# PHYSICALLY ILL CHILDREN'S SELF-PERCEPTIONS AND THE MOTHER'S PERCEPTIONS OF HER CHILD'S NEEDS

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LUPE REBEKA SAMANIEGO

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Thesis Approved:

Thesis Adviser

Barbara J. Weiner

BoldHelm

Dean of the Graduate College

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#### CHAPTER I

#### INTRODUCTION

There is a general tendency in our society to avoid the topic of death or to repress concerns associated with it. Studies have shown, however, that while individuals may overtly express indifference toward death, many negatively-toned feelings and emotions are observed when projective techniques are employed to assess covert behavior (Roberts, Kimsey, Logan and Shaw, 1952; Alexander, Colley, and Alderstein, 1957; Jeffers, Nichols, and Eisdorfer, 1961).

Children's questions concerning death are often neglected or not fully answered (Mitchell, 1967). "Though death is one of the most frequent clinical syndromes even in childhood, the management of the dying child is superficially discussed or is completely ignored in most textbooks that deal with children "(Easson, 1970, p. 5).

New sophisticated parents, who talk easily with their children about sex and birth, find it hard to speak with them about death and its meaning. But when anything as prevalent as death is excluded from easy communication, it creates an emotional vacuum into which fear and anxiety, mystery and uncertainty come (Jackson, 1965, p. 45).

However, studies show that children whose parents had been more open in discussing death with them had better control and more appropriate feelings when dealing with the concept of death and were better able to imagine conditions in which they would die comfortably (Golburgh, Rotman, Snibbe and Ondrach, 1954; Portz, 1965).

The overall research in the area of death and dying is very limited. It is even more lacking when dealing with the dying patient, especially the child. Yet, investigations into the dynamics of the dying child would contribute to medical progress in further understanding the emotional concomitants to physical illness. Investigations would aid tremendously in the prediction, and in the understanding, of the dying child's needs, as well as his family's. Therapy programs specifically aimed at reducing the emotional suffering incurred by the dying child could then be established.

The present literature review will explore three aspects of death as they are related to the child. First, the general understanding of death as conceptualized at different ages will be reviewed; second, studies concerning children with a life-threatening disease will be summarized; and third, the emotional responses of physically ill children's parents and their effect on the child will be explored.

# CHAPTER II

# REVIEW OF THE LITERATURE

# A. Concepts of Death at Different Age Levels

A child's conception of death differentially develops with age. Through the use of varied projective techniques investigators have observed the attitudes of children regarding death; such techniques have included written compositions, drawings, story completion tests, and recorded discussions of death (Cousinet, 1939; Anthony, 1940; Gessel, 1940; Nagy, 1948). Researchers have found from three to five different stages of development in children's thoughts about death (Cousinet, 1939; Anthony, 1940; Nagy, 1948; Peck, 1966). Childers and Wimmer (1971) noted that children not only understand the universality of death, but observed that their understanding increases as their age level increases. Peck (1966) found that the development of children's thinking about death was influenced by the mental age or I.Q. of the child. When chronological age was held constant, the level of understanding was positively correlated with mental age. Specifically, she found that the levels of understanding in children with average I.Q.'s were significantly different from the levels of understanding in children with high I.Q.'s. The concept levels, however, were not significantly different in the low and average I.Q.'s. The social class position of the child's family did not appear to modify the development of the concept of death in the child.

There is not a clear understanding of the meaning that death has to a child before the age of four or five. However, different observations in the young child's views of death have been noted. These include the child regarding death as equivalent to a departure, sleep, or going on a journey (Nagy, 1948; Freud, 1952). Mitchell (1966, p. 55) acknowledged that before the age of four or five children "recognize death as a change of state. Immobility is almost synonymous with death." According to Cousinet (1939), young children may not accept the idea of death altogether. Illig and Bates-Ames (1955) stated that under the age of five it is extremely difficult to discover what meaning a child attaches to death.

In summary, it is apparent that there is a vague understanding of the meaning that death has to a young child. Researchers agree that young children before the age of four or five can sense loss. Yet, a child in this age period does not conceptualize death as a final process (Anthony, 1940; Gessel, 1940; Nagy, 1948; Jackson, 1965; Mitchell, 1967). Therefore, death is not seen as a biological process during this age period.

Between the ages of five and nine children attach meaning to death, but rarely in biological terms (Cousinet, 1939; Anthony, 1940; Gessel, 1940; Nagy, 1948; Jackson, 1965). Nagy (1948) noted that during this age period, death is often personified and that it is made contingent upon the actions of others. Cousinet (1930) acknowledged that children in this age period sometimes substitute a severe but curable illness for death. According to Gessel (1940), a seven year old child may express a morbid concern in death's rituals; he may also begin to

suspect his own mortality. As the child matures, however, he is able to accept the idea that he himself may one day die.

A certain degree of maturation, therefore, has to be reached before there is any realization that death is a final, biological process. A young child before the age of five conceptualizes death as a temporary process. A child between the ages of five and nine has not yet reached the maturity needed to view death as a terminal process. However, it is not until the ages of eight or nine that the concept of death is referenced as a biological process. It is also during this eight to twelve age period that the realistic conception of death occurs (Cousinet, 1939; Anthony, 1940; Gessel, 1940; Nagy, 1948; Jackson, 1965).

Piaget (1959) dealing more specifically with the child's concept of life agrees that between the ages of eight and twelve the child defines life by movement. This is followed by a stage in which life is regarded as the property of animals and plants. During this age period the child clearly distinguishes between animate and inaminate objects.

While the conceptualization of death as a biological process occurs somewhere between the ages of eight and twelve, the disappearance of death as a troublesome concept also occurs during this period. Alexander and Alderstein (1958) conducted a study which measured whether children in three age groups responded to death words with greater latencies and increased galvanic skin responses (GSRs) than they did to basal words. While children in the five through eight— and thirteen through sixteen— age groups showed significant decreases in skin resistance to death words when compared to basal words, the nine through twelve age group showed no reliable differences in skin resistance to

death words as compared to basal words. They discussed their results in terms of cultural expectations and ego stability found in the nine through twelve age group. They stated:

...the interval from the ninth through the twelfth year has been labelled the pre-adolescent period, a time of latency. Measured in terms of psychological stress it is generally regarded as being a rather benign age. Roles are well defined. Aggressive outlets are sanctioned by the culture in games and activities. In short, no great new demands are introduced. It is, as life goes, a 'Golden Age.' During this period questions about death disappear from the conscious repertoire as though this matter is no longer of interest. Children at this age seem to be too much involved in the routine of life and its attendant pleasures to be concerned with the concept of death (p. 175).

In summary, literature on the child's conception of death is limited. There is general agreement, however, that the age group between the eighth and twelfth year conceptualizes death as a final process. A child in this age period seems to have reached the maturity needed to view death as a biological process. Yet, thoughts about death and dying are less frequent in this age range. Characteristic of this pre-adolescent period is the lack of psychological stress which is generally encountered in other age groups. Therefore, a child in this age group may not respond with increased emotional intensity to the concept of death due to demands placed upon him (Alexander and Alderstein, 1958).

# B. Children with a Life-Threatening Disease

Just as the psychological literature contains very few controlled observations on the physically well child's view of death, controlled studies considering the reactions of children who are actually dying are also very scarce. Of those studies that have been conducted,

researchers have noted a resigned, apathetic, and fatalistic approach to life in children with a life-threatening disease as their disease progressed (Richmond and Waisman, 1955; Murstein, 1958; Natterson, 1960; McCully, 1963; Waechter, 1969). Regardless of the level of awareness about the prognosis of his illness, a child with a life-threatening disease is constantly faced with threats to his self-image (Freud, 1952; Bergmann, 1966). His feelings of self-worth and basic trust are constantly challenged (Hoffman and Futterman, 1971). A child with a life-threatening disease is basically an insecure child who suffers much anxiety about his illness (Natterson, 1960; Morrissey, 1963; Easson, 1970). These feelings with which the child with a lifethreatening illness must cope, however, are often not directly observable. Explicit or overt concern about death is less prevalent (Richmond et al., 1955; Hoffman et al., 1971). Yet, when projective techniques have been employed, researchers have noted that children with a life-threatening illness express themes of loss and loneliness more often than do well child controls (Murstein, 1958; McCully, 1963; Waechter, 1969). Their feelings are projected onto dolls and puppets (Hoffman et al., 1971). Waechter (1969) has also noted that the themes of children with a life-threatening disease contained much more threats to body integrity than did a comparison group.

In brief, the life of a child with a life-threatening illness involes constant interruptions and separations. Doctor's visits, medical
procedures, and hospitalization are but few of the forces with which
he must cope and over which he has very limited control. He must also
cope with feelings of loss, loneliness, anxiety and fear that may
accompany his life-threatening illness. There is usually very little

communication concerning his illness between himself and his parents (Hoffman, et al., 1971). As a result, his feelings are rarely verbalized.

This failure of the child to communicate concerns about death and dying has been attributed to taboos placed upon the subject in our culture (Glaser and Strauss, 1968; May, 1969; Kubler-Ross, 1969; Hoffman et al., 1971) rather than to a lack of awareness on the part of the child. There is also an attempt to repress the anxiety concerning death in our culture (Richmond et al., 1955; May, 1969; Easson, 1970).

In summary, a child with a life-threatening disease must cope with feelings of loss and loneliness, with threats to his self-image, and with his anxieties about his illness. There is a general tendency to repress feelings about death and dying in our culture, and a general lack of parent-child communication concerning the child's fears and illness.

# C. The Effects of Parental Attitudes on the Physically Ill Child

Coupled with the insecurities that his illness may bring, the child with a life-threatening disease must also cope with the emotional turmoil experienced by his immediate family, especially his mother.

The mother-child relationship has been regarded as playing an essential role in the child's illness (Freud, 1952; Natterson, 1960). Dealing specifically with children with a life-threatening disease, Natterson (1960) concluded that children's illnesses constituted death threats to their mothers. He noted:

The mother-child relationship is generally regarded as the most reciprocally intense of interpersonal relationships. It is assumed that, because of the maximal intensity of the relationship, identification of the mother with the child is maximal in these cases. Therefore, the threat of death to the child poses a symbolic threat of death to the mother and consequently should ellicit reactions to the threat in the mother. In a sense the mother faces death, experiences it, and survives it (p. 461).

Natterson (1960) observed that mothers of leukemic children who survived more than four months from the time of the diagnosis experienced three phases of reaction. Denial of the child's prognosis was characteristic of the first phase. In the second, the mothers directed their energy toward measures that offered hope of saving their child. The third phase marked the acceptance of the prognosis. However, the mothers tended to direct their energy toward other forces and away from their children.

Similar observations were noted by Bozeman, Orback, and Sutherland (1955). Attempts to prolong the child's life as well as insistence upon bodily contact with their child were frequently observed. Feelings of helplessness, anger, defeat, guilt, and shame have also been noted (Bozeman et al., 1955; Natterson, 1960; Hoffman et al., 1971). At times guilt feelings may intensify to the degree that the fatal illness may fulfill hostile or infanticidal wishes toward the physically ill child (Rheingold, 1967).

A number of authors have dealt with the specificity of the parent's emotional responses to a child's illness, although not necessarily lifethreatening. While various tangible factors may directly affect the child's illness, parental attitudes have also been regarded as playing a significant role. Preoccupied with the child's body, a mother may employ forceful techniques that she had not used in times of health, and

often neglects her normal child rearing practices (Freud, 1952; Glaser, 1960). Freud (1952) believed that "during severe bodily illness the mother's own emotional upset and her inevitable concentration on bodily matters act as distorting factors and leave little room for objective observation of the child's psychological reactions (p. 69)."

Another factor that may interfere in the parent's awareness of their child's feelings is that of anxiety. Most parents express difficulty in handling their own anxiety when dealing with their child's illness. This interferes in their being able to emotionally support their physically ill child (Goffman, 1957). The effects of parental anxiety have been studied by a number of authors (Vander Veer, 1949; Barsky, 1956; Campbell, 1957; Dimock, 1960). Vander Veer (1949) suggested that the parent's anxiety is transmitted to the child by contangion, with the child sensing and absorbing his parent's anxiety. Campbell (1957) investigated the contangion hypothesis and suggested that the mother's tenseness may be communicated to the child through her methods of physically handling him. Moore (1957) noted that a physically ill child becomes confused when he cannot use his parent's behavior as a guide. While most parents may become overprotective and oversolicitous in their behavior toward their physically ill child, the opposite reaction may at times take place. Due to the parent's feelings of guilt and hostility toward the child or his illness, they may reject the child. This creates adverse effects on the child and makes it difficult for the child to accept his illness (Cooley, 1951). Fearful of perpetuating dependency on their child, the parents may fail to provide the care and affection that the child needs (Freud, 1952; Glaser,

1960). Langford (1948) described the development of intense parental anxiety and noted how the child may be traumatically affected. He stated:

There may be a great deal of underlying hostility toward the child and guilt-laden feelings about this which bring out markedly irrational fears in the parent of an infantile love object; the fear of loss of the child through the illness intensifies the parent's anxiety and helps the child to maintain his regressive personality functioning brought on by the illness. The parent may have then relatively little impetus to help the child regain his previous level of maturity; the child's passive dependent infantile status fits so well into the parent's own underlying psychological needs. Other parents may feel guilty and anxious about their failure to have prevented the illness in the child, unrealistically believing that they should be able to prevent all illnesses in their children...(p. 247).

In summary, research regarding parental attitudes toward their physically ill child support the position that the emotional turmoil experienced by the parents during a child's illness may significantly affect the child. Parental reactions are determined to a large extent by the threatening aspects of the child's illness. The threat may be even greater in connection with the anticipation of death and loss. The emotional turmoil suffered by the parents, as well as the total parental involvement directed toward a child's illness, serve as interfering forces in the parent's awareness of the child's psychological reactions. Due to the mother's preoccupation with her own feelings of helplessness, anger, guilt, depression, and anxiety, a mother may fail to recognize her child's own feelings about his illness. Finally, a parent may fail to express fears and concerns about death and dying due to taboos placed upon the subject in our culture.

# D. Hypotheses

The present study investigated two sets of hypotheses. The first was concerned with children's self-perceptions and the second with the mother's projected perceptions of her child's views. These perceptions were investigated as being differentially affected by a child's current state of physical health.

Kubler-Ross (1969) indicated that the interpersonal relations of adult critically ill patients often change dramatically from the way they were prior to the individual's illness. Thomas and Weiner (1974) also noted that adult critically ill patients show a greater need for inclusion, control, and affection in interpersonal relationships than do non-critically ill patients or well controls. The current investigation hypothesized that similar relationships would hold for children. Specifically, significant differences were hypothesized between the average scores of children with a life-threatening illness, children with a non-life-threatening illness, and well child controls on a non-projective psychological instrument that measures a child's expression of and desire for inclusion, control, and affection in interpersonal relationships.

A second set of hypotheses related to the mother's perceptions of each of these three groups of children. It was hypothesized that due to the intensity of the emotional turmoil experienced by the mothers of children with a life-threatening illness, and due to the lack of expression of fears concerning death and dying in our culture, the mother's projected perceptions of children with a life-threatening illness would differ more from their child's wanted and expressed need

for affection, control, or inclusion in interpersonal relationships than mothers of children with a non-life-threatening illness or well child controls.

# CHAPTER III

#### **METHOD**

# A. Subjects

Twenty-one subjects (<u>Ss</u>) were employed in the study. In order to control for age and intellectual effects on conceptualization of death which might affect interpersonal relations, only children between the ages of ten and fourteen and of not subnormal intelligence were employed.

Three groups of subjects were investigated. The first group consisted of seven patients who had been diagnosed as having a life-threatening illness (LTI) but who were not being treated with cortico steroids. The second group consisted of seven patients who had been diagnosed as having a non-life-threatening illness (NLTI). The third group consisted of seven well child controls (WCC).

The mothers of each of these twenty-one children served as subjects through testing their awareness of their child's feelings.

# B. Dependent Variables

The hypotheses concerning the interpersonal relations of children with a life-threatening illness, non-life-threatening illness, and well child controls were tested with the Fundamental Interpersonal Relations Orientation Behavior Test for Children (FIRO-BC). The FIRO-BC was also employed in testing the mother's awareness of her child's feelings.

The FIRO-BC (Schutz, 1972) is a non-projective instrument that measures a child's expression of and desire for inclusion, control, and affection in interpersonal relationships on a scale of 0 to 9.

The six dependent variables derived from the FIRO-BC are:

- 1. Expressed inclusion (eI) score on the FIRO-BC. This score reflects a child's general need to establish and maintain a satisfactory relationship with respect to interaction. This score reflects just how comfortable a child is around other children, in that the higher the score, the more comfortable he is with other children.
- 2. Wanted inclusion (wI) score on the FIRO-BC. This score reflects a child's general need to establish and maintain a satisfactory relationship with respect to association. The higher the score, the less selective he is in choosing his associates.
- 3. Expressed control (eC) score on the FIRO-BC. This score reflects the need to establish and maintain a satisfactory relationship with respect to control and power. It reflects the willingness to assume responsibility and to make decisions. The higher the score, the more willing the child is to take on the responsibilities of a leadership role.
- 4. Wanted control (wC) score on the FIRO-BC. This score reflects the extent that a child wants others to control him and to make decisions for him. The higher the score, the more dependent is the child and the more reluctant he is to make decisions.
- 5. Expressed affection (eA) score on the FIRO-BC. This score reflects the need to establish and maintain a satisfactory relationship with respect to love and affection. It reflects how willing a child is to develop close intimate relationships. The higher the score, the more readily a child becomes emotionally involved with other children.
- 6. Wanted affection (wA) score on the FIRO-BC. This score reflects how selective a child is with whom he forms deep relationships. The higher the score, the less selective he is with whom he establishes close interpersonal relationships.

### C. Procedure

The data collection was conducted in an out-patient clinic of a Southcentral United States Medical School.

The following directions were read aloud by the experimenter  $(\underline{E})$  to the child:

"These questions ask about how you feel or act with other children. There are no right or wrong answers; everybody has his own ideas. Try to tell how you really act, not how you wish you acted or how someone else wants you to act."

The following directions were read aloud by  $\underline{E}$  to the child's mother:

"These questions ask about how your child feels or acts with other children. Please answer these questions as you feel your child will answer them. There are no right or wrong answers. Every child has his own ideas. Try to tell how your child really acts, not how you wish he acted or how someone else wants him to act."

# D. Experimental Design

Two step-wise linear discriminant function analyses were computed to examine differences among the three groups (subjects with a life-threatening illness vs. subjects with a non-life-threatening illness vs. well child controls). The analysis provides a discriminant function for each group based on a weighting system maximizing the variance between groups while minimizing the within groups variance. Each subject receives a discriminant function score and is assigned to that group whose mean discriminant function is closest to that score. One analysis was for the children's scores and the other was for the mothers' scores. To further investigate the influence of a life-threatening illness the WCC and the NLTI groups were combined and compared to the LTI. Therefore, two other step-wise linear discriminant function

analyses were computed to examine differences among these two groups. (subjects with a life-threatening illness vs. subjects with a non-life-threatening illness and well child controls). One analysis was for the children's scores and the other was for the mothers' scores. The scores of each of the six FIRO-BC scales served as the predictor variables.

A 3 x 2 (groups x mother vs. child perception) repeated measures analysis of variance was then computed to examine main and interaction effects for each of the six FIRO-BC variables.

The Pearson-product-moment correlation coefficient was computed on the child-mother scores for the six dependent FIRO-BC variables for the three groups to further assess the nature of the relationship between child and mother perceptions.

#### CHAPTER IV

#### RESULTS

The first phase of the study was conducted to isolate factors which would differentiate among children with a life-threatening illness vs. children with a non-life-threatening illness vs. well child controls. The group mean scores on the six FIRO-BC scales are reported in Table I (see Appendix C). When the three groups were compared, the discriminant function revealed a trend towards significant differentiation when employing in combination the variables wanted control (wC) and wanted affection (wA), ( $\underline{F} = 2.65$ ,  $\underline{df} = 2.18$ , p < .10 and  $\underline{F} = 3.35$ ,  $\underline{df} = 2.18$ , p < .10, respectively).

To further investigate the influence of a life-threatening illness, the WCC and the NLTI groups were combined and compared to the LTI group. Results of this discriminant function analysis indicated that the variable that statistically differentiated between the two groups was wanted affection, (wA), ( $\underline{F}$  = 6.68,  $\underline{df}$  = 1,19, p < .025; see Appendix C, Table II for the variable means for these two groups and Table III, for the  $\underline{F}$  values on each of the six variables when these two groups were compared).

The second aspect of the study was concerned with the similarities and differences between the mother's perceptions of her child and the child's self-perceptions. Results of the discriminant function analysis for mothers when the three groups were compared (LTI vs. NLTI vs WCC)

indicated a trend towards significance in the area of expressed inclusion (eI), ( $\underline{F}$  = 3.15,  $\underline{df}$  = 2,18, p < .10; see Appendix C, Table IV, for the  $\underline{F}$  values for each of the six variables when these groups were compared).

Results of the discriminant function analysis for mothers of the LTI group vs. mothers of the NLTI and WCC groups were non-significant for all six FIRO-BC variables, with none of the  $\underline{F}$  values exceeding 1.00.

To independently assess the group x mother vs. child perception data on each of the six dependent variables, 3 x 2 repeated measures analyses of variance were conducted. Of the six variables, two revealed significant differences. There were in the areas of expressed inclusion (eI) and wanted control (wC). (See Appendix C, Table I, for the means for the six variables for mothers and children for the three groups).

The 3 x 2 repeated measures analysis of variance with expressed inclusion (eI) as the dependent variable showed significant interaction effects between groups (LTI, NLTI, WCC) and perceptions (child vs. mother), (F = 5.63, df = 2, 18, p < .025). Three t-tests for simple effects revealed the following differences. The mothers of children with a NLTI perceived significantly higher expressed inclusion than the children reported (f = 2.44, f = 18, p < .05). The mothers' perceptions of WCC indicated a trend toward lower expressed inclusion than the children reported (f = 2.02, f = 18, p < .10). No significant difference was found between the mothers' perceptions of the the children and the children's self-perceptions in the group diagnosed with a life-threatening illness (See Figure 1).

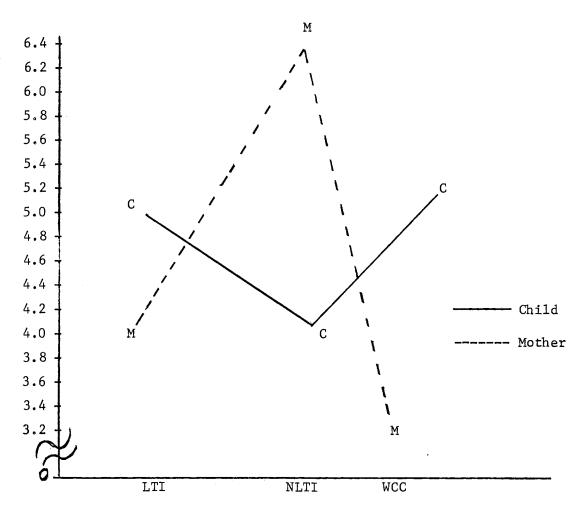


Figure 1. Mean Perception Scores on Expressed Inclusion (eI) for Children and Mothers Across Groups

Significant main effects were found between groups for the dependent variable wanted control (wC), ( $\underline{F}$  = 3.79,  $\underline{df}$  = 2,18, p < .50). Tukey's test revealed significant differences between children with a NLTI and WCC ( $\underline{q}$  = 3.79,  $\underline{df}$  = 3,18, p < .05). Specifically, children with a NLTI reported wanting less control than WCC. There were no

significant differences between the scores of children with a LTI and WCC ( $\underline{q} = -2.68$ ,  $\underline{df} = 3,18$ ) or between the scores of children with a LTI and children with a NLTI ( $\underline{q} = 1.20$ ,  $\underline{df} = 3,18$ ).

In the 3 x 2 repeated measures analysis of variance for wanted affection (wA) there were no significant main or interaction effects. However, because of the discriminant function results on the wA variable, a t-test was done comparing the mother's perceptions of the children and the children's self-perceptions for the group diagnosed with a LTI. There was a trend for mothers of children with a LTI to perceive less wanted affection than the children reported ( $\underline{t} = 1.71$ ,  $\underline{df} = 18$ , p < .10), (See Figure 2).

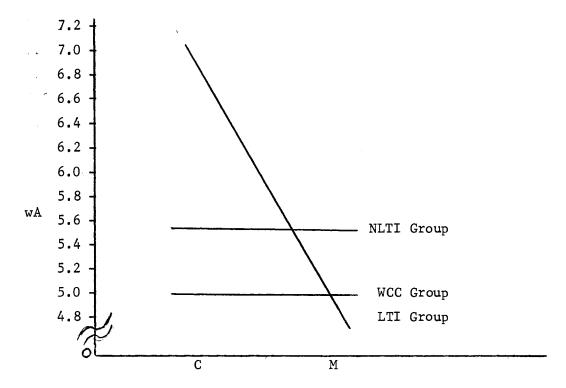


Figure 2. Mean Perception Scores on Wanted Affection (wA)
For Children and Mothers

To further assess the nature of the relationship between child and mother perceptions, the Pearson-product-moment correlation coefficient was computed on the child-mother scores for the six dependent FIRO-BC variables for the three groups. (See Appendix C, Table V). As can be seen, the LTI group is lowest in the general level of correlations indicating less congruence between child and mother scores with only one area exceeding a .30 correlation. Next in the general level of magnitude with five of the six areas exceeding a .30 correlation, was the relationship between mother-child scores in the NLTI group with a significant correlation on expressed control  $(\mathbf{r} = +.87, \mathbf{df} = 5, \mathbf{p} < .05)$ . In the WCC group, however, the scores were most highly related, with significant correlations in expressed affection  $(\mathbf{r} = +.85, \mathbf{df} = 5,$ 

p < .05) and in wanted affection ( $\underline{r}$  = +.81,  $\underline{df}$  = 5, p < .05) Here, four of the six areas exceeded a .30 correlation.

# CHAPTER V

#### DISCUSSION

The 21 children that were employed in this study were within the 10 to 14 age range. Often neglected by researchers in the area of death and dying, this age period includes the development and maturation of a child's self-concept. With this developing awareness of his separate identity, a child within this age range is better able to conceptualize that death and dying means an impending loss of significant realtionships. He can also better identify the gains associated with his "perceived freedom" of life (Steiner, 1970). He is, therefore, less able to avoid the full emotional implications of his disease.

It is with full awareness of the small sample sizes and limited significance found in this study that this discussion is presented. However, clinical interpretations of the data will be presented as this is an emerging area of investigation.

An illness brings with it uncomfortable and threatening periods. It brings with it threats to the child's "perceived freedom" to live. These periods may be even more threatening with the increased severity of the disease. Periods of hospitalization and treatment experienced by children with a life-threatening illness may contribute to the child's disturbing awareness of a possible "not me". A child may

handle the anxieties brought about by such awareness with defensive maneuvers, although not necessarily appropriate to his needs.

The variable that statistically differentiated between children with a life-threatening illness vs. children with a non-lifethreatening illness and well child controls was wanted affection. appeared that the need for emotional support was increased with the severity of the illness. The need for affection reflects the child's desire to be appreciated and valued. It is reasonable to assume that a child with a life-threatening illness would want more affection than other children. However, it is more important to note the implications of this desire. A child with a life-threatening illness faces a threat to his "perceived freedom" of life; he fears not obtaining the emotional security and affectional comfort that is needed in his life. "Even when a person knows it is impossible to recover a freedom, the psychological reactance aroused by the loss of the freedom still impels him to want it" (Brehm, 1972, p. 22). It should be noted, however, that though children with a life-threatening illness reported wanting more affection than other children, they did not necessarily express a greater need. The need for greater emotional support seems to go unexpressed and may go unmet. This reluctance for a child with a life-threatening illness to solicit more emotional support from others when greater support is needed and wanted, may result in frustration and loneliness. This in turn, may manifest itself in anger, bitterness, and resentment towards himself and others.

With the development of his own individuality and self-concept, a child within this 10 - 14 age range also strives to become more independent. Being newly aware of the feeling of self-sufficiency, a child

within this age range strives to master this feeling. Sickness, however, brings with it a feeling of enforced dependency, a feeling which the child may whole-heartedly rebel against. For example, in the area of wanted control, children with a non-life-threatening ill-ness reported wanting to be significantly less dependent on others than did well children. Well children, however, wanted the least independence.

This decreased desire for dependence on others found in children with a non-life-threatening illness reflects, perhaps, the child's hesitancy to give himself up to the care of others. Brehm (1972) noted that a person is motivationally aroused any time he feels that one of his freedoms has been threatened or eliminated. This motivational arousal, called "psychological reactance" moves a person to attempt to restore whatever freedom is threatened or eliminated (Brehm, 1972). Indeed, it is as if a physically ill child becomes more sensitive to the restrictions imposed upon him. He does not like being controlled, does not want as much control, and struggles against this enforced dependency. Fearful of losing self-control, a child must emphasize to himself that he is really self-sufficient and independent. This may overtly manifest itself through his uncooperative behavior and failure to follow medical advise.

Physically well children, on the other hand, did not desire as much independence as did children with a non-life-threatening illness.

More secure in their physical health, well children need not be fearful of losing control. Therefore, they do not need to struggle against an enforced dependent role.

Just as a child with a non-life-threatening illness fears the loss of self-control, a child with a life-threatening illness faces a greater threat to his independence. He faces the loss of total control that comes with the process of dying. The seriousness, as well as the frightening aspects of the illness, may in turn, produce a greater need to be taken care of than was found in children with a non-life-threatening illness. It is as if the child with a life-threatening illness is struggling between the fear of losing total control and his need to be taken care of.

In summary, children with a life-threatening illness reported wanting but not expressing the need for more affection than children who were well or had a non-life-threatening illness. This need for greater emotional support from others may therefore go unmet. Children with a non-life-threatening illness reported wanting to be more independent than well children. This was interpreted as reflecting the child's fear of the loss of self-control that may accompany a physical illness. Children with a life-threatening illness, however, did not significantly differ from either the well control or the non-life-threatening ill group. This was interpreted as reflecting the child's struggle between his fear of the loss of total control that comes with the process of dying, and his need to be taken care of.

The second aspect of the study was concerned with the mother-child relationship. By virtue of her position, a mother represents a very significant, if not the most significant, adult in a child's life. A mother provides most of the routine nurturant care and emotional support, as well as furnishing patterns of emotional response which her child

might imitate. The crucial role of the mother has been recognized by many researchers. The influential characteristics of the mother on the child have often been noted. Very little emphasis, however, has been given to the mother's objective perceptions of her child's self-perceived needs and desires. Accurate recognition of these needs is important in order to provide the emotional support that the child needs and seeks. The degree of intimacy in a mother-child relation-ship, as well as the accurate recognition of a child's needs, is of great importance during times of illness.

The results of this study indicated that, in general, the perceptions of mothers and children were more positively related for the well control group. That is, mothers of children who are well see the needs of their child quite accurately, particularly in the areas of wanted and expressed affection. The mother's and child's scores in the group with a non-life-threatening illness were less accurately related. The weakest relations were between the mother-child scores in the group diagnosed with a life-threatening illness. Specifically, mothers of children who are dying are generally less perceptive of their child's needs. However, there were some specific exceptions to the overall correlation based observations. In the area of expressed inclusion, the mothers' perceptions of children with a non-life-threatening illness and of well child controls differed significantly from the child's self-perceived desires. Mothers of children with a non-lifethreatening illness projected on their child a significantly higher expressed desire to interact with others than the child reported. This may be a reaction to her child's overt negativism and isolation; a mother projects a greater need for her child to interact with others.

There was a trend for mothers of well children, on the other hand, to perceive a lower expressed desire to interact with others than the child reported.

In both the non-life-threatening illness and well child control groups, the mothers' perceptions were significantly different from their child's. There was no significant difference, however, in the group diagnosed with a life-threatening illness. Mothers of children who are dying seem to be more perceptive of the child's expressed desire to interact with others. This sensitivity is important but in itself, is not sufficient to fulfill the desire. Physical presence alone does not fulfill wanted, but unexpressed, wishes and desires. In order for a mother to help her child cope with his feelings of loss, a child must feel that he is truly appreciated and valued. The results of this study showed, however, a trend for mothers of children with a life-threatening illness to perceive less wanted affection than the child indeed wanted, perhaps justifying any failure to provide the affection. This can have serious effects in both the care of the child and in the communication between mother and child. A child with a life-threatening illness must feel free to express his fears, his suspicions, his fantasies, and his anxieties regarding both life and death, as well as dying. It is, therefore, important that parents, physicians, hospital personnel, family and friends be perceptive of this greater need for affection found in children with a life-threatening illness. If this need is not perceived, and therefore not met, a child with a life-threatening illness may die painfully frustrated and lonely.

In summary, the mothers of children who are well were generally more accurate in perceiving their child's needs. Mothers of children

who are dying, however, were generally less accurate in perceiving their child's needs, except when the child expresses the desire to interact with others. This sensitivity is important but not sufficient to fulfill the desire. If a mother is to help her child cope with feelings of loss and loneliness, it is important that she be sensitive to her child's wanted but unexpressed needs and desires.

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## APPENDIX A

GUIDELINES FOR SUBJECT SELECTION

AND SUBJECT CHARACTERISTICS

#### SUBJECTS WITH A LIFE-THREATENING ILLNESS:

The guidelines for choosing the LTI child patients were: (1) that the child be an out-patient having a disease that is serious and potentially fatal, (b) that the disease be well progressed, (c) that the child be rational, (d) that the child not be in such pair or under the treatment of cortico-steroids so that it would inhibit his participation, and (e) that the child, his parents, and his attending physician approve of his participation in the research. The seven child patients had been diagnosed as having leukemia.

### SUBJECTS WITH A NON-LIFE-THREATENING ILLNESS:

The guidelines for choosing the NLTI child patients were: (a) that the child be an out-clinic patient having a disease not considered to be critical, (b) that the child be rational, (c) that the child not be in such pain or under sedation so that it would inhibit his participation, and (d) that the child, his parents, and his attending physician approve of his participation in the research. Of the seven child patients, two had urinary tract infections, two had intestinal infections, one had a would infection, one had osteomyelitis of his right tibia, and one had an arm fracture.

#### WELL CHILD CONTROLS:

Children from a Southcentral United States university community, and in good health, were obtained as <u>Ss</u> and matched on age, sex, and race to the LTI and NLTI groups. There were two 14 year old white males, one 14 year old white female, three 12 year old white males, and one 10 year old white male.

## APPENDIX B

FUNDAMENTAL INTERPERSONAL RELATIONS ORIENTATION-BEHAVIOR TEST FOR CHILDREN (FIRO-BC)

| Place a number from 1 to 6 in the bo                                | x in front of each question.                             |
|---|--|
| For the questions on this page, the                                 | numbers mean:  |
| •   | 4. a few 5. one or two children children                 |
| 6. no children  |  |
| I try to make other children do what I want them to do.             | I don't get very friendly with other children.           |
| I try to be very friendly and to tell my secrets to other children. | I like other children to choose me for a friend.         |
| I like children to invite me to take part in what they're doing.    | I take orders from other children.                       |
| What I do depends a lot on what other children tell me.             | I like children to act very friendly to me.              |
| I like children to act as if they don't know me very well.          | I try to be friendly to other children.                  |
| I try to take charge of things when I am with other children.       | I like children to ask me to join in what they're doing. |
| I act unfriendly with other children.                               | I follow what other children are doing.                  |
| I like children to ask me to take part when they're talking         | I like other children to get to know me very well.       |
| about something.  | I try to have close, warm friendships with children.     |
| I let other children take charge of things.                         | I let other children tell me what to do.                 |
| I like children to act friendly to me.                              | I like children to act very                              |
| I try to have other children do things the way I want them done.    | friendly and tell me their secrets.                      |

For the questions on this page, the numbers 1 to 6 mean: 1. almost all 2. a lot of 3. sometimes 4. once in 5. almost 6. never the time the time a while never When other children are playing I try to have friends that I games, I like to join them. can be very friendly with and tell my secrets to. I try to take charge of things when I'm with children. I like children to ask me to join in what they're doing. I try to have close, warm friendships with children. I let other children tell me what to do. I like other children to invite me to their houses when they I like children to act not too are having friends over. friendly to me. What I do depends a lot on what I try to include other children other children tell me. in my plans. I like children to act as if I try to be the boss when I am they don't know me very well. with other children. When a group of children gets I try to get very friendly with together to do something, I other children and to tell them like to join in with them. my secrets. I try to make other children I like children to invite me to do what I want them to do. things. I try to have close friendships I follow what other children are with children. doing. I like to be invited to parties. I like other children to get to know me very well. I take orders from other When children are doing things children. together, I like to join them. I like children to act very I try to have other children do friendly to me. things I want done. When I'm going to do something I like to tell other children

I try to ask other children to

do it with me.

what to do.

| Ш | I like other children to choose me for a friend.                 |
|---|--|
|   | I like to go to parties.   |
|   | I try to have other children do things the way I want them done. |
|   | I try to have other children around me.                          |
|   | I join clubs.  |

APPENDIX C

TABLES

TABLE I

VARIABLE MEANS FOR THE SIX FIRO-BC VARIABLES FOR MOTHERS
AND CHILDREN FOR THE THREE GROUPS (LTI, NLTI, WCC)

| <del></del> |        |     |      |      | MEANS |      |      |      |
|-------------|--------|-----|------|------|-------|------|------|------|
|             |        |     | eI   | wI   | еC    | wC   | eA   | wA   |
| LTI:        | CHILD  | n=7 | 5.00 | 5.57 | 5.57  | 3.71 | 4.57 | 7.00 |
|             | MOTHER | n=7 | 4.14 | 6.00 | 6.29  | 4.43 | 3.71 | 4.86 |
| NLTI:       | CHILD  | n=7 | 4.14 | 3.71 | 5.71  | 3.29 | 5.00 | 5.43 |
|             | MOTHER | n=7 | 6.43 | 5.71 | 5.57  | 3.86 | 5.29 | 5.43 |
| WCC:        | CHILD  | n=7 | 5.43 | 6.14 | 5.57  | 5.57 | 3.86 | 5.00 |
|             | MOTHER | n=7 | 3.43 | 5.29 | 6.29  | 5.00 | 3.86 | 5.00 |

VARIABLE MEANS ON THE SIX FIRO-BC VARIABLES FOR CHILDREN
WITH A LIFE-THREATENING ILLNESS VS. CHILDREN
WITH A NON-LIFE-THREATENING ILLNESS AND
WELL CHILD CONTROLS

| 00 4.78  |                      |
|----------|----------------------|
|          |                      |
| 57 4.92  |                      |
| 57 5.64  |                      |
| 71 4.42  |                      |
| 57 4.42  |                      |
| .00 5.21 |                      |
|          | .71 4.42<br>.57 4.42 |

TABLE III

F VALUES ON THE SIX FIRO-BC VARIABLES DISCRIMINATING BETWEEN CHILDREN WITH A LIFE-THREATENING ILLNESS VS.

CHILDREN WITH A NON-LIFE-THREATENING ILLNESS AND WELL CHILD CONTROLS

| Variable            | df   | F     |  |
|---------------------|------|-------|--|
| Expressed Inclusion | 1,19 | 0.04  |  |
| Wanted Inclusion    | 1,19 | 0.27  |  |
| Expressed Control   | 1,19 | 0.01  |  |
| Wanted Control      | 1,19 | 0.51  |  |
| Expressed Affection | 1,19 | 0.02  |  |
| Wanted Affection    | 1,19 | 6.68* |  |

<sup>\*</sup> p < .025

TABLE IV

F VALUES ON THE SIX FIRO-BC VARIABLES DISCRIMINATING BETWEEN MOTHERS OF CHILDREN WITH A LTI VS. MOTHERS OF CHILDREN WITH A NLTI VS. MOTHERS OF WCC

| Variable            | df   | F                 |  |
|---------------------|------|-------------------|--|
| Expressed Inclusion | 2,18 | 3.15 <sup>a</sup> |  |
| Wanted Inclusion    | 2,18 | 0.13              |  |
| Expressed Control   | 2,18 | 0.18              |  |
| Wanted Control      | 2,18 | 0.60              |  |
| Expressed Affection | 2,18 | 1.02              |  |
| Wanted Affection    | 2,18 | 0.07              |  |

a p < .10

TABLE V

PEARSON-PRODUCT MOMENT CORRELATION COEFFICIENTS FOR CHILD-MOTHER SCORES ON EACH FIRO-BC DEPENDENT VARIABLE FOR THE THREE GROUPS (LTI, NLTI, WCC)

| GROUP | e-Inclusion | w-Inclusion | e-Control | w-Control | e-Affection | w-Affection |
|-------|-------------|-------------|-----------|-----------|-------------|-------------|
| LTI   | 0.63        | 0.06        | -0.01     | -0.01     | 0.01        | 0.18        |
| NLTI  | 0.44        | 0.48        | 0.87**    | 0.40      | -0.04       | 0.30        |
| WCC   | 0.26        | 0.18        | 0.72      | -0.56     | 0.85*       | 0.81*       |

<sup>\*</sup> p < .05

<sup>\*\*</sup> p < .025

## APPENDIX D

CONSENT FORM FOR SUBJECTS WITH A LIFE-THREATENING ILLNESS

THE UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER - OKLAHOMA CITY, OKLAHOMA

| DATE                                    | _                                |
|---|----------------------------------|
| CHILD'S NAME                            | <u>-</u>                         |
| MEDICAL RECORD NUMBER                   | <del>-</del>                     |
| I, hereby voluntarily authorize         | Name of Researcher               |
| University of Oklahoma Health Services  | Center, and such assistants that |
| may be designated to perform the follow | ring study:                      |

The nature and purpose of the procedures or treatment, the research aspects, the possibility of discomfort, complications and benefits have been fully and understandably explained to me. All inquiries have been answered to my satisfaction, therefore, I agree and consent to the study described herein with the knowledge and understanding that medical and psychological studies and investigations are not exact sciences and that no warrantees or guarantees have been made to me concerning the proposed procedures or study.

I understand that strict confidentiality will be observed of all data collected under the guidelines established by the University of Oklahoma Health Sciences Center. Complete anonymity will be preserved and data will be released only to qualified professionals for scientific or training purposes.

I further understand and agree that the data and information related to and resulting from the study may be used for publication in scientific journals but that my name shall not be disclosed in association with these publications without my specific written permission.

I hereby authorize the authorized medical personnel of the University of Oklahoma Health Sciences Center to retain and use for scientific or teaching purposes, or to dispose of at their convenience any data taken from or resulting from this study.

I have been instructed and understand that I am free to withdraw this consent and to discontinue my participation at any time. I further certify that my participation in this study is in the interest of advancing science and/or my own personal well being as well as my child's, and that other considerations, if any, are secondary to my voluntary participation.

By signing this consent form, I have not waived any of my legal rights or released this institution from liability for negligence. Should any problems arise during this study, I may take them to the Research Affairs Office in Room 120 of the Medical School Building, Phone: 271-4690.

The contents of this form have been fully explained to me and I certify that I understand and agree with its contents.

|         | SIGNATURE OF CHILD'S PARENT OR GUARDIAN |
|---------|---|
|         | SPECIFY RELATIONSHIP TO CHILD           |
|         | PHYSICIAN'S SIGNATURE                   |
|         |   |
|         |   |
| WITNESS | <del></del>                             |
| WITNESS |   |

# VITA '

### Lupe Rebeka Samaniego

### Candidate for the Degree of

### Master of Science

Thesis: PHYSICALLY ILL CHILDREN'S SELF-PERCEPTIONS AND THE MOTHER'S

PERCEPTIONS OF HER CHILD'S NEEDS

Major Field: Psychology

Biographical:

Personal Data: Born in El Paso, Texas, December 17, 1949, the daughter of Mr. and Mrs. J. L. Samaniego, Sr.

Education: Graduated from Father Yermo High School, El Paso, Texas, in May, 1968; received Bachelor of Arts degree in Psychology from The University of Texas at El Paso, Texas, in August, 1971; enrolled in Master's program at Oklahoma State University, 1971-1973; completed requirements for the Master of Science degree in Psychology at Oklahoma State University in July, 1974.

Professional Experience: Counselor, summer of 1970, Salem's Rehabilitation Facilities, Salem, Oregon; research assistant, Department of Psychology, Oklahoma State University, 1971-1972; graduate teaching assistant, Department of Psychology, Oklahoma State University, 1972-73; Psychology Trainee III, The Veteran's Administration Hospital, Oklahoma City, Oklahoma, 1973-1974.