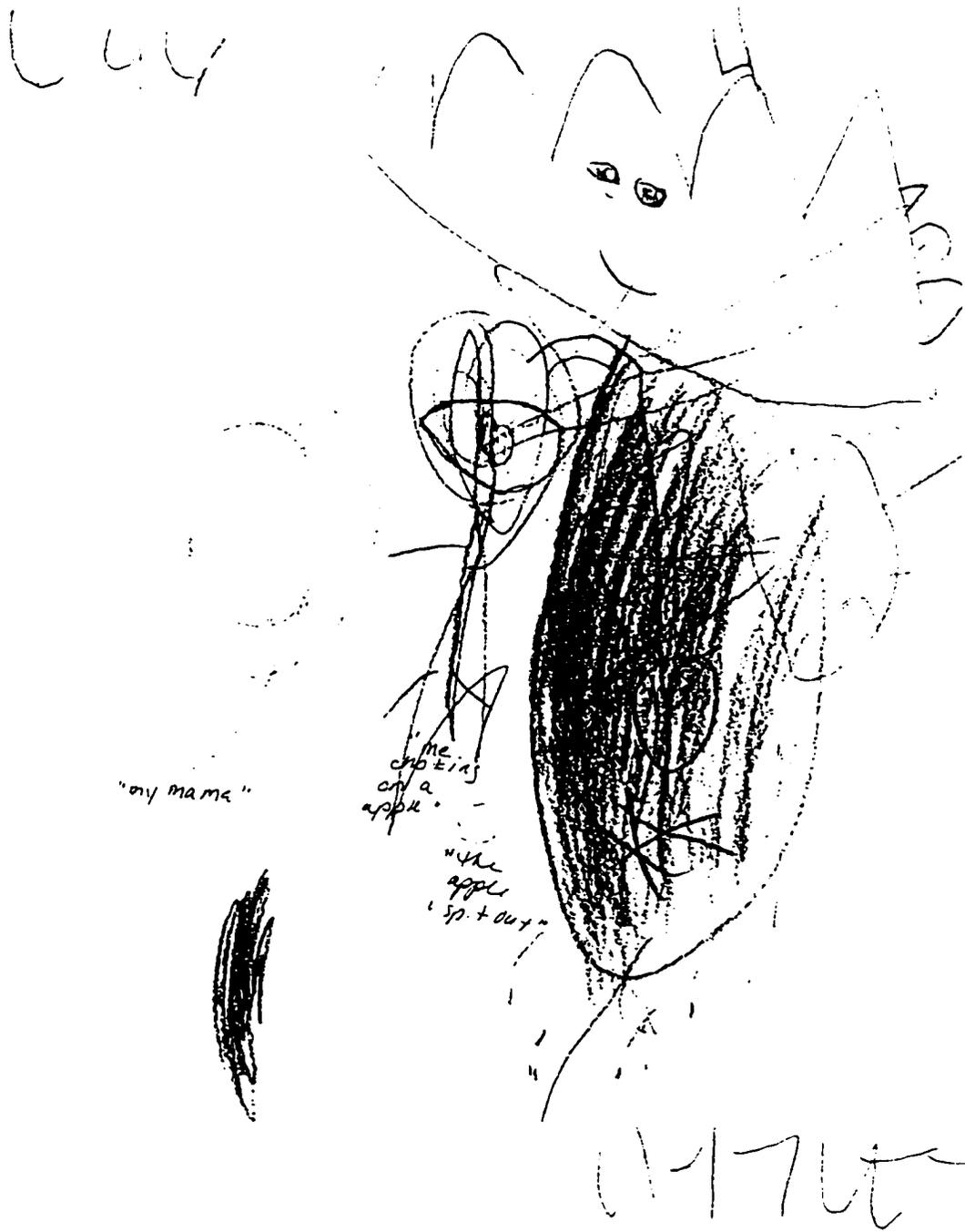
**Tanya, who had also been informed about her illness in the past month, told several stories about her drawings which contained threatening images of choking. In her KFD (see Figure 6) she described what happened when her family brought her a birthday cake,**

**"My mommy and my dad . . . and my grandma said 'happy birthday' to me. I was sleeping when they said 'happy birthday.' They came with my cake. I was holding it and they smashed it into my face because I like it. I like to smash cakes in my face, because mama gave me the cake and I smashed it in my face."**

**As she described her Tree drawing (see Figure 28) later in the interview, she repeated the choking theme,**



Figure 27. Sara's Person Drawing.



**Figure 28.** Tanya's Tree Drawing.

"This is me trying to pick the apple . . . . I choked on it . . . because I didn't chew it . . . so here is the apple, choked in my neck . . . then I picked it and eat it and swallow it real slow . . . . The tree was waking up, so I left his apples alone because he wanted his apples, so he decided to wake up. He saw me picking his apples up and then he pulled my ear up to his stomach and he ate me. He ate me, that's what he did . . . then spit me out."

The Tree drawing of another child also contained threatening imagery.

Produced by David, Figure 29 depicts an apple tree that he could climb to get the fruit. He described how the apples tasted,

"Like apple juice. It tastes good. If you pick the bad one with the brown spot, never eat the brown spot. It might be poison or you never know, you might get sick by it."

Two children told stories about killing animals. For example, Brisha said this about her House drawing (see Figure 30) when she was asked what it needed,

"It doesn't need anything else. All it needs is the roaches to be killed because there is a lot of roaches in there because they've been leaving food on the floor."

Another girl, Ana, not informed about her diagnosis, told a rather troubled story about her Tree drawing (see Figure 31). In the tree, she drew two birds and a nest with eggs. Flying overhead was a large flock of birds. As she pointed to one, she explained what happened to it,

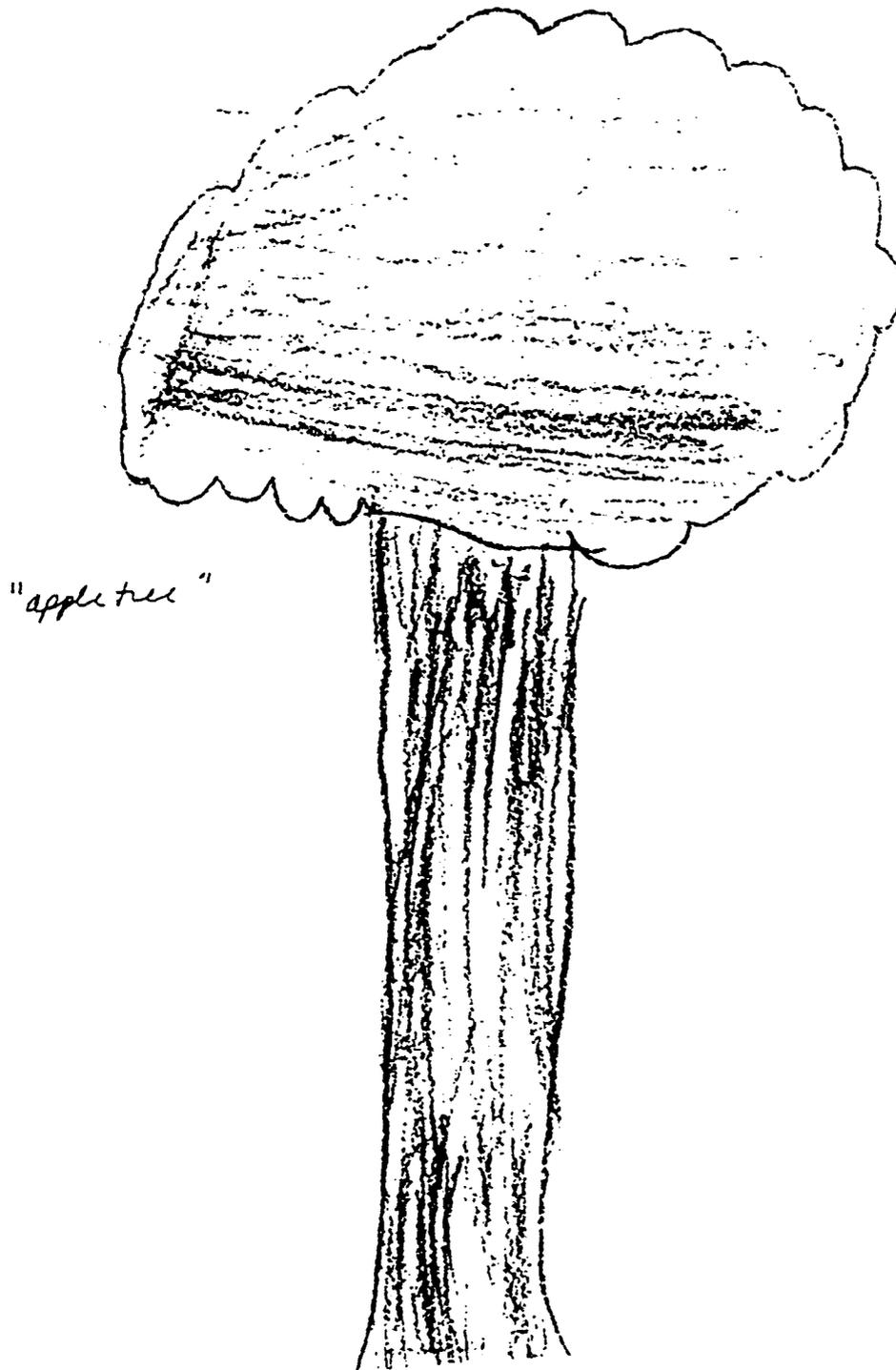


Figure 29. David's Tree Drawing.

HOUSE

"her house .... my baby sitter "

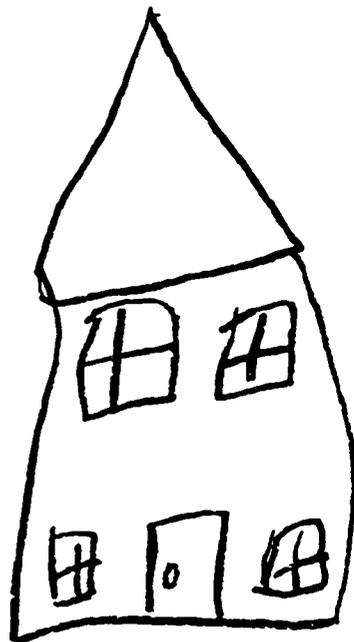
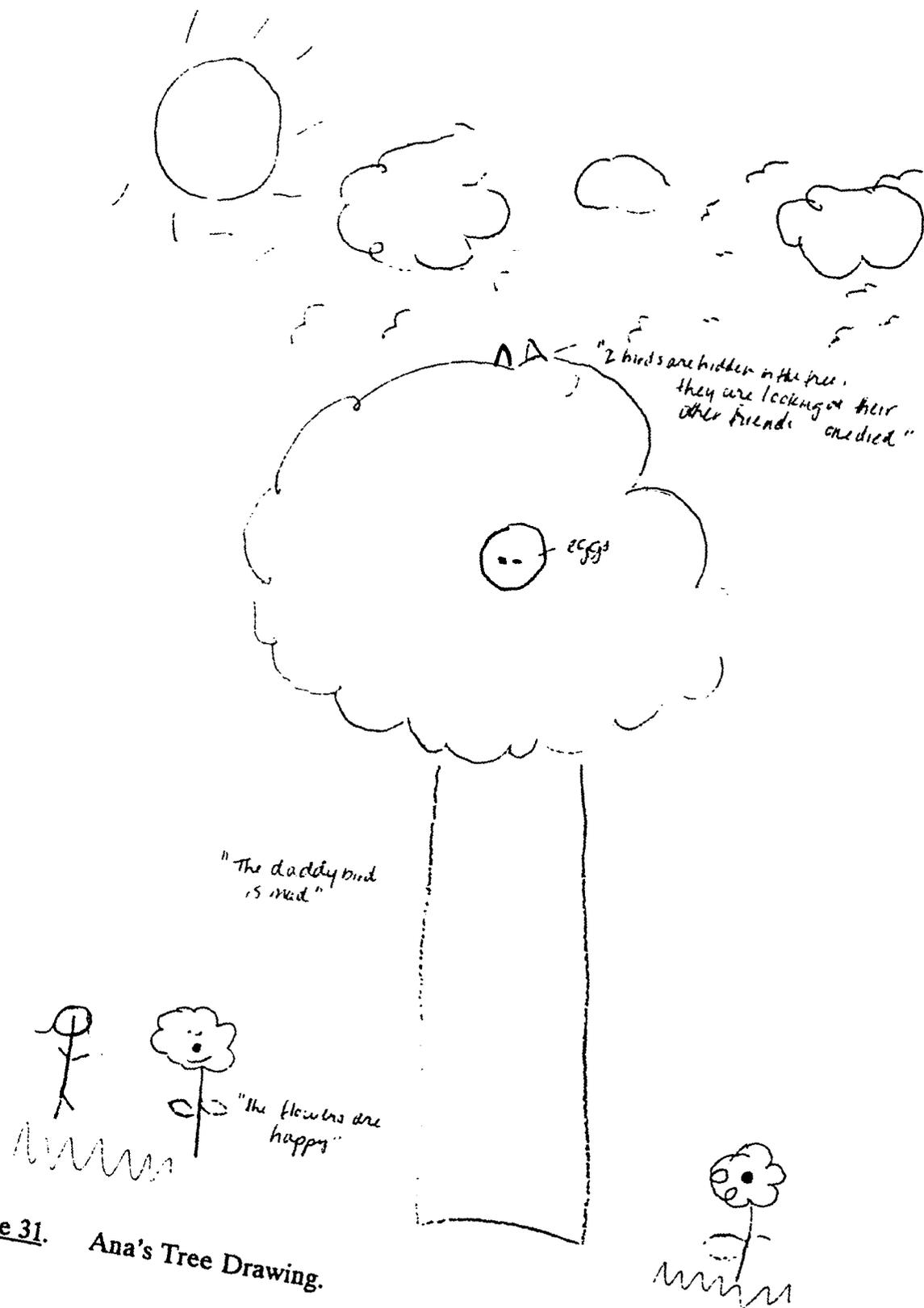


Figure 30. Brisha's House Drawing.



**Figure 31.** Ana's Tree Drawing.

**"It was killed . . . . The beaver killed him."**

**Finally, Jorge worried about mutilation when he speculated about what might happen to the tree he drew in Figure 25,**

**"It would be sad if they wrote on it. Like write words on the tree . . . if it gets cut with a knife."**

**Taken together, these images of being punctured, choked, eaten, poisoned, killed, and mutilated suggest that the children experienced severe emotional distress, whether or not they were told about their illness. Such findings indicate that these children were in desperate need of support.**

**Fantasy, escape and evasion. The extent of the children's emotional distress, the perception that their families were unavailable to talk with them about the illness, and the degree to which they held themselves in low esteem may have made it increasingly difficult to cope with their disease. Many children, particularly those whose parents had died, used fantasy, escape, and evasion to deal with their catastrophic situation.**

**Two boys told elaborate stories about family trips to popular tourist destinations with their surviving parent or guardian and the parent that died. David's KFD (see Figure 23) generated an imaginative description of his family trip,**

**"First we went in a limo to Sea World, and me and my uncle and my grandma were in the limo, and had water, videos, radios, sports, and all**

that . . . [now that we're at the show] I'm watching, my mom, and my uncle and me are watching Shamu."

A family trip to the zoo was depicted in Jamie's KFD (see Figure 32) which he drew after his father died,

"My mom, my dad, and me . . . . We're going in to see the white bears, brown bears, and the seals at the Zoo."

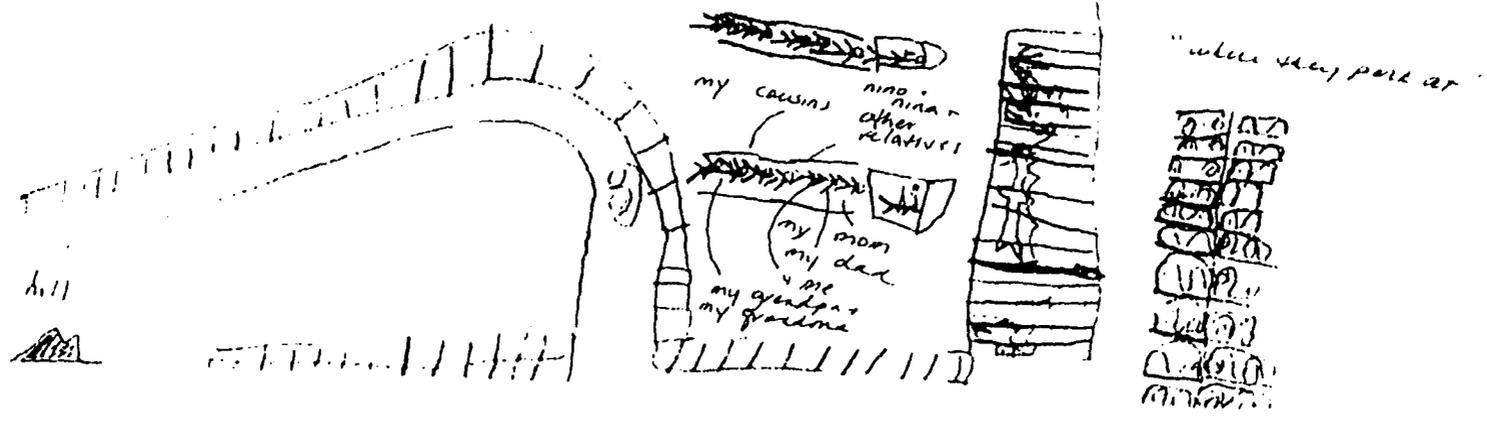
Jorge's fantasy took the form of a family get-together to paint his uncle's house, which is drawn in black in his KFD (see Figure 9). However, his verbal description was much more colorful,

"About 1 year ago me and my uncle were happy painting the house. We took pictures on the roof, right here, when we finished. We took pictures and everyone was great. [We were thinking about] making it more beautiful, like new . . . we were feeling happy . . . thinking about how it is going to look when we finish. [We painted it] pink."

Other children told stories about escape and evasion. In her story about her KFD (see Figure 3), Brisha repeatedly described the same thing when asked what she and her father were doing,

"Running around the house with my daddy . . . . We ate, then we started running around the house . . . [next] we are going to run to the store . . . [my daddy's thinking about] running . . . . She's thinking about running, too. Yeah, that's me."

"we're going into see the  
white ones, brown ones, & the seals"  
"we're at the zoo"



**Figure 32.** Jamie's KFD.

When asked if there was anything else she wanted to say about her drawing, she answered,

"We are running around the house like this . . . eight times around the house."

Migel used multiple evasions when asked about his drawings. Phrases and words like "I don't know," "no," and "nothing" were used to answer almost every question he was asked about his drawings, particularly the House (see Figure 33), and the Tree (see Figure 34). According to standard projective drawing interpretations, these drawings suggest, respectively, his adjustment to his home and intimate relationships as well as his ability to cope with his environment. These topics may have been too threatening to discuss at the time of his interview. Of equal interest was his description of 'foggy' weather in both drawings, a condition that symbolizes an inability or unwillingness to see what may lie ahead. Given the losses he has already suffered, this style of coping may have been adaptive for him.

Use of color. Over one-third of the drawings produced by the children in this study were monochromatic, an indication of significant emotional distress. This finding was more common among children who were older, experienced the death of a parent, and told about their diagnosis.

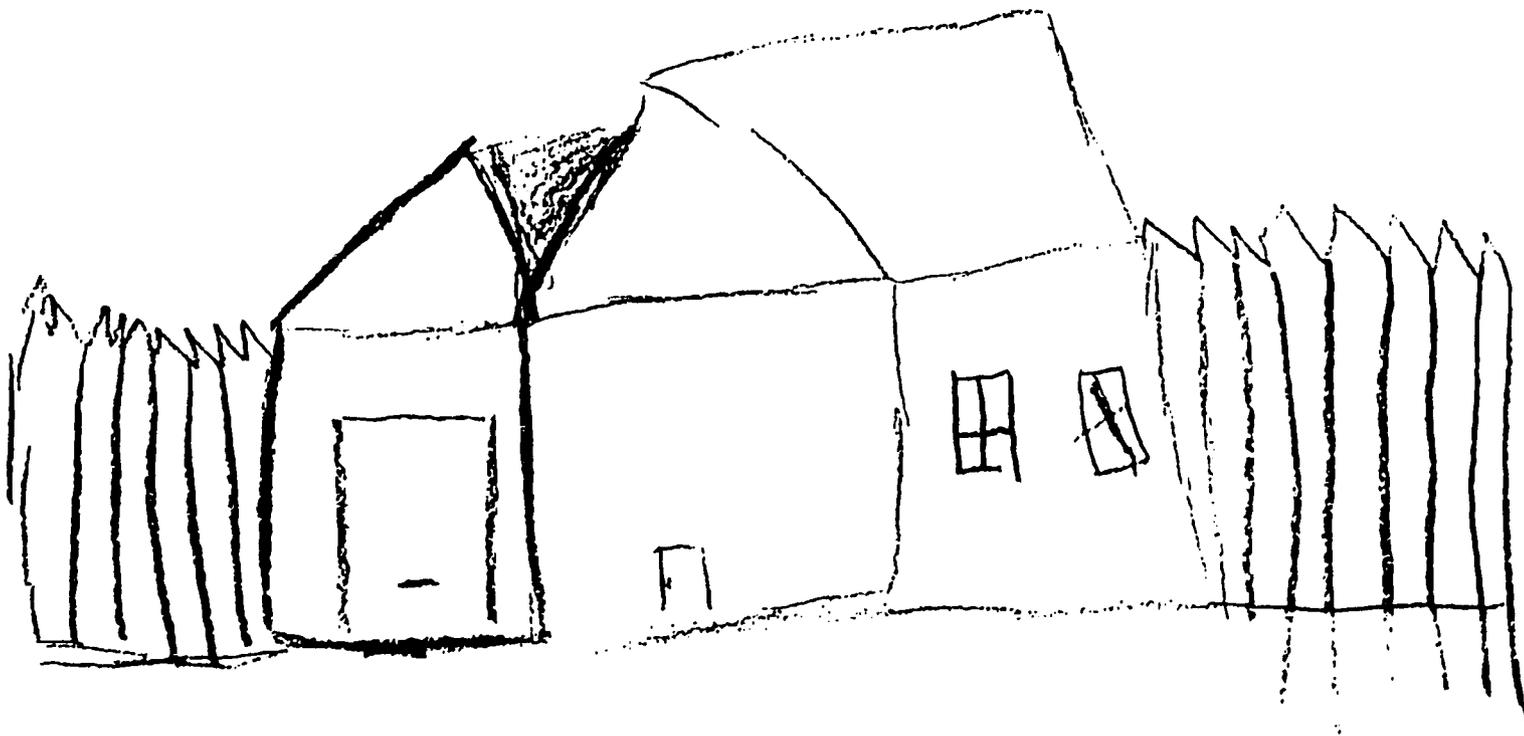


Figure 33. Migel's House Drawing.



**Figure 34.** Migel's Tree Drawing.

### Summary

In summary, abundant examples of emotional distress were found in the children's drawings and conversations. When evaluated in the context of their poor self-image and negative perceptions about the extent to which communication about their illness was possible within their families, it is evident that these children required more information and support than their families and health care team provided.

### Summary of Findings

Several important findings emerged from the conversations with parents and guardians, as well as the children's drawings and their stories. These will be addressed in this section.

First, the findings suggested that children who were told about their illness did not perceive that communication and support were available within their families. Instead, the children's drawings and stories indicated pervasive signs of isolation, poor self-esteem, and severe emotional distress, similar to the findings from children who had not yet been informed. This was the most salient but unexpected finding of the study. At the same time, parents and guardians did not perceive the extent of their children's distress.

A second finding related to the children's awareness of their illness before they were told. According to the data from parents, guardians, and children, many of the children demonstrated some knowledge of their illness but pretended

not to know if they had not yet been informed. This finding supports other data from studies of children with cancer.

Third, by the time the data were collected, most of the children had been informed about their illness, four within 1 month of the study. This finding was unanticipated. Parents and guardians were initially reluctant to reveal the diagnosis because they feared that knowledge of the stigmatizing, life-threatening nature of HIV infection would harm their children. Most parents and guardians, however, eventually found the courage to end the secrecy that surrounded the diagnosis, but this decision typically took place after a lengthy interval of 4 years.

The illness was revealed in stages in order to soften the impact of the diagnosis on the children. Before parents and guardians revealed the diagnosis, they used a variety of euphemisms to explain the reason for medicines, blood tests, and clinic visits. Later, terms like "sickness" and "virus" were used to describe the illness, followed by more emotionally laden words such as "HIV" and "AIDS." Few parents were ready to reveal the fatal outcome of the illness or parental risk behaviors that led to the children's infection. Disclosure was more likely if the children were older, more symptomatic, asking about their illness, and able to participate in school or camp activities where HIV would be openly addressed. Most of the parents and guardians believed that it was their responsibility to inform their children about the illness.

Finally, no distinct patterns of ethnicity, gender, or family type could be identified in the data to explain which parents or guardians were most likely to

reveal the diagnosis or keep it concealed. Because all the children generated drawings and stories suggesting poor psychosocial health, no differences based on these variables was identified among them.

The discussion of these findings will be presented in the next chapter. They will be considered in light of the strengths and limitations of the study as well as other relevant literature. Implications of the study will be related to future research, clinical practice, and nursing education.

## CHAPTER VI

### DISCUSSION OF THE STUDY

This study explored the psychosocial response of children with HIV infection to communication about the illness by parents and guardians. The children's perceptions about the availability of information and support within their families as well as their self-image and emotional state were elicited in order to evaluate whether parents and guardians gave them the information they needed. The strengths and limitations of the study, the relationship of the findings to the literature, and the implications of the findings will be discussed in this chapter.

#### Strengths

It is a rare opportunity for an investigator to conduct research about a topic that is surrounded by fear, hatred, and death. The obstacles to such research are magnified immeasurably when the focus is upon children whose identity parents wish to keep hidden in order to protect them from the ridicule and harm of others. Such oppressive and threatening social conditions in which children with HIV infection and their families live make it difficult for anyone from the 'outside' to enter their secretive worlds.

At the time parents, guardians, and children initially sought care in the UCSD Mother-Child HIV Program, they entered an uncertain world, not knowing

if their secret could be entrusted to the health care professionals who would manage their children's care. As time went on, it was not uncommon for parents and guardians to give the investigator, and other members of the health care team, highly confidential information about risk behaviors such as bisexuality, drug use, and previous sexual encounters never before disclosed. Such intimate knowledge of the lives of these families placed the investigator in a position similar to that of a trusted family member. Their willingness to allow the investigator to enter their lives for the purposes of this research was a privilege not likely to be extended to someone unknown to them. Therefore, this study provides a unique opportunity to learn about the experience of families living with HIV and AIDS.

Another strength of the study was the feedback given the investigator by the parents and guardians during their interviews. Many of them expressed appreciation for the opportunity to discuss a topic that had been troubling them for some time. For several, the conversation with the investigator represented the first time they were able to verbalize their thoughts and feelings about their fears and what they should say to their children. The process of the investigation was as important to them as the findings.

#### Limitations

In addition to the strengths of the study, there were also limitations. First, the findings of this investigation should not be applied to other populations of parents, guardians, and children with HIV infection because of the qualitative

design of the study. Second, while two-thirds of the participants were Latino, no conclusions about the impact of ethnicity and culture on the findings should be drawn from the study because there were insufficient numbers of other cultural groups represented to warrant such comparisons.

Third, the poor psychosocial health of the children who participated in the study cannot be directly and entirely attributed to the patterns of communication about their illness within their families. There were many other variables to explain their psychosocial distress. In addition, it is quite possible that if the children had been interviewed on another day, they might have produced drawings with very different themes than those they projected at the time of their interview. Nevertheless, the data from this investigation are useful for generating important questions for further study because they illuminate for the first time the inner world of children living with HIV infection and the struggle of their parents and guardians to reveal the illness.

#### Cultural Considerations

The data from the study did not elucidate any major religious or cultural conditions which influenced what parents or guardians said about the illness. When asked for their perspective, the majority of adult participants seemed puzzled by this line of inquiry. Only one father, an African American, was able to identify how the stigma of his daughter's illness reminded him of the racial discrimination he had experienced throughout his own lifetime. For this reason,

he wanted to protect his daughter from knowing about her illness, although he indirectly disclosed it 1 month before the study.

There may be several explanations for the inability of the investigator to elicit how religious and cultural beliefs influenced what parents and guardians said. For some, there may have been a reluctance to reveal information of this nature to the investigator, who did not share a similar ethnic or cultural background with the majority of the participants. For others, spiritual or cultural beliefs may have been difficult to identify or articulate because these are so deeply internalized and embedded in the thoughts and acts of daily life. Consequently, their influence upon what parents and guardians said may not have been easily evaluated.

Strategies to capture these data in future studies might include: (a) the use of interviewers whose ethnic and cultural identity is similar to the participants, (b) descriptions of how cultural beliefs influence what people say or do in other situations, and (c) a set of written questions given to the participants in advance of the interview to allow time to process these ideas. In future studies, it will be important to document successful strategies when conducting research with culturally diverse populations, particularly those involving vulnerable groups of parents and children.

### Practical and Theoretical Findings

Because parents and guardians are ultimately responsible for the well-being of children, interventions designed to benefit the health of children are often

directed at their parents. For this reason, the investigator sought to understand their perspective. Without this knowledge, recommendations about improving the psychosocial health of children with a stigmatizing, life threatening illness may never be implemented by parents and guardians if they are only based upon the children's point of view. Parental readiness to tell was therefore identified as the predominant dimension to emerge from the data because it determined if, when, and what children were told about their illness and potentially impacted their psychosocial health. This dimension represented the opportunities parents and guardians provided their children to ask for and receive information about the illness and support for their self-image and emotional health.

The ability of parents and guardians to overcome fear of discrimination was critical to their capacity to create a open, hopeful dialogue with their children about the illness. Before parents and guardians were able to reveal the diagnosis to their children, they told other family members and friends in order to estimate the risk of rejection and hostility. Often these conversations involved the disclosure of their own HIV diagnosis, or that of their spouse or adult child. Parents and guardians believed that children who were told about the stigma of the disease and its association with suffering and death would be harmed by this knowledge. For these reasons, they avoided conversation about the illness with their children. This avoidance took place over intervals of 2 to 8 years, depending upon when the children were first diagnosed and when and if they were eventually informed about their illness. It is not difficult to comprehend

how such protracted silence, secrecy, and isolation impacted the psychosocial health of the children in the study, even for those who were finally told.

The family circumstances of the children also added practical significance to the findings of the study. For example, there were many traumatic experiences which impacted the psychosocial adjustment of all the children in the study. The parents of six children had already died of AIDS. The violent death of one father, the cancer-related deaths of two other parents, and the estrangement of three of the children from a surviving parent more than likely significantly influenced the depiction of emotional distress in their drawings and conversations. In addition, the social discrimination experienced by two of the children because of their mother's HIV diagnosis must have severely impacted their self-image and emotional health. These experiences, along with the physical effects of the disease, painful procedures, and unpleasant daily medications were more than enough to explain the pervasive themes of distress found in the children's drawings and conversations.

#### Theoretical Model

Given the overwhelming evidence of distress among the children, attention should be directed toward the development of interventions which will ameliorate this distress. This may be done by evaluating the components of the process of communication in the investigators's model of interaction between parents or guardians and their children (see Figure 1).

The model is useful because it illustrates the key conditions which emerged from the study to influence parental readiness to tell. The conditions were conceptualized in three domains: cognitive, perceptual, and physiological. There were three parental conditions: (a) beliefs about telling children about life-threatening illness (cognitive), (b) fear of stigma and death (perceptual) and (c) illness and death (physiological). Three conditions found in the study related to the children: (a) their intensity of questions about their illness or their parent's (cognitive), (b) their social and emotional response (perceptual), and (c) signs of their illness (physiological).

As the conditions evolved over time, the parents and guardians were more capable of revealing the illness. For example, when the stigma of the illness seemed less threatening to the parents and guardians because of support they received from others they had already told, they began to consider informing their children. In a similar way, as the children's cognitive and emotional capacities developed from the point of diagnosis, they began to ask about their illness. While there is no historical data from this interval to suggest how the children who were told perceived the availability of information about their diagnosis prior to disclosure, the children's drawings and stories from this investigation indicate that whatever information and support they were given was not enough to alleviate their distress. Had parents and guardians been aware of this earlier, it is possible they might have been inclined to say more about the illness.

There were other ways in which the conditions which emerged from the study related to parental readiness to tell. For example, as the conversations with the parents and guardians suggest, the illness and death of parents had a profound influence on what parents and guardians said to their children about the illness. Many parents and guardians reported that a parent's illness or death from AIDS or another disease delayed disclosure, even though some of them perceived their children to be old enough to know that something was wrong.

At the same time, two-thirds of the children in the study had developed visible signs of their own illness and required more frequent clinic visits and daily medications. The pervasive themes of threat and distress found in their drawings and stories indicate they were aware of the seriousness of their illness as well as their parent's. This awareness prompted many of the questions their parents and guardians reported they asked. Again, had parents been aware of the extent of the children's knowledge about their own illness, as well as the parent's, they might have decided to engage their children in a more open dialogue about the illness.

The patterns of communication, labeled parental readiness to tell, which emerged from the study were found to be consequences of these conditions. These interactions were revealing, pretending, and concealing the illness. They may be better understood by considering them within the framework of "awareness contexts" developed by Glaser and Strauss (1965). Their framework is useful for understanding how one context leads to another and the potential of this

process for transforming an interaction into one that embodies less psychosocial distress.

In their study of hospitalized dying patients and their interaction with families and hospital personnel, Glaser and Strauss proposed that social interaction can be explained by four types of awareness about the patient and the illness. They described their typology in the following manner:

An open awareness context obtains when each interactant is aware of the other's true identity and his own identity in the eyes of the other. A closed awareness context obtains when one interactant does not know either the other's identity or the other's view of his identity. A suspicious awareness context is a modification of the closed one: one interactant suspects the true identity of the other or the other's view of his own identity, or both. A pretense awareness context is a modification of the open one: both interactants are fully aware but pretend not to be (p. 670).

In this investigation, no examples were found in the data for the closed awareness context. Most of the children in the study had been deliberately informed about their illness by either parents or guardians. Four had not been told: Alana, Ana, Sonia, and Jorge. Unfortunately, Alana declined to draw or be interviewed so that her awareness of her illness is unknown. The second child, Ana, displayed barriers to communication in her adopted family (see Figure 7) and themes of threatening weather and death in her drawings (see Figures 19 & 31), indications that she may have had some awareness of her illness. She was

relatively asymptomatic and did not require daily HIV-related medications, but she had monthly blood tests and had suffered a serious infection in her blood in the past year which did not require hospitalization.

Jorge, who had hemophilia and profound immunosuppression from his HIV infection, had experienced several painful dermatological conditions and had difficulty gaining weight. Diagnosed when he was three, he had been accidentally informed by medical personnel a year before the study. He knew the names of all of his HIV-related medications and knew when and how to take them. His drawings (see Figures 9, 16, 25, & 26) demonstrated his severe depression, isolation, and distress. Both Ana and Jorge exemplified the suspicion awareness context, where one interactant, in this case both children, suspected the truth about their illness.

Abundant evidence for the open and pretense awareness contexts was found in the interview and drawing data. Several families displayed signs of an open awareness context after the diagnosis was revealed. In one case, the interview data of Migel's mother was congruent with the themes of anger and depression depicted in his drawings (see Figures 5, 11, 33, and 34). He was informed about his illness 1 year before, 7 years after he was diagnosed,

"He's angry for getting sick because of his HIV . . . he complains [about] feeling uncomfortable, going to the doctor, all of that."

In another case, Carla's grandmother reported what her granddaughter understood about her illness, which was diagnosed 2 years before and revealed to her 1

month before the study. Her daughter died of AIDS the year before the grandmother was interviewed,

" . . . she has told me is that she is having the same symptoms as her mother."

Carla's drawings (see Figures 2, 22, & 24) depicted her depression and the sense of mortality she verbalized to her grandmother.

There were several examples of pretense awareness context among the families who participated in the study. In this case, both interactants (parents or guardians and children) were fully aware of the children's illness, but pretended not to be. This type was best represented by Sonia who was diagnosed 4 years before and had not yet been informed about her illness. Her comments about her Person drawing demonstrated how she pretended not to know about her illness,

"She knows because when she comes to my house, she sees that I drink medicines and she asks 'why do I have to take medicines . . . ?' And I told her 'cause I don't really know about that but my mom does know. And my mom tells her 'cause I need to eat more."

It is not surprising that her drawings depicted themes of isolation and depression (see Figures 8, 17, & 21).

In retrospect, efforts on the part of parents, guardians, and health care professionals to conceal the diagnosis from the children represented attempts to maintain a closed awareness context, where the stigmatizing, life-threatening

nature of the illness was not acknowledged. Children who might have been truly unaware of their illness while they were asymptomatic inevitably suspected that something was wrong as their physical condition deteriorated and as their cognitive and emotional capacities developed. During this process, they moved to a suspicion awareness context.

Parents and guardians in the study reported that three children never sought clarification about their illness from the time of their diagnosis until their parents and guardians decided it was time to inform them. If children as young as 3 years of age were aware of their cancer diagnosis, a finding from Bluebond-Langer's research (1978), then it is possible that the children in this study suspected for several years and experienced similar feelings of isolation and distress.

For children who were certain about their diagnosis but pretended not to know, they entered the pretense awareness context where considerable energy and care were needed to convince parents and guardians that they were still unaware of their illness. Bluebond-Langer (1978) proposed that the children in her study did this in order to protect their parents from engaging in conversations that were too painful. The fact that some of the children with HIV infection in this study demonstrated no visible reaction when the diagnosis was accidentally, indirectly, or deliberately revealed supports the possibility that they still found it necessary to engage in what Bluebond-Langer called "mutual pretense," even though at that moment their parents or guardians may have been ready to tell.

The data from this study did not demonstrate more positive indicators of psychosocial health among children who entered the context of open awareness once they were told about their diagnosis and acknowledged this awareness. This finding can be explained by the fact that the children remained in either a closed, suspicion, or pretense awareness context far too long, where they did not receive sufficient information and support. Instead, they suffered their debilitating, stigmatizing, life-threatening illness in chronic silence and isolation.

#### Synthesis of Findings with Relevant Literature

The children's drawings and stories indicated that many of them were aware of the life-threatening nature of their illness. This finding is consistent with research in childhood cancer, which suggested similar levels of awareness among school-age children (Bluebond-Langer, 1978; Malone, 1982). Related studies found that children who perceived themselves to be ill blamed themselves for their disease and suffered a loss in self-esteem (Bibace & Walsh, 1980; Kister & Patterson, 1980). These findings may explain the poor self-image suggested by the children in their drawings in this investigation.

The lengthy duration between diagnosis and disclosure found in this study during which the illness was concealed may explain, in part, why the children's drawings and stories did not suggest better psychosocial health. This finding is consistent with studies in childhood cancer, which found that poorer long-term psychological adjustment was associated with children who: (a) were informed about their illness more than 1 year after diagnosis, (b) were informed after the

age of 6 (if diagnosed as an infant), or (c) discovered their diagnosis on their own or were accidentally told by someone outside their family (Slavin et al., 1982; Spinetta & Maloney, 1978). Binger (1984) also suggested that children with cancer who were not told about their illness suffered emotionally because of lost opportunities to receive realistic hope from their parents and health care providers.

The findings from this study also lend support to other pediatric HIV literature which suggested that parental fear of the stigma of the illness would lead to its concealment from children with this diagnosis as well as others outside the immediate family (Olson et al., 1989; Spiegel & Mayers, 1991). The fear of the stigma of the illness and its potential to hurt the children was repeatedly mentioned by the parents and guardians, who took elaborate steps to keep the diagnosis concealed. Goffman (1963) described this process more than three decades ago in his discussion of how parents managed information about their children's stigmatizing conditions in order to protect their identity.

The parents and guardians reported that the need to keep the diagnosis secret also led to social isolation, preventing them from seeking sources of social support for themselves and their children that might have ameliorated their distress. This finding has also been described in the literature (Andrews et al., 1993; Meyers & Weitzman, 1991; Sharts-Hopko, Regan-Kubinski, Lincoln & Heverly, 1996; Spiegel & Mayers, 1991). Similarly, the social isolation of the parents and guardians in this study was described in research involving families

with childhood cancer. They also experienced stigmatization because of their children's illness (Van Dongen-Melman & Sanders-Woudstra, 1986).

In summary, the findings from this study support much of the related literature found in writings about stigma, childhood cancer, cognitive and emotional development, and pediatric HIV infection. The process of interaction and communication about the illness between parents, guardians, and children with HIV infection found in this investigation embodied many of the constructs already described in the literature.

#### Nursing Implications

Because the optimal care of children with HIV infection is multidisciplinary, implications derived from this study should be utilized by nurses as well as other pediatric professionals. The findings from this study are relevant in three areas: research, practice, and education.

#### Nursing Research

Several implications can be drawn from the study. First, it demonstrates a way to conduct qualitative research directly with children about sensitive issues that are important to investigate. This information is needed because there are relatively few qualitative studies involving children reported in the literature. Of those, only a handful incorporate the use of drawings. This approach, however, has begun to receive more attention in recent years, particularly in the nursing literature (Malkiewicz & Stember, 1994). The combination of two interpretive methods, grounded theory and projective drawings, to elicit experiential data from

children represents an attempt to add knowledge to the much needed body of literature which addresses qualitative research with children.

Second, this investigation has implications for research involving vulnerable participants. Its feasibility was highly dependent upon the investigator's identity as a member of the multidisciplinary team which provided the children's clinical care. Because the study concerned an illness surrounded by considerable secrecy and fear in a vulnerable population already overwhelmed by a number of social stressors, its completion depended upon several important factors: the therapeutic relationship already established by the investigator with the participants, the integration of the interviews into the schedule of care the children were already receiving, and the flexibility and availability of the investigator when unpredictable events required an interview to be rescheduled. In addition, there were times when the study created an additional burden to the already difficult work of the clinical support staff. Their assistance and support, however, were crucial to the completion of the study and cannot be emphasized enough.

The findings from this study need to be confirmed in three specific areas. First, does the core category, parental readiness to tell, and its conditions and consequences describe the process of communication in other populations of parents and guardians caring for children with HIV infection? Replication of this research with other cultural groups would enhance understanding of the influence of the Latino culture upon the findings of this study. Second, can the children's psychosocial responses found in this study be identified in other groups of

children living with HIV through the projective techniques selected for this investigation? Third, can cases be found in other studies to represent a closed awareness context? If so, how would this finding relate to the children's psychosocial health?

These questions could be answered through the design of larger, longitudinal studies that would capture data over time and better elicit how the process of communication evolves. Once the validity of these findings is established, interventions should be tested and correlated with measures of coping, social support, psychological distress, and disease progression.

### Nursing Practice

The need for this study evolved from the clinical practice of the investigator who had been involved in the care of children with HIV infection and their families through the UCSD Mother-Child HIV Program. The study was conducted in order to address an important clinical problem: how to advise parents and guardians about talking with their children about the illness. Data from the interviews and drawings demonstrated the complex and reciprocal nature of communication between parents and children about their life-threatening, stigmatized illness. Many factors influenced what parents said and how their children responded socially and emotionally. The findings suggest that the children's response reinforced what parents continued to say as time went on.

In retrospect, the health care professionals involved in the care of the children, parents, and guardians did not do enough to foster an on-going dialogue

about the illness among the participants in order to address parental fears and ameliorate the children's psychosocial distress. In order to better serve these children and their families in the future, projective techniques should be an integral component in the assessment of children's social and emotional health to determine their need for information and support. This assessment should be ongoing, just as other aspects of the children's illness are regularly monitored. Specific interventions that are culturally and developmentally appropriate can then be recommended to facilitate an open dialogue about the illness. These might include individual counseling as well as the development of support groups for parents, guardians, and children with a focus on maintaining an open, hopeful dialogue about the illness.

It should be stated here that the strategies already developed by the UCSD Mother-Child HIV Program to provide culturally-competent advocacy, information, and support to the children and families in their care, particularly those who are Latino, should continue to be utilized. These strategies include the recruitment and assistance of bilingual, bicultural staff, the assignment of a Latino "buddy" or mentor to families who are newly diagnosed, and the sponsorship of activities and facilities which provide respite, recreation, and socialization.

#### Nursing Education

Preparation of nurses to care for future populations of children with HIV infection should take place primarily on the graduate level. It is at this point of development that students are more able to synthesize knowledge of complex

physiological and psychological conditions within a sociocultural context that affects children and their families who are often vulnerable and in need of multiple levels of care. Moreover, an ethical framework of decision-making is needed to sort out the sometimes conflicting needs of individual children, parents, other family members, and the community.

Nursing faculty should seek opportunities for graduate students to gain experience in the care of children and families living with stigmatized, chronic, life-threatening illness in outpatient, community, and home environments. This becomes increasingly important as the majority of health care services for chronic illness moves out of tertiary care settings.

#### Summary

From conceptualization of the study through analysis of the interviewing and drawing data, the investigator's interest was to understand how parents, guardians, and children managed and responded to information about a devastating illness that threatened the survival of at least one family member, and often more. This understanding was needed because parents and guardians were often reluctant to reveal the nature of the illness to children even when they were old enough to grasp that something was wrong, as the data from the study suggest. Because the benefits of telling children about life threatening illness found in other studies were not valued sufficiently by parents and guardians of children with HIV infection, it was difficult to persuade them to tell. Therefore, the findings from this investigation will provide a greater understanding of what

**children with HIV infection and their parents or guardians need in the form of information and support. This knowledge will foster development of interventions to improve the psychosocial health of children living with HIV.**

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## APPENDIX A

## DESCRIPTIVE SUMMARY ABOUT CHILD PARTICIPANTS

<u>Pseudonym</u>	<u>Age</u>	<u>Descriptive Summary</u>
Ana	6.4	Lives with adoptive parents and siblings past 3 years. Estranged from biological parents. No visible signs of illness. Not told, diagnosed 3 years ago.
Sara	6.4	Lives with adoptive parents and siblings past 5 years. Estranged from biological parents. Poor weight gain and growth (rash). Told 1 month ago, diagnosed 6 years ago.
Tanya	6.5	Lives with maternal grandmother and siblings past 4 years. Mother sick with AIDS. Father killed 1 year ago. Poor weight gain and growth (rash). Told 1 month ago, diagnosed 3 years ago.
Alana	6.7	Lives with father and brothers. Mother died of AIDS 1 year ago. No visible signs of illness Not told, diagnosed 4 years ago.
Brisha	6.9	Lives with father. Mother died of AIDS 4 years ago. Poor weight gain and growth. Told 1 month ago, diagnosed 4 years ago.
Chris	7.8	Lives with maternal grandmother. Mother died of AIDS 5 years ago. No visible signs of illness Told 1 year ago, diagnosed 7 years ago.

<u>Pseudonym</u>	<u>Age</u>	<u>Descriptive Summary</u>
Jamie	7.9	Lives with mother who has AIDS. Father died of AIDS 1 year ago. Poor weight gain and growth (rash). Told 8 months ago, diagnosed 4 years ago.
Sonia	8.3	Lives with both parents and brother. Mother very sick with AIDS. Dad with HIV, but fewer signs of illness. No visible signs of illness. Not told, diagnosed 4 years ago.
David	8.3	Lives with maternal grandmother. Mother died of AIDS 1 year ago. Mediport, biweekly infusions. Told 3 years ago, diagnosed 5 years ago.
Carla	10.1	Lives with maternal grandmother and cousins. Mother died of AIDS 1 year ago. Poor weight gain and growth. Told 1 month ago, diagnosed 2 years ago.
Migel	10.7	Lives with mother and brother. Father died of cancer 2 years ago. Poor weight gain and growth (rash). Told 1 year ago, diagnosed 8 years ago.
Jorge	11.8	Lives with maternal aunt and uncle, siblings and cousins. Mother died of cancer 4 years ago. Hemophilia, Mediport, poor weight gain and growth (rash). Not told, diagnosed 8 years ago. Accidental disclosure 1 year ago.

## APPENDIX D



Instone Proposal

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UNIVERSITY OF CALIFORNIA - SAN DIEGO

CONSENT TO ACT AS A RESEARCH SUBJECT

Susan Instone M.S.N., C.P.N.P. is conducting a research study to find out more about how children with HIV infection respond emotionally to information they have been given by their parents about the illness. My child and I have been asked to take part because my child has HIV infection.

If I agree to be in this study, I will be interviewed for approximately one hour at the UCSD Treatment Center without my child present. Next, Ms. Instone will meet with my child for about 30-45 minutes without myself present. My child will be asked to draw four pictures and tell a story about them. I will then be invited to join my child so that I can review what my child has drawn. I may also be asked to talk with Ms. Instone a second time for about 30 minutes. If I agree, all conversations will be audiotape recorded. If I prefer to speak Spanish during these interviews, an interpreter will assist Ms. Instone.

If my child or I reveal information about abuse or neglect that my child may have experienced, Ms. Instone is required by law to report this information to Child Protective Services, County of San Diego.

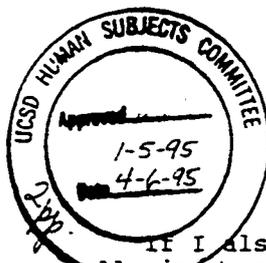
I may ask questions before I sign this consent and that later I can call Susan Instone at 543-8080 if I have any further questions about the study.

The conversations will be confidential and audiotapes and transcriptions will not be identified with my name. Furthermore, they will be kept in a locked file when not in use. Ms. Instone will only use the following terms about my child's illness when interviewing my child (please initial in the space provided):

\_\_\_\_\_ I do not want Ms. Instone to disclose any information to my child about his/her HIV infection.

\_\_\_\_\_ The following information may be shared with my child.

Name of illness \_\_\_\_\_  
 My child's stage of illness \_\_\_\_\_  
 Name of medicines \_\_\_\_\_  
 Reason for coming to clinic \_\_\_\_\_  
 \_\_\_\_\_  
 Reason for blood draws \_\_\_\_\_  
 \_\_\_\_\_  
 How my child became HIV infected \_\_\_\_\_  
 \_\_\_\_\_



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Instone Proposal

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If I also have HIV infection, Ms. Instone will only use the following terms about my illness when interviewing my child (please initial in the space provided):

\_\_\_\_\_ I do not want my child to have any information about my illness.

\_\_\_\_\_ The following information may be shared with my child about my illness.

Name of illness \_\_\_\_\_

Stage of my illness \_\_\_\_\_

Name of medicines I take \_\_\_\_\_

Reason I go to the clinic \_\_\_\_\_

How I became HIV-infected \_\_\_\_\_

There may be no direct benefit to me or my child as a result of our participation in this study. The investigator may learn more about how children with HIV infection feel about what they have been told about their illness. This knowledge will help nurses and doctors counsel parents about what to tell their children about HIV and AIDS.

There is little risk to me or my child, except that we may be uncomfortable with some of the questions. If there is anything my child or I do not wish to discuss, we may refuse to answer and we may end the conversation at any time.

Participation in this study is entirely voluntary. My child and I may withdraw at any time without jeopardy to the medical care my child is already receiving at this institution.

I have received a copy of this consent document to keep and "The Experimental Subject's Bill of Rights."

I agree to participate. I agree to have my conversation audiotaped.

\_\_\_\_\_  
Signature of Subject

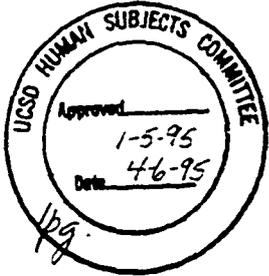
\_\_\_\_\_  
Date

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Signature of Researcher

\_\_\_\_\_  
Date

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Signature of Witness

\_\_\_\_\_  
Date



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Instone Proposal

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UNIVERSITY OF CALIFORNIA - SAN DIEGO

CONSENT TO ACT AS A RESEARCH SUBJECT

Susan Instone M.S.N., C.P.N.P. is doing a study to find out what it is like for children who have to take medicine every day or have to come to clinic to get shots. I have been asked to take part because I come to clinic alot.

If I want to be in her study, I will meet with her for about one half hour at the UCSD Treatment Center. She will ask me to draw four special pictures and then ask me some questions about them. If I agree, Ms. Instone will use a tape machine to record what I say. She will not put my name on the tape.

If I get tired or I don't feel like drawing or talking anymore, I can stop at any time.

I agree to be in her study. I agree to talk into a tape recorder.

_____	_____
Signature of Child	Date
_____	_____
Signature of Parent	Date
_____	_____
Signature of Researcher	Date

## APPENDIX E



95-9  
Propuesta de Instone  
14

Page 1

UNIVERSIDAD DE CALIFORNIA, SAN DIEGO  
DOCUMENTO DE CONSENTIMIENTO PARA PARTICIPAR COMO  
SUJETO EN INVESTIGACION.

Susan Instone M. S. N., C. P. N. P. está conduciendo un estudio de investigación para saber más acerca de como los niños con HIV responden emocionalmente a la información que se les ha dado por sus padres acerca de la enfermedad. A mi hijo(a) y a mi se nos ha pedido participar porque mi hijo(a) está infectado con HIV.

Si acepto participar en este estudio, seré entrevistado(a) aproximadamente por una hora en el Centro de Tratamiento de UCSD sin que esté presente mi hijo(a). Después, la Sra. Instone verá a mi hijo(a) de 30 a 45 minutos sin que yo esté presente. A mi hijo(a) se le pedirá que haga cuatro dibujos y que diga una historia acerca de ellos. Entonces se me pedirá que me reúna con mi hijo(a) para que revise lo que mi hijo(a) dibujó. También quizá se me pida que hable con la Sra. Instone una segunda vez por aproximadamente 30 minutos. Si acepto, todas las conversaciones serán grabadas en un cassette. Si prefiero hablar español durante estas entrevistas, un interprete ayudará a la Sra. Instone.

Entiendo que tal vez se me harán preguntas antes de que firme el documento de consentimiento y que más tarde puedo hablar con Susan Instone al 543-8080, si tengo otras preguntas acerca del estudio.

Entiendo que las conversaciones serán confidenciales y que las grabaciones en el cassette y los documentos no tendrán mi nombre. Además, estarán en un gabinete cerrado con llave cuando no se estén usando. También entiendo que la Sra. Instone usará solo los siguientes términos acerca de la enfermedad de mi hijo(a) cuando se le entreviste (por favor ponga sus iniciales en el espacio correspondiente):

\_\_\_\_\_ Yo no quiero que la Sra. Instone de información a mi hijo(a) acerca de su infección por HIV.

\_\_\_\_\_ La siguiente información podría ser compartida con mi hijo(a).

Nombre de la enfermedad \_\_\_\_\_  
El estado de la enfermedad de mi hijo(a) \_\_\_\_\_  
Nombre de las medicinas \_\_\_\_\_  
Razón por la que viene a la clínica \_\_\_\_\_  
\_\_\_\_\_



95-9  
Propuesta de Instone  
15

Razón por la que se toman las muestras de sangre \_\_\_\_\_

Como fué mi hijo(a) infectado con HIV \_\_\_\_\_

Si yo también tengo la infección HIV, entiendo que la Sra. Instone solo usará los siguientes términos acerca de mi enfermedad cuando entreviste a mi hijo(a) por favor ponga sus iniciales en el espacio correspondiente):

\_\_\_\_\_ yo no quiero que mi hijo(a) tenga ninguna información acerca de mi enfermedad.

\_\_\_\_\_ La siguiente información puede ser compartida con mi hijo(a) acerca de mi enfermedad

Nombre de la enfermedad \_\_\_\_\_

El estado de mi enfermedad \_\_\_\_\_

Nombre de las medicinas que tomo \_\_\_\_\_

Razón por la que vengo a la clínica \_\_\_\_\_

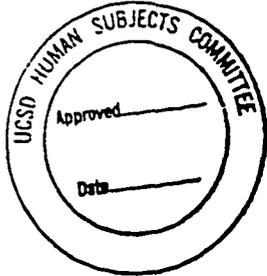
Como fui infectado(a) con HIV \_\_\_\_\_

Tal vez no haya ningún beneficio directo para mí o mi hijo(a) como resultado de nuestra participación en este estudio. La investigadora quizá aprenda más acerca de como los niños con la infección HIV se sienten acerca de lo que se les ha dicho de su enfermedad. Este conocimiento ayudará a las enfermeras y a los doctores a aconsejar a los padres de que deben decirle a sus hijos acerca de HIV y AIDS ("SIDA").

También entiendo que hay poco riesgo para mí y mi hijo(a) con excepción de que quizá exista incomodidad con alguna de las preguntas. Si hay algo que yo y mi hijo(a) no desee contestar nos podemos negar a contestar y podemos terminar la conversación cuando queramos.

La participación en esta investigación es enteramente voluntaria. Yo puedo/mi hijo(a) puede retirarse del estudio cuando yo quiera sin que esto perjudique el cuidado médico que mi hijo(a) ya está recibiendo en esta institución.

Yo he recibido una copia de este documento de consentimiento para conservar y una de "Los Derechos Como Sujeto Participante en Investigación".



95-9  
Propuesta de Instrone  
cont. 15

Yo, la persona que firma a continuación , entiendo las explicaciones anteriores. Yo acepto participar. Yo estoy de acuerdo de que se graben en un cassette mi conversación.

\_\_\_\_\_  
Firma del Sujeto

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Nombre del Investigador

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Firma del Testigo

\_\_\_\_\_  
Fecha

Translation by Dr. Gloria E. Bensussen