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LONELINESS IN SCHOOL AGE CHILDREN WITH
CHRONIC LIFE THREATENING ILLNESS

by
Tamar Krulik
B.A., Tel Aviv University 1970
B.A., Tel Aviv University 1972
M.N., University of Pittsburgh 1972

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

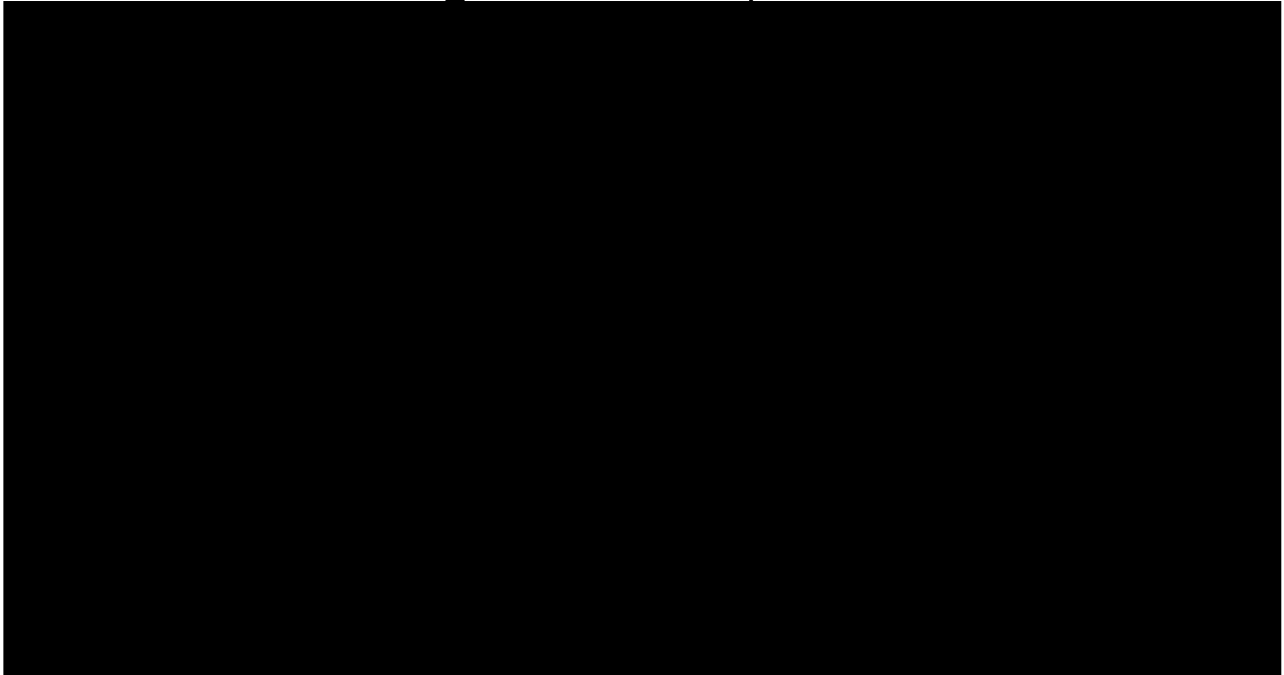
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LONELINESS IN SCHOOL AGE CHILDREN
WITH CHRONIC LIFE THREATENING ILLNESS

Tamar Krulik
School of Nursing
University of California, San Francisco

ABSTRACT

The major purpose of this study was to explore the phenomenon of loneliness in school age children living with chronic life threatening diseases (CLTD). Two questions were addressed. The first question was: do children with chronic life threatening disease differ in their loneliness manifestations from healthy children? Using concepts from Sullivan's theory on interpersonal relations, Goffman's theory on stigma, and Rotter's social learning theory in the conceptual framework, the researcher hypothesized that children with CLTD would differ in their loneliness manifestations from the healthy children. The second question was: what strategies do parents of children with CLTD and medical personnel use to deal with the problems of communication with the child, side effects of illness and treatment regimen, and death anxiety of the child (variables identified in the literature as conducive to loneliness in childhood)?

The study sample was composed of 20 children with CLTD and their mothers and 20 healthy children and their mothers who served as a comparison group. The subjects were Caucasian, the children were of both sexes and between the ages

of six to ten years, and the ill children were between two to 90 months after diagnosis.

The children's loneliness manifestations were assessed by responses to a set of projective pictures, by their choices for interaction on an interpersonal interaction scale (Who Scale - designed for this study) and their choices of interpersonal distance on the Comfortable Interpersonal Distance Scale (CID). Parents' and medical personnel's strategies were assessed through indepth interviews with the mothers of the ill children.

The study hypotheses were partially supported. Children with CLTD responded with more aloneness subcategory loneliness themes, preferred fewer children for interaction and chose more adults for interaction in the "public domain" situations, and placed one friend at a further distance than did healthy children. The children with CLTD did not differ from the healthy children on the rest of the loneliness themes nor the placement of other figures. The strategies identified were: all parents and medical personnel adopted open approach to communication, both about the illness trajectory and death. Some parents adopted a religious approach for explaining death and especially life after death. Most parents were very creative in their "normalizing tactics". These strategies seemed to deter loneliness in CLTD children.

Of the 20 children with CLTD, 11 (55 percent) were

rated as having higher levels of loneliness than the rest of the ill group (their scores on two or three of the study measures were above the mean of the ill group). Variables associated with higher levels of loneliness were identified: the child was within four months of crisis in his illness and/or suffered from visible side effects of illness and treatment at the time of the interview and/or received detailed descriptions on being "happy, but very alone" in heaven.

Several implications for practice were derived from the study: the need to educate health care professionals so that they can guide parents and educate the general public, especially school teachers, as to the occurrence, origins, and manifestations of loneliness in CLTD children. Programs specially designed to alleviate loneliness in children with CLTD should be developed. In the area of research there is a great need to arrive at operational definitions of loneliness, establish valid and reliable tools to assess loneliness, and design and evaluate experimental programs geared toward the lonely child.

Eugene A. DeLoe
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TABLE OF CONTENTS

	<u>Page</u>
ABSTRACT	ii
ACKNOWLEDGEMENTS	v
LIST OF TABLES	ix
LIST OF FIGURES	xi
 Chapter	
I. INTRODUCTION	1
The Scope of the Problem	5
The Purpose of the Study	6
Significance of the Study	7
II. CONCEPTUAL FRAMEWORK AND STUDY QUESTIONS	10
Study Questions	22
Definition of Terms	23
III. REVIEW OF THE LITERATURE	25
Selected Views on Loneliness	26
Origins of Loneliness in Childhood	30
Origins of Loneliness in the Experience of a Child with Chronic Life Threaten- ing Illness	38
IV. METHODOLOGY	57
The Sample	57
Study Instruments	60
The Who Scale	61
Comfortable Interpersonal Distance Scale (CID)	68
Projective Pictures	75
Maternal Interview	78
Data Collection Procedure	80

V.	FINDINGS	87
	Sociodemographic Characteristics of All Subjects and Selected Medical Characteristics of the Children with Chronic Life Threatening Illness included in the Sample	88
	Findings Related to the First Study Question	94
	Interrelationship of Outcomes on the Three Study Tools	105
	Findings Related to Study Question Number Two	107
	Strategies Related to Communication with the Child	107
	Strategies Related to Management of "Being Different" due to Illness and Treatment Side Effects	118
	Strategies Related to Management of the Child's Death Anxiety	128
	Analysis of Loneliness	136
VI.	DISCUSSION	143
	Discussion of Findings Related to the First Study Question	143
	Discussion of Findings Related to the Second Study Question	151
	Discussion of Overall Loneliness	155
	Limitations of the Study	158
	Implication for Practice	159
	Recommendation for Further Research	164
	Summary	167
	BIBLIOGRAPHY	170
	APPENDICES	
1	The Who Scale	179
2	The Who Scale, First Version	184
3	The CID	192
4	Projective Pictures	194
5	Instructions to Child on Projective Pictures	204
6AB	Scoring Scheme and Coding Document	206
7	Inter-Rater Reliability on Scoring of Responses to Projective Picutres	214
8	Maternal Interview Schedule	216
9	Consent Form	233
10	Sample of Aloneness Themes of Ill Children	236

LIST OF TABLES

<u>Table</u>		<u>Page</u>
5.1	Parents' occupations according to Hollingshead (1965) occupational scale . . .	90
5.2	Distribution of ill subjects according to the nature of their illness	91
5.3	Range and mean of illness duration number of hospitalizations and number of side effects	92
5.4	Illness state at time of interview	93
5.5	Loneliness themes of children with CLTD compared to loneliness themes of health children	95
5.6	Comparison of affect and outcome of stories by children with CLTD and healthy children	96
5.7	Frequencies of negative and positive affect for the whole sample	97
5.8	Comparison of choices of adults versus children for interaction between children with CLTD and healthy children	100
5.9	Preference for interaction with adults by child health state and age	101
5.10	Preference for interaction with children by child health state and age	101
5.11	Comparison of mean difference of children with CLTD with mean distance of healthy children on the CID	103
5.12	Comparison of mean alienation of children with CLTD with mean alienation of healthy children on the CID	104
5.13	Correlations of scores on the three study tools	106

<u>Table</u>		<u>Page</u>
5.14	Number of mothers according to degree of open communication	109
5.15	Children's knowledge of illness aspects according to mothers' report	112
5.16	Subjects scores above and below the mean on the three study measures	140
6.1	Means of children's responses to a set of projective pictures in Waechter's, Spinetta's, and the present study	146

LIST OF FIGURES

<u>Figure</u>		<u>Page</u>
1	The interrelation of social learning theory concepts	19
2	State I communication	20
3	State II communication	20
4	Parents' and medical personnel's channels of communication to significant figures in the child's social milieu	108
5	Open communication with the child with chronic life threatening illness in regard to "living with the illness" and to "dying"	154

CHAPTER I

INTRODUCTION

The present study is designed to explore the phenomenon of loneliness in school age children living with chronic life threatening illness. Loneliness is a universal experience, an inevitable part of growing up and living. Loneliness is defined as

An emotional state in which the individual is aware of the feeling of being apart from others, along with the experience of a vague need for other individuals. Loneliness has an unpleasant connotation in contrast to mere solitude or aloneness in which the individual may be alone physically, but does not experience the negative or unpleasant aspect of loneliness. It can occur in the presence of other individuals (Leiderman, 1969, p. 156).

Hymel and Asher (1977) maintain that there are two important elements in defining a lonely, socially isolated child. "One is that the child lacks friends and the other is that the child is not generally accepted by peers (Hymel and Asher, 1977, p. 23). The lonely child can be actively rejected or be unnoticed and ignored by his peers. As a result the child may engage in solitary play, watch other children play from the side, or seek adults' attention (Moustakas, 1972; Wayne, 1968). The lonely child is often characterized by poor academic performance (Bonney, 1971).

Sullivan (1953), Goffman (1964), Peplau (1966), and Moustakas (1972) identify the following salient variables related to loneliness in childhood: blocked communication to the child, the stigma of differentness, withdrawal of peers and others, rejection and ostracism. The same variables may operate in the experience of a child with chronic life threatening illness.

Many authors identify blocked communication among different family members and the sick child, as well as family members among themselves as a common problem resulting from a diagnosis of a life threatening illness (Denning, Gluckson, and Mohr, 1976; Travis, 1976; Toch, 1977). Other salient problems facing a child with a chronic life threatening illness are: the child's being different from siblings and peers and therefore bearing a stigma (Goffman, 1964); experiences of being rejected and being ostracized shade the sick child's interpersonal relationships especially with peers. Parents as well as teachers tend to withdraw from the child both emotionally and physically (Kaplan, Smith, and Grobstein, 1974; Spinetta, 1974). In addition the sick child's death anxiety is a potential source of loneliness (Waechter, 1968). The first question posed by the investigator is: do children with chronic life threatening illness differ in their loneliness manifestation from healthy children?

Cancer and cystic fibrosis are among the leading

chronic life threatening illnesses in childhood (Cancer Statistics, 1977). Consequently, the investigator chose to study school age children with cancer and cystic fibrosis. Because the survival rates beyond the first or second year were very low, the diagnosis of cancer or cystic fibrosis was considered an acute and fatal illness.

In the 1950's most children with cystic fibrosis survived only through infancy or early childhood. A study in survival patterns in cystic fibrosis for the years 1966-1972 concluded that the age for 50 percent survival has increased from 10.4 years in 1966, to 18.1 years in 1972 (Warwick, Pogue, Gerleer, and Neslitt, 1975). Due to constant improvement in diagnosis and treatment, there is an increasing number of young adults with cystic fibrosis leading normal adult lives with only minimal limitations (Waechter and Blake, 1976, p. 725). Similar patterns characterize the increase in survival rates for cancer. For all forms of cancer occurring in children under the age of 15, the five-year survival rate age adjusted for normal life expectancy has increased to 33 percent. The first temporary remissions in leukemia were achieved in 1947. Today in some medical centers which provide comprehensive cancer care, the five-year survival rate rises to 50 percent for children with acute lymphocytic leukemia as some individuals even reach 10 years survival time (Cancer Facts and Figures, 1977).

These facts call for a change in our outlook.

. . . these diseases are now chronic rather than acute and rapidly fatal as in the past. Problems that alter the quality of life become apparent, whereas quantity of life was previously the main concern. There are a number of problems that substantially alter the life style of these children and their families (Lansky, Lowman, Vats, and Gyulay, 1975).

Among these problems there are medical realities of living with cancer and cystic fibrosis which contribute to the child's "being different" and may promote his loneliness.

Visibility. Most children with cystic fibrosis have a large, rounded chest, a square shoulder line, and a markedly distended abdomen. Children under intensive treatment for cancer may lose their hair, develop a moon-face, and may have visible postoperative scars.

Treatment. The treatment regimen includes frequent visits to the clinic for check-ups and procedures in the range of blood tests and x-rays for the child with cystic fibrosis, to bone marrow and lumbar punctures for the child with leukemia. Occasional periods of hospitalization occur during episodes of either exacerbation of the illness or intensive treatments. The ongoing treatment at home, for the child with cystic fibrosis, means daily postural drainage exercises, close watching of a fat-free diet, and daily medications. For most children under treatment for cancer, home care means daily medications for at least several years.

Side Effects of Illness and Treatments. The most common side effects of cystic fibrosis are: frequent, heavy coughing, passing of foul smelling stools, and frequent respiratory illness which may lead to frequent absences from school. The treatment for cancer may result in an array of side effects including low energy, excessive weight gain, headaches, nausea, and vomiting, which also lead to periodic school absences. Both groups of children are very vulnerable at times to bacterial and viral infections. They are therefore frequently isolated from other children and crowds in an effort to prevent infections.

Parents and medical personnel are the key figures in managing the psychological impact of the chronic life threatening illness on the child. Their reactions to diagnosis, treatment, and prognosis, as well as their strategies to deal with the many problematic facets of the illness, will influence the child's ability to be social or to withdraw into loneliness. The second question posed by the investigator is: what strategies do parents of children with chronic life threatening illness and medical personnel use to handle the problems of communication with the child, side effects of illness and treatment regimen, and death anxiety of the child?

THE SCOPE OF THE PROBLEM

In the United States, cancer is second only to acci-

dents as the cause of death in children one to fourteen years of age. Average annual incidence rates of cancer per 100,000 population were computed by the National Cancer Institute for the years 1969 to 1971. The Institute's data, based on information from seven metropolitan areas and two states, showed that for the five- to nine-year age group, the incidence rate for cancer in all sites was 10.0; of it, leukemia was 3.1 and brain and other nervous system 3.0 per 100,000 (Third National Cancer Survey, 1975). In 1976 the estimated number of new cases of cancer in the United States was 6,400 among children and 2,800 cancer deaths (Myers, Young, Silverberg, and Heise, 1976).

Cystic fibrosis is considered the ninth cause of death among children aged one to fourteen (Cancer Statistics, 1977). The disease appears in approximately one in every 1,500 live births (Waechter and Blake, 1976). In the United States there are approximately three million births per year, which means that 2,000 children are born with cystic fibrosis every year.

THE PURPOSE OF THE STUDY

The purpose of the present study is two-fold. First, it describes how school age children with chronic life threatening disease differ in their loneliness manifestations from healthy children on three indirect measures of loneliness. Second, it identifies from parents' reports

the strategies they, as well as the medical personnel, use to handle the psychological problems of living with chronic life threatening illness.

SIGNIFICANCE OF THE STUDY

Children with fatal illness often find themselves largely alone with their fears, anxieties and uncertainties at a time when comfort, nearness and sympathetic understanding is most important to them. Fear, isolation and fantasy can be more painful than physical death and loss of human communication may accompany and exaggerate fear and physical discomfort (Waechter, 1972, p. 155).

No research has been done on the phenomenon of loneliness in children with chronic life threatening disease. Therefore, we lack basic knowledge as to its occurrence, its origin, and what can be done to alleviate loneliness. This study will describe the occurrence of loneliness either as an ongoing experience the child has with the illness, or as a periodic experience around crisis episodes of diagnosis, relapse of illness, or approaching death. This knowledge could help parents, health care providers, teachers, and other significant adults to identify loneliness in the child and raise awareness to its existence. Once loneliness is identified and assessed, measures to prevent its further development can be instituted in the child's social environment. Effective strategies to deter loneliness can serve as guidelines for intervention with the sick child and the family.

Prevention and intervention are important since loneliness and unpopularity in childhood have long term effects on the lonely individual. Moore (1974) concludes from his study that lonely adults tended to be socially isolated in childhood. Unpopular children are more apt to be disproportionately represented later in life in community psychiatric registers (Cowen, Pederson, Babigan, Izzo, and Trost, 1973). Roff, Sells, and Golden (1972) report on a high positive relationship between percentage delinquent and low peer acceptance scores among 40,000 children in 21 cities. Stengel (1971) concludes that "social isolation is the common denominator of a number of factors correlated with a high suicide rate" (Stengel, 1971, p. 28). The quest of understanding loneliness is relevant to a child's quality of life in the present. It is also relevant to his future mental health.

Knowledge gained from this study could serve as guidelines to nursing care of children in other conditions which may be conducive to loneliness, e.g. children with chronic non-life threatening illness, physically handicapped children, children of divorce, battered children.

In this chapter the investigator examined the nature and scope of chronic life threatening illness in childhood in relation to the possible occurrence of loneliness in the sick child. The purpose and significance of the study were

stated. In the next chapter the conceptual framework and the study questions derived from it will be presented.

CHAPTER II

CONCEPTUAL FRAMEWORK AND STUDY QUESTIONS

Basic concepts from Sullivan's Interpersonal Theory (1953), Goffman's theory on stigma, and Rotter's Social Learning Theory (1972) compose the conceptual framework for the present study. The three assumptions underlying the conceptual framework are: (1) lack of peers' acceptance and fear of ostracism are potential components of loneliness in the school age child (Sullivan, 1953); (2) need for acceptance and fear of ostracism characterize the stigmatized individuals' strategies of managing their social environment (Goffman, 1964); (3) previous reinforcements relating to acceptance or ostracism as well as the preference the individual holds for them, will influence his social behavior in the future (Rotter, Chance, and Phares, 1972).

In his Interpersonal Theory, Sullivan addresses himself to the development of the experience of loneliness throughout childhood. He defines loneliness as "the exceedingly unpleasant and driving experience connected with the inadequate discharge of the need for human intimacy, for interpersonal intimacy" (Sullivan, 1953, p. 290). Each developmental stage has its typical needs that, unless

gratified, will lead the child to experience loneliness. The infant experiences a basic need for contact and tenderness. In the preschool years the satisfaction of the need for interest and participation of significant adults in the child's play becomes central to deter loneliness in the child. A strong need for peers characterizes the school age period. Along with the need for peers, comes the need for peers' acceptance. Bitter fear of ostracism accompanies the need for acceptance. The fear of ostracism means the fear of being accepted by no one of those whom one must have as models for learning how to be human.

Sullivan further describes the segregation of the juvenile society into groups. There are often prestigious ingroups composed of the "right people" in the "right place" and parallel outgroups including the outcasted. Illness or physical handicap often serve as the crucial reason for the child's exclusion from the ingroup. According to Sullivan, it is possible for the ostracized outgroup youngsters to establish interpersonal relations one with the other, however, evidence exists that these interpersonal relations are not successful substitutes for being part of the ingroup.

In summary, Sullivan's theory suggests that unmet needs for warmth, intimacy, and acceptance will enhance the development of loneliness in childhood. The natural tendency of parents to provide warmth and maintain intimate relationships with the child may be altered by the presence of

chronic life threatening illness in the child. Parents often use physical and emotional withdrawal from the sick child as one strategy of coping with the diagnosis of life threatening illness and the illness trajectory (Futterman and Hoffman, 1973; Kaplan et al., 1974). Spinetta (1974) claims that similar tendencies to withdraw from the sick child characterize some of the medical team relations with the child. Also teachers often turn away from and avoid the sick child and his family as a result of difficulties generated by personal inability or lack of knowledge in management of seriously ill children (Kaplan et al., 1974). Peers may ostracize the sick child since he looks different or is unable at times to take active part in their activities (McGrae, 1975). The patterns underlying the sick child's contacts with his peers or significant others in his social milieu can be best explained by Goffman's theory on the management of stigma.

Goffman (1964) states that a person will be stigmatized when there is evidence that he possesses an attribute that makes him different from others.

In all . . . various instances of stigma . . . the same sociological features are found: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him . . . He possess a stigma, an undesired differentness . . . (Goffman, 1964, p. 5).

The stigma causes the discrediting of the individual

possessing the stigmatizing attribute. He is reduced in the "normal's" mind from a whole and usual person to a tainted, discontented one. Goffman classifies three types of stigma: tribal stigma, such as race or religion; blemishes of character, such as mental disorder, weak will, or addiction; and abominations of the body, such as illness and physical deformities. He further differentiates the stigmatized as either discredited or discreditable. A discredited person is one whose stigma is apparent and known; a discreditable person is one whose stigma is not known. Goffman emphasizes that despite the important difference between the two situations, particular stigmatized individuals are likely to have experiences with both situations. Management of social situations becomes the central issue for the discredited individual, whereas management of information is central to the discreditable one.

Children living with chronic life threatening illnesses will face both situations at different periods. They will be discredited when undergoing intensive treatment for cancer. Most children will lose their hair due to specific drugs and irradiation. In the case of the child with cystic fibrosis, discrediting occurs when the child develops a barrel-like chest and distended abdomen. These visible stigma divulge to the public two important facts: one, that the child is sick and furthermore, that most likely he

suffers from life threatening illness. Along with feelings of pity for the child, many adults who have not come to terms with serious illness may feel anxious and uncomfortable in the child's presence, largely because the very sick remind them of their own vulnerability (Kaplan et al., 1974). In many cases the sick child becomes a target for his siblings' and peers' teasing. The commonly known norms which govern interpersonal contacts give way to uncertainty, uneasiness, and destructive patterns of behavior for both the stigmatized child and its significant others. As a result, the contacts of the sick child with "normals" may lead to shame, anxiety, inferiority, and anger.

The very anticipation of such contacts can of course lead normals and the stigmatized to arrange life so as to avoid them Lacking the salutary feedback of daily social intercourse with others the self isolate can become suspicious, depressed, hostile, anxious and bewildered (Goffman, 1964, p. 12, 13).

When the cancer patient is in remission or the mild cystic fibrosis patient is free from visible body changes, they face the problem of information management which is typical to the discreditable person. They constantly engage in conflict over whether to conceal or to disclose. For them:

The issue is not that of managing tensions generated during social contact, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let or not let on; to lie or not to lie, and

in each case to whom, how, when, and where (Goffman, 1964, p. 42).

How should the sick child explain to his friends or teachers his frequent absences from school when he appears to be healthy, or how would he manage to take medications at specific times without being "caught"? How should he explain his need for a special diet or his hesitations in regard to spending the night at friends' homes? The issue might get more complicated when the sick child's parents hold different ideas about information management than the child does. The child can find himself in conflict with self as well as with his parents.

On one hand, the child and family who decide to conceal the fact that the child is sick will probably avoid close relationships. "The more time the individual spends with another the more chance the other will acquire discrediting information about him" (Goffman, 1964, p. 86). Even close relationships which existed prior to acquiring the stigma become compromised. If, on the other hand, the child and family decide to disclose the fact that he is sick, they take the risk of being rejected. Some people believe that some forms of cancer or cystic fibrosis are contagious, therefore they will limit their contacts with sick children and also instruct their children to avoid them. Others might reject the sick child out of their uneasiness and confusion at his presence. In both situa-

tions the family and the child live under the constant stress of their secret becoming known, or of possible negative reactions from their social environment. In summary, the consequences of stigma management as stated by Goffman assert a pervasive effect on interpersonal relationships. Avoidance of contact and blocking of intimate relationships precede loneliness.

Selected principles from Rotter's (1972) Social Learning Theory explain and predict how the avoidance behavior of the stigmatized child might develop. The main interest of Rotter's theory is the study of interaction of the individual and his meaningful environment in relatively involved social situations. The theory aims at describing and predicting events.

Rotter proposes two levels of analysis: a basic molecular level which is primarily suited for controlled experimental research, and a broader level, which is more appropriate for clinical practice. The basic level concepts are related in the following way:

The potential that any behavior will occur in a given situation is dependent on the individual's expectation concerning the occurrence of reinforcement in that situation and the value that the reinforcement will have for him (Berger and Lambert, 1968, p. 109).

The second level concepts which are the interest of this study are based upon the above basic concepts. The concepts are:

Need Potential refers to a group of behaviors that are functionally related in that they lead to the same or similar reinforcements. Freedom of Movement refers to a mean expectance that a set of related behaviors will lead to functionally related reinforcements. Need Value refers to the mean preference value for a set of functionally related reinforcements. These broader concepts are related to each other, of course, since need potential is a function of freedom of movement and of need value (Berger and Lambert, 1968, pp. 109-110).

The Situation. From the Social Learning Theory view each situation is composed of cues serving to arouse in the individual certain expectancies for reinforcement of specific behaviors.

Social Learning Theory broader concepts are used to show what might happen to open communication and active contact when the child is sick with chronic life threatening illness. This explains the avoidance behavior, which may develop and become conducive to loneliness.

Communication, State I. The child learns through experiences that his communications are met with adequate answers, his parents show pleasure in responding to him, his emotions when communicated bring feelings of understanding and closeness (positive reinforcements). In Social Learning Theory concepts: this child has a high degree of FREEDOM OF MOVEMENT (his expectancy for positive reinforcements after communication is high). He also has a high NEED VALUE (preference for these reinforcements is high). Therefore his NEED POTENTIAL (the likelihood for functionally related behaviors to occur) for communicative behaviors is high.

In a situation that calls for communication we can predict that the child will communicate openly (see Figure 2).

Communication, State II. The child with chronic life threatening disease may realize from experience that his questions are avoided; his emotions when communicated, might result in distancing and rejection (negative reinforcements). In Social Learning Theory concepts: this child has a low degree of FREEDOM OF MOVEMENT (his expectancy for positive reinforcements after communication is low). He also has a high NEED VALUE (preference for positive reinforcements is high). Therefore his NEED POTENTIAL for communicative behaviors is low. According to Social Learning Theory:

When freedom of movement is low while need value is high, we have a situation of conflict. To escape punishment and failure in an area of great importance to him, the individual adopts various avoidance behaviors defensive and avoidant behaviors are acquired and maintained because they are positively reinforced by the avoidance of a strong negative reinforcement (Rotter et al., 1972, pp. 36-37).

In a situation that calls for communication, we can predict that the child will learn to avoid open communication (see Figure 3). The development of the child's avoidance of contacts with peers follows a similar process as the development of avoidance of open communication described above.

The State I to State II development is only a prototype useful for illustrating how a certain process can be under-

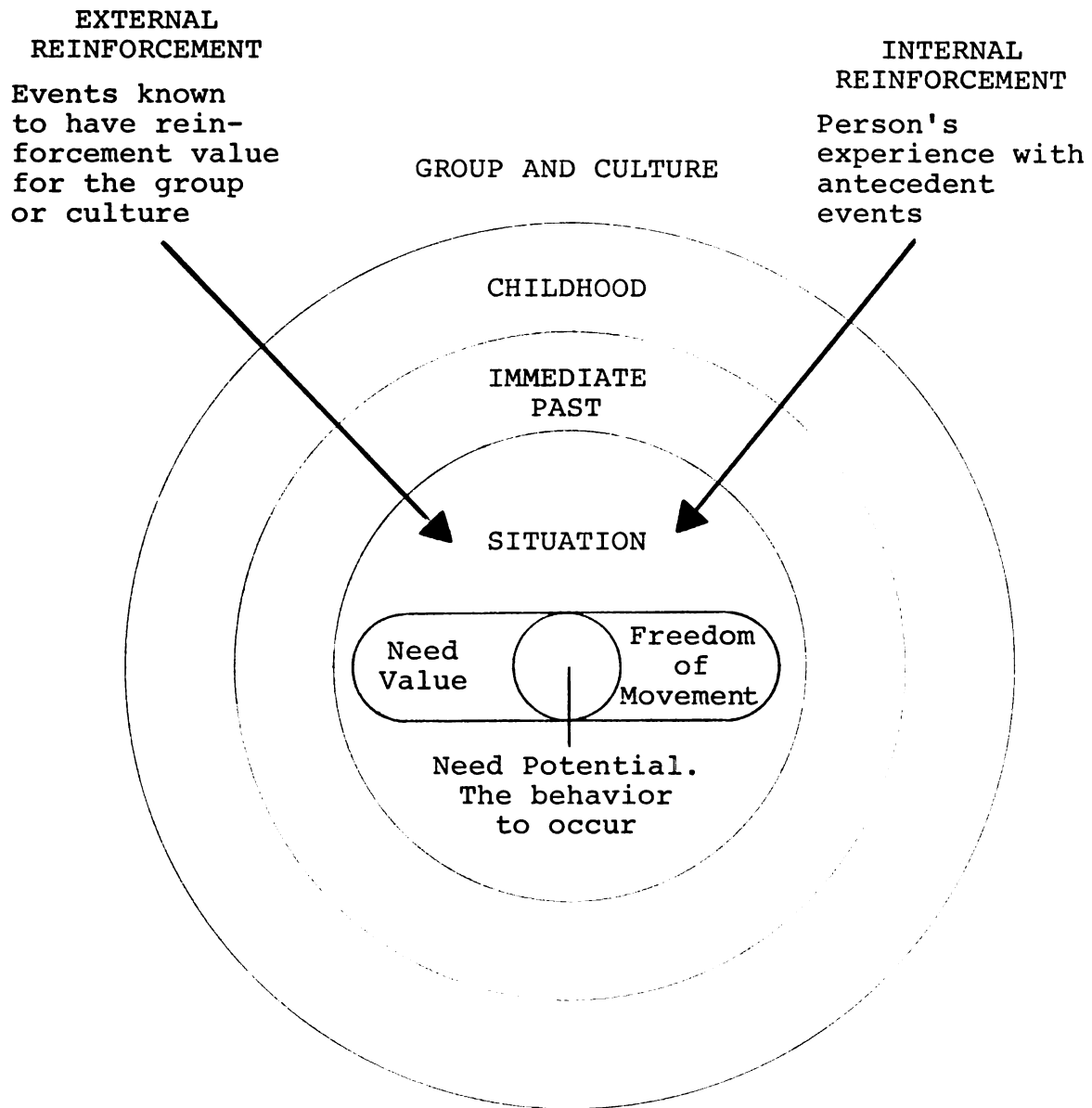


FIGURE 1: The interrelation of Social Learning Theory concepts (investigator's interpretation).

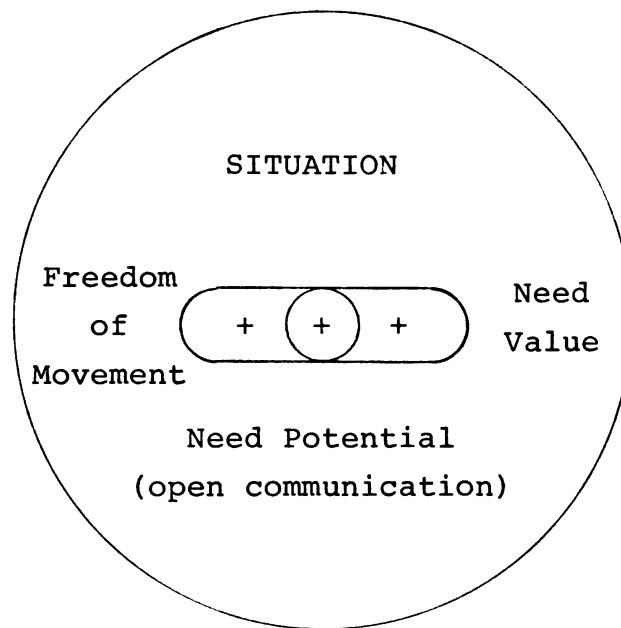


FIGURE 2: State I

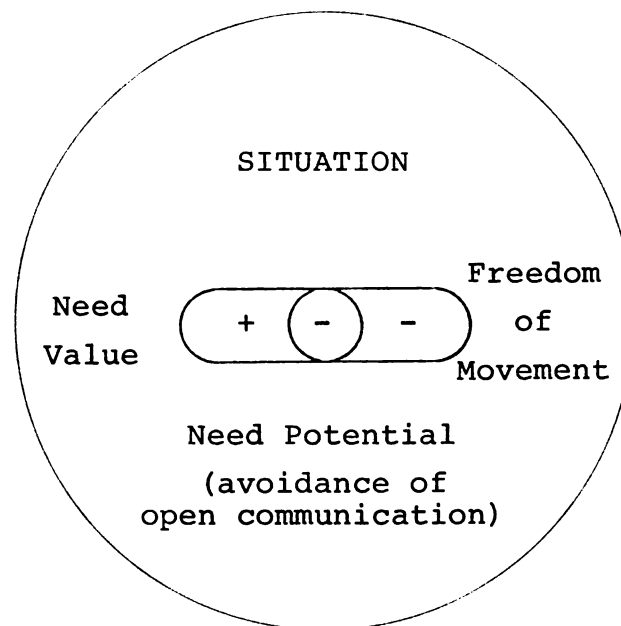


FIGURE 3: State II

stood via Social Learning Theory. In order to explain and predict the behavior of a specific child, it is necessary to investigate relevant antecedent events in the life of this individual child, e.g. his social development, previous experience with illness, etc. Social Learning Theory utilizes an historical approach to the study of personality. "It should be recognized, however, that the degree of reconstruction of the past that is necessary must always be gauged in terms of ones' predictive purposes" (Rotter et al., 1972, pp. 4-5).

In the above discussion INTERNAL REINFORCEMENTS were considered. EXTERNAL REINFORCEMENTS are determined by the culture and the group to which a child belongs. Norms, as to open versus closed communication, psychological and physical distances preferences will influence the "prototype process".

Lack of perfect correlation between group and individual values suggests that we should be prepared to make predictions from group values where feasible, but also check our guesses against data from the history of the individual (Rotter et al., 1972, p. 17).

Social Learning Theory provides a framework for looking at the development of avoidance behavior in a systematic way. It dictates the necessity of assessing the child's past history, the influence his wider culture, his immediate family, and peer group have upon him. Social Learning Theory also provides the four key concepts (situation, need

potential, need value, and freedom of movement) which enabled the investigator to focus on particular units of human interactions, which might lead to loneliness.

STUDY QUESTIONS

I. Do children with chronic life threatening disease differ in their loneliness manifestations from healthy children? Three hypotheses derived from this research question:

- (1) Children with chronic life threatening disease (CLTD) will respond with more loneliness themes (i.e. aloneness, separation, death anxiety, threat to body integrity, suicide) than will healthy children to a set of projective pictures (need potential for social behaviors is low).
- (2) Children with CLTD will be more adult oriented in their choices than will healthy children on a preference or interpersonal interaction scale (preference for positive reinforcements from interaction with adults is higher).
- (3) Children with CLTD will place human figures in a further distance than will healthy children on an interpersonal distance scale (expectancy for positive reinforcements from closeness is low).

II. What strategies do parents of children with CLTD and medical personnel use to deal with the problems of:

communication with the child, side-effects of illness, and treatment regimen and death anxiety of the child?

DEFINITION OF TERMS

Manifestations of Loneliness. (a) Responses of loneliness themes to a set of projective pictures; (b) preference for interpersonal distance on the Comfortable Interpersonal Distance Scale; (c) preference for interpersonal interaction on the Who Scale.

Chronic Disease.

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by nonreversible pathological alterations, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care (Commission on Chronic Illness, 1956, in Strauss, 1975, p. 1).

Chronic Life Threatening Disease. Chronic disease for which a ten-year survival rate of 50 percent or less is predicted.

Healthy Child. Child free from any illness at the time of the study and has not had serious illnesses in the past.

Behavior Potential. Behavior is defined as all human responses to a meaningful stimulus and having an effect on the environment. The behavior with the highest potential is the one most likely to occur. Behavior can be directly

observed or can be inferred from the presence of other behaviors.

Reinforcement Value. The degree of the person's preference for that reinforcement to occur if the possibilities of occurrence of all alternatives were equal. Any event can be defined as a reinforcement when it can be shown that the event changes the potentiality for occurrence of a given behavior. Internal reinforcement is defined as the person's experience or perception that an event has occurred which has some value for him.

This value may be either positive or negative. Positiveness or negativeness of value is determined by resultant effects upon the frequency of observable behavior. External reinforcement refers to occurrences of events or outcomes known to have predictable reinforcement value for a group or culture to which the person belongs (Rotter et al., 1972, p. 17).

Expectancy.

The probability held by the individual that a particular reinforcement will occur as a function of a specific behavior on his part in a specific situation or situations (Rotter et al., 1972, p. 12).

In this chapter the development of the study conceptual framework and the study questions were discussed.

CHAPTER III

REVIEW OF THE LITERATURE

There are many questions around the phenomenon of loneliness. What is loneliness? How can one describe it? Is it a feeling, an emotional state? Is it an inevitable part of human existence? Is there only one kind of loneliness, or are there several? How does loneliness develop in childhood and in illness?

In a "voyage" through the literature to discover the mystery of loneliness, the investigator found as many versions of loneliness as the number of writers who wrote about it. Authors in a number of disciplines - philosophy, sociology, psychology, psychiatry, religion, and the fine arts - emphasize the importance of loneliness as a human experience. However, due to limited systematic research on loneliness, there is little conceptual clarity about the subject (Bradley, 1969). The common identified theme in the writings is that loneliness means being psychologically apart from others without being able to communicate to others what one is experiencing. In extreme cases of loneliness, the lonely individual may not be able to admit his loneliness, even to himself.

This review of the sociological and psychological

literature on loneliness covers the following issues:

- I. Selected views on loneliness
- II. Origins of loneliness in childhood
- III. Origins of loneliness in the experience of a child with chronic life threatening disease.

I. SELECTED VIEWS ON LONELINESS

To a certain degree, loneliness is a characteristic of modern society. Wood (1953), Moustakas (1961, 1972), and Slater (1976) agree that loneliness is not a unique problem of the lonely individual. The modern man lives in an impersonal world in which he has few meaningful and enduring ties. Social and cultural changes caused men to discard old personal ties to the extended family, the closed neighborhood, and his religious relationships. Instead, Wood (1953) states there is an increase in the processes such as individualization, differentiation, specialization, segregation, stratification, competition, and urbanization, which tend to become unduely isolating.

Slater (1976) suggests three basic human desires that are deeply and uniquely frustrated by the modern American culture. First, the desire for community - the wish to live in trust, cooperation, and friendship with those around one. Second, the desire for engagement - the wish to be involved with ones' social and physical environment. Slater points to a tendency of the individual in modern

times to treat persisting and major social problems by either avoiding or escaping the issues. He speaks of a "toilet assumption - the notion that unwanted matter, unwanted difficulties, unwanted complexities, and obstacles will disappear if they are removed from our immediate field of vision" (Slater, 1976, p. 21). This tendency permits modern man to "put away", to institutionalize the aged, psychotic, retarded, and infirm.

The third desire, according to Slater, is the wish for dependence - for the opportunity to share with others responsibilities and decision making processes. Slater concludes that the three desires are suppressed in our society out of a commitment to individualism. The passion for success leaves very little space for interdependence or non-competitive relations. The unfulfillment of the above desires is conducive to loneliness.

Wood (1953) discusses the issue of relations further. She claims that interest relations in our society are such that selection of contacts is made from the point of view of the services the relations render to the individual in his race for success, are taking the place of sentiment relations characterized by intimacy, mutual attachment, satisfaction of the need for affectionate response and a sense of belonging. Individualization and competition are the underlying separating processes within groups. In addition, there are common society norms that contribute to

separation and alienation between groups, e.g. race, religion, class, generation, and sex.

The three writers agree that man in modern society suffers from degrees of loneliness, characterized by feelings of rejection, separation, and alienation* from one another and in some cases, also from the self. They also agree that loneliness can be experienced both when a person is physically alone or interacting with other people. The salient underlying theme is that of impaired communications.

Most people adopt certain defensive behaviors to alleviate the anxiety of loneliness. Moustakas writes:

It is absolutely necessary to keep busy, active, have a full schedule, be with others, escape into the fantasies, dramas, and lives of others on television or in the movies. Everything is geared toward filling and killing time to avoid feeling the emptiness of life and the vague dissatisfactions of acquiring possessions, gaining status and power, and behaving in the appropriate and approved ways. The escape from loneliness is actually an escape from facing the fear of loneliness (Moustakas, 1972, p. 32).

Moustakas (1961) and Lindenauer (1970) differentiate between two types of experiences of loneliness. One is the neurotic loneliness anxiety and the other is creative and existential loneliness. The anxiety of loneliness as described above is a defense people use in an attempt to eliminate loneliness with very little potential for success.

*For extensive discussion on social alienation, see Lysten, M., Social Alienation: A review of current literature, The Sociological Quarterly 13, 1972, pp. 90-113.

The lonely person has another option besides running away and trying to escape from his loneliness. He can recognize and accept the organic nature of his loneliness and see its value for self growth. He then will experience what Moustakas and Lindenauer identify as the creative and existential loneliness. Only after surviving the confrontation with existential loneliness, "by steeping oneself in the experience and allowing it to take its course and to reveal itself is there hope that one's world will achieve harmony and unity" (Moustakas, 1972, p. 21). To experience one's creative loneliness is a prerequisite for establishing deep and meaningful relationships with others (Lindenauer, 1970).

Tanner (1973) relates to loneliness as a disease to which no one has an immunity and identifies its origins in the individual's fear of love. Tanner claims that the lonely individual tends to suffer from self doubt and is therefore afraid to take risks and to love. The lonely person usually holds others responsible for his fear of love. Unless the individual will learn through a process of personal growth to assume responsibility for the consequences of loving, there is no hope for his loneliness to be cured.

Both loneliness anxiety and existential loneliness are considered as healthy loneliness, where the powers to alleviate it lie with the lonely individual. At times, he

might need some help and guidance from others. But there is another kind of loneliness that is considered pathological. Frieda Fromm-Reichmann (1959) describes her experience of persisting difficulties in reaching the loneliness of the schizophrenic patient. Detailed discussion of pathological loneliness is beyond the scope of this review.

All human beings suffer from loneliness to a certain extent. We cannot explain why some individuals are lonelier than others and more affected by their loneliness. The search for origins of loneliness in childhood may provide insights to these questions.

II. ORIGINS OF LONELINESS IN CHILDHOOD

Clancy and McBride (1975), Sullivan (1953), and Tanner (1973) describe the origins of loneliness in infancy. Sullivan suggests that the infant's unmet needs for contact and warmth will lead to loneliness. Tanner adds that often the very young child reaches out for love and love is not returned. Along with feeling rejected, the child can interpret this lack of response by doubting his own self worth, concluding that there must be something about him that is unlovable. According to Tanner, doubt in one's self worth and the developing of fear of love are proved passes to loneliness.

Clancy and McBride propose that when parents (especially the mother) are unable to respond appropriately to the

infant's needs over a period of time, an isolation syndrome will develop in the infant. Following a breakdown in the early bonding process between mother and child, "there may progressively emerge a pattern of behaviors which decreases their interrelationship so that the child eventually reaches a state of social isolation" (Clancy and McBride, 1975, p. 198).

These authors identify five typical situations in which the isolation syndrome is more likely to arise: (1) a child is in an institution with no mother or mother substitute; (2) the infant is separated from his mother because of too low birth weight or neonatal illness, which requires long periods of hospitalization; (3) the infant has recognized illness or abnormalities which may result in the development of abnormal relationships with the mother or significant others in the family (the last two situations may apply to the cases of early identified cystic fibrosis or of congenital cancer in the infant); (4) a child is born to a family with severely abnormal relationships; and (5) an autistic child. Bakwin (1942), Spitz (1945, 1946), and Bowlby (1960) describe similar situations in their works.

Clancy and McBride emphasize the importance of early diagnosis of the isolation syndrome along with a clear plan for intervention. They warn that untreated isolation syndrome may result in multiple aspects of developmental retardation, especially in social skills and language

development and pathological loneliness later in life. The underlying goal for intervention is to assist the development of effective communication between mother and child in the form of reciprocal interaction and warm affective bonds.

Moustakas (1961) lists many incidents where the growing child can experience loneliness. Among them he lays stress on the loneliness of the hospitalized child, who may feel abandoned by his parents and separated from his social milieu. Both Moustakas (1972) and Tanner (1973) point out that normal loneliness in children is due to a great extent to many parents' constant imposition of demands and expectations of the child. The constant pressure on the growing child to obey, to behave, and to conform inhibits any opportunity for his self expression or uniqueness. The parents' lack of genuine interest in the child as a separate person leads to a sense of alienation and an end result of loneliness (Sullivan, 1953; Peplau, 1966).

In writing his memories, C. G. Jung (1963) refers to his experience with childhood loneliness, illustrating the preceding statements:

As a child I felt myself to be alone, and I am still, because I know things and must hint at things which others apparently know nothing of, and for the most part do not want to know. Loneliness does not come from having no people about one, but from being unable to communicate the things that seem important to oneself, or from holding certain views which others find inadmissible (Jung, 1963, p. 356).

Moustakas (1961) stresses his theme that loneliness can be a very creative experience when it is accepted by the individual child himself. He claims that most people who stand out in their work in art, music, literature, and science are often lonely people with long histories of loneliness beginning in childhood. Unfortunately, often childhood loneliness does not result in creative loneliness, but in loneliness anxiety.

Loneliness in the child tends to be identified when the child enters the school-age period. This period is characterized developmentally by the great need for peer group and peer acceptance. The importance of peer group acceptance for the normal development of the school-age child stimulated research in the areas of: the development of social cognition and social skills (Shantz, 1975); the phenomenon of peer relations in childhood (Campbell, 1964); and methods for identification and modes of intervention with socially isolated children (Bonney, 1971; Hymel and Asher, 1977).

In an extensive review of research literature on peer group relations in childhood, Campbell (1964) points to the role of the broader social context on children's peer groups. Broad cultural, sub-cultural, and family variations influence the atmosphere, values, and practices of the peer group. These variations also influence the individual child's approach to the peer group. Salient for the

present research is the fact that these differences play a major role in the acceptance, rejection, separation, and ostracism of different children.

Campbell calls attention to another issue highly relevant to the present study: what are the criteria for acceptance or rejection in the peer group? He differentiates between criteria related to personality and social characteristics and skills and abilities. Campbell reports on research findings that show friendliness and sociability to be associated with high acceptance in the group, and social indifference and withdrawal to be attributes of low status or rejected children.

It is very hard to decide where the process starts. Is it rejection that generates the withdrawal, or is it withdrawal that generates rejection? Kohn (1966) provides some light on the question via his research findings. He states: (1) The child creates his own social environment both in respect to quantity and quality of contacts. He gets what he puts out. (2) "The child manages to bring about that kind of approach from the world that validates in a sense his own approach to it" (Kohn, 1966, p. 99).

Kohn studied eleven children's interactions with peers through different types of observation. The children were studied intensively for an entire school year. Kohn expresses his concern that the findings are based on a small sample of children and therefore limited in their

generability. He considers the findings highly suggestive, but recommends their confirmation with a larger sample.

Reese (1961) adds that there is a relationship between the child's self concept and sociometric choices. He concludes that highest acceptance in the group is related to moderate self concept scores and lowest acceptance in the group to low self concept scores. Horowitz (1962) also reports that in the middle grades of elementary school the less popular children tend to think less well of themselves.

The skills and abilities criteria for peer acceptance are physical appearance, muscular strength, and athletic ability, especially among boys. Campbell (1964) sets forth two other facts that are of great relevance to the present study. First, the fact that in groups that have been established for some time, stability in preferences of children is the rule. The second fact is that in forming groups, reputations of different children are quickly established and they are more stable than the child's behavior. Once the child has received low scores on sociometric measures, there is a tendency for these low scores to persist. Once he has the reputation of an unpopular child, it will be very hard for him to change this reputation by changing his behaviors. The lonely child may meet obstacles in his efforts to alleviate his loneliness through reaching for warmth, contacts, and friends. In summary, it appears that in order for the school-age child

to be accepted and popular in the peer group, he needs to be physically well, appealing, able to compete, have high levels of self esteem, possess social skills, and tend to utilize them in peer interaction.

Sullivan (1953) maintains that illness in the very young child is one of the common causes leading to loneliness. It evolves from retardation in interpersonal relations which the child carries with him to the juvenile era (school-age). Further, when the child is ill during the school-age period, he is apt to develop social handicaps due to school absences and inability to participate competently in games and competitions. The underlying theme to the process of developing loneliness as a result of illness, is the child's being different in both the physical and emotional aspects than his healthy peers. Being different is known to be a target for ridicule and discrimination (Peplau, 1966).

A great deal of research effort has been invested to establish optimal methods of identification and interventions with isolate children. Using a peer nomination technique, Gronland (1959) found that about six percent of third through sixth grade children have no friends in their classrooms. Hymel and Asher (1977) report on eleven percent of 205 children who received no nominations as "especially liked" by their classmates in the third through fifth grades.

The emphasis of these studies is on assessment and

coaching of isolated children. The studies are lacking in providing basic analysis of the characteristics of the isolated children, the ways they are different from the popular ones, and suggestions as to the origins of their isolation. The statistics gained in these studies should be accepted with caution since the data are based on sociometric nominations done only in the school setting. Some positive correlations with either mothers' reports on the child's isolation at home or with sociometric nominations done in the neighborhood would make a stronger case for the statistics.

In conclusion, loneliness belongs to the experience of living and growing up. However, some children may be lonelier than others. The identified factors conducive to loneliness in childhood are: unmet needs for warmth and contact, lack of genuine interest in the child, impaired communications between the child and significant others, and the child being different from his siblings and peers. In the next section discussion will evolve around the relationship between selected identified factors conducive to loneliness and aspects in the experience of living with chronic life threatening disease. Additional factors unique to the fatal prognosis will be emphasized.

III. ORIGINS OF LONELINESS IN THE EXPERIENCE OF A CHILD WITH CHRONIC LIFE THREATENING ILLNESS

Children living with chronic life threatening illnesses are a focus for studies since the early 1950's. Parents, families, and medical personnel are the main source for information gathering. The early literature consists mainly of clinicians' unsystemized observations and interviews with the above as to their reactions to diagnosis, treatment, and death. The main focus was on the grieving process, since death was a definite outcome within a short time period (Bozeman, Orbach, and Sutherland, 1955; Chodoff, Friedman, and Hamburg, 1964; Wallace and Townes, 1969). Few reports deal with the subject of fatal illness from the child's point of view and even these reports are not based on data gathered from the children directly (Evans and Edin, 1968; Knudson and Natterson, 1960; Morrissey, 1965). Waechter (1968) followed by Spinetta (1972), who studied death anxiety in children with fatal illness, were the first to design a systematic study and use children as their main source for data gathering.

In different reports children are identified as displaying anger, fear, depression, guilt, anxiety reactions, acceptance, and even hope (Burgert, 1972). In addition, the concept of loneliness is mentioned as part of the child's experience with the disease (Burgert, 1972; Northrup, 1974; Tropauer, Franz, and Dilgard, 1970; Waechter,

1968); the experience of loneliness per se has not been studied in children with chronic life threatening illness.

The investigator has identified four major origins for potential loneliness in the sick child: (1) the fact that the sick child is different than his siblings and peers (this origin applies also to chronic nonlife threatening illness); (2) a matrix of impaired communications characterizes the experience of a child living with chronic life threatening illness; (3) the tendency of parents and significant others toward withdrawal and distancing from the sick child; and (4) the sick child's death anxiety.

1. The Sick Child's Difference from His Siblings and Peers

The chronically sick child must deal with the fact that he is neither healthy nor can he live a normal life in a world which admires physical health and normalcy (Cytryn, Moore, and Robinson, 1973). The difference is inherent in the nature of the illness. The illness imposes changes in energy for physical activity, changes in appearance (Richmond and Waisman, 1955), changes in daily routines (diet, exercises, medications), and at times poses restrictions on contacts with others to avoid contagion or in an attempt to keep the condition secret (Cytryn et al., 1973). Unfortunately, data on how the sick child views himself and his differences are scarce and scattered.

Cytryn and his associates (1973) evaluated 29 children

with cystic fibrosis. In their sample ten children were six to nine years of age. The children expressed concerns about their self concept and body image in different ways and in different contexts. In their human figure drawings there were in some cases clear indications of concerns about body disfigurements, e.g. disproportionately large and detailed chest area, or small constricted figures. Other children produced fantasy material in response to Rorschach tests which suggests that they saw themselves as younger than they were, dependent, and inadequate. Tropauer et al. (1970) studied 20 children with cystic fibrosis and 23 mothers. The ages of the children ranged from five through twenty. They collected data through extensive psychiatric interviews and the observations by the clinic director. The children were asked about their experiences in relation to the illness. The adolescents' responses show preoccupation with death and ultimate disability, worries about alteration in their physical growth and restrictions on social life, concerns of being different from their friends, and non-acceptance by their peers. Bakwin and Bakwin (1972) and Knowles (1971) report similar findings.

The younger children "complained frequently about interruption of play, dietary deprivations, or the physical limitations which prevented them from keeping up with others" (Tropauer et al., 1970, p. 208). In addition, seven mothers voiced strong concerns about the child's

impaired social adjustment, e.g. "lost initiative to make friends", "avoids close friends". The authors also report that in this study the manifestations of the child's anxiety were not solely related to the severity of the illness and disability.

Tropauer et al.'s report has some weak points. The sample is small and covers a large age span which limits possible generalizations. The authors do not report the exact methods for data collection (interview schedule, number, and qualifications of interviewers) or data analysis; therefore, the study cannot be replicated. However, the results provide highly suggestive observations about the children's perceived differentness.

Denning, Gluckson, and Mohr (1976) report on six papers dealing with various aspects of the psychological and social problems secondary to cystic fibrosis. The authors of these papers reach a common conclusion that cystic fibrosis consistently produces psychological and social problems in the patient, his parents, and his family. McAnarney, Pless, Satterwhite, and Friedman (1974) discuss an agreement among writers that children with chronic illness have more frequent psychosocial disturbances than do healthy children. They studied 42 children six to seventeen years old with chronic arthritis and 42 healthy children selected as matched controls. All subjects were tested on self concept, general personality, and projective measures. The results

of these tests suggest that more children with arthritis view themselves as "different", "inferior", or "less worthy" than their healthy peers. Although all of the differences in these appraisals were not statistically significant, the research results suggest the agreement that children with chronic illness have a tendency to manifest more psychosocial difficulties than their healthy peers.

Besides the nature of the illness and its side effects, there is another major source for the child to feel different. Parents of children with chronic life threatening illness tend to treat the sick child in a different way than before diagnosis (Easson, 1970) and different than his siblings (Lascari, 1969). They will adopt what Boone and Hartman (1972) identify as the "benevolent over-reaction". The term reflects parental actions which include over protection, over indulgence, and permissiveness. It is clinicians' opinion that the "favorite child syndrome" (Benoliel, 1972) results at first in the child's confusion and anxiety and in the long run causes lack of self esteem, initiative, and self control (Boone and Hartman, 1972). Favoritism and over protection of the sick child may generate sibling jealousy and anger (Burget, 1972).

Recent research challenges the common agreement that chronically ill children are a psychologically deviant population (Bedell, Giordani, Amour, Tavormina, and Boll, 1977). Tavormina, Kastner, Slater, and Watt (1976) and

Gayton, Friedman, Tavormina, and Tucker (1977) voice strong critique on previous studies on psychosocial problems of chronically ill children and their families. Tavormina and associates write: "Since most of the studies in the current literature were based on assumptions, clinical impressions, subjective evaluations or abbreviated projective techniques, the findings should be considered tentative and largely speculative" (Tavormina et al., 1976, p. 101). These two groups of researchers propose to study the "deviance notion" with more standardized and systematic measurements. Further, Tavormina et al. (1976) studied 144 chronically ill children five to nineteen years old. Their sample is composed of 20 children with asthma, 78 with diabetes, 30 with cystic fibrosis, and 16 with hearing difficulties. The children took a battery of psychological measures in an attempt to sample areas of personality functioning previously cited as important in chronically ill children. For most of these measures, there are known norms from healthy children. They found that the overall patterning of scores for these individuals closely approximate scale norms across instruments. They conclude that the results demonstrate the normalcy rather than the deviance of the sick children.

Gayton et al. (1977) also found no significant difference between the mean scores of 26 children with cystic fibrosis and their healthy siblings. These children were tested on similar psychological measures as used in the

previous study. They conclude that their study does not support the idea of considerable emotional upset in the child with cystic fibrosis. The validity of using siblings as healthy comparisons is questionable, since they are known to be also affected by their sibling's illness (Burget, 1972).

Even though the overall scores of both studies show closeness to normalcy, a close look at part of the subscales of the Tavormina study discloses some areas of difference. "The cystic fibrotic youngsters were more dependent, less mature, and voiced more problems with intellectual and school status and their physical appearance" (Tavormina et al, 1976, p. 109). Further, the authors state that realistically these children are different, but not deviant and the study results illustrate some of the children's attempts to come to grips with reality. Both groups of researchers suggest to change the shift in research from "maladjustment orientation" to focus on the strengths and resilience of children with chronic illness.

In conclusion, although much of the findings are based on clinical experience rather than research findings, the pattern in the literature suggests that the major contributors to the child's being and feeling different are (1) the nature of the illness and side effects which result in alterations in physical appearance, physical competence, and self image, (2) the change in parent expectations and dis-

ciplining which result in anxiety, lowered self esteem, and possible friction with siblings.

2. Impaired Communications with the Sick Child

Waechter (1968), Singher (1974), and Northrup (1974) identify lack of or restriction of open communication between different family members or medical personnel and the sick child about the nature and impact of the disease as one of the major sources for potential experience of loneliness. Alteration in communications might be the result of parents' and medical personnel's adoption of the "protective approach" (Share, 1972). According to this approach, the ill child and often his siblings should be shielded from knowledge of the disease, diagnosis, and prognosis (Evans, 1968; Lascari, 1969; Sigler, 1970). The "protective view" argues that the child's defenses are inadequate for coping with the anxiety that would flow from knowledge of the possible imminent death (Share, 1972). Evans (1968) agrees that fear of death is universal, but claims that this fear is often dealt with effectively by suppression and rejection. Therefore, Evans states that open discussion with the sick child about his illness will destroy these excellent defense mechanisms and increase his anxiety. In order to maintain the "protective approach" parents and medical personnel are required

to avoid subjects that might lead to the child's questioning of the illness, ignore some of the child's overt or covert clues regarding his serious concerns, or denying the child's expressed concerns by brushing them aside or giving false reassurance. Sometimes it requires physically distancing oneself from the child to avoid difficult encounters (Share, 1972,p. 194).*

The child who soon learns that his communications are not welcomed, that discussion is taboo and turns adults away from him, may isolate himself and indulge in private fears and fantasies (Northrup, 1974; Singher, 1974; Vernick, 1973). The end result of such communication processes is that the child feels lonely and abandoned at the very time when he is most in need for meaningful communication with a trustworthy adult (Vernick and Karon, 1965).

Binger, Ablin, Feuerstein, Kushner, Zoger, and Mikkelsen (1969) document this loneliness. They undertook a retrospective study in which they interviewed 20 families who lost their child from leukemia.

As parents attempted to protect their children from the concerns of the illness, older leukemic children attempted similarly to protect their parents; the children who were perhaps the loneliest of all were those who were aware of their diagnosis but at the same time recognized that their parents did not wish them to know. As a result, there was little or no meaningful communication. No one was left to whom the child could openly express his feelings of sadness, fear or anxiety (Binger et al., 1969, pp. 415-416).

*Share reviews the controversial issue of "protective" versus "open" approach in the literature, tending toward the "open" approach.

Waechter (1968) studied death anxiety in school-aged fatally ill children. She reports that although most of these children were not directly informed as to the nature of their illness, they indicated a considerable preoccupation with death, feelings of loneliness and isolation. In a study of mothers' adaptation to the threatened loss of their children through leukemia, Friedman et al. (1963) included few observations related to the children. It was their impression that acknowledgement of the illness "is often helpful especially in the older child in preventing the child from feeling isolated believing that others are not aware of what he is experiencing or feeling that his disease is "too awful"to talk about (Waechter, 1968, p. 610).

Lack of meaningful communication with the child occurs not only as a result of the belief in shielding the child. Most parents and medical personnel who adopt this approach feel helpless, inadequate, and too anxious to talk openly with the child (Northrup, 1974; Vernick, 1973; Vernick and Karon, 1965; Waechter, 1968). Vernick (1973) writes "On the whole we tend to decide for ourselves what the child needs to talk about purely on the basis of what we feel would be most comfortable for us to discuss with him" (Vernick, 1973, p. 106).

Northrup (1974) strongly believes in "open communication". She states "We must destroy the barrier of silence and free the child from both isolation and alienation"

(Northrup, 1974, p. 1968). The "open communication" approach has many strong proponents (Ablin, Binger, Stein, Kushner, Zoger, and Mikkelsen, 1971; Singher, 1974; Vernick, 1973). They propose that the often expressed dichotomy of "to tell or not to tell" appears as a meaningless question (Waechter, 1968). Rather, they agree that efforts should be geared to create a supportive environment in which the child will feel safe to ask any and all questions, share his concerns, and manifest his anxieties. Honesty and frankness are most important for reaching the child and maintaining the supportive environment.

Ablin et al. (1971) state that for

younger children the "truth" about their illness might be no more than an acknowledgement that they have a serious disease about which their parents are very concerned. Older children know already . . . because the seriousness of the disease is so obvious, there remains little of the "truth" to tell other than to acknowledge that the parents know and understand the child's concerns and fears and that all possible will be done to relieve them (Ablin et al., 1971, pp. 363-364).

There is little research on the effects of open communication on the sick child's levels of loneliness, feelings of separation, general anxiety, and death concerns. Binger et al. (1969) report on two families of adolescents who experienced more meaningful relationships with the sick children after a frank discussion with them about their diagnosis and prognosis. Waechter (1968) found in her

study that only two out of the 16 children with fatal illness were given an opportunity to discuss their concerns with their parents. She demonstrated a highly significant relationship between the opportunity to discuss and the child's overall test scores showing less general anxiety and fewer concerns about death, separation, and loneliness.

Vernick and Karon (1965) report on a two-year program at the National Cancer Institute which included 51 children from the ages of nine to twenty, hospitalized for leukemia. The authors utilize life space interviews with children and weekly group meetings with children, parents, and staff. Their goal was to develop the supportive environment. Every child was told his diagnosis and at the same time an outline for a potentially helpful therapeutic regimen was discussed. "On the basis of observations and discussions with these children, the authors conclude that there were no significant adjustment problems in any of the 51 patients" (Share, 1972, p. 200). Most children used the opportunities to ask relevant questions about their illness and treatment and to share their intense concerns (Vernick, 1973).

Bluebond-Langer (1974) concludes a discussion on communication and terminally ill children:

Dying is difficult to do alone, and yet in so many ways it cannot be shared. If anyone is aware of this, it is the dying child. He knows and observes the restrictions against speaking about death. If he tries to break taboos, he rarely does so directly and then, perhaps, only in a highly symbolic manner (Bluebond-Langer, 1974, p. 180).

Therefore "giving a child such an opportunity (for discussion) does not heighten death anxiety: on the contrary, understanding acceptance and conveyance of permission to discuss any aspects of the illness may decrease feelings of isolation and alienation" (Waechter, 1971, p. 1170).

3. Parents' and Significant Others' Anticipatory Grief

Diagnosis of life threatening illness in a child usually generates anticipatory mourning processes in parents and medical personnel. Futterman and Hoffman (1973) define anticipatory mourning as "a set of processes that are directly related to the awareness of the impending loss, to its emotional impact and to the adaptive mechanisms whereby emotional attachment to the dying child is relinquished over time" (Futterman and Hoffman, 1973, p. 130).

There are functional and dysfunctional consequences of anticipatory grief for the dying child, his family, and the medical treatment team (Benoliel, 1974). Isolation and alienation of the sick child as a result of the anticipatory grief (Benoliel, 1974; Easson, 1970; Spinetta, Rigler, and Karon, 1974) can be considered as a major dysfunctional aspect of the grieving process. Parents' behavior often demonstrates:

1. Intermittent clinging as well as distancing from the sick child (Futterman and Hoffman, 1973).
2. Gradual detachment of emotional investment in the

child and redirection of energies toward other relationships or "replacements" for the dying child. Chodhoff, Friedman, and Hamburg (1964) report on high percentage of pregnancies and adoptions among couples with a dying child within their sample.

3. Completion of the mourning process and withdrawal of emotional investments from the dying child before his death. This situation results in the "living dead" syndrome. The child may be emotionally dead as far as the family is concerned while he is still physically alive (Easson, 1970).
"Because the family members have mourned him too early and too completely, the child may find himself isolated and alone. He has been mourned and laid to rest even before he is dead" (Easson, 1970, p. 79). Unfortunately, there is little systematic research to support any of the above statements.

Similar features characterize the dysfunctional facet of the anticipatory grief which the medical team may also display. Physicians and nurses may (1) get involved in distancing behavior, place the dying child in a distant and remote room (Northrup, 1974), or make only quick contacts with him from the doorway (Glaser and Strauss, 1965); (2) avoid patients and parents out of feeling inadequate

and helpless in supporting the sick child and family (Burgert, 1972; Singher, 1974); (3) when death is imminent, may react with sadness and depression (Burgert, 1972). These behaviors enhance loneliness in the child and his family.

Spinetta et al. (1974) used interpersonal distance measures in an attempt to objectify the sense of isolation said to be present in a school-age child with fatal illness. Their sample consists of 25 hospitalized leukemic children aged six to ten and a matched group of 25 chronically ill children. When asked to place significant figures (father, mother, doctor, nurse) in a hospital room replica, the leukemic children placed the figures at distance significantly greater than did the matched group. For both groups the distance of placement increased in subsequent admissions; the leukemic children, however, increased the figures' distance significantly more than did the chronically ill. Based on Social Learning Theory and Interpersonal Distance Theory, the authors infer that the placement of the figures by the leukemic children is reflective of a growing sense of isolation. They conclude that the children react to significant adults who tend to reduce the quality and quantity of interaction with them.

Avoidance and distancing from the sick child and his family may also be a part of teachers' reactions to diagnosis and treatment effects of life threatening disease in the child (Kaplan, Smith, and Grobstein, 1974). Rejection, withdrawal, avoidance, and distancing from the sick child

are potential origins for loneliness.

4. The Sick Child's Death Anxiety

Mijuskovic (1977) and Waechter (1968) emphasize the link between death anxiety and loneliness in the sick child.

Children are not, at least at first, afraid of death, because they cannot comprehend or imagine what a permanent loss of consciousness might mean They are, however, terrified of the dark because it symbolizes aloneness. Thus, they are often afraid of going to sleep at night, not because they fear never awakening again, but rather because they are horrified by the prospect of being conscious and alone. We do not fear death, we fear loneliness What horrifies us concerning death is the possibility that our consciousness will continue but that it shall be the only one. We imagine ourselves . . . existing alone within a dark . . . universe, wandering the solitary, limitless expanses of space (or blackness) and time, in absolute desolation (Mijuskovic, 1977, pp. 118-119).

Mijuskovic sheds light on two issues: (1) full comprehension of death is not prerequisite to the experience of death anxiety; and (2) death anxiety evolves due to the perceived loneliness in separation from the known secure world to an unknown lonely space. These two issues are crucial in discussing death anxiety in the fatally ill child and its relatedness to loneliness.

Evans and Edin (1968), Debusky (1970), and Sigler (1970) claim that the child under ten lacks the intellectual ability to formulate the concept of death and therefore is not aware of his own impending death. Natterson and

Knudson (1960), Morrissey (1965), Lawler, Nakielny, and Wright (1966), Spinetta (1974), and Vernick (1973) nevertheless report on some children experiencing and expressing death anxiety as early as age four. Waechter's 1968 classic study on death anxiety in fatally ill school-age children represents a turning point to rigorous and systematic research on this subject. Her subjects are 64 children between six and ten. There are four groups of 16 subjects each - children with fatal illness, children with chronic non-fatal illness, children with brief illnesses, and healthy children. All children were asked to respond with stories to a set of projective pictures. In the findings, Waechter reports that the fatally ill children express significantly more imagery relating to death, separation, loneliness, and body integrity than the comparison groups. She concludes that concern with loneliness may be related to concern about death.

Kastenbaum (1967), Koocher (1975), and Wiener (1973) maintain that the maturing schoolage child who moves into the concrete operational stage of cognitive development acquires an increasingly accurate understanding of death and dying. It is important to note that even though there are studies on the development of the death concept in healthy children and studies on death anxiety in children with life threatening illnesses, no studies document either death anxiety in healthy children or the comprehension of

the concept of death by children manifesting death anxiety.

A story of a six-year-old with leukemia summarizes the relationship between death anxiety and loneliness.

This is about a little boy. He looks very lonesome, all by himself. Maybe he is sick. Maybe he wishes somebody would take care of him. And that's why he is sad. He gets very sick all alone and he dies and he goes to heaven (Waechter, 1968, p. 151).

The literature reviewed varies in depth and methodologies. It provides an overall thought of the origins and characteristics of loneliness in modern society, identifies some of the salient variables related to loneliness in childhood (e.g. impaired communications, the child being different from his siblings and peers, unmet needs for warmth and contact), and points to the direction these variables may operate in the experience of a child with chronic life threatening illness.

However, this knowledge is not adequate. There are still very basic methodological issues to be resolved. The literature is lacking a conceptual consensus as to the definition of loneliness and its related terms as, for example, aloneness, solitude, or social isolation that are often used interchangeably. The concept must be carefully operationally defined to facilitate more rigorous research and the establishment of standardized tools for assessment and measurement of loneliness. Since loneliness is a universal experience, there is a further need for the study of

degrees of loneliness of the individual across ages and wellness states.

To promote the study of loneliness, knowledge about additional major variables conducive to loneliness and their relative weight must be obtained. In addition, there is a need for studies of possible strategies to deal with the identified variables conducive to loneliness and their effectiveness for alleviating loneliness.

This study attempts to assess if life threatening disease in childhood can be considered as an additional variable conducive to loneliness in the child. The study also explores the strategies a group of parents used to deal with some of the already known variables related to loneliness.

CHAPTER IV

METHODOLOGY

This study was designed to explore the phenomenon of loneliness in school-age children living with chronic life threatening illness. Since there was no previous research on this subject, a descriptive study was conducted.

THE SAMPLE

The sample consisted of 40 school-age children and their mothers divided into two groups of 20 pairs. Group I were children with chronic life threatening disease and their mothers. Group II were healthy children and their mothers, used as a comparison group. The criteria for sample selection for both groups were:

1. Children aged six to ten.
2. Child and family - caucasian.
3. Families living within a radius of 150 miles of San Francisco.

The rationale for the criteria:

1. The rationale for choosing children between the age of six to ten is twofold: (a) during middle-childhood (about seven to eleven years), the so-

called concrete operations sub-period stage of cognitive development is achieved. In this stage as opposed to the pre-operational cognitive stage the child "seems to have at his command a coherent and integrated cognitive system with which he organizes and manipulates the world around him" (Flavell, 1963, p. 165). The child is also able to shift rapidly back and forth between his own viewpoint and that of the other person, and can understand others' roles and experiences (Phillips, 1969). These components are prerequisites for experiencing a state of loneliness as defined in this study. (b) During the elementary school years, children become increasingly involved with peers in different activities. This is the time when the peer group tends to become the arena for social status, social acceptance, or rejection (Ausubel and Sullivan, 1970). The fear of ostracism by one's peers is a major contributor to the child's loneliness (Sullivan, 1953).

2. The rationale for choosing caucasian families only was to eliminate possible effects of cross-cultural differences in child rearing practices and approach to illness.
3. The residence criteria was merely to facilitate data gathering.

In addition, there were criteria for the children with chronic life threatening disease:

1. Children with chronic disease for which a ten-year survival rate of 50 percent or less is predicted.
2. Disease onset - diagnosis was made at least two months prior to the study; it takes an average of two months of intensive medical treatment before a child can usually resume his/her regular activities.
3. The child is under follow-up in an outpatient clinic.
4. The child is not hospitalized at the time of the study in order to avoid anxieties related to present hospitalization.

The sick children were selected from the following outpatient departments of a large western university medical center:

Pediatric, Hematology, and Oncology

Cystic Fibrosis Clinical Center

Radiation Therapy

Pediatric Immunodeficiency Clinic

A convenience sample was obtained by contacting parents of sick children through the departments until a sample of 20 sick children was reached. The healthy children who served as a comparison group were selected by age, sex, marital

status of mother, and social class to match the sample of sick children. A convenience sample was obtained by contacting parents of healthy children through the investigator's acquaintances until there were 20 children in the comparison group.

STUDY INSTRUMENTS

A thorough review on tests and measurements for adults and children, as well as the relevant literature in child development, was unproductive in finding an instrument for measuring degrees of loneliness in childhood. The only existing scale for measuring degrees of loneliness in adults was developed by Bradly (1969), but it did not seem appropriate for use in the present study because the language and structure were geared for adults. Sociometric measures are commonly used in research on children's friendships, peer relations (Hymel and Asher, 1977), or for identifying isolated children (Bonney, 1971); however, their implementation involves testing whole classes, a costly and impractical tool to gain information about one specific child.

Because of the lack of instruments for the direct measurements of loneliness in children, the four instruments used in the present study serve as proxy measurements of loneliness.

The Who Scale

The Who Scale was designed by the investigator for the present study as a measure of the child's preferences in interpersonal interactions. Social Learning Theory (Rotter et al., 1972), Personal Space Theory (Hall, 1964), and Sullivan's (1953) Interpersonal Theory were used as the theoretical framework for the scale. (Note that S.L.T. and Sullivan's theory were part of the theoretical framework of the present study.)

According to Sullivan (1953), the juvenile era (school-age) is the actual time for becoming social. It is the period during which the child is moving away from the home situation and experience with siblings, to the peer world. The child experiences a strong need for peers along with the need for acceptance. These needs, if met, provide the path for becoming social and popular, however, if unmet, provide the path for becoming lonely.

Whether the child will initiate or enjoy interactions with peers will depend on his experience of reinforcements in previous contacts. As suggested by Social Learning Theory (Rotter et al., 1972), the potential for any behavior to occur in a specific situation is the function both of the expectancies the individual holds for certain reinforcements to follow the behavior and the value that he attaches to these reinforcements. Positive reinforcement in the past strengthen the expectancies of positive reinforcement

in future similar situations. In combining S.L.T. with Sullivan's theory, one can assume that a school-age child who tends to experience positive reinforcements from his interactions with peers will be more likely to choose peers for interaction in a specific situation.

Most interpersonal behavior takes place within the different zones of personal space. Hall (1961) conceives of personal space as a series of concentric circles with the individual as their center. He labels these circles zones as the intimate (0-18 inches), the casual-personal (19-48 inches), the social-consultative (49-144 inches), and the public domain (Hall, 1964). Hall proposes that both the degree of intimacy and the particular function of the relationship will determine the specific zone in which certain types of interactions will take place (1963b).

The assumption underlying the Who Scale is that the preference the child shows in choosing different figures (or no one) for interaction or communication is reflective both of his degree of sociability/loneliness and of the zone in which the proposed interaction is most likely to take place. The more social school-age child will choose more peers for interactions in the public domain, fewer in the semi-intimate and intimate domain. In moving from sociability to loneliness, the child will choose in a descending order less peers, then less sibs, then will turn to his parents and further in various situations only to

self. The lonelier the child is, the less apt he is to choose peers even in situations occurring in the public domain zone.

The Scale (Appendix 1)

The Who Scale is a paper and pencil measure. The scale is composed of 16 stimuli - typical situations in which the child is the main actor. The subjects were instructed to pick their choice for each situation as to with whom they would like to interact or communicate. The choices were people with whom the child is most likely to interact (i.e., father, mother, siblings, friend, or someone else). An "only me" choice was added to give space for a subject's possible preference not to interact. The simulated situations were drawn from realistic situations common to children, representing a modified version of Hall's three zones.

The stimuli - situations can be divided into three groups. Group 1 is similar to Hall's public domain. In this group the items describe "public" situations where the main actor is already a part of a large group of interacting people (e.g., a party, big project, team). It is expected that peers will be the figure of choice in these situations for the healthy school-age child. Group 2 is called "semi-intimate". In this group the items describe situations in which the main actor is alone (e.g., on a

deserted island or a pilot of a rocket to the moon). It is expected that preference for interaction will spread among the choice - figures. Group 3 is called "intimate" or "within self". In this group the items described situations in which the main actor is experiencing strong feelings (e.g., fear, sickness, shame, loneliness, sadness). It is expected that parents will be the figures of choice in most of these situations for the healthy school-age child.

Various scores were assigned to each subject: (1) a set of scores with each score representing the number of times the subject chose each one of the possible figures for each group (e.g., number of "father" choices in Group 1); (2) total number of each choice across the groups (e.g., total number of "mother" choices in the scale); (3) total number of adults, including father, mother, and other adults chosen, and total number of children, including siblings, young relatives, and friends.

Validity

The very basic question the investigator had to answer was whether the scale was valid as a proxy measurement of loneliness. The three theories included in the framework provided theoretical validation. Six experts in child-development, psychology, and child-psychiatry were used to obtain face validation (i.e., by agreeing that the scale was appropriate for serving as a proxy measurement of lone-

liness). To establish content validity, Kerlinger's (1973) method was used. Validity was sought for (1) the content of the scale's items, (2) the structure of the scale items in three groups.

To determine the validity of the items' content five experts in child development were presented with a 46-item scale (Appendix 2). They were instructed to evaluate whether the scale's items were appropriate stimuli situations for making a choice (preference) about interaction/communication. They were further asked to (1) rank the items from one to three as to their semantic appropriateness for use with children, (2) evaluate whether the stimuli situations provided each choice figure with equal chance to be picked (e.g., a situation describing a clinic hallway would be biased toward picking mother, father, or medical personnel since friends usually do not accompany a child to a doctor's visit), and (3) evaluate whether the items called for sex biases (e.g., going fishing is more typical for boys in this culture).

There was a 100 percent agreement among the five judges as to the appropriateness of the stimuli situations for making a choice about interaction/communication. Taking into account the experts' judgment on clarity of language, equal chance, and sex biases, 24 out of the 46 items were chosen for the test retest reliability studies.

To determine the validity of the scale's structure,

thirteen adults, both male and female, were presented with a 19-item scale. They were not advised as to the three different groups of stimuli. The adults were asked to "go back to their childhood" and respond to the scale as if they were six to ten years old. The summary of the results showed that, except for responses to three items, the pattern of the responses coincided with the three-group structure. For the Group 1 situations, there was a high preference for interaction with peers. For the Group 2 situation, the preference responses spread more among the different choice figures, but still were relatively high for interaction with peers. For Group 3 situations there was an interesting split. Two items that depicted positive emotional feelings were related to high preference for interaction with peers. Four items that depicted negative emotional feelings were related to high preference for interaction with parents, other adults, or only with self. The results supported the validity of the structure and pointed out that healthy, sociable school-age children will tend to choose peers for interactions in the public domain zone and parents, other adults, or no one for interactions in the intimate zone. In the semi-private zone, there is a variance in choices with tendency toward peers.

Pre-testing

The 46-item scale was also pre-tested for clarity of

language, attraction of the different items to children, and duration of completion with four school-age children. As a result of this pre-testing, along with the comments from the child-development experts, 24 items were chosen to compose the scale for a test-retest reliability study. Items were rejected mainly for lack of semantic clarity. The average time for completion of the scale was 25 minutes.

Reliability

To establish reliability, the test-retest method was employed. Twelve healthy school-age children were tested on the 24-item scale. After three weeks, they were tested again. All children were caucasian and came from middle class intact families living in a suburb of San Francisco. They were a convenience sample and were similar in socio-economic status to most of the children who then participated as subjects in the study. The group was composed of five boys and seven girls. The age range was six to ten years with six children in the six to eight group and six children in the eight to ten group. The test-retest reliability was computed in two steps. Step one: the percentage of agreement (test-retest) on each item for each subject was computed. The mean percentage agreement for all subjects on the 24-item was 66.7 percent. Step two: each item was checked separately for the number of children who responded to it twice in the same way. Items to which less than 50

percent of the children responded in the same way in the test-retest were rejected. Seven items failed to meet this criterion. The mean percentage agreement for all subjects on the 17 remaining items was 80.2 percent. A decision was made to use 16 items in the scale for the present study. These items were evenly divided to represent the three groups. Item number 16 was added to give a positive closure to the scale; responses to it were not included in the analysis. The investigator was able to establish only a beginning level of validity and reliability; further studies with large populations are needed.

Comfortable Interpersonal Distance Scale (CID)

The CID is a modified and improved version of previous measures of interpersonal distance (Duke and Nowicki, 1972). Duke and Nowicki (1972) adopted from Sommer (1959) the term "personal space" for the interpersonal distance phenomenon. In 1974 Spinetta used personal space as a measure of a dying child's sense of isolation as a part of a larger study on death anxiety in fatally ill children. Using measures of personal space, different experimenters devised the concept of psychological/psycho-social distance (Spinetta, 1974). This concept pertains to individual differences in the degree of desired interpersonal intimacy or disassociation. The assumption underlying the personal space measures is that "the amount of physical distance placed between

human figures is reflective of psychological distance . . . (therefore) . . . psychological closeness is related to physical proximity" (Tolor and Donnon, 1969, p. 851). Duke and Nowicki (1972) concluded from their data that interpersonal distance is the result of an interaction between an individual's prior history of reinforcement vis a vis others, as well as the context in which the behavior occurs. Integration of interpersonal distance behavior into Rotter's (1972) Social Learning Theory, which emphasizes these two factors, provided the theoretical framework for the scale.

The Scale (Appendix 3)

The CID is a paper and pencil measure in a diagram form that can be conceived as a plane with eight radii emanating from a common point. The length of each radius is 80 mm. The diagram is presented to the subjects as an imaginary round room where the end of each radius represents an "entrance" to the room. The subjects were asked to imagine themselves standing in the middle of the diagram room, while different stimuli-persons approached them along the radii, starting from the different entrances. By making a mark on the appropriate radius indicating where they would like the person to stop, the subjects revealed their preferable physical distance from the approaching stimulus person. The stimuli-persons can vary among studies depending upon the content of each study. Prior to specific experimental

stimuli, one should begin with "anchor-stimuli": (1) a person that the subject likes very much to whom he wants to be very close, (2) a person that the subject dislikes very much and from whom he wishes to be far away (personal communication with Duke, March 7, 1977).

Since the chronically sick child's interactions with parents, siblings, and peers have been identified as a potential source for loneliness (Northrup, 1974; Share, 1972; Singher, 1974; Waechter, 1968), the investigator chose them as the appropriate experimental stimuli for the present study. Each subject was asked to respond to the approach of his father, mother, siblings (in case he/she had siblings), and friends, whom he had identified on the Who Scale. In cases where a radius was unused, the child was asked to pick his choice as to whom else he would like to invite into the room. In addition, the concept of perceived alienation was examined by changing the instructions (Duke, personal communication, March 7, 1977). The subjects were asked to imagine that the stimulus-person is staying at the entrance and they, the subjects, were approaching him/her. The subjects then had to indicate how close they thought the person would let them approach him/her before he/she would stop them. The measure of perceived alienation was added, since previous researchers (Spinetta, 1974) claimed that parents, as well as medical personnel tend psychologically to isolate the child with chronic life

threatening disease and that the child's sense of loneliness can be increased by awareness of this growing psychological distance.

Two scores were assigned to each subject. One, a distance score - the distance in millimeters between the mark on the specific radius and the center of the CID. Two, an alienation score - the distance in millimeters between the mark on the specific radius and the entrances.

Reliability

There are no reliability studies for the six to ten year age group for this instrument. The reliability studies done by the authors included a sample of high school and elementary school (ten to thirteen years old students). In these studies only two basic stimuli were presented to the subjects - same sex and opposite sex strangers. The test-retest reliability for the elementary school sample, as opposed to the high school sample, exhibited only minimally acceptable correlations. The authors explained these low correlations as a result of methodological constraints. The first constraint was the students' ages. Previous research (Guardo, 1969; Meisels and Guardo, 1969) suggested that a major change in preferred distance from others occurs at or around puberty. Since the students in the reliability study were in the age range of 10-13, they may have been in the midst of this transition. Duke and Nowicki believed

that this factor had the effect of lowering the reliability estimates for this group. The second constraint was a concurrent school project. The students took part in a behavior modification project designed to improve, among other areas, the interpersonal relations between children and teachers. Duke and Nowicki suggested that over a period of four months, when the retest was administered, the project might have had an effect on the patterns of interpersonal distancing of these students and as a result of this inconsistency, the reliability scores were low. Nevertheless, they believed that the tool is psychometrically sound and can be used successfully with young children (Duke and Nowkcki, 1972; 1976).

It is the investigator's judgment that the above reliability study was poorly designed, since both constraints could have been easily predicted and therefore avoided. Nevertheless the investigator decided to use the CID despite the fact that there are no sound reliability studies (see discussion, p. 74).

Validity

To establish validity the construct validation method was used. Martin (1972) and Johnson (1972), who were two of Duke and Nowicki's students, correlated distances on the CID to actual behavior (i.e., preferred distances from real life stimuli). Martin (1972) reported correlations of

.65-.71 in a group of white college students, and Johnson (1972) reported correlations of .83 and .84 in a sample of black college students.

The Advantages and Limitations of Using the CID in this Study

Advantages:

1. The CID is the best existing proxy measurement of loneliness the investigator was able to identify.
2. The scale is very simple to administer to a wide age range.
3. The scale is presented in a play-like mode and is very attractive to young children.
4. Administration of the scale does not require preparation of elaborate materials or special settings.
5. The use of the scale allows for flexibility in choosing the stimuli according to the study content.
6. As opposed to other measures of interpersonal distances (e.g., using silhouettes or real life figures), the CID is free from possible contaminations by the figures' size, sex, or color.
7. Scoring of results is simple and objective.

Limitations: The only apparent limitation of the scale is the low test-retest reliability found for young

children. Although the lack of established reliability is a serious limitation, there is enough collateral evidence to support its use. In an extensive review of the literature on personal space research, Evans and Howard (1973) cited 73 studies dealing with the various aspects of the personal space phenomenon. Ten of the cited studies reported using children as young as four years of age as their subjects. The tools used in the above studies were either measures of distances from real life figures or a paper and pencil task with figures shown in silhouette. However, the CID is based on the same principles and theory of interpersonal space. King (1966), in a study of pre-school children, and Meisels and Guardo (1969), in a study of the development of personal space in which third graders were included, showed that their young subjects were able to exhibit comprehension of the phenomenon and presented negative correlation between amount of personal distance and degree of liking and acquaintance. These results support the use of interpersonal distance measures with children.

In conclusion, the advantages of the CID outweigh its limitations and it is appropriate for use as a proxy measurement of loneliness with school-age children. The investigator is aware of the need for a sound reliability study for the six to ten year age group; unfortunately, such a study was beyond the scope of this dissertation.

Projective Pictures

A modified Thematic Apperception Test was employed to elicit children's indirect and fantasy expressions of loneliness. The set of nine projective pictures used in this study consisted of five pictures from the Thematic Apperception Test (Murray, 1943) and four pictures designed by Waechter (1968) for a study of death anxiety in children with fatal illness. The set was used by Waechter in this study of hospitalized children aged six through ten years in order to elicit content related to illness and hospitalization. In her results Waechter reported on a number of loneliness themes and loneliness imagery in the children's responses.

The Set (Appendix 4)

The pictures, listed in the order in which they were presented to each child, were:

1. A child in front of a violin (TAT I)
2. Two boys in adjoining beds (Waechter)
3. Small child in hallway outside closed door to ICU (Waechter)
4. Boy in front of mural depicting operation (TAT 8BM)
5. A child lying in bed and a nurse standing nearby with her back turned (Waechter)

6. Figure outlined in open window (TAT 14)
7. Child in bed and three adults, one wearing a white coat standing outside the door (Waechter)
8. Woman entering room, hand on face (TAT 3GF)
9. Small child sitting in a doorway of cabin (TAT 13B)

(Waechter's pictures were used with her permission.)

The pictures were shown individually to each child and were always presented in the same order. The child was requested to tell a story about each picture. He was asked to include in the story what he/she thought was happening in the picture, what the people were thinking about, how they were feeling, and how he thought the event would end. The child was assured that there were no correct or incorrect responses. Nondirective encouragement was supplied if a child had difficulty continuing a story he/she had started (e.g., it is good, it is your story). If a story contained a reference to illness but the child did not indicate its nature, a question eliciting the nature of the illness was asked. (The exact wording of instructions and probes are listed in Appendix 5.)

The stories were recorded on tape. Each child told a story about each picture and all pictures were administered in a single session.

Scoring Scheme

The scoring scheme (Appendix 6) was devised by the investigator for analyzing the children's responses. Each story was analyzed for its main theme, its affect, and its outcome. The content analysis method was used to determine the categories for the themes, affect, and outcome. Four identified themes were considered as highly related to loneliness, either as anxieties conducive to loneliness (i.e., separation anxiety, death anxiety, and threat to body integrity anxiety), or as a possible result of loneliness (i.e., suicide). All other themes were considered as unrelated. Only stories that contained loneliness related themes were further analyzed for their affect and outcome; the remainder were scored as unrelated. The identified categories for affect were positive and negative and for outcome the categories were negative, neutral, and positive.

A set of scores was compiled for each child. The set was composed of scores as: number of themes according to the different categories, number of themes with negative or positive affect, and number of themes with negative, neutral, and positive outcomes.

Validity

Unfortunately, validity for this instrument has not been established. As a clinician, this investigator believes

that the set has content validity and is one of the best existing instruments for eliciting loneliness themes. Since 1968, the same set of projective pictures has been used by investigators studying hospitalized and non-hospitalized fatally ill and non-fatally ill school-age children (Parkas, 1974; Peters, 1975; Spinetta, 1972). This set consistently elicited themes related to a wide variety of illness concerns, loneliness, and separation being part of them.

Inter Rater Reliability

Every fifth protocol (eight subjects) was examined by an independent coder, a psychiatric nurse specialist, using the scoring scheme. The degree of agreement on themes, affect, and outcome for each protocol was computed. For the eight protocols there was 97 percent agreement on themes, 93 percent on affect, and 97 percent on outcome (see Appendix 7). The differences were discussed and the two coders arrived by agreement at one score.

Maternal Interview

A maternal interview schedule (Appendix 8) was developed for this study. The data were gathered to provide background information as to what strategies were used by both parents and medical personnel in handling the child's illness. The interview included both structured and open-

ended questions* covering demographic data and information on variables thought to be associated with loneliness. The following variables have been identified in the literature as potential source or influence on loneliness in childhood:

1. Parent-child relationships
2. Child-sibling relationships
3. Child-peer relationships
4. Child at school
5. Child's experience with present illness
6. Child's previous experience with illness, loss, and separation
7. Child-parent communication
8. Family communication
9. Family handling of the child's "being different"

Questions related to the life threatening illness were eliminated from the interview with mothers of healthy children. The interview was checked for clarity and duration of administration with three mothers, two of sick children and one mother of a healthy child. All three mothers said the questions were clear and found the interview to be interesting and thought provoking. The interview with the mothers of the sick children lasted two hours and the interview with the mother of the healthy child lasted one hour.

The interviews with the mothers of the sick children

*Some of the interview questions were taken with permission from Waechter's (1968) parental interview schedule.

were analyzed according to the variables listed. The analysis identified the strategies used by both parents and medical personnel in handling the problems of communication, side effects of illness and treatment regimen, death anxiety of the child, and the parents' anticipatory grief. The interviews with mothers of the healthy children were not analyzed in the present study and will serve as a data bank.

DATA COLLECTION PROCEDURE

The data were collected over a period of five months from May to October of 1977. The investigator started the negotiations with the heads of the Pediatric, Hematology and Oncology Clinic and the Cystic Fibrosis Clinic long before data collection was to begin. At the Pediatric, Hematology and Oncology Clinic the investigator took part as a nurse, exercising mainly the role of a participant observer for a period of a year and a half. Besides using this time as a very rich learning experience, the investigator found it very important to establish rapport with the clinic team prior to acquiring the sample. Most of the clinic patients take part in one or two research projects during their illness trajectory. The team is very aware of this fact and is attempting to save these patients any additional burden, e.g., exposure to an insensitive researcher or to a questionable research protocol. They are

therefore cautious in granting access to their patients. When the research protocol was established, it was shared individually with the various team members, the head of the clinic, the clinical nurse specialist, and the clinic social worker. At this point their cooperation was granted.

At the Cystic Fibrosis Clinic the negotiations started by presenting the study to the clinic social worker*, who expressed her enthusiasm as to its worth. With her help, the research protocol was shared with the physician responsible for one part of the clinic and the clinic nurse. After reviewing the protocol, their permission to approach the clinic patients was granted. The study was then presented to the clinic director, who checked the investigator's clinical expertise and asked her to share the study with the child psychiatrist - consultant to the clinic. Only after the psychiatrist gave his approval and expressed his interest in the study, did the director of the clinic give permission and promise cooperation toward acquiring a sample. Also, this clinic is cautious in granting access to its patients for the same reasons as discussed above.

Permission to approach patients in the Radiation Therapy Department was given after sharing the research protocol with one of the senior physicians and the clinical nurse specialist. This clinic accepted the permission

*This social worker participated in E. Waechter's study on death anxiety in children with fatal illness and was familiar with some of the instruments used in the present study.

granted by the other two clinics and the approval of the campus Committee on Human Research as references. At a later point, the study was also presented to the senior physician of the Pediatric Immuno-Deficiency Clinic, who agreed to cooperate after due consideration.

After approval of the study by the University Committee on Human Research, both the team of the Pediatric Hematology Clinic and the social worker from the Cystic Fibrosis Clinic contacted parents of patients who met the study criteria. The parents were asked for permission to be approached by the investigator. All parents who were contacted expressed interest in the study. The investigator then telephoned the parents and explained the nature of the study and its instruments, as well as the time involved in completing the interviews for both mother and child. A time for the investigator's visit was set in most cases; in others, agreement was established, but the interviews were postponed to a later date.

Sixteen out of the 20 subjects were recruited through these two clinics. Three parents were contacted by the clinical nurse specialist in the Radiation Therapy Department and one parent was contacted by the physician from the Pediatric Immuno-Deficiency Clinic. The same procedure was then used by the investigator. It is important to note that there was no single refusal from parents to participate in the study. This fact can be explained by the rapport and

positive relationships these patients have with the clinics' personnel.

The sample of healthy children and their mothers was acquired through acquaintances. Three of the investigator's acquaintances contacted their friends, or the parents of their children's schoolmates, to inquire whether they would be interested in participating in the study. The investigator then contacted these parents, using the same procedure as with the mothers of the sick children. Except for one refusal, all parents contacted agreed to take part in the study.

All interviews took place at the families' homes. At the time of the interview, it was clear to the investigator that all mothers prepared their children for the investigator's visit. Since the investigator did not leave specific guidelines with the mother as to what to say to the child, it was interesting to watch their initiative in explaining the visit to the child. Some of the explanations to the sick group were: "This is Ms. _____. She is Dr. X's friend and she wants to know about you so she will ask you some questions." Or "Ms. _____ is interested in how children play with their friends" Or "Ms. _____ wants to know about your illness." The common explanation that was given to the healthy group was that the investigator was a friend who was doing game-like tests with children. The investigator then explained to the child that she was specifically

interested in how children manage or socialize at home, with friends, or at school, and how they make their choices in games.

In case both mother and child were present when the investigator arrived, she told them that she would prefer to talk with each of them in private. She then let them decide who would be the first. The reasons for doing the interviews separately were that the maternal interview touched upon some very sensitive and painful experiences. It was expected that mothers would not feel free to answer many of these questions in their child's presence. Some of the children's responses also could be biased or influenced by the mother's presence. In most cases, it was agreed that the mother would be the first one to be interviewed and the children went to play. In some cases the mothers planned to start the interview when the child was at school.

At the beginning of the session, the investigator explained the consent form (Appendix 8), shared with the mothers the instruments to be used with the child, and answered any additional questions the mother asked. After the mother signed the consent form, the interview started. Interviews lasted from one hour, mainly with mothers of healthy children, to five hours with a few mothers of sick children. All but two interviews were completed in one session. The two mothers were very distressed and needed time to talk and share the pain. The interviews were completed

on the second visit, held within a week following the first session.

At the beginning of the session with the child, the investigator explained the study to the child and asked for his/her verbal consent to participate. She then asked a few questions about school or favorite games to warm up the conversation. After the child had given consent, the testing started. The sequence of the testing was as follows:

1. The Who Scale
2. The Comfortable Interpersonal Distance Scale
3. The set of projective pictures

The rationale for this sequence was to proceed from the easiest and least stressful task to the more complicated and sensitive one after some rapport had been developed and the child experienced a sense of mastery in completing the first task. All children enjoyed responding to the first two tasks. With the responses to the projective pictures, some children needed verbal encouragement to complete the set. Only one sick child, who became very distressed during the storytelling, asked to stop, and her request was honored. Administration time for the three tasks was 20 to 35 minutes. After completion of the tasks, the investigator usually talked with the child for a short time to give him/her a sense of closure.

SUMMARY

In this chapter the study design, sample, tools, and procedure for data collection were discussed.

CHAPTER V

FINDINGS

The findings of this study are presented in four sections. The first section presents the sociodemographic characteristics of all the subjects and selected medical characteristics of the children with chronic life threatening illnesses included in the sample. The second section presents findings related to the first study question and the derived hypotheses. The third section presents findings related to the second study question. The fourth section presents an analysis of loneliness of the sick group.

Statistical Analysis. The statistical analysis of the data was done at the University of California Computer Center, San Francisco campus, using the programs Statistical Package for the Social Sciences (Nie, Hull, Jenkins, Steinbrenner, Bent, 1970) and RMEAS program, version 3 (Bostrom, unpublished program, 1977). Data were analyzed by child's wellness, age, and mother's marital status using subprograms: frequencies, T-tests, two-way analysis of variance, and Pearson correlations.

I. SOCIODEMOGRAPHIC CHARACTERISTICS OF ALL SUBJECTS AND
SELECTED MEDICAL CHARACTERISTICS OF THE CHILDREN WITH
LIFE THREATENING ILLNESSES INCLUDED IN THE SAMPLE

The sample consisted of 20 children with chronic life threatening illness and their mothers, and a comparison group of 20 healthy children and their mothers. Since the subjects were matched for age, sex, mother's marital status, and number of siblings (in most cases), these variables were computed for the whole sample.

There were 14 (35 percent) girls and 26 (65 percent) boys in the sample. The number of boys almost doubled the number of girls. This finding is in line with the cancer incidence rates reported by the National Cancer Institute (1975). Their data show that for the group of five to nine years old, the incidence rates for boys were 8.7 per 100.000 and for girls, 6.1 per 100.000, which is 30 percent less. The age range of the children was from six to ten years. The mean age was six years and nine months. Twenty-three children were in the six to eight year group and 17 in the eight to ten year group. The range of grades in school was from first to fifth with 28 (70 percent) children in the first two grades. The number of siblings ranged from none to five, with a mode of one sibling.

Twenty-four (60 percent) children came from intact families. In 16 (40 percent) families the mother was separated from the child's father, in three (7.5 percent) out of these 16 families the mother was remarried. The

separation rates in this group (30 percent) were higher than the national figures for mother headed families. The U.S. Bureau of Census reported that in 1973, only 10 percent of white children under 18 were living in a mother headed family. Four out of the six separated mothers of children in the ill group reported that the separation from the child's father occurred prior to the child's diagnosis. Only in two cases separation occurred when the disease was already present. The age range of the mother and father was 25 to 47 years, with the mode in the 31 to 35 year subgroup. Parents' education ranged from partial high school to graduate work in a university. Seventy-seven percent of the mothers and 85 percent of the fathers had been involved at least one to three years in college or university work. This finding may be related to the fact that the study was conducted among caucasian families in predominantly urban and suburban areas. At the time of the study, 20 out of the 40 mothers and 38 out of the 40 fathers were working. Parents' occupations range from higher executive to semi-skilled (Table 5.1).

Chi square cross-tabulations of parents' education, occupations, and work status showed no significant difference between the parents of the children with chronic life threatening illness and parents of healthy children. The sociodemographic characteristics of children with chronic life threatening illness and their parents and healthy

TABLE 5.1. PARENTS' OCCUPATIONS ACCORDING TO
HOLLINGSHEAD (1965) OCCUPATIONAL SCALE.

Occupation	Mother		Father	
	N	%	N	%
Higher executive	3	7.5	11	27.5
Business manager	12	30	9	22.5
Administrative personnel	2	5	5	12.5
Clerical and sales workers	8	20	6	15
Skilled manual employees	3	7.5	7	17.5
Semi skilled	1	2.5	1	2.5
Unskilled and housewives	11	27.5	1	2.5

children and their parents were similar. Some of the homogeneity of the subjects was due to the sample selection criteria and some to the matching procedure.

Medical Characteristics of the Life Threatening Illnesses Group

The nature of illness, illness duration, and illness severity varied among the 20 children in this group.

TABLE 5.2. DISTRIBUTION OF SUBJECTS ACCORDING TO THE NATURE OF THEIR ILLNESSES.

Illness	N	%
Acute lymphoblastic leukemia	8	40
Cystic fibrosis	4	20
Brain tumor	3	15
Lymphoma	1	5
Malignant melanoma	1	5
Neuroblastoma	1	5
Rhabdomyosarcoma	1	5
Immunodeficiency disorder	<u>1</u>	<u>5</u>
TOTAL	20	100

Illness duration ranged from two to 90 months in two cases. Only in three cases the duration exceeded 36 months.

The mean for the group was 22.4 months. All children were hospitalized at first for diagnosis establishment and beginning course of treatment. Subsequent hospitalizations were mainly due to illness exacerbation and treatment complications. The side effects of both illness and treatment were divided into two groups: (1) visible - hair loss, weight gain, small stature, surgery scars, imbalance and coordination disorder, recurrent infections, and coughing; (2) non-visible - headaches, low energy levels, and gastro-enteral disturbances. The most common side effects were hair loss, gastro-enteral disturbances, and low energy levels. Ten children out of the 20 presented visible side effects at the time of the interview.

TABLE 5.3. RANGE AND MEAN OF ILLNESS DURATION, NUMBER OF HOSPITALIZATIONS, AND NUMBER OF SIDE EFFECTS.

	Range	Mean
Illness duration in months	2-90	22.4
Number of hospitalizations	1-6	2.4
Number of side effects of illness and treatment	1-5	3.1

Mothers were asked how sick their child was at times throughout the illness. Seven answered very sick, eight

answered quite sick, and five answered mildly sick. None of the children was hospitalized at the time of the interview or in the month prior to it. Except for one child who was approaching death, the children were in various stages of remission.

TABLE 5.4. ILLNESS STATE AT TIME OF INTERVIEW.

Illness State	N	%
Illness in remission:		
1. within four months from diagnosis	4	20
2. after four months since diagnosis	13	65
3. within four months after relapse	2	10
Approaching death	1	5

Twelve out of the 20 children attended the Pediatric Hematology Clinic that has a distinct and formalized approach to psycho-social care. The children shared a few common side effects and treatment modalities; otherwise, they varied in their illness experience.

II. FINDINGS RELATED TO THE FIRST STUDY QUESTION

Study question number one was: Do children with chronic life threatening illness differ in their loneliness manifestations from healthy children? Three hypotheses derived from this research question.

Hypothesis 1

Children with chronic life threatening disease (CLTD) will respond to a set of projective pictures with more loneliness themes (i.e. aloneness, separation, death anxiety, threat to body integrity, and suicide themes) than healthy children. The analysis of these study sample stories produced 101 loneliness themes:

37 threat to body integrity themes

17 death anxiety themes

12 aloneness themes

7 suicide themes

The T-test results (see Table 5.5) show no significant difference between the total number of loneliness themes in the responses of the children with CLTD and the total number of loneliness themes in the responses of the healthy children. However, children with CLTD responded with more aloneness subcategory themes ($p < .03$) than the healthy children.

TABLE 5.5. LONELINESS THEMES OF CHILDREN WITH CLTD COMPARED TO LONELINESS THEMES OF HEALTHY CHILDREN.

Variable		Mean	SD	T-Value	DF	2-Tail Prob
Aloneness themes	h	0.15	0.36	-2.24	26.28	.034*
	s	0.60	0.82			
Separation themes	h	1.45	1.31	1.25	33.93	.21
	s	1.00	0.91			
Death anxiety themes	h	0.75	0.96	1.18	31.90	.24
	s	0.45	0.66			
Threat to body integrity themes	h	2.4	0.99	-1.00	30.06	.32
	s	2.85	1.75			
Suicide themes	h	0.30	0.92	0.44	26.22	.66
	s	0.20	0.42			
Total number of themes	h	5.05	1.73	-0.09	37.38	.93
	s	5.10	1.97			

h = healthy

s = sick

* $p < .05$. For this study $p < .05$ was considered the lowest level of statistical significance acceptable.

Tests of significance difference for the affect and outcome of the story responses show no significant difference between stories of children with CLTD and stories of healthy children.

TABLE 5.6. COMPARISON OF AFFECT AND OUTCOME OF STORIES BY CHILDREN WITH CLTD AND HEALTHY CHILDREN.

Variable		Mean	SD	T-Value	DF	2-Tail Prob
Positive affect main and others	h	0.15	0.36	0.47	36.90	.64
	s	0.10	0.30			
Negative affect main and others	h	3.63	1.80	0.05	35.46	.96
	s	3.60	2.34			
No affect indicated	h	1.30	1.08	-0.27	37.37	.78
	s	1.40	1.23			
Positive outcome	h	3.90	1.88	1.77	37.16	.08
	s	2.75	2.19			
Neutral outcome positive	h	0.05	0.22	0.0	38.00	1.00
	s	2.75	2.19			
neutral outcome negative	h	0.60	0.99	-0.83	31.72	.41
	s	0.95	1.60			
Negative outcome	h	0.10	0.39	1.45	19.20	.16
	s	0.0	0.0			

h = healthy s = sick

The effect of the combination of the children's health state and age on their responses to the projective pictures was analyzed by a two-way analysis of variance. The effect of the combination of the children's health state and their mother's marital status on their responses was also analyzed by the same analysis. Only one combination of variables produced significant difference by the two-way analysis of

variance tests (children's health state and age) among the groups in their stories' themes, affect, and outcome. The sick children in the group had significantly more aloneness themes than the healthy children ($F = 3.8$; $p < .01$). The older ill children (eight to ten) had significantly more aloneness themes than the younger (six to eight) sick children. (For examples of aloneness themes, see Appendix 8.)

Children with CLTD responded with significantly fewer unrelated stories ($p < .002$) than healthy children. Children with CLTD tended to reject pictures more (mean 1.10) than healthy children (mean 0.40). Both groups of children responded with more stories with negative affect (mean 3.6) than positive affect (mean 0.1) and with more stories with positive outcome (mean 3.4) than negative outcome (mean 0.05; see Table 5.7).

TABLE 5.7. FREQUENCIES OF NEGATIVE AND POSITIVE AFFECT FOR THE WHOLE SAMPLE.

Affect	N	%
Negative:		
Sadness	28	41
Sickness	21	30.9
Fearful	8	12
Worrisome	4	5.9
Anger	4	5.9
Frustration	1	1.4
Positive:		
Good	2	2.9
Satisfied	0	0

While telling the stories higher anxiety levels were noticed in the sick children than in the healthy children. The sick children were very hesitant and took longer periods of time to study the pictures before answering, and their stories were shorter, using in many cases, only few words. The healthy children were in most cases quick in their responses and involved in quite elaborate stories. To illustrate this point, two prototype examples of children's stories in response to the same picture (Form F) are presented. The story of a sick child reads: "He is looking out the window; that's all." The story of a healthy child reads: "He has been in the dark all his life and he has never seen light, because he has been blind, and finally he gets touched by the light and he sees the light, the right way to go He feels happy He is thinking, 'oh, wow, look at this stuff I have missed, pretty skies and birds singing.'"

In conclusion, hypothesis 1, that children with chronic life threatening illness will respond to a set of projective pictures with more loneliness themes than healthy children, was not fully supported by the findings. The difference in total number of loneliness themes was not significant. However, there was a significant difference between the two groups in the number of subgroup aloneness themes.

Hypothesis 2

Children with CLTD will be more adult oriented in their choices than will healthy children on a preference for interpersonal interaction scale (Who scale).

The difference of number of adult choices between the two groups of children was only marginally significant ($p < .07$). The sick children tended to choose adults for interaction in more occasions than the healthy group (see Table 5.8). Analysis of the results according to the three subgroup items of the scale shows that on items of domain 1 ("public situations") children with CLTD chose adults significantly more ($p < .02$) than healthy children. In the choices to the other two domains there was no statistical difference. The difference of number of children choices between the two groups was highly significant ($p < .005$). Healthy children preferred to interact with other children more than sick children did.

The combined effect of child health state and age on adult choices was tested by analysis of variance. The results show marginal significant effect of the child's health state ($F = 3.86$; $p < .057$). The effect of age on adult choices was not significant.

The combined effect of child's health state and age on choices of children was also tested by analysis of variance. The results show highly significant effect of the child's health state ($F = 9.28$; $p < .004$), but no significant effect

TABLE 5.8. COMPARISON OF CHOICES OF ADULTS VERSUS CHILDREN FOR INTERACTION, BETWEEN CHILDREN WITH CLTD AND HEALTHY CHILDREN.

Variable		Mean	SD	T-Value	DF	2-Tail Prob
Number of adults for all domains*	h	6.9	1.51	-1.86	35.34	.071
	s	7.95	2.01			
Adult choices for domain 1	h	0.20	0.41	-2.34	25.64	.02**
	s	0.75	0.96			
Adult choices for domain 2	h	2.15	1.18	-1.09	36.71	.28
	s	2.6	1.42			
Adult choices for domain 3	h	4.0	1.14	1.14	37.85	.88
	s	4.0	1.07			
Children choices for all domains	h	7.45	1.09	3.00	34.74	.005***
	s	6.20	1.50			

*Items on the Who scale divided into three domains:
 (1) "public situation", (2) semi-private domain, and
 (3) private domain.

**p < .05

***p < .01

h = healthy

s = sick

TABLE 5.9. PREFERENCE FOR INTERACTION WITH ADULTS
BY CHILD HEALTH STATE AND AGE.

	Six to Eight	Eight to Ten	Row Total
Healthy: N	11	9	20
\bar{X}	6.45	7.44	6.9
SD	1.63	1.24	1.52
Sick: N	12	8	20
\bar{X}	7.58	8.5	7.95
SD	1.68	2.4	2.01
N	23	17	40
\bar{X}	7.04	7.94	7.42
SD	1.72	1.92	1.84

TABLE 5.10. PREFERENCE FOR INTERACTION WITH CHILDREN
BY CHILD HEALTH STATE AND AGE.

	Six to Eight	Eight to Ten	Row Total
Healthy: N	11	9	20
\bar{X}	7.82	7.0	7.45
SD	1.25	0.71	1.10
Sick: N	12	8	20
\bar{X}	6.25	6.13	6.20
SD	1.14	2.03	1.51
N	23	17	40
\bar{X}	7.00	6.59	6.82
SD	1.41	1.50	1.45

of the child's age ($F = 1.27$; $p < .26$) on his preference for interaction with children. (see Tables 5.9 and 5.10).

Analysis of variance according to child's wellness and mother's marital status produced no significant difference among the groups. In summary, Hypothesis 2, that children with CLTD will be more adult oriented in their choices on the Who scale than will healthy children, was only partially supported. Overall, the sick children tended to choose more adults and significantly less children for interaction than did healthy children, and on the "public" domain items, the sick children differed significantly from healthy children in their choices to interact with adults.

Hypothesis 3

Children with CLTD will place human figures in a further distance than will healthy children on an interpersonal distance scale (CID).

The mean distance of all figures for the children with CLTD was not significantly different than the mean distance of all figures for the healthy children. Although there was no significant difference between the two groups in relation to the mean distance, there was a trend of the sick children to place mother in further distance than healthy children (see Table 5.11). Only on distance from a second friend did the sick children differ significantly from the healthy group.

TABLE 5.11. COMPARISON OF MEAN DISTANCE OF CHILDREN WITH CLTD WITH MEAN DISTANCE OF HEALTHY CHILDREN ON THE CID.

Variable		Mean	SD	T-Value	DF	2-Tail Prob
Distance someone you like	h	14.55	12.85	-0.39	37.90	.69
	s	16.20	13.55			
Distance someone you don't like	h	57.80	22.4	0.19	36.55	.84
	s	56.55	18.31			
Distance father	h	7.0	7.2	-0.17	36.62	.86
	s	7.3	5.9			
Distance mother	h	4.6	3.9	-1.77	26.57	.08
	s	8.35	8.6			
Distance sib 1	h	15.06	18.05	-0.87	28.98	.39
	s	20.00	14.6			
Distance sib 2	h	11.80	10.14	-1.47	7.92	.17
	s	24.57	21.29			
Distance friend 1	h	12.65	13.81	-1.54	35.62	.13
	s	20.45	17.99			
Distance friend 2	h	7.5	5.0	-2.85	14.65	.012*
	s	20.23	15.23			
Mean distance for all figures	h	16.60	6.1	-1.32	33.74	.19
	s	19.80	8.91			

*p < .05

h = healthy; s = sick

There was no statistical difference on alienation scores between the children with CLTD and healthy children (see Table 5.12).

TABLE 5.12. COMPARISON OF MEAN ALIENATION OF CHILDREN WITH CLTD WITH MEAN ALIENATION OF HEALTHY CHILDREN ON THE CID.

Variable		Mean	SD	T-Value	DF	2-Tail Prob
Alienation someone you like	h	13.50	14.7	-0.19	31.84	.85
	s	14.4	13.2			
Alienation someone you don't like	h	49.05	25.24	-0.10	28.88	.91
	s	50.0	27.38			
Alienation father	h	7.55	13.06	0.95	25.50	.35
	s	4.53	4.86			
Alienation mother	h	6.25	7.70	-0.03	31.93	.97
	s	6.33	6.87			
Alienation sib 1	h	13.56	14.12	-0.79	25.31	.43
	s	17.84	14.74			
Alienation sib 2	h	11.00	17.26	-0.75	14.56	.46
	s	16.14	11.15			
Alienation friend 1	h	14.15	16.90	0.68	32.00	.50
	s	11.00	10.43			
Alienation friend 2	h	9.38	9.10	-0.92	15.90	.37
	s	13.70	12.46			
Mean alienation all figures	h	14.70	8.80	-0.29	33.59	.77
	s	15.50	7.81			

h = healthy

s = sick

In addition, analysis of variance subprogram was used to test the combined effect of child's age, mother's marital status, and child's wellness on mean distance and mean alienation scores. The results show no significant difference among the groups on mean distance and alienation scores. Pearson correlation between distance scores and alienation scores was also computed. There was a high correlation ($r = .67$; $p < .001$) between mean distance and mean alienation. Hypothesis 3, that children with CLTD will place human figures in a further distance than will healthy children on the CID, was not supported by the findings.

Summary of Findings Related to the Three Hypotheses

The three hypotheses were not fully supported by the findings. Nevertheless, the sick children responded with more aloneness themes, chose children less frequently to interact with, preferred adults for interaction in "public situations", tended to place their mothers and placed one friend further than did healthy children.

Interrelationship of Outcomes on the Three Study Tools

Correlations were done for each of the study tools scores resulting in low correlations between all tools (see Table 5.13).

TABLE 5.13. CORRELATIONS OF SCORES ON THE THREE STUDY TOOLS.

Number of Themes		Who Scale		CID Scale	
		Total Number of Adults	Total Number of Children	Mean Distance	Mean Alienation
Aloneness	R	0.13	-0.11	0.24	0.25
	S	.19	.23	.06	.07
Separation	R	-0.03	0.05	-0.01	0.12
	S	.41	.36	.47	.23
Death Anxiety	R	-0.08	0.11	-0.01	0.12
	S	.29	.24	.47	.23
Threat to Body Integrity	R	0.14	-0.09	-0.21	0.02
	S	.18	.28	.08	.4
Suicide	R	-0.14	0.31	0.19	0.18
	S	.18	.02	.11	.14
Total Number of Themes	R	-0.04	0.09	-0.01	0.14
	S	.39	.28	.45	.15

		Mean Distance	Mean Alienation
Total Number of Adults	R	-0.08	-0.00
	S	.3	.48
Total Number of Children	R	0.14	0.05
	S	.19	0.37

R = Correlation; S = Significance

III. FINDINGS RELATED TO STUDY QUESTIONS NUMBER TWO:

What strategies do parents of children with chronic life threatening disease and medical personnel use to deal with the problems of communication with the child, side effects of illness and treatment regimen, and death anxiety of the child?

The strategies parents and medical personnel used to deal with these problems were identified by content analysis of interviews with the mothers of the children with CLTD.

Strategies Related to Communication with the Child

All parents and involved medical personnel adopted the "open approach" to communications. The degree of openness and amount of communication varied according to the specific communication topic (i.e. the nature of the illness, treatments, side effects of illness and treatment, and prognosis) and the recipient of the communication. In order to create channels for open communication, communication was initiated to significant figures in the child's social milieu.

Figure IV depicts the different channels both parents and medical personnel had established.

Communication to the Child

Some mothers believed that the child should be told the "whole truth" on all topics immediately after diagnosis. One mother stated, "Yes, I feel the kids have a right to know. She is the one that has it, I don't. I think she has

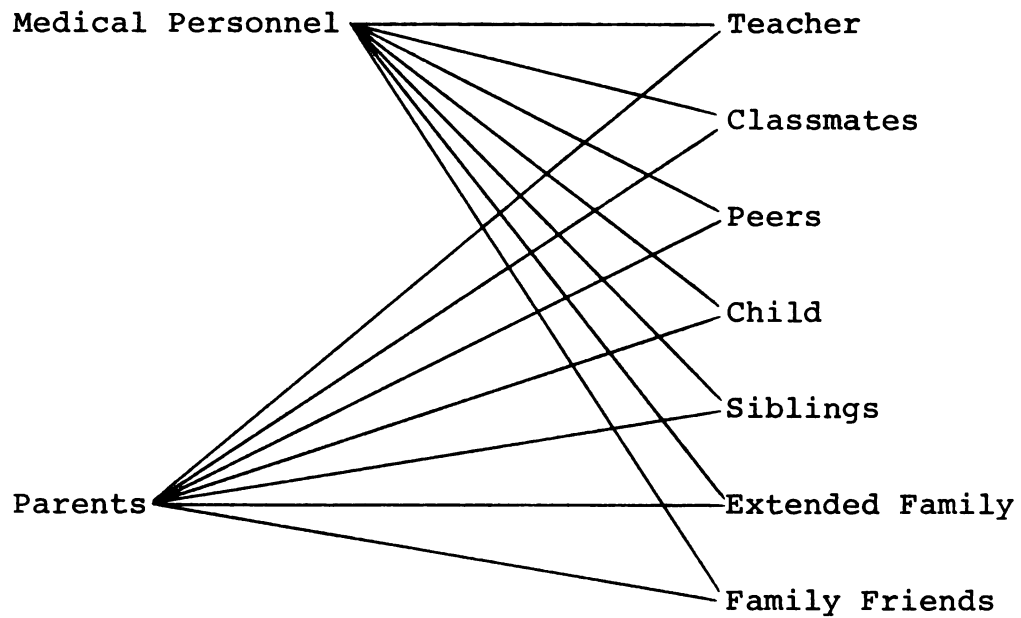


FIGURE IV. PARENTS' AND MEDICAL PERSONNEL'S CHANNELS OF COMMUNICATION TO SIGNIFICANT FIGURES IN THE CHILD'S SOCIAL MILIEU.

a right to know what can happen and what can't happen. Her disease is what matters and she has to live with it. That is the way I put it to her from the beginning, as soon as I found out." Other mothers thought that the child should have an overview of his illness and prospective treatments at the beginning and then deal with the questions as they arise (in most of these families the child was diagnosed before his fifth birthday). Only five mothers felt that the child should be spared from some parts of the truth, mainly the burden of fatal prognosis (see Table 5.14).

TABLE 5.14. NUMBER OF MOTHERS ACCORDING TO DEGREE OF OPEN COMMUNICATION.

Variable	N	%
child should be told the "whole truth"	10	50
child should be told only when he asks, and then the "whole truth"	5	25
child should be spared from some part of the truth (fatal prognosis)	5	25

All mothers perceived medical personnel to be supportive of their particular stance. In seven cases, the child attended an initial family conference where the medical personnel involved in his care and different family members

and their significant others sat together and discussed the diagnosis, prognosis, illness trajectory, treatments, and possible side effects. This conference* served as a positive starting point of open communication for these families. Throughout the illness experience all mothers perceived medical personnel as very honest with the child. Medical personnel shared with him his progress, treatment schedule, and answered all his questions with sincerity. Fourteen mothers reported on the development of trust relationships between the child and his consistent caregivers which helped him to go through many painful procedures and anxiety fraught questions.

Seventeen out of the 20 children knew the name of their illness. Most mothers thought the child should hear the name from them to eliminate the possibility of a child's friend revealing to the sick child, "You are sick with leukemia and you are dying". Sixteen children received explanations as to the nature of their illness. All children with cystic fibrosis knew about the genetic aspect of the illness and understood to some extent the degree of lung and intestinal involvement. Children with malignancies knew of "a fight between good cells and bad cells" and of "a tumor - a growth that was growing with no control". A seven-year-old explained to the investigator the nature of his

*For detailed discussion, see A. Ablin et al., A conference with the family of a leukemic child. American Journal of Diseases in Childhood, 1971, 122, 362-364.

malignant melanoma, "There is something inside me; I have got something inside me. A mole. It is not okay. It is eating me up. Yak. Like it was eating me for dinner. The moles and my chemotherapy are fighting with army, tanks, and the chemotherapy is winning." A very imaginative and serious ten-year-old boy talked about how he visioned his brain tumor. "I kind'a vision it as kind of a black substance in the head, just growing like a fungus or something, just growing all around. And I vision it regularly right in there (pointing to the scar on his head) and it's kind of flaky too."

All parents were very open about check-ups and treatment procedures. They always prepared the child a day in advance as to what was going to happen in the clinic. While carrying out the procedures the doctor and nurse explained to the child every step and how much pain to expect. Mothers thought that the preparation and knowledge helped the child to express his feelings about these treatments, to gain some control over what was happening to him, and especially to establish trust relationships with parents and medical personnel.

All children were told about the chronic aspect of the illness, "an illness that you will have to live with and get treatment for all your life". The prognosis of possible death was discussed with ten children. All children were aware of the fact that the medications were keeping the

disease from relapse and four children were also aware of the possible failing of medication and subsequent death.

TABLE 5.15. CHILDREN'S KNOWLEDGE OF ILLNESS ASPECTS ACCORDING TO MOTHERS' REPORT.

Variable	Number of Children		
	Yes	No	Not Sure
Diagnosis	17	3	
Nature of illness	15	4	1
Procedures and treatment schedules	18	1	1
Side effects of illness and treatment	18	1	1
Fatal prognosis	12	6	2

Most mothers thought that they were very open and honest with the child, allowing him to ask any question and to express his feelings about the illness, treatment, and side effects. One mother raised an important concern: "The only thing that I am worried about is whether I am explaining things clearly without also expressing my fears, or how I feel about it." Other mothers felt good about the fact that they were able to share with the child their anger, sadness, and sorrow about his illness. Some parents were very careful to prevent an environment of secrecy around the child's

illness "we have always talked about it (the illness) in front of him and with the doctors. Whenever we wanted to ask questions we always made sure that he was in the room when we asked them so that he could hear too, because it is his body. And we have always been open in our family."

Eight mothers felt that the child's father was not able to be as open as they were (in four of these cases the mother was separated from the child's father - separation had occurred before the child was diagnosed). "You know, if he ever has any questions, I answer them. His sister answers them. Bob*, he is the one who clamps up." And another mother, "He asked his dad a couple of questions one time and he just got a funny look on his face. And I think Billy depends on me to be pretty truthful and tell him in the best words that I can." Once couple that felt unable to communicate openly with their child took a workshop on personal communications which "helped us then greatly". No parent regretted any degree of openness. In general, mothers felt that keeping open communication drew the family closer together than it had been before the illness.

Communication to Siblings

Parents and medical personnel communicated to the child's siblings in a similar way as they did to the sick child himself (13 families had other children older than

*All names used are fictitious.

five years). Parents were very open with siblings in discussing the child's illness, its nature, treatments, and side effects. Except for two families, all siblings were aware of the fatal prognosis of the child. Some siblings came to the initial family conference at the medical center or accompanied the child to visits at the clinic. Physicians often asked siblings if they had any specific questions or concerns about their brother's/sister's illness.

The reasons for including siblings as mentioned by mothers were: "sibling will understand the parents' upset-ness"; "sibling will understand why child is getting extra attention and wouldn't feel left out"; sibling will accept the sick child's angry feelings, his moodiness, and low levels of energy; sibling will be able to communicate better with the sick child and parents about the illness. As a result, in seven families the siblings got involved in the sick child's care and helped him, especially toward the outside world. Three mothers knew that the child shared with his siblings feelings and concerns that he never shared with them. "Lisa is very helpful with Todd. When they are away from home, at school, and Todd is sitting on a bench by himself and Lisa is playing, she will always stop playing with whoever she is playing and go over and sit with her brother. She always stands up for Todd. She always makes sure Todd is taken care of at birthday parties when the other children are having the cake . . ." Another mother

related, "Whenever Johnny is going for a bone-marrow (test), the girls ask their classmates to pray for him and he feels really good about it." And the Smith family: "We explained to Kevin what was wrong with Danny and that he had to take the medicine, but the medicine would make his hair fall out, the medicine would make him fat and would make him very nasty and angry. And so Kevin understood and has turned out to be Danny's best friend." Some siblings were very alert to the need for the treatment regimen. "One night we didn't do the postural drainage and Michael got all worried and said angrily, 'if you won't do the exercises right, Jay will die'".

Three siblings perceived the sick child to be very vulnerable and allowed him to tease and kick them. As a result, the sick child, who sensed their strange preferential treatment, pulled away from his siblings. Other siblings' reactions were anger, jealousy, sadness, and worry. Open communication with siblings was considered by several mothers as the only way to reduce potential feelings of isolation and rejection for the siblings.

Communication to Teachers, Classmates, and Peers

All mothers contacted the teacher and discussed with her the child's illness, treatment, possible side effects, and limitations. Mothers of children with cystic fibrosis gave the teacher, in addition, the Cystic Fibrosis Founda-

tion special pamphlet for teachers. Most mothers felt that teachers were understanding of the child's special needs (e.g. taking pills, frequent trips to the restroom, coughing, rest breaks). No child reported the teacher's initiating discussion with him about his illness, and one mother thought that the teacher was actively avoiding the child. Fourteen teachers discussed the child's illness with the class, mainly to prepare the children to accept the sick child's side effects and possible school absences. Many mothers were unclear as to what the teachers actually shared with the class. Some teachers also encouraged the children to keep contact with the sick child by sending him cards or going to visit in his home.

Medical personnel were very supportive of the mother's communicating with the teacher and the teacher to the class. On one occasion, a nurse from the clinic went to a child's class before his return to school after a diagnosis of cancer. She discussed with the children the diagnosis, the treatments the child was going through, possible side effects and future hospitalizations. She also emphasized some necessary measures of caution in interacting with the child to "prevent injury to the child's head - hitting, pushing, throwing a ball". The sick child's mother reported that these classmates were extremely understanding and the child's reentry to the school was "smooth".

Only a few mothers initiated communications with the

child's peers. One mother always explained to new friends about the child's illness, treatments, and side effects. Another mother called her child's friends' mothers and asked them to talk to their children about the child's illness. All of these mothers felt that informing the child's friends reduced the amount of teasing and increased understanding.

Communication to Extended Family and Family Friends

All mothers told members of the extended family and close friends about the child's illness and its progress. A few mothers used their mothers as confidants and main emotional support. Most mothers did not feel that their friends were able to understand what they were going through. In some cases members of the extended family or family friends attended the initial family conference. A few also joined the mother and child in clinic visits. They were always welcomed by the medical personnel and their questions or concerns were dealt with.

Open communication between mother and father in regard to illness aspects and their concerns and feelings was a prerequisite to open communication with the sick child, the siblings, and the outside world. Although in some families the mothers seemed to carry "the brunt of open communication", fathers were in basic agreement to the approach. Medical personnel tried to intervene whenever communication between the parents seemed to fail. Communication between the

child's parents and their ability to communicate openly with the sick child, the siblings, extended family, friends, teachers, and the child's peers was a crucial element in enhancing family unity.

Strategies Related to Management of "Being Different" Due to Illness and Treatment Side Effects

The strategies related to management of side effects of illness and treatment were mainly geared toward reducing the child's feelings of being different from his siblings or friends. Fifteen mothers were aware of the child's feeling different from his peers and siblings. One mother reported, "Of course she feels she is different. Had she not been sick, her physical development would be a lot better than it is. Her attitude about herself is naturally based on a sort of physical image of herself which doesn't please her at all. As far as her body is concerned . . . she is pretty self-conscious about how thin she is." Children tended also to feel the difference in their own activity levels as compared to their peers'. "Johnny is riding his bike, but not as far or in all places like his friends. He is not able to go with a group of friends to spend the whole day running in the park. I am sure that that bothers him a lot." For some children this inability to participate in all activities caused them to be excluded from the group. One mother complained, "The kids begin to play a lot of games that boys

play. And Mikey wants to play too, but they wouldn't allow him to join because of his leukemia." Another mother described her son's perception of difference from his siblings. "Lately I can see great resentment that his brothers and sister are able to go to school and he can't. And I see a lot of jealousy that they are well and he is not. And he shows it by attacking them verbally. He will say 'you are stupid', or he will just scream at them."

On some occasions the child's feeling of being different was enhanced by reactions from the surroundings. In public places some children had to face strangers staring at them and careless remarks. A mother's story of how her child dealt with a stranger's remarks reads as follows. "We went to the movie once when he was bald and a fellow was looking at him for a long time. And that man said to Jimmy, 'hi, how are you doing? It looks like you got a nice haircut there.' Jimmy answered promptly, 'It is not a haircut. I have got leukemia.' And the guy said, 'oh, excuse me!' and turned his face away." The same child also reacted: "When people were beginning to stare at him he would say, 'you know what I have got, how come my hair is falling out?' They would say 'no', and he would say 'because I got leukemia, that's why.'"

Mothers of nine children reported that the child had been teased frequently by classmates and friends. Seven children got teased because of hair loss ("baldheaded freak"

or "baldie") and two due to small stature ("shrimpy"). Mothers differed in their responses. Three called the teacher and asked for her intervention. Two mothers called the parents of the children who teased the sick child and asked them to talk to their child. Two mothers themselves talked to the teasing children and explained the illness and presenting side effects. Two mothers felt that the child could manage the teasing by himself. These children learned that telling the truth was the easiest way to stop the teasing and questioning. "Whenever the kids will say 'what's wrong with you? Why are you so skinny and coughing?', Stevie will say, 'I have got cystic fibrosis' and they will go 'oh' and turn to their business." All these mothers felt that their own as well as their child's interventions were successful in reducing subsequent teasing.

All parents felt that the child would be better able to tolerate his difference from other children after understanding the reasons for treatments, some restrictions, and the characteristics of the side effects. They invested a lot of time in explaining these aspects to the child. Some parents found related books to be helpful in finding simplified versions of explanation. On the one hand there were some parents who adopted a preventive approach. They always prepared the child ahead of time to the possible coming side effects. They thought that the child needed some time to get used to the idea or that they needed time to prepare a

solution to the problem (e.g. preparing a wig for future hair loss). On the other hand, other parents adopted the reactive approach. They thought that it was better to deal with problems as they arise and not to get the child all upset before time. For parents it was often painful and frustrating to explain the need for treatments and justify side effects as "worthwhile". Dave was seven years old and wanted his mother to come up with a solution for the leukemia. "I don't have a solution, I told him. And this was the hardest bridge to go over. He had been saying, 'well mother, I am taking all the medicine. We are going to Dr. A. like we are supposed to. I look good. I feel good in general and I am getting well. Ain't I?' The hardest thing for me was to know that there was no guarantee and I had to tell him that we have to go on with the treatments and just have good faith."

Medical personnel were helpful in explaining to the child his treatment, restrictions, and side effects which were discussed at the clinic visits. They always shared with the child and parents their experience on alternative measures in dealing with prospective problems.

Most mothers were very innovative in initiating "normalizing tactics" to manage dietary restrictions, postural drainage, medications, hair loss, and low energy levels:

Dietary restrictions. Only in one family out of the four with children with cystic fibrosis was there an ongoing

battle about food management. This mother felt that she failed in all strategies to control consumption of sweets. Fortunately the child was only mildly sick and the sweets did not affect him immediately. Other children suffered immediately after every "sneaking". Two mothers started to cook a fat-free diet for the whole family. Another mother sent the cystic fibrosis cookbook to a cooking class at school and the whole class cooked and ate the appropriate food. When the child was invited to parties or eating out, the mothers baked a special cake and sent it along with the child. They also called the hostess in advance to notify her about dietary restrictions. Three mothers gave the children permission to regulate their enzyme pills in case they sneaked on foods in parties.

Postural drainage. All mothers were very careful to adapt the postural drainage time to the child's play time. None of the mothers felt that it was "fair" to call the child in for exercises. One mother initiated at an early age doing the physical therapy in front of other neighborhood children. "Then they will all get on the floor and want me to do it to them too to see what it feels like." In another family everyone would get on the floor and do the physical therapy as part of the family exercises.

Medications. In some families the child was responsible for taking his medications. These mothers had a lot of confidence that the child understood the importance of the pills

and was mature enough to handle his medications. In one case the school did not allow the child to keep his pills and required him to deposit them in the principal's office. The mother was aware of the child's embarrassment in having to ask for his pills every day in the office and decided to fight the school policy. In two families siblings got their vitamin pills while the sick child got his medication "so that no one would feel left out".

Hair loss. Most families with older sick children thought that hair loss was one of the major traumas for the child and for them. One mother of a child who relapsed after being in remission for several years explained, "Hair loss is the worst part. It was the hardest on everybody. It is just a constant reminder. When they have all their hair you forget about the leukemia and have your days when it doesn't worry you. But when you see him without hair, you are just aware every minute . . . and then because they get teased." Many families prepared the children for possible hair loss. Most of them thought that a wig would be an acceptable solution. It was all of these parents' experience however, that the child wore the wig only for a short time and then exchanged it for hats, scarves, or nothing. All parents and medical personnel emphasized frequently to the child that hair loss was a temporary condition and assured him that hair would grow back.

Low energy levels. None of the mothers had set any

special limits on how much time and in what activities the child should engage. One mother had to argue with the physical education teacher that she should let the child decide his limits and should not be afraid of his participating in exercises. It was usually the children who limited their own activities when they felt tired or distressed. When mothers realized that the child did not have the energy to go out and play, some used to invite children to the house. They also invited children to spend the night when they thought their child might enjoy having a friend, since he could not spend a night away from home. Many of the children were involved regularly in sports like baseball, soccer, swimming, and scouting. One child "has been on the baseball team and didn't quite finish the season because his legs got so bad. The team wanted him so badly that they made him just bat the ball and his friends all took turns running for him so he wouldn't have to run the bases." To reduce possible differences in academic achievement as a result of school absences and reduced energy levels, some mothers arranged for a home tutor, extra help at school, or helped the child daily with school work.

Management of Discipline

Another area of great concern for all mothers was the management of discipline. At the time of the interview, all

mothers were very aware of their possible tendency to treat the child differently than his siblings due to the illness and side effects. All mothers except one made a conscious attempt to treat the ill child in the same way they treated his siblings, or as if he were a healthy child. They discouraged siblings from making special allowances. They did not want the child "to be socially retarded in addition to his illness". Parents were also alert to the danger of the child developing high dependency. "You know the tendency to drop anything and cater to him. I realized dependency could be a problem. So early on I fostered a sense of independence in him." All mothers remembered that immediately after diagnosis and in few cases for several years, they wanted to protect and compensate the child by refraining from limit setting. One mother's story of these first months illustrates the complexity of the problem. "It was the first year of her illness, you know. I did everything. I dropped whatever I was doing and went into her room. And she saw me doing that. I was so afraid for her life, I thought these were her last days and I had so much fear in me about her dying that I gave in to every whim and wish. I mean, I would even overlook the fact that she pushed one of her sisters down or something. It was pretty bad for a time . . . Jane was just totally outrageous. She even got between me and Bob. She realized that she can separate us. When I felt that she really needed me at night, or I was mad at

Bob, I would go to her room and get in bed with her and leave Bob to be furious at me and at her . . . I felt Bob wasn't doing enough for Jane and he felt ripped off because I was always with her. I think she realized she was a pretty powerful person over us." The family was close to a breaking point when they included their physician in their problems. They spent four sessions with him, sorting out their feelings and he explained to them the need for discipline. "We got clear that we needed to set up a discipline type of thing with Jane and not feel guilty about it. After that we started disciplining her and being happier with each other. And it was remarkable how Jane changed. I think that all the time she was getting the message of 'you are sick and that is why you can do anything, because what you have got is really bad', or something like that. We started setting conditions and limits and she had to accept them. I remember that she was happier than she ever was when I started punishing her. Finally Jane felt that she belonged to the family, I guess. She also started to talk about what she was going to do when she grew up. It was remarkable. Before, I think she figured that she wasn't really going to grow up. But as soon as mommy and daddy figured there wasn't anything wrong with her and that she could be punished just like anybody else, I guess, she started thinking 'maybe I am going to grow up'".

Three mothers, who were at times completely involved

with the child, reported that their involvement resulted after a while in resentment of the child for consuming all their time and energy. They all realized that at a certain point they started actively to distance the child from them, leaving him distraught and confused.

All mothers perceived medical personnel as firm in their belief of the need to continue with reasonable limit setting and discipline. Discipline was often a topic for discussion in family conferences at the clinic. In three cases the physician intervened and encouraged the parents "to set limits in the chaos". All families were satisfied and happier after implementing these suggestions.

Problems with discipline and complete involvement with the child were involved in one family facing the child's terminal stage. In this case both parents were aware of what was happening, but made a decision to give in to most of the child's wishes. "Whatever we do, we have to do with the thought and understanding and foresight of what is best for Danny, not for us right now." The mother was also aware of imposing their closeness and fear upon the child. "He probably would really love to get away from me or adults - you know - just go off with his brothers down to the creek or to the park. You know, just get away from adults. But I can't let him do that. I just - I could, I am sure - there are lots of people that would just go ahead and let them - but right now, I don't feel comfortable in doing that. To

say 'go on, have fun, and I will see you later'. I can't do that. I have to feel that one of us is near him in case he has pain or something. And I wouldn't let him out of my sight." This family was trying very hard to balance between the need for discipline and the tendency to give in to a dying child.

It was very obvious that as long as these children were in remission, parents' great efforts to resume normalcy showed positive results. However, in time of crisis most management measures toward discipline and involvement as well as strategies toward dealing with side effects of illness and treatments were failing.

Strategies Related to Management of the Child's Death Anxiety

Several sources for possible death anxiety in the child were identified from interviews with the mothers. Death anxiety was generated from the child's inner perception of his physical condition, parents' and significant others' beliefs about the child's prognosis, the child's awareness of a death of another child with the same diagnosis, and the child's previous experiences with death.

Death Anxiety Generated by the Child's Inner Perception of His Physical Condition

A few mothers reported that their children expressed concerns about death while in extreme pain or suffering from very low energy levels. One child who sensed his slow physical deterioration asked the physician with worry, "What are you going to do if that (this medication) doesn't work?" When he thought that he was getting new chemotherapy he said, "My cystplat didn't work, did it?" and later in the day asked his parents, "Am I going to die?" This child was aware that the drugs he received were experimental and their failure meant death. Both parents and medical personnel tried to convey to the child that even though the specific drug was not effective, they still had other alternative drugs and mainly "they had hope".

Death Anxiety Generated by Parents' and Significant Others' Beliefs about the Child's Prognosis and Death in General

Parents and significant others were often unaware of how they transferred their hopes, uncertainties, concerns, fears, and beliefs to the child. Two children's experiences were: a seven-year-old, "He knew he was really sick. Robert did know it was serious in the beginning because we told him. I mentioned the word 'die' once and he just screamed. He said 'quit talking about me as though I was dead already, because I am not dead'. I hadn't realized

what I was saying, but my husband says that I talk an awful lot and say a lot not realizing that Robert can hear me and that he understands." And another child: "And I came into the hospital room one day and my ex-husband's mother and all the relatives were sitting there around his bed, praying around his bed, kneeling down, and she was crying and crying and my husband was against the wall like making sure that nobody would come into the door. Until that time Jody knew that he was ill and he had already been told that he had leukemia, but the impact of that sort of death situation really hit him. When I walked in he screamed, 'mommy, mommy!' he was so terrified."

Twelve mothers said that they and their children were aware that the child was not going to live beyond childhood. They experienced different stages of anticipatory grief. Three mothers stated that they felt good knowing that they provided the child with at least some good years. For this reason one mother thought that the slow dying process was preferable over a sudden death. ". . . just to send a child away, off to school and all of a sudden God takes him. I mean at least we have a warning and we are able to do all the things that we want to do - well maybe not all the things, but most. We are doing a lot of things that maybe we might not ever do if that child were to be taken away just off the street one day. So I would rather do it this way. . ."

Setting the child's future in a time frame seemed to help another mother, who tried to maintain quality of life. "Now I realize that unless something unforeseen in the next few months will happen, he is going to be with us for a while. I know from Dr. R. and his x-rays how he is, and his lungs are pretty good. So I give myself a time limit. I think, okay, he is probably going to be all right for at least five years. So I think about these five years, plan them now, and if you can think about five years, then you are okay."

Although the prognosis of death was discussed with ten children only, seventeen children expressed their death anxiety in different ways. Some stated "I don't want to die" or asked "Am I going to die?" It was the experience of many of these mothers that the child's questions about death took them completely by surprise when they were the least prepared with an answer. Mothers' answers demonstrated on the one hand their ongoing efforts to find a meaning, to deal with and to have some mastery over the concept of death. The most common answer to the child's question "Am I going to die?" was "We are all going to die one day; I don't know when you are going to die." In an attempt to reduce the child's anxiety, some mothers tried to equalize his chances of dying with those of other family members. One child was told "Nobody knows when anybody is going to die. I told Andy 'mommy could get in the car tomorrow and go on the

freeway and get in an accident and you would never see me again, maybe', I said and 'the same goes for you'. I tried to explain it really in his terms. I said 'you could do anything; you could be driving down the road with daddy one day and get in an accident and you and Laurie could both die.' I said 'life and death really have no say. You might live until you are 50 or 60 years old.' But I feel they don't make it past teenage or whatever."

Many mothers discussed death with their children mainly as a response to their questions. In two families with older siblings the topic was brought up on purpose by the parents in family discussions. These parents felt that by "bringing it to open family discussion, it made it okay for Linda to work it in her head". Many mothers used their religious beliefs in trying to answer their child's questions. Some mothers tried to convey to the child that he was a special person if "God was ready to take him". "We have always said 'Jay, you are special, you know. God only gives things like this to special people that he knows can handle them'. And he said 'why do I have to be special? I don't want to be special anymore. I want to be like anybody else. Why does God do this to me?'".

There were a few other children who agreed with Jay that death of a child "was very unfair". These mothers also believed in life after death and discussed with the child the image of heaven. "We have talked about dying when he

was younger, when he got it. We had a little book. That was Children's Letters to God. It showed pictures of heaven with merry-go-rounds and horses and we told him that he was lucky because he was so sick, he could have died and gone to heaven. But the medicine made him better and now he was fine. He said 'If I were to die, would I get to ride merry-go-rounds and a horse?' And I said 'You can ride a horse forever and forever up in heaven' and he had a beautiful picture of heaven. Later, when he grew older, he didn't care how beautiful heaven was going to be. He didn't want to leave me. He always said 'When I die, will you promise to die at the same time?' So he won't be alone up in heaven. I told him that some day we will all be together again, but he wants to make sure we all die at the same time. He doesn't want to be alone up there or down here."

Three mothers talked with the child a lot about the child's grandparents who died. They frequently looked together at the family albums and told the child "funny stories" about the grandparent so that the child would get to know him/her and "wouldn't be afraid to be alone and not to know anyone up in heaven". Two children, who had known, loved and missed their grandparents were "waiting to go to heaven to see grandpa again". The non-religious explanation that a few mothers adopted was "When you are dead, it is only your body that dies. But your soul is leaving the body and can stay with us forever. We wouldn't be able to see

you, or to talk to you, but the soul would always be with us." Only one mother told the child that she didn't know what to expect after one dies. She further explained that there were different beliefs about it and that everyone has the right to believe in what seems right to them.

Two children seemed to find specific ways in dealing with their death anxiety. A nine-year-old "has suddenly developed a tremendous interest in the mystical, in ghosts, in witchcraft, and all these bizarre things . . . I think that this is Ronny's way of trying to work it through." The other child, a seven-year-old "always liked animals, but now he is really into it. He just wants to watch new life. He just lately insisted on getting a Mama and a Papa rat and he wanted them to have some babies. And everything lately that he has talked about - he wants it in pairs and wants it to have babies."

Mothers of three children claimed that their child had no death related concerns. All other mothers reported that they were always willing to hear and discuss the child's questions and concerns. Although they frequently felt pained and uncomfortable, they never turned the child's question down or changed the subject. A few mothers found it to be very helpful to hold the child closely while they talked about death. Some mothers were constantly trying to understand more about death by reading related books and attending seminars and workshops on death and dying.

Five children attended a special group for children with fatal illnesses run by a child psychiatrist and three volunteers. The mothers of these children knew that death was discussed in the group. Although they did not know any details about the discussions, they felt very positive about the group. One mother related, "There are other children there who are also terminally ill and maybe just the group situation, or knowing other children who are also terminally ill, really satisfied a lot of the needs and questions Dave had that I can't answer or that he hasn't been able to find answers to anywhere else." Otherwise mothers reported very little on medical personnel's ways of dealing with the child's death anxiety.

Death Anxiety Generated from Death of a Child with the Same Illness and Previous Experience with Death

Three children knew about the death of another child with cancer or cystic fibrosis. They were very upset and one child hardly said a word for two days. Mothers felt that this knowledge enhanced the child's death anxiety. They dealt with it by pointing to the difference of the illness trajectory of the other child. Nurses supported the mothers' approach and told the child how more seriously ill the other child had been at the time of his death. A few children experienced at a young age the death of their grandparent. Parents discussed these deaths openly with the

child. Except for one child who became very upset, the young children did not seem to be affected. Three children experienced the death of a younger sibling. The mothers sensed that at times the child associated his fate with the sibling's death. Most children had had pets that died. Many of them buried the animals. Mothers did not recall specific upsetness or questioning around the animals' death.

Death anxiety generated much anguish in parents and children. They constantly struggled to master the uncertainty and fear associated with death. This struggle was often failing, although the subject of death was dealt with very openly.

IV. ANALYSIS OF LONELINESS

A certain degree of loneliness in the child was reported by nine mothers. Although they had frequently communicated openly with the ill child, they realized that he was keeping "a lot of things to himself", mainly about his illness trajectory and possible death. Three mothers were sure that his illness and possible death frightened the child more than he was willing to talk about. "I am sure Ron has a lot of fears; initially he would ask a lot of questions. He would tell me how badly he felt about his hair falling out and things like that. But lately he is very moody. He has asked very, very little and expressed very little in terms of fear and so forth." And another mother, "I just feel

that she wants to know more about her illness, but is very afraid to ask. I hear her asking it in some indirect ways . . ." Two parents felt that the child was not sharing his fears because he wished to protect them. "She must have fears of death, but she never told me about them. She is protecting me." And the other parent reported, "He is kind of complicated in the sense that he keeps a lot inside. He is our oldest and he is bright. And he can read a lot into a situation. There are a lot of times when the feedback that you get is what he thinks that you want to hear, not what he feels. We do try to pull things out of him, but he is like that." Except for this mother, the other eight mothers respected their children's silent fears and accepted their lack of sharing without trying to actively intervene. The inability to share one's fears and concerns may result in loneliness.

Some mothers related the child's loneliness to him being rejected by others. Three children were rejected by their friends. "Right now he is not having anybody coming to the house. He is kind of rejected." A nine-year-old would just "watch the children play from the side and only rarely do they ask him to join." Three mothers felt that different members of the extended family were also actively avoiding or distrancing the child and the immediate family. One mother said, "Ironically right after she was diagnosed, it seemed like everybody just sort of left town. To Debby

it meant that three people she loved were suddenly gone out of her life. And I think part of it was their inability to handle being around me or her and their fears. Because they were here when she was very sick, they saw her, but shortly after that they were gone." In another family the grandfather was "too pained" to be around the child, or talk to him. The parents knew that the child was very upset and sad by his loved grandfather's avoidance behavior. "Jay's grandpa can't stand the thought that Jay has cancer. Jay loves his grandpa dearly and he misses him coming around. When he does come, he is a nervous wreck and I almost wish he wouldn't come. He can't relax and just be good company to Jay. I think that he is the one that is losing out. Jay is too. But he is the one that is going to lose out before it is all over. Because he won't have another chance." The same mother spoke of others avoiding the family. "My cousin probably will not come around for fear that it is contagious. A close friend, when I told her that Jay had cancer two years ago, never came back to visit and we were very close friends. She had two little boys Jay would play with until he first had that melanoma removed." Jay's reaction was "oh, they just hate us".

In addition to the mothers' reports, the investigator rated the overall loneliness of the ill children as higher or lower, based on the child's scores on the three study tools. Subjects scoring above the mean of the ill group on

two or more of the three measures were rated as higher loneliness; those scoring below the mean on two or more of the three measures, were rated as lower loneliness. Out of the 20 subjects, 11 were rated with higher loneliness and nine were rated with lower loneliness (see Table 5.16).

The interviews were analyzed qualitatively to identify the variables that could possibly contribute to higher loneliness. This analysis revealed that the group of children with higher loneliness did not differ from the group of children with lower loneliness on the strategies their parents used for communications about the nature of the illness and treatments. They also did not differ significantly on the strategies parents used to deal with the child's differentness. However, they did differ in their parents' strategies for dealing with death anxiety. Seven out of the 11 children with higher loneliness received detailed information about life after death, as opposed to only two out of the nine children in the group of the children with lower loneliness.

Looking at the medical characteristics of the children in both groups, it became apparent that five out of the 11 children with higher loneliness were within four months since crisis (i.e. diagnosis, relapse, failing drugs). Ten out of the 11 children with higher loneliness had visible side effects of illness and treatment at the time of the interview. (There were only seven children in the ill group

TABLE 5.16. SUBJECTS' SCORES ABOVE AND BELOW THE MEAN ON THE THREE STUDY MEASURES.

Subject Code Number	Mean Total Number of Loneliness Themes	Mean Total Number of Adults Selected on the Who Scale	Mean Distance of Placement for All Figures on the CID	Total Above Mean
1	+	+	+	3
2	-	-	-	0
4	+	+	-	2
5	-	+	-	1
6	-	+	-	1
7	-	+	+	2
8	-	+	+	2
9	-	-	+	1
10	+	-	-	1
13	+	+	+	3
16	-	+	+	2
18	+	-	-	1
19	-	-	-	0
21	+	-	+	2
25	-	-	+	1
26	+	+	-	2
30	-	+	-	1
31	-	+	+	2
32	+	-	+	2
33	+	+	+	3

+ = above mean

- = below mean

who were within four months since crisis, and 12 children who had visible side effects of illness and treatment.) A detailed description of heaven and "all the fun the child will have there alone", along with the child's illness state and visibility of side effects seemed to be the major variables conducive to higher loneliness in the ill children of this study.

In the next chapter the findings will be discussed. Their implications to clinical practice in pediatrics will be considered and recommendations for future research will be made.

CHAPTER VI

DISCUSSION

The discussion in this chapter will evolve around the study findings, their interpretation and their relatedness to previous research, the study limitations, the implications for practice, and recommendations for further research. The medical team in one of the clinics, which 12 out of the 20 ill children attended, has a clearly defined and institutionalized philosophy regarding open communication (see footnote, p. 110). For this team open communication means sharing with the child his diagnosis, the illness trajectory and treatments, as well as the possible prognosis. Parents are encouraged to maintain this approach by answering the child's questions honestly. The other clinics which the rest of the sample population attended (eight children) also adopted the open approach to communication with the child, but their strategies to maintain open communication were not institutionalized. Parents in this study followed the open approach philosophy and the findings of this research should be viewed with this fact in mind.

DISCUSSION OF FINDINGS RELATED TO THE FIRST STUDY QUESTION

Children with chronic life threatening illness differed in their loneliness manifestations from the healthy children. The ill children responded with more aloneness themes to a set of projective pictures, chose children less frequently for interaction, preferred adults in the "public domain" situations on a preference for interaction scale, and placed a second friend further on an interpersonal distance scale than did the healthy children. The three hypotheses derived from the study question were partially supported by the findings. The following findings did not support the hypotheses: children with chronic life threatening illness did not differ significantly from healthy children in the number of death anxiety, separation anxiety, threat to body integrity, and suicide themes (these themes together with aloneness themes were the subcategories of loneliness themes). The ill children also did not differ significantly from the healthy children on their placement of human figures, father, mother, siblings, and first friend.

Both healthy and ill children did not differ in their loneliness themes and placement of human figures according to their age and their mothers' marital status. The only exception was that older ill children (eight to ten) responded with more aloneness themes than did younger ill children (six to eight years old). According to social development (Sullivan, 1953) theory, older school age chil-

dren have a need for group acceptance and one special friend, the "chum". While the younger children in this study could still find social support within their families, the older children were lonelier when rejected by the group and unable to find a "chum".

How do these findings compare to previous research? There are no published studies on loneliness in children with CLTD. However, Waechter (1968) and Spinetta (1973) are the only researchers who conducted a systematic study on areas related to loneliness in children with CLTD. In their studies on death anxiety in fatally ill school age children, Waechter (1968) and Spinetta (1973) analyzed the children's responses to a similar set of projective pictures. Spinetta also studied the concept of interpersonal distance as a measure of the dying child's sense of isolation (Spinetta, Rigler, and Karon, 1974). Waechter reported that the children with chronic life threatening illness responded with significantly more death anxiety themes and loneliness and separation themes (in her study they were one category) than did healthy children. The groups in her study did not differ significantly in threats to body integrity themes. In contrast to Waechter, Spinetta found that in their responses, children with chronic life threatening illness (CLTD) differed significantly on threats to body integrity themes than children with chronic non-life threatening illness. None of the children in his study made overt references to the

concept of death. These children also responded with only a few separation anxiety themes. A comparison of the present study findings and previous research is summarized in Table 6.1.

Although Spinetta's research was a replica of Waechter's study, his findings differed from hers. He does not provide explanations for the variations in his published material. From the published material on Spinetta's research, this author also could not explain his different findings as compared to Waechter's and the present study's results. Therefore, the author chose to compare the present study with Waechter's research only. Waechter's findings support the first hypothesis of this study that children with CLTD respond with more loneliness themes than do healthy children. As compared to the present study, Waechter documented on the one hand more death anxiety themes in the CLTD children, and on the other hand no death anxiety themes in the healthy children. Three factors may account for these differences. The most important difference between the two studies lies in the historical time change between 1968 and 1977. The two study samples came from two "different generations".* Waechter's study was conducted at the time when survival rates for children with cancer and cystic fibrosis were lower than they are today. Very few children with

*This methodological issue is often discussed as a problem of cross sectional research (Nunnally, 1973).

TABLE 6.1. MEANS OF CHILDREN'S RESPONSES TO A SET OF PROJECTIVE PICTURES IN WAECHTER'S, SPINETTA'S, AND THE PRESENT STUDY.

Themes	(Waechter (1968)					Spinetta (1973)		Present Study		
	CLTD (F)	C	B	H	Signifi- cance	CLTD (F)	C	CLTD	H	Signifi- cance
Loneliness and separation themes	1.00	.13	.13	0	.01		minimally present	.60* 1.00**	.15* 1.45**	.03 N.S.
Death anxiety themes	2.25	.25	.38	0	.001		non-existing for both groups	0.45	0.75	N.S.
Threats to body integrity themes	1.00	.25	.43	.19	N.S.		significantly higher for F group (means are not available)	2.85	2.40	N.S.

*loneliness

**separation

CLTD = chronic life threatening illness

C = chronic non-life threatening illness

B = brief hospitalizations

H = healthy children

cystic fibrosis survived beyond adolescence and few children with cancer survived beyond three years from the time of diagnosis. These facts left hardly a doubt in the parents' minds as to the fatal outcome of the illness. It is likely that parents transferred their feelings of doom to their children. Imminent death, accompanied by death anxiety, were probably more central to these families' lives than they are today when higher survival rates and possible cures instill hope.

Also, at the time of Waechter's study, discussion of death, especially with children, was taboo. Most parents and medical personnel used the "protective approach" in communications with the fatally ill child. Waechter claimed that the children's death anxiety resulted mainly from lack of open and honest communication about their diagnosis and prognosis. In contrast, parents and medical personnel in this study belong to a society where death and dying are discussed more openly. The medical personnel caring for this study population, who witnessed for years the ill effects of closed communication, themselves adopted and encouraged all parents to adopt the "open approach" in their communications to the child about his illness and possible death. The change in the communication approach may be partially responsible for the fewer death anxiety themes found in the ill children's stories in this sample.

A similar line of thought may explain why healthy

children in this study did not differ from the ill children in the number of death anxiety, separation anxiety, and threats to body integrity themes. Mothers of both healthy and ill children reported on their children viewing frequent depiction of violence and death on television. Such exposure may raise the healthy child's awareness of death and his death anxiety levels, while the ill child, by virtue of his illness, was already aware of death and harbored death anxiety. The author does not know how television viewing of death was dealt with by parents. The variance between healthy and ill children in this study lay in the fact that the ill children seemed to receive more explanations regarding death. The fact that indiscriminate exposure to the idea of death may increase death anxiety in the healthy children, while open discussion geared to the ill child, may reduce some of his death anxiety, may explain the similarity in number of death anxiety themes in the stories of the two groups of this study.

Along with open discussion of death, both healthy and ill children were widely exposed to pictures and talk of crime, violence, separation, and divorce. In the children's stories the common themes of threat to body integrity depicted gun shots, theft, and robbery. Common separation themes for all children involved "a very sad woman, who was left by her husband who will never come back". It seems that in relation to anxieties of separation and body inte-

grity the atmosphere in which all these children were living affected both ill and healthy children alike and thus blurred the differential impact of the illness upon the children's fantasies.

The third factor explaining the difference between the two studies is that Waechter's was conducted in a hospital setting, while this study was conducted in the child's home. Hospitalizations for children with CLTD are usually associated with crisis of diagnosis, exacerbation of illness or approaching death. Crisis in these illnesses may be highly related to increased death anxiety in both parents and children. Therefore one can expect higher levels of death anxiety in hospitalized children than in those at home.

Increased survival rates, increase in open communication, and the home setting may explain the differences in findings between Waechter's and the present study.

Spinetta and his associates (1974) compared the distances at which children with leukemia placed four adult dolls (nurse, doctor, mother, father) to the distances at which children with chronic non-life threatening illness placed the same dolls. The children were asked to place the dolls where these figures usually would stand and then to place them wherever the child would like them to be. The fatally ill children placed the doll figures in further distance than did the children with chronic non-life threatening illness, following both cues. The authors concluded

that their findings were reflective of a growing sense of psychological separation of the fatally ill child from meaningful adults in his life. These findings support the present study's third hypothesis that children with CLTD will place human figures at a further distance than will healthy children, which however, the findings of this study failed to support.

The difference in the findings seems due to the different tools and not to the validity of interpersonal distance as a measure of isolation: (1) In the present study interpersonal distance was measured by the CID, a paper and pencil test which asks for a higher level abstraction than does the placing of dolls; (2) The investigator did not distinguish between cues asking for "real" versus "wishful" placement. For some children it seemed too distressing to place the human figures at a far distance, when they had a choice of resorting to wishful thinking. This fact may explain why there was no significant difference between the placements of the ill and healthy children in the present study.

The ill children's responses on the Who scale supported the author's conceptualization that choices for interaction are based upon reinforcements from previous experiences, along with the value the individual holds for the interaction (social learning theory). The children with CLTD who may experience negative reinforcement (e.g. teasing, rejection) from interaction with peers chose fewer children for

interaction than did the healthy children. These children also chose significantly more adults for interaction even in "public domain" situations. This fact reflects high degrees of loneliness according to the theoretical frame of the Who scale. The lonelier the child, the less likely he is to choose peers even in "public domain" situations.

The combined findings of the three studies supported all three hypotheses of this research. It is this author's impression that the differences in the findings among the three studies may point to the salience of open communication and crisis as crucial variables determining CLTD children's loneliness manifestations. In the next section the impact of using open communication indiscriminately upon the children's loneliness will be discussed.

DISCUSSION OF FINDINGS RELATED TO SECOND STUDY QUESTION

All parents developed coping strategies for the problems of: communications with the child and significant others in his social milieu, the "differentness" of the child, and the child's death anxiety. These strategies reflected the families' strength and resilience in dealing with ongoing problems of living with chronic life threatening illness. Many mothers were very innovative in their striving for normalizing the child's life. They thereby reduced the child's differentness and the amount of teasing and rejection he had to experience (for examples from the

case material, see pp. 118-128).

The literature for health professionals suggests that open communication and inclusion of the child in the decision making process are desirable, but are not yet considered common practice (Shane, 1972; Vernik, 1973; Waechter, 1968). No systematic research of the use and implications of open communication exists. While adopting the open approach, parents and medical personnel in this study seemed to reduce the child's concerns and fears about unknown treatments, the nature of the illness and side effects of treatment. They thereby seemed to deter some of the loneliness expected in a closed communication atmosphere. However, by so doing some parents seemed to increase the child's anxieties and loneliness around death and in particular in regard to afterlife. This investigator speculates that two parallel processes occurred when discussing "living with the illness" as opposed to "dying".

In open communication about "living with the illness", both parents and medical personnel, according to the mother's perceptions, were successful in gaining the child's trust. They were also able to convey security that they could help. By knowing in advance about procedures, treatments and side effects of treatment, the child achieved some sense of control and predictability over the illness. They probably succeeded in alleviating some of the child's loneliness, mainly by turning the illness into "a together experience,

something that we can all go through together". In return, most children openly expressed their fears, concerns, anger, and fantasies surrounding the illness and treatment and thereby maintained the open communication process.

In their open communications about death, many parents unknowingly shared their anxieties, fears, and inability to deal with death with the child. Some of them thus instilled distrust and insecurity, especially in regard to their capacity to help the child in his death. The underlying message was "we can't help you in death; it is something you will have to go through by yourself". Most of the parents' explanations about the time of death which "can occur any day to anybody" raised the child's anxiety about having no control and no predictability toward his death, as well as the death of the people he loves and needs most - his parents.

It is this author's speculation that the detailed picture of heaven which some parents painted for the child as a place where the child can go and "play forever and ever with no limitations, only very alone", raised the child's loneliness and feeling of desertion in death. These answers to questions about death may lead to closed communication, initiated by the child, which may enhance his loneliness. Figure V will depict the two processes of open communication.

These findings point to two stages of loneliness in children with CLTD. In situations where parents and medical personnel adopt the closed communication approach, Stage I

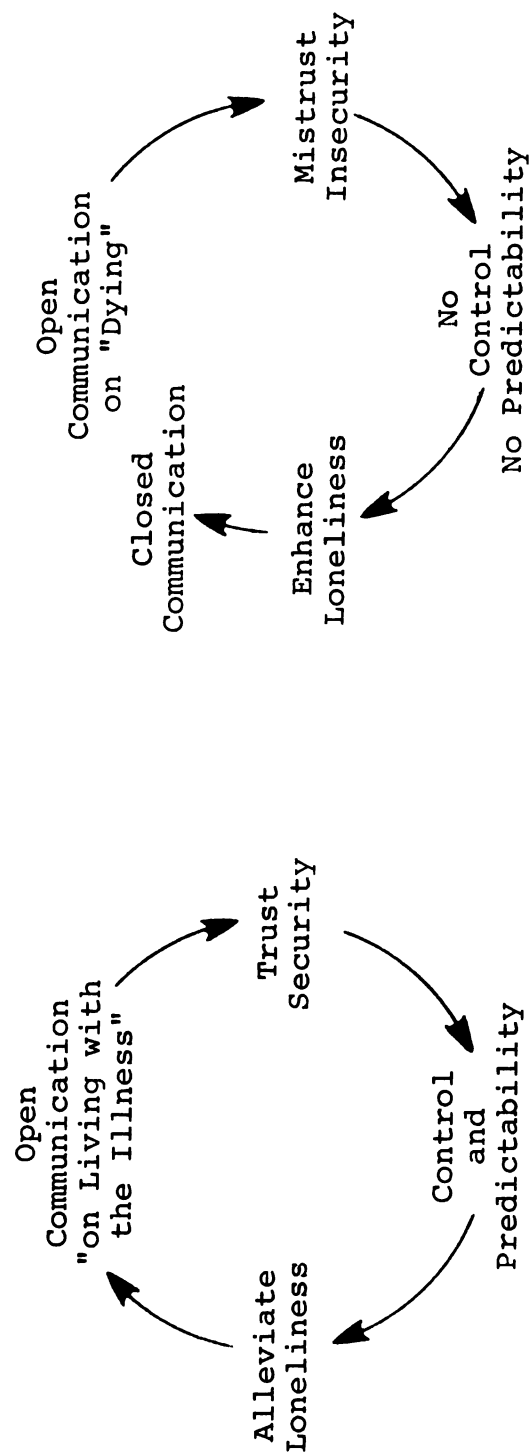


Figure V. Open communication with the CLTD child in regard to "living with the illness" and to "dying".

loneliness develops. No permission is given and the atmosphere is not conducive to the child's sharing his fears, concerns, and anxieties about the nature of his illness and his possible death. In the situation of open communication the child's stage I loneliness could be alleviated. However, when open communication is indiscriminate, the child is likely to experience stage II loneliness related to death and afterlife. This explanation is in line with Mijuskovic's (1977) concept of loneliness in death.

DISCUSSION OF OVERALL LONELINESS

Analysis of the loneliness of the ill group revealed that 11 children out of the 20 in the sample expressed higher levels of loneliness (scored above the mean of the ill group on at least two of the three study tools). The lonelier children were closer to the experience of crisis in their illness (within four months), received a more detailed picture of life after death, and suffered from more visible side effects of medication than did those children who were less lonely.

Death anxiety may increase in children undergoing crisis as a result of messages both from within the body and from the environment. Increase in death anxiety is likely to be followed by questions about death. If answers to these questions are loaded with anxiety, uncertainty, and descriptions of "aleness in heaven", one should expect the child's

loneliness to increase. Crises are also characterized by very low energy levels, mood swings, irritation and restlessness due to the child's illness and heavy medication. Some mothers reported on self induced loneliness initiated by the child who was too tired and irritated to want any friends close to him. At times this situation continued for weeks. During crisis the child's differentness is most obvious to himself and others and there is very little parents can do, besides providing warmth and understanding, to ease his pain. This is the time when many mothers become completely consumed with the care of the child, which ultimately resulted in the mothers' resentment of the child and the child's increase in loneliness. Loneliness seems to reach different levels throughout the illness trajectory, with peaks at times of crisis.

For the less lonely children, who were long into remission, the open approach to communication and active strategies to reduce differentness, appear to be successful in alleviating their loneliness. The fact that the lonelier children had more visible side effects, concurs with Goffman's theory of avoidance behavior related to visible stigma. These children were more often avoided and rejected by their peers and even by family members.

In conclusion, the children with CLTD in this study were lonelier than were the healthy comparison group. While open communication probably alleviated some loneliness

related to illness and treatment in some children, indiscriminate open communication about death and life after death seemed to increase loneliness in other children. Children under crisis and/or children with visible side effects of illness or treatment, and/or those children who received detailed descriptions of life after death, seem to be at higher risk to develop loneliness.

LIMITATIONS OF THE STUDY

The limitations of the study are primarily related to the study sample, limited theoretical development of the concept of loneliness and study tools. A small, nonrandom sample imposes limitations on generalizing the findings to other populations of children with CLTD, especially since children with cystic fibrosis and cancer were represented in the sample. Sample size also imposes limitations on choice of statistical tests for analysis of the data. The lack of conceptual clarity and of an operational definition of the concept of loneliness results in a dearth of appropriate tools for measuring degrees of loneliness. This required the investigator to resort to indirect and nonstandardized measures of loneliness, which were theoretically sound, but had only beginning levels of validity and reliability. The Who scale was designed by the investigator for this study. Pretesting of this scale provided only initial measures of the tool's validity and reliability.

The major weakness of the CID and the Who scale lies in the fact that the instruments' cues did not call for differentiation between real situations and wishful thinking. This fact reduces their sensitivity to experienced loneliness. For example, one child, who was confined to his home for a long time period due to his illness and whose mother indicated with sadness that he has absolutely no friends, chose friends to interact with on many items on the Who scale.

When asked to name any of his friends, the child answered "no one in particular". His choices of children seemed to reflect his wish to have a friend, while in reality, he was very lonely. In another case the child's parents were divorced and the father had moved to another state. The child had not seen her father for the last two years and the mother reported that the child felt very deserted by her father. This child placed the father in zero distance to her on the CID. She might have felt deserted, but at the same time wished for her father's closeness. This problem could in part have been eliminated if measures were taken of both the real and fantasy (wishful) situations.

The lack of positive correlation among the three study tools raises additional concern as to their validity in measuring loneliness. The tools may have measured different dimensions of loneliness. If this were the case, one would not expect high correlations between these tools.

The lack of previous research related to loneliness in children and the exploratory nature of the study enable the author to only speculate on the effect of variables as open communication about death, the child's illness state, and visible side effects upon the child's loneliness. Quasi experimental or experimental research is needed to validate these effects.

IMPLICATION FOR PRACTICE

The implications for use of the study findings fall into four major categories: education of health care profes-

sionals; guidance of parents of children with CLTD; education of the general public, especially school teachers; and establishment of programs to aid the child in alleviating his loneliness. The first step toward helping the child is to make health care professionals fully aware of the occurrence of loneliness, its possible sources, and manifestations. This knowledge will enable them to recognize the lonely child, assess the level of his loneliness, and identify its sources. When guiding parents in regard to the psychological and social impact of the illness upon the child, the medical team should share knowledge about loneliness and its sources. Only then can strategies for alleviating loneliness be developed.

Regarding strategies for alleviating loneliness, the findings of this study support the recommendation of many clinicians for the use of open and honest communication with the child about his illness and prognosis. Adults, communicating with the child about his possible death, must first come to terms with their own fears, uncertainties, and unresolved anxieties about illness and death in general, and about their child's illness and prognosis in particular. Children tend to become anxious whenever they sense anxiety in adults. Therefore, health professionals who encourage parents to adopt the open communication approach must first assess the parents' ability to discuss the illness and its prognosis openly without transferring undue anxiety to the

child. It seems advisable that after diagnosis, when parents are in shock and under high stress levels, the caregiver should initiate talking to the child in the parents' presence, serving as a role model for them. Parents could also be encouraged to rehearse their discussions regarding illness and prognosis with the child. Such rehearsal offers an opportunity to clarify parents' possible misconceptions and dilemmas about the child's illness and treatment. Parents should be further prepared for common questions children ask about their illness. Special attention should be paid to discussions with the child regarding death and afterlife. Both health care professionals and parents must train themselves to listen carefully to the child's questions. Often adults tend to give children detailed answers for which they did not ask. While explaining death and afterlife to children, parents should be alerted so to avoid adding to the child's fear of separation and desertion in death by "comforting" stories about the child being happy, but very alone in heaven.

The period of the first hospitalization can be used to assist parents with their overwhelming anxiety. Unless parents express readiness to discuss the illness and prognosis openly with the child, they should not be encouraged to do so at this time. Parents should know that the medical team is willing and able to handle the child's questions as long as the parents are still struggling with their own

unresolved anxieties.

Parents should also be alerted to the increased probability of the child developing loneliness in times of crisis. Even though parents cannot share the physical pain and anguish of restlessness and low energy, they can convey their understanding and give the child their warmth and closeness. If a child needs distance, parents should be encouraged to respect this need yet remain willing to offer closeness as soon as the child is ready for it.

An additional strategy to alleviate loneliness related to death is providing parents, who choose to let the child die at home, with the necessary supportive services. Such services include preparation of parents for their role of caregiver to a dying child, provision of effective pain control, frequent home visits, and 24-hour availability for support in times of emergency by a member of the medical team. Parents, who opt for the home death route, will then be able to assure the child that he will not be left to die alone or apart from his family.

Parents should be made aware of the existence of self help groups of parents (e.g. the Candlelighters). Parents are able both to extend emotional support to other parents and to exchange valuable knowledge regarding the management of the child's differentness, his discipline, fears, and concerns. The medical team should discuss with the parents the advantages of joining such a group as opposed to the

possible disadvantages of experiencing additional pain and anxiety. Such anxiety may be provoked when, for example, a parent of a newly diagnosed child hears in the group about another child who relapsed or is approaching death after years of being in remission.

The general public should be better informed about the nature of chronic life threatening illnesses and the problems the ill children are facing. Special attention should be given to inform the public that these illnesses are not contagious, so that people do not distance themselves from the ill child or instruct their children to do so out of fear of contagion.

When returning to school the child is very vulnerable to developing loneliness as a result of teasing and possible rejection by his classmates. It is desirable for the medical team to contact the school teacher and school nurse to inform them about the child's illness. Several goals can be achieved by this contact:

1. The teacher will learn about the nature of the illness, treatments, side effects, and restrictions.
2. The teacher will receive the medical team's assessment of the child's emotional state and his special needs, so that she can be helpful to this child.
3. With the parents' and the child's permission, the teacher can be encouraged to discuss with the class the nature of the child's illness and prep-

are them as to the possibility of visible side effects and temporary limitations.

4. Suggestions could be made to the teacher for class projects on subjects such as life, illness, and death. These projects would enable the ill child to join his peers in their efforts to understand and master these concepts without him being the focus of the discussion. Many of these tasks could effectively be handled by the school nurse.

As to programs for the CLTD child, therapeutic groups should be established. With the support of an experienced and warm professional using play, drawings, psycho-drama, music, etc., these children would have an opportunity to work through some of their fears, concerns, and anxieties which they may not be able to share in their healthy environment.

Loneliness is a state basic to human existence and even small success in alleviating its anguish, increases the quality of life.

RECOMMENDATION FOR FURTHER RESEARCH

This study succeeded in shedding some light on the phenomenon of loneliness in children with chronic life threatening illness. The research also demonstrated the difficulties and limitations in studying this phenomenon due

to the lack of conceptual clarity and an operational definition of loneliness. Therefore, the concept of loneliness must be operationally defined with care before any further research on loneliness in other groups of socially vulnerable children can be successfully conducted. The operational definition will then facilitate more rigorous research and the establishment of standardized tools for assessment and measurement of loneliness in childhood. There is also a need for a study to identify the major variables conducive to loneliness and their relative weight.

After the above described is accomplished, loneliness should be studied in other groups of children and adolescents at risk (e.g. children with chronic non-life threatening illnesses and physical handicaps, siblings of chronically ill or disabled children, children of divorce, battered children, and children of chronically ill or stigmatized parents).

Loneliness is a universal experience. But most of the research on the subject has focused on the experience of white middle class American subjects. This author suggests that the study of loneliness in children be broadened to other cultures with different rules related to the identified variables conducive to loneliness (e.g. communications, personal closeness, or dealing with death and afterlife). Cross cultural research on loneliness has the potential for shedding light upon the blind spots within each culture in

an area of knowledge so basic to human existence.

A vital avenue of research is the identification of strategies for intervention. Experimental research should then evaluate the effectiveness of these strategies in alleviating loneliness in children. For example, the impact of open discussions about death on the ill child's death anxiety and loneliness could be studied by an experimental research.

Until now, all researchers of children with CLTD, including this author, looked at certain psycho-social phenomena such as death anxiety, self concept, or loneliness in these children at given points of their illness trajectory. This was done regardless of the length of the illness or the age of the child at the time of diagnosis. These studies provided valuable primary knowledge. This author identified different levels of loneliness in children who were close to a crisis in their illness. This fact led her to believe that the time has come to move into longitudinal designs. This design should provide a picture on the development of the different phenomena from diagnosis throughout the illness trajectory. It is obvious that the chronological age of the child at the time of diagnosis should be a major criterion for sample selection. In large scale research, whenever feasible, studies should include different age groups over time. Such a cross sequential design can provide information on the development of the different psychological and social phenomena over time in relation to the length and

stages of the illness and the chronological age of the child.

SUMMARY

Loneliness in school age children with CLTD was studied by interviewing 20 children with CLTD and their mothers, and 20 healthy children and their mothers who served as a comparison group. The childrens' loneliness manifestations were assessed by loneliness responses to a set of projective pictures, by their choices for interaction on an interpersonal interaction scale (Who scale), and their choices of interpersonal distance on the Comfortable Interpersonal Distance scale. Using concepts from Sullivan's theory on interpersonal relations, Goffman's theory on stigma, and Rotter's social learning theory as the conceptual framework, the researcher hypothesized that children with CLTD would differ in their loneliness manifestations from the healthy children on the three measures.

The three hypotheses were partially supported. Children with CLTD responded with more aloneness subcategory loneliness themes, preferred fewer children for interaction and chose more adults for interaction in the "public domain" situations, and placed one friend at a further distance than did healthy children. The children with CLTD did not differ from the healthy children on the rest of the loneliness themes nor the placement of other figures. In addition, parents' and medical personnel's strategies to handle the

problems of communication with the child, the child's differentness, and the child's death anxiety (variables identified as conducive to loneliness in childhood) were assessed from the maternal interview.

All parents and medical personnel adopted the open approach to communication, both about the illness trajectory and death. Some parents adopted a religious approach for explaining death and especially life after death. Most parents were very creative in their "normalizing tactics".

Of the 20 children with CLTD, 11 (55 percent) were rated as having higher levels of loneliness than the rest of the ill group. Variables associated with higher levels of loneliness were identified: the child was within four months of a crisis in his illness; and/or received detailed descriptions on being "happy, but very alone" in heaven; and/or suffered from visible side effects of illness and treatment at the time of the interview. Several implications for practice were derived from the study: the need to educate health care professionals so that they can guide parents and educate the general public, especially school teachers, as to the occurrence, origins, and manifestations of loneliness in CLTD children. Programs especially designed to alleviate loneliness in children with CLTD should be developed. In the area of research there is a great need to arrive at operational definitions of loneliness, establish valid and reliable tools to assess loneliness, and design and evaluate

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APPENDIX 1
THE WHO SCALE

THE WHO SCALE

Code Number: _____

Birth Date: _____

Grade: _____

Siblings: 1. Age _____ Sex _____

2. Age _____ Sex _____

3. Age _____ Sex _____

Interview Date: _____

Dear friend:

This is a game about who you share things with, things you do, see, or think about. There are 17 sentences describing things different kids like to share with different people. I shall read these sentences to you and ask you to pick your choice of "what would you like to share with whom?" All choices are right.

Thank you!

Father	Mother	Only Me	Brother or Sister	Friend	Someone Else

1. You can invite anyone you wish to your birthday party; you would invite....
2. If you were on a deserted island, who would you like to be with you?
3. You are worried about something. You would tell your worries to...
4. You organize a team. Who do you want to be on it?
5. You are in a boat on a lake. Who would you like to be with you?
6. You are afraid to go to the hospital. Who would you tell?
7. You are putting on a play. Who would you like to play the part of a true friend?

Father	Mother	Only Me	Brother or Sister	Friend	Someone Else

8. You are alone in a room. Who would you like to join you?
9. You were frightened the last time you had to get a shot. Who would you tell?
10. You take part in a big project. Who do you want to be your partner?
11. You are going to be a pilot of a rocket to the moon. Who would you take with you?
12. You feel lonely. Who do you tell?
13. You are in a party. Who would you like to sit next to you?
14. You are in the yard by yourself. Who would you like to join you?

15. You feel ashamed. Who do you tell?
16. Something made you cry. Who do you tell?
17. You fell great. Who do you tell?

TOTAL

Father	Mother	Only Me	Brother or Sister	Friend	Someone Else

Child known as:

very sociable, outgoing
somewhat reserved
lonely

Informant:

Adult	Child	
AF =	CHF =	OM =
AO =	CHO =	
Group I	A =	OM =
Group II	A =	OM =
Group III	A =	OM =

APPENDIX 2
THE WHO SCALE

THE WHO SCALE

Dear friend:

Please read the below sentences carefully. Pick your choice from the columns on the right side of the page. Make an "X" in the column that fits your choice. You can only choose one answer. All answers are right. Thank you!

1. You can invite anyone you wish to your birthday party; you would invite...
2. If you were on a deserted island, who would you like to be with you?
3. You are worried about something; you would tell your worries to...
4. Something exciting happened in school; with whom would you share it?

Father	Mother	No One	Brother or Sister	Friend	Someone Else

Father	Mother	No One	Brother or Sister	Friend	Someone Else

5. You like to watch TV.
With whom to do you watch?
6. In your book there is a
great joke; to whom would
you tell it?
7. You take part in a school
performance; who would
you invite to watch the
show?
8. You are afraid to go to
the hospital; who would
you tell?
9. During the last medical
check-up, the doctor said
that you are very brave;
with whom would you share
this information?
10. You had a good dream; who
would you tell it?
11. You are in bed; you think
about....

Father	Mother	No One	Brother or Sister	Friend	Someone Else

12. You didn't take your medicine; who would you tell?
13. You built a little house in the woods; who would you invite to come and visit?
14. You do not like one of the kids in your class; you could complain to...
15. You won a school competition; who would you tell?
16. You look outside your window; who would you like to see passing by?
17. You like your teacher; who would you tell?
18. You are in a boat on a lake; who is with you?
19. You like one of the kids in your class; who would you tell?

Father	Mother	No One	Brother or Sister	Friend	Someone Else

20. You would like to be surprised by...
21. The nurse at the clinic said something about your condition which you didn't understand; who would you ask for an explanation?
22. You want to buy your mother a special gift and you don't know what to buy; who would you consult?
23. While waiting in the clinic hallway you saw a little kid crying; who would you tell?
24. You would like to be invited to go out by...
25. You had a bad dream; who would you tell?
26. You have a lovely picture book; with whom would you share it?

Father	Mother	No One	Brother Or Sister	Friend	Someone Else

27. A friend whom you met in the hospital wrote you a letter. With whom would you share the letter?
28. You go fishing; who would you take along?
29. You would like to surprise your...
30. The doctor says you don't need anymore medicine; who would you tell?
31. You go for a pizza; who would you like to join you?
32. You are drawing a picture of a person; who will be in it?
33. You got a big cake; who would you share it with?
34. You feel lonely; who would you tell?

Father	Mother	No One	Brother Or Sister	Friend	Someone Else

35. You are going to be a pilot of a rocket to the moon. Who would you take with you?

36. You are in the hospital for a day; who would you like to come visit you?

37. You were frightened when you had to get a shot; who would you tell?

38. You write a story about your best friend. You write about...

39. You are in an ice cream parlor. Who is with you?

40. You got chosen for the class team; who would you tell?

41. You know that you have gained weight and your clothes don't fit. With whom would you discuss it?

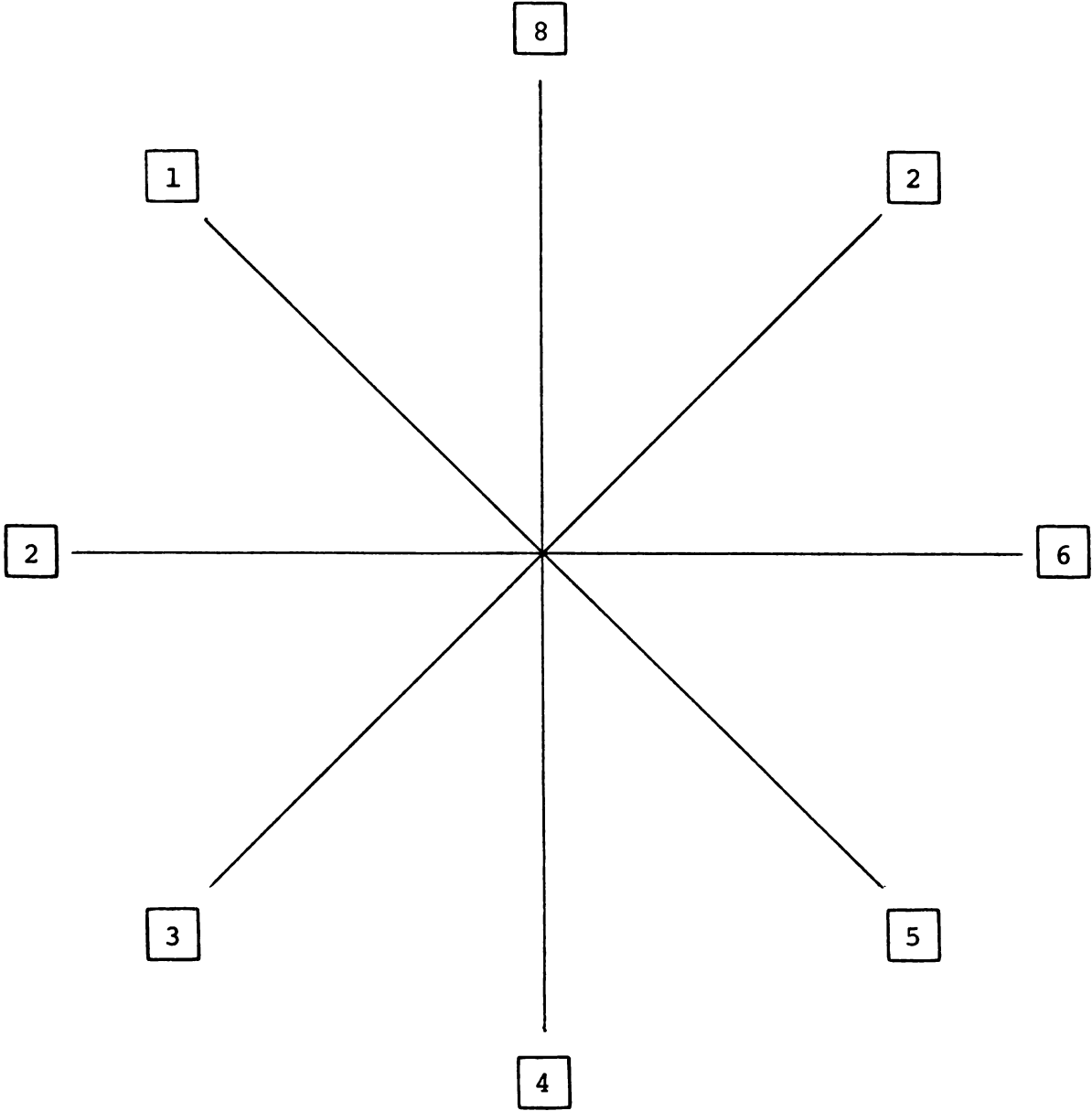
42. You are in the yard playing ball; who would you like to play with?
43. You don't feel well and can't do your homework; who would you tell?
44. Your grandparents want to take your picture; who would you like to be in the picture with you?
45. You didn't get chosen for the class team; who would you tell?
46. You just discovered a great game; who would you like to play it with?

Father	Mother	No One	Brother or Sister	Friend	Someone Else

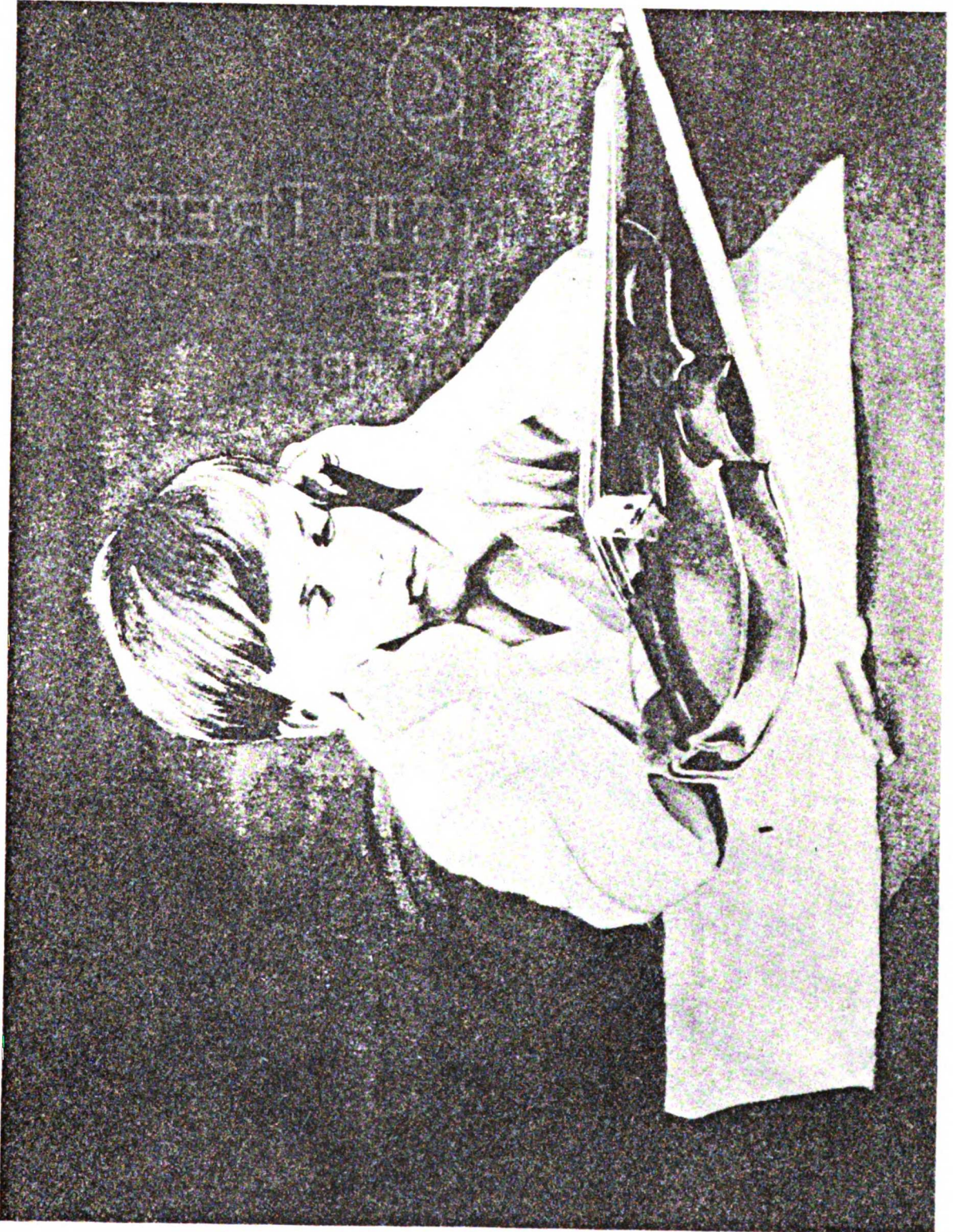
APPENDIX 3

CODE NUMBER:

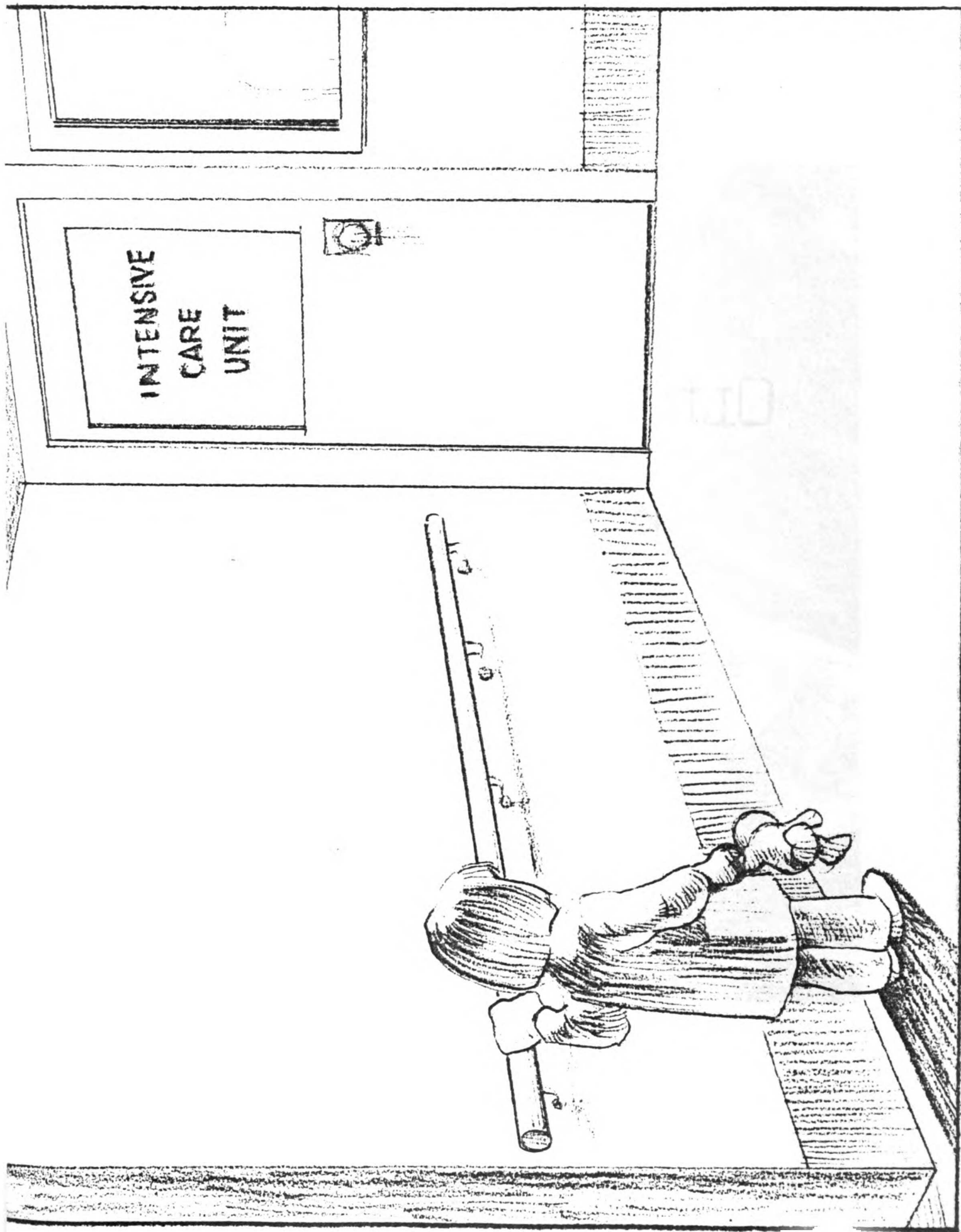
DATE:



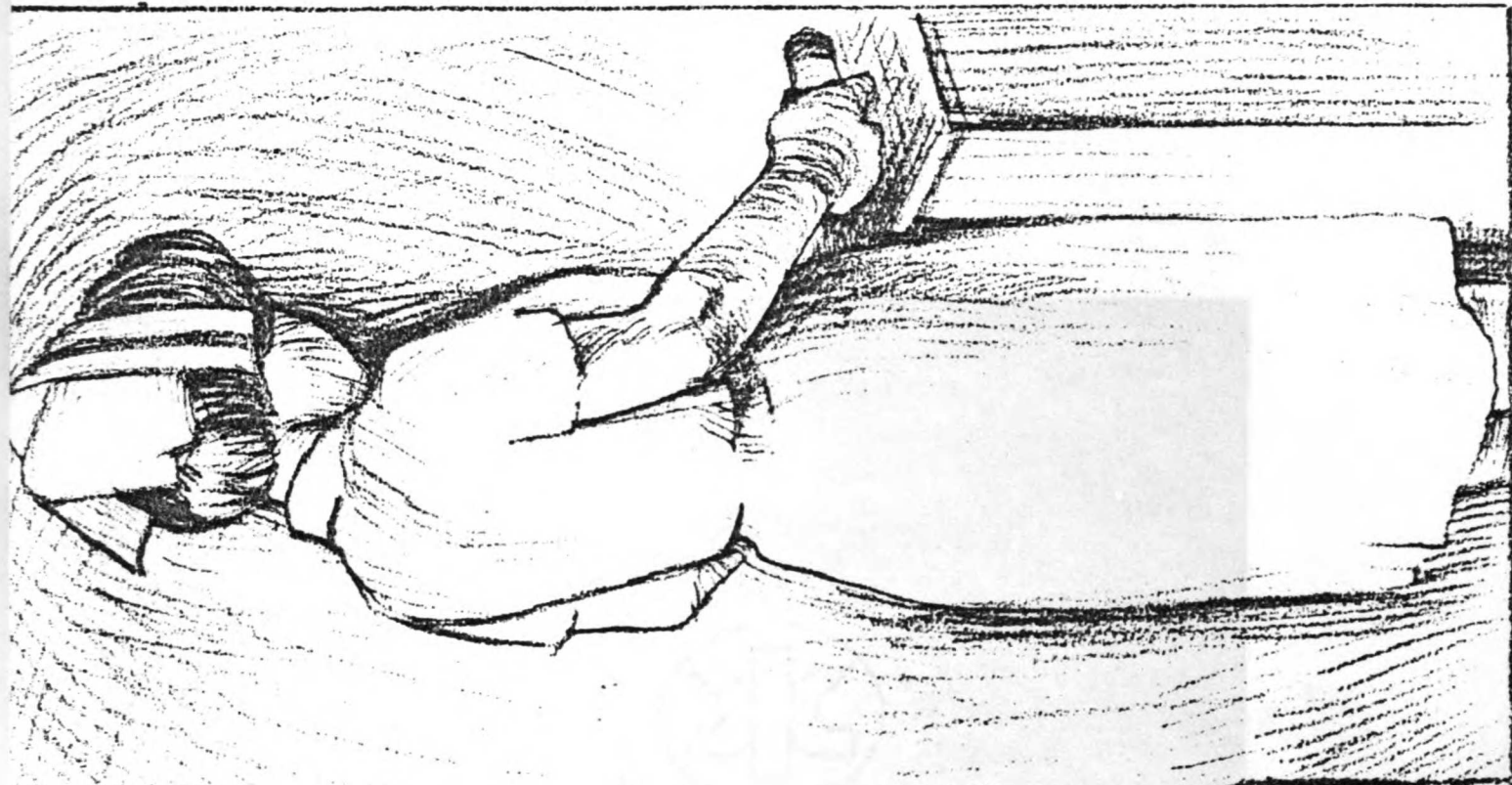
APPENDIX 4
PROJECTIVE PICTURES

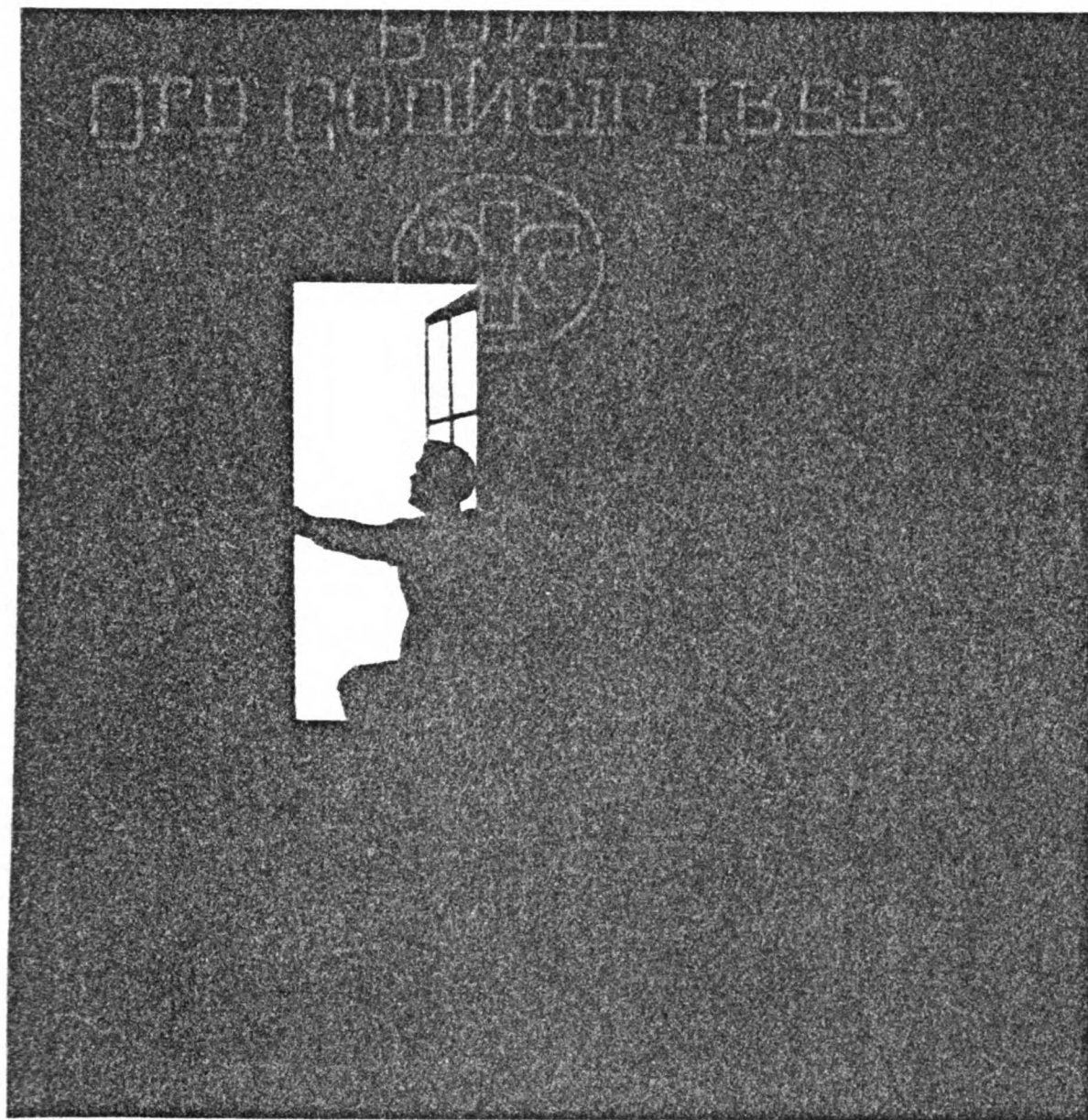






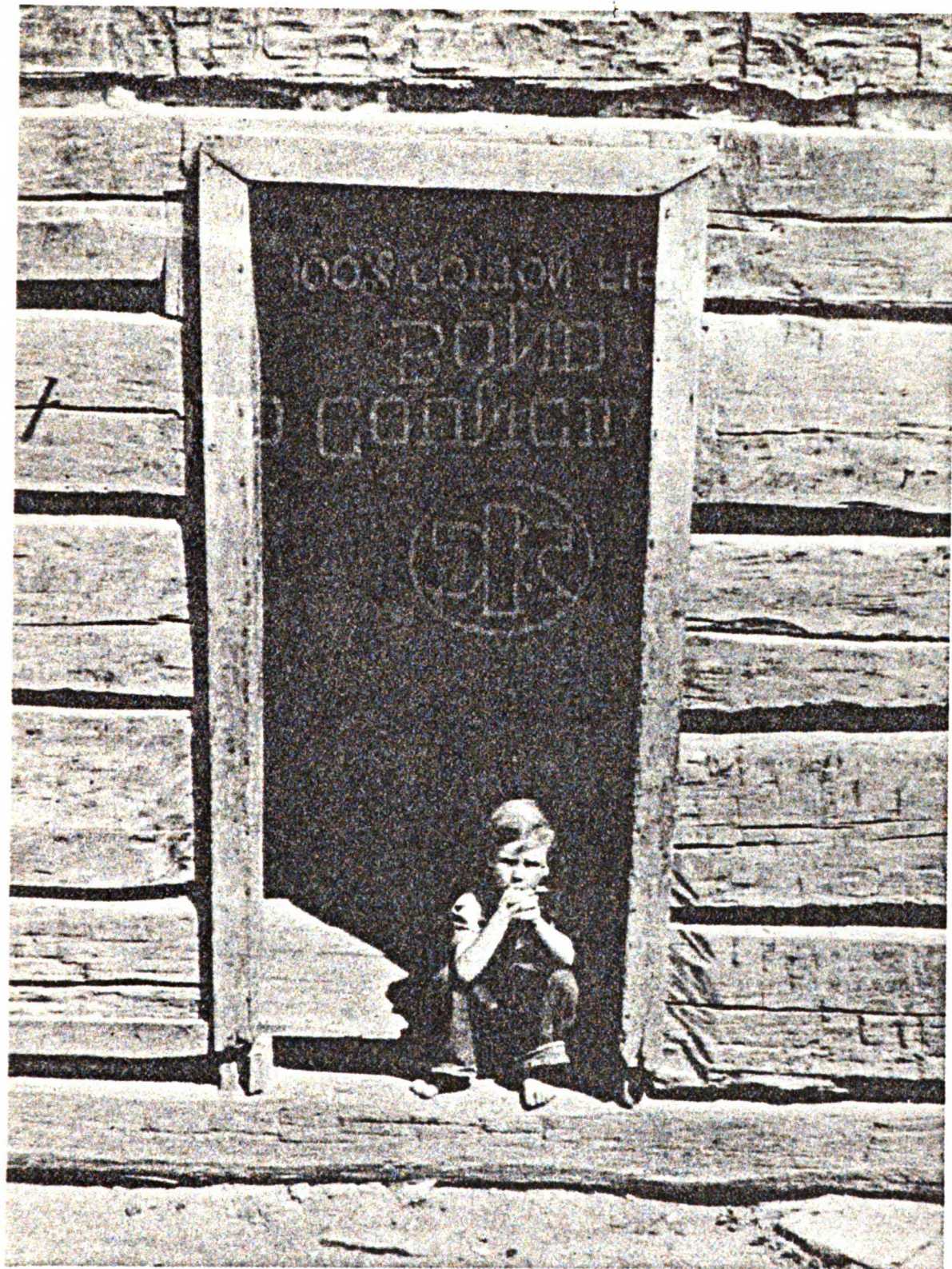












APPENDIX 5

INSTRUCTIONS TO CHILD ON PROJECTIVE PICTURES

INSTRUCTIONS TO CHILD ON PROJECTIVE PICTURES

The following instructions were given to the child:

"Please tell me a story about each picture that I will show you. Make it as interesting and exciting as you can. It can be any kind of story you want to tell. There are no right or wrong stories. Tell me what you think is happening in the picture; what do you think happened before? What do you suppose the people are thinking or feeling and how do you think the story will end?"

If a child needed encouragement to continue a story, the question, "Then what?" was asked, or the researcher assured the child that he "was doing a good job". When the child described events of illness but did not volunteer spontaneously statements about the nature of the illness, the question, "What do you think is wrong with the child?" was asked.

APPENDIX 6A
SCORING SCHEME

CODE NUMBER:

FORMS	UNRELATED		REJECTED	T H E M E S				
	Affect			Loneli- tion	Separa- tion	Death Anxiety	Threats to Body Integrity	Suicide
	+	-						
FORM A								
FORM B (Main actor)								
FORM B (Sec actor)								
FORM C								
FORM D (Main actor)								
FORM D (Sec actor)								
FORM E (Main actor)								
FORM E (Sec actor)								
FORM F								
FORM G (Main actor)								
FORM G (Sec actor)								
FORM H								
FORM I								
TOTAL								

FORMS	O U T C O M E			
	Positive	Neutral + + - -	Negative	I Don't Know
FORM A				
FORM B (Main actor)				
FORM B (Sec actor)				
FORM C				
FORM D (Main actor)				
FORM D (Sec actor)				
FORM E (Main actor)				
FORM E (Sec actor)				
FORM F				
FORM G (Main actor)				
FORM G (Sec actor)				
FORM H				
FORM I				
TOTAL				

APPENDIX 6B

PROJECTIVE PICTURES: CODING DOCUMENT

PROJECTIVE PICTURES: CODING DOCUMENT

DIRECTIONS

1. The stories will be checked for main themes of: loneliness, separation, death anxiety, threats to body integrity, and suicide.
2. A story that does not contain any of the above themes will be scored as unrelated and will not be analyzed any further.
3. A picture would be scored as rejected when the response from the child is "I don't have a story to this one" or "I don't know".
4. Each story will be scored only once for its main theme.
5. The general affect that accompanied the theme and the theme's outcome will be also recorded.

THEMES

The narrator of the story states directly or indirectly that:

1. Loneliness: The actor/s in the story was/is aware of the feeling of being apart from others, unrelated to others, different from others.

2. Separation: The actor/s in the story was/is about to be left behind by another person's departure (going away, death). The actor/s was/is leaving someone else behind by departure, going away.
3. Death Anxiety: The actor/s in the story was/is dying or is under the threat of death in the future.
4. Threats to Body Integrity: The actor/s in the story was/is sick, hurt, in a need for medical care, or under the threat of bodily intrusion.
5. Suicide: The actor/s in the story was/is taking an action that might be dangerous to his well being (or is thinking about it).

AFFECT

1. Positive Affect (main actor): There is a statement about the main actor experiencing feelings of happiness, satisfaction, worthiness.
2. Negative Affect (main actor): There is a statement about the main actor experiencing feelings of sadness, fear, worry, sickness, anger, frustration, disgust.
3. Positive Affect (others): There is a statement about others experiencing feelings of happiness, satisfaction, worthiness.
4. Negative Affect (others): As above.
5. I Don't Know (others): There is a statement "I don't know" about affect.

OUTCOME

The outcome of the theme is:

1. Positive: There is a statement about a change to the positive direction - sick to well, sad to happy.
2. Neutral: No change.
 - a. Negative remained negative, sad - sad.
 - b. Positive remained positive, happy - happy.
3. Negative: There is a statement about a change to the negative direction - sick to dying, happy to sadness.
4. I Don't Know: There is a statement "I don't know" about outcome.

APPENDIX 7

INTER-RATER RELIABILITY OF SCORING RESPONSES TO PROJECTIVE PICTURES

INTER-RATER RELIABILITY OF SCORING
RESPONSES TO PROJECTIVE PICTURES

Eight protocols were coded by a second coder. The following are percentages of agreement between the two coders.

Case No.	Themes	Affect	Outcome
2	100%	100%	100%
7	90%	60%	70%
12	100%	100%	75%
19	100%	100%	100%
24	86%	100%	86%
29	100%	100%	100%
34	100%	86%	100%
39	100%	100%	100%
Average Percentage Agreement Between Two Coders	97%	93%	97%

APPENDIX 8
MATERNAL INTERVIEW SCHEDULE

MATERNAL INTERVIEW SCHEDULE

Subject Number:

Date of Interview:

Child's Sex: M F

Child: h s

Child's Age:

Child's Birthdate:

Diagnosis:

BACKGROUND INFORMATION

- 1a. First, I would like to get a picture of the family.
How many children do you have?

1 2 3 4 5 6 7 or more

- 1b. How old are they? Could you start with the oldest and tell me the age of each one and if they are a girl or a boy?

1 _____

2 _____

3 _____

4 _____

5 _____

6 _____

7 _____

- 1c. Who lives with you and with x in the same household?

- 2a. Has x been with you all his(her) life, or have you been separated from him(her) at any time other than hospitalization?

1 separated

2 never separated (skip to question 3)

2b. How many times were you separated?

2c. How long were you separated the longest time?

_____ years _____ months _____ days

2d. How old was x then?

3a. Has x been with his(her) father all his life, or have they been separated at any time, other than x's hospitalization?

1 Separated

2 Never separated (skip to question 4)

3b. How many times were they separated?

3c. How long were they separated the longest time?

_____ years _____ months _____ days

3d. How old was x then?

3e. What is your marital status?

1 Single

2 Married

3 Widowed

4 Divorced

5 Separated

3f. (If x does not live with father in same household) How often does x see his(her) father? For how long?

MOTHER-CHILD RELATIONSHIP

4. I would like to get to know x a bit better. Tell me what kind of a child he(she) is; what will describe him(her) best?
- 5*. How was he(she) when he(she) was _____ (a year prior to diagnosis)?
- 6a. I am wondering if you could tell me more about the things you and x do together?
- 6b. How much attention does x seem to want from you?
- 1 Very much
 - 2 Moderate
 - 3 Very little
- 6c. Does x ever have times when he(she) hangs on to your skirts?
- 1 Quite often
 - 2 Sometimes
 - 3 Almost never
- 6d. How do you feel about it?
- 1 Very pleased
 - 2 Pleased
 - 3 Somewhat irritated
 - 4 Very irritated
- 6e. How do you generally react when x wants your attention when you are busy?
- 1 Very patiently
 - 2 Patiently
 - 3 Impatiently
 - 4 Very impatiently
 - 5 Ignore x

- 6f. Most children are irritating once in a while. In what way does x get on your nerves?
- 6g. Do you show your affection toward each other quite a bit, or are you fairly reserved people, you and x?
- | | |
|---------------------|-----------------|
| 1 Very affectionate | 3 Reserved |
| 2 Affectionate | 4 Very reserved |
- 6h. Do you ever find time to play with x just for your own pleasure? Tell me about that. (Who initiates?)
- 6i. How does x get along with his(her) father? Are they close?
- | | |
|--------------|--------------------|
| 1 Very close | 3 Somewhat distant |
| 2 Close | 4 Distant |
- 7a. How do you handle it when x behaves in ways that you don't like?
- 7b. How do you reward him(her) for good behavior and how do you punish x?
- 7c. Do you handle the other children in the same way?

CHILD AND SIBLINGS (If x does not have siblings, skip to question 9)

- 8a. Would you tell me how x and his(her) brother(s) and sister(s) get along together?
- 8b. What sort of things do they like to do together?
- 8c. All brothers and sisters quarrel of course. How is x about this?
- 8d. How do you feel about it, when they quarrel?

- 8e. Does x have a special relationship with any one of his(her) siblings?
- 8f. Do you discuss with your other children any problems that x might have, like illness, school, etc.?
- 8g*. Do your other children know about x's illness? What do they know?
- 8h. Have they ever expressed any feelings about it? Anger, jealousy, worries, or wishes?

CHILD AND FRIENDS

- 9a. Would you tell me something about how x and his friends get along together?
- 9b. What sort of things do they like to do together?
- 9c. How much of x's free time does he(she) spend with his friends?
- | | |
|--------------------|--------------------|
| 1 All the time | 3 Some of his time |
| 2 Most of the time | 4 Very little time |
- 9d. Does x seem to enjoy being with his(her) friends?
- | |
|--------------|
| 1 Very much |
| 2 Fair |
| 3 Not at all |
- 9e. Could you tell me who is x's best friend?
- 9f. Do you put any limits as to how much time x can play with friends? For what reasons?

- 9g. When was the last time that x spent a whole day outside the home with friends? When was the last time x stayed over night with friends?
- 9h. All friends quarrel of course. How is x about this?
- 9i. How do you feel about it, when they quarrel?
- 9j. There are times when children prefer to stay home rather than go out and play with their friends. Does this happen to x?
- | | |
|--------------|----------|
| 1 Very often | 3 Seldom |
| 2 Often | 4 Never |
- 9k. Does he(she) have special reasons to stay in?
- 9l*. Do you feel that x's friends treat x in any way different since he(she) got sick? **Because he(she) is sick?
- 9m. How would you describe your child?
- | |
|-------------------------------|
| 1 Very friendly and outgoing |
| 2 Friendly, somewhat reserved |
| 3 Lonely |
- 9n. When x is with other children playing,
- | |
|--|
| 1 x usually initiates games |
| 2 x sometimes initiates games |
| 3 x usually responds to other children's suggestions |
| 4 x usually watches from the side |
| 5 x usually plays alone |

FEARS

- 10a. Now I would like to talk a little about some of the things that frighten children. All children are afraid of some things, of course. Could you tell me about some of the things that frighten x?
- 10b. What seemed to frighten him(her) when he(she) was younger?
- 10c. How did you know that x was scared? How do you know now?
- 10d. How do you handle this with x?

CHILD AT SCHOOL

- 11a. Now I would like to know something about x's life at school. Has x attended
- 1 Nursery school
 - 2 Kindergarten
 - 3 School
- 11b. Is x attending school now?
- 1 Yes, what grade?
 - 2 No, for what reasons?
- 11c. Has x seemed to enjoy school?
- 1 Very much
 - 2 Moderate
 - 3 Not at all

11d*. What arrangements have been made for x to continue school-work since he(he) has been ill?

- | | |
|-------------------|--------------------|
| 1 No arrangements | 4 Peer teaching |
| 2 Parent teaching | 5 Special tutoring |
| 3 Sibs teaching | 6 Other |

11e*. Has it seemed to work out satisfactorily?

- 1 Yes
- 2 No

Why?

11f. How well does x do at school?

- | | |
|-------------|--------|
| 1 Excellent | 3 Well |
| 2 Very well | 4 Poor |

11g*. How well did x do before he(he) got sick?

- 1 Better
- 2 The same
- 3 Worse

11h*. How does x feel about it?

12a*. Does x's teacher know about x's illness?

- 1 Yes
- 2 No (skip to question 13)

12b*. Who told the teacher?

12c*. What arrangements has she(he) made to help x at school?

12d*. Did she ever discuss x's illness with him(her)?

12e*. Did she ever discuss x's illness with the other students? What did she tell them?

13a. What happens when x misses some days at school?

13b. Does x miss a lot of school? For what reason?

13c*. Some children feel that they have been singled out because of their illness. How does x feel about it?

13d. Does x usually take part in school trips?

13e. Does x take part in extra-curricular activities? Which?

13f*. What special arrangements have been made with the school due to x's illness (dietary, rest, gym, not feeling well . . .)?

13g. Does x ever talk about what he(she) would like to be when he(she) grows up?

13h. How do you feel about it?

ILLNESS EXPERIENCE

14a. Now I would like to change the subject and talk about x's experience with illness.

*First, can you tell me how long x has been ill?

14b. How long is it now since x's last hospitalization?

_____ years _____ months _____ days

14c. How long is it since his(her) last visit to the clinic?

_____ months _____ weeks _____ days

- 14d. How many times has x been hospitalized?
- 14e. When and for what?
- 15a. Parents prepare their children for coming to the clinic in different ways. Could you tell me what you do?
- 15b. Almost all children worry some about coming to the clinic even with the best preparation. Does x give any indication about the particular things that worry him(her)?
- 16a. Some parents feel that children should be "in the know" about their illness, and others feel that children should be spared this knowledge. How do you feel about this?
- 1 Child should be told the whole truth
 - 2 Child should be told only when he(she) asks, and then the whole truth
 - 3 Child should be spared from some parts of the truth
 - 4 Child should be told as little as possible
- 16b. How do x's doctor and nurse feel about this?
- 16c*. What does x know about his(her) illness?
- 1 The diagnosis and prognosis
 - 2 The diagnosis, but no prognosis
 - 3 Version close to diagnosis, no prognosis
 - 4 False diagnosis, false prognosis
- 16d*. Can you tell me (in your child's words) how he(she) explains his illness and treatments to others?

- 16e. Does he(she) ask you any specific questions about it?
- 1 Asks
 - 2 Doesn't ask (skip to question 17)
- 16f. How do you handle this with x?
- 1 Answer the whole truth to the best of your knowledge
 - 2 Answer part of the truth (what do you leave out?)
 - 3 Give a false answer (What?)
 - 4 Change the subject
 - 5 Not answer
- 16g. Does x seem to ask these questions at different times?
- 16h. Has this changed any during his(her) illness?
- 16i. Is there anyone else he(she) asks questions or discusses the illness with? (What about x's doctor and nurse?)
17. Many children x's age have questions or fears about death. What about x?
- 18a. Could you tell me about x's mood generally and what he(she) seems to be thinking about?
- 18b*. Has this changed any since he(she) fell ill?
- 19a. I would like to know something about the things x likes to do. What are the kinds of things that seem to interest x most?
- 19b*. Are there things he(she) likes to do and cannot do because of the disease?

19c. Did x watch any TV shows dealing with sick children ("Eric", "Something for Joey")? What was his(her) reaction?

19d*. What do you think would have been different in x's life had he(she) not been sick?

COURSE OF ILLNESS*

20a. Different children experience illness in different ways. How sick was x at times?

1 Very sick

2 Quite sick

3 Mild

20b. Has your child experienced any side effects from the treatments (like losing hair, feeling nauseous, or gaining weight)?

20c. Can you describe in what way?

20d. How did you handle it?

20e. How did your child react to it?

PREVIOUS EXPERIENCE WITH ILLNESS AND LOSS

21a. Some children have learned more about illness and loss than others. Some parents feel children should be spared these experiences. Others feel their children should learn about them. How do you feel about this?

21b. Has x had the experience of being around somebody seriously ill in the immediate family?

1 Yes (Who?)

2 No

21c. Has x lost someone he/she was very fond of?

1 Yes (Who?)

2 No

21d. Had x ever had a pet which died? What happened?

EXPERIENCE WITH RELATIVES AND FRIENDS

22a*. Who are the people in the extended family who know about the nature of x's illness?

22b*. How about friends?

22c. Does any of the relatives or friends have a very close relationship with x? Can you describe it?

23a*. When somebody in the family has been sick for a long time, it seems to be hardest for the mother, especially when there are other children to care for. How much of a problem has this been for you?

23b*. Has x needed a great deal of your time and attention?

23c. Do you have someone you can trust and confide in?

1 Yes (Who?)

2 No

23d. Is there someone who would give you any help in case you need it?

23e. Do you find yourself feeling lonely?

1 Quite often

2 Sometimes

3 Almost never

23f. When you have the time to do exactly as you please, what is your favorite thing to do?

When did you do this last?

24a*. What would you say was x's worst experience with the illness?

24b*. How about for you?

25*. Some people feel there are also positive aspects to the illness. How about you?

26. What are the (other)* health problems in your family?

This brings us pretty much to the end of the questions I wanted to discuss with you. There are just a few more general questions I have.

27a. How old are you? How old is x's father?

27b. How many years of school do you have?

1 0-4 years

2 5-8 years

3 High school incomplete

4 High school completed

5 Post high school, business, or trade school

6 1-3 years college

7 4 years hospital completed

8 Post graduate college

27b. (continued) And x's father?

- 1 0-4 years
- 2 5-8 years
- 3 High school incomplete
- 4 High school completed
- 5 Post high school, business, or trade school
- 6 1-3 years college
- 7 4 years hospital completed
- 8 Post graduate college

27c. What are your professions?

Mother

Father

27d. Do you work? What kind of work?

Mother

Father

27e. If working, how do you feel about your job?

- 1 Very satisfied 2 Fairly dissatisfied
- 2 Fairly satisfied 4 Very dissatisfied

27f. If not working, when was the last time you held a job?

- 1 Never worked 4 3-5 years ago
- 2 Less than one year 5 More than 5 years ago
ago
- 3 1-2 years

27g. Are you looking for a job?

CLOSURE*

I wonder now if there are any other things you feel are important for us to know in taking care of children with chronic life threatening diseases, or in being helpful to their parents. Please tell me anything which has been important for you, hard for you, or helpful to you since x became sick which we haven't touched upon.

Thank you!

APPENDIX 9
CONSENT TO ACT AS A RESEARCH SUBJECT

University of California
San Francisco

Project Identification
Number: _____

CONSENT TO ACT AS A RESEARCH SUBJECT

Ms. Tamar Krulik, a nurse working on her doctorate, has explained the study to me. She can be reached at 564-9387 if I have any further questions.

I understand that the purpose of this study is to learn how both well and chronically ill children socialize with their sibs, friends, and adults.

1. I hereby agree to have Tamar Krulik ask my child to see if he/she would like to perform the following game-like tasks.
 - a. Tell stories about nine pictures;
 - b. Make choices on an Interpersonal Interaction Scale (who they would like to play or share things with);
 - c. Tell how close he/she would like people to stand to him/her on a paper and pencil measure.
2. I understand that some children get upset by telling stories to projective pictures, or frustrated by being asked to perform tasks. Other children enjoy telling the stories and performing the tasks.
3. I understand that the completion of this task will take about 30 minutes and will be done in my home.
4. I understand that Tamar Krulik will interview me about how my child socializes with his/her sibs, friends, or adults, and what his/her experience with illness is.
5. I also understand, as Ms. Krulik and I talk during this interview, that some of the questions may touch upon painful experiences and may be upsetting to me. I understand that sharing my experience with Ms. Krulik may or may not provide any comfort to me directly.
6. The interview will take about 90 minutes and will be held in my home.

Consent to Act as a Research Subject
Page 2

7. I understand that there will be no direct benefit to me or my child. It is hoped that findings from this study may benefit other children and their families in the future.
8. Neither my child nor me is receiving any compensation for participation in this study.
9. I understand that all interviews will be tape-recorded, if I agree. If I do not agree, then written notes will be taken.
10. I understand that Ms. Krulik will take all the necessary precautions to protect my and my child's identity.
11. I understand that my child may decline to enter the study and both my child and I may withdraw from it at any time without jeopardy.

Child's name _____

Mother's name _____

Date _____

Father's name _____

Date _____

APPENDIX 10
SAMPLES OF ALONENESS THEMES

SAMPLES OF ALONENESS THEMES

IN RESPONSE TO FORM A

A 7.5-year-old boy: "He is thinking to make a toy and he is going to make a mouse hole. So that the mouse can come out there. He feels very sad because he doesn't have any friends to play with; he has no friends that live by him. The story will end that he will just have to not play with any friends.

A 7.8-year-old boy: "He's looking at his desk. He is sad because all his friends teased him and left."

IN RESPONSE TO FORM C

A 10-year-old boy: "I think the father is in there in the intensive care unit and she has nobody to turn to so she is just waiting alone in the hall and just thinking about her dad."

An eight-year-old boy: "She doesn't look like she wants to be there. She wants her mother. She feels terrible she's all alone. There's no one around; she is standing there in the hallway and just standing and standing."

IN RESPONSE TO FORM F

An eight-year-old boy: "This child is in trouble and his mother will leave him in that room alone. He can't even find his way out of it, I don't think. So dark.


A 7.9-year-old boy: "The man is going down in a dark cellar. He is probably feeling so lonely thinking that he doesn't want to be there. At the end he will not need to go down anymore."

IN RESPONSE TO FORM I

A 9.9-year-old girl: "He is just sitting there; he don't have no one to play with. He is sad watching all the kids playing and they didn't ask him to play; maybe they don't like him. Maybe he goes after this and play with them."

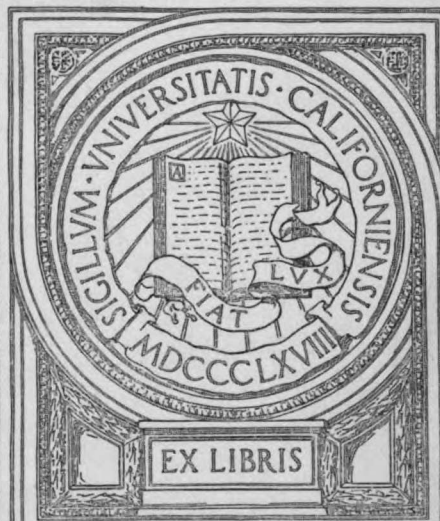
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