CHILDHOOD CANCER AND FAMILY LIFE:
CONCEPTUALIZING THE PERCEPTION OF THE SIBLING

by

KATHERINE E. McLAUGHLIN
B.Sc.N., University of Saskatchewan, 1959

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE STUDIES
(The School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA
October 1982
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Department of

The University of British Columbia
1956 Main Mall
Vancouver, Canada
V6T 1Y3

Date October 2/82
CONCEPTUALIZING THE PERCEPTION OF THE SIBLING

This study was designed to investigate the sibling's view of living in a family where another child was being treated for cancer. Specifically, the purpose of the study was to conceptualize the sibling's perception of day to day living when another child in the family is being treated for cancer.

Eight children belonging to two families participated in the study. Two conversation sessions were held with each child, either individually or in a group, during which the interviewer elicited descriptions of daily life. Using the constant comparative process associated with grounded theory, concepts identified as emerging from the data were the special status of the ill child, and a new normality. The process of redefining normality was identified as the central variable which accounted for the majority of the variation in behavior. This redefinition of normality appeared to make it possible for siblings to process problems in such a way as to make life viable (Glaser 1978, p. 57).

The results of this study support other research which indicates that the child's view of the world is different than the adult's. Relating the findings of this study to the literature has resulted in specific suggestions for nursing research for elucidating the sibling's view. The implications for nursing practice are discussed within the framework of Orem's general theory of nursing.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>vi</td>
</tr>
<tr>
<td><strong>CHAPTER I: INTRODUCTION</strong></td>
<td>1</td>
</tr>
<tr>
<td>Introduction to Problem and Purpose</td>
<td>1</td>
</tr>
<tr>
<td>Background to the Problem</td>
<td>4</td>
</tr>
<tr>
<td>Statement of Problem and Purpose</td>
<td>6</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>6</td>
</tr>
<tr>
<td>Significance of this Study for Nursing</td>
<td>7</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>8</td>
</tr>
<tr>
<td>Summary of the Introduction</td>
<td>8</td>
</tr>
<tr>
<td><strong>CHAPTER II: REVIEW OF THE LITERATURE</strong></td>
<td>9</td>
</tr>
<tr>
<td>Introduction</td>
<td>9</td>
</tr>
<tr>
<td>Siblings of Chronically Ill Children</td>
<td>10</td>
</tr>
<tr>
<td>Siblings</td>
<td>15</td>
</tr>
<tr>
<td>Methodology</td>
<td>18</td>
</tr>
<tr>
<td>Summary of the Literature Review</td>
<td>19</td>
</tr>
<tr>
<td><strong>CHAPTER III: METHODOLOGY</strong></td>
<td>21</td>
</tr>
<tr>
<td>Introduction</td>
<td>21</td>
</tr>
<tr>
<td>Obtaining the Sample</td>
<td>21</td>
</tr>
<tr>
<td>Criteria for Sample Selection and Underlying Rationales</td>
<td>23</td>
</tr>
<tr>
<td>Making Contact with the Siblings</td>
<td>26</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>27</td>
</tr>
<tr>
<td>A. The Parental Consent</td>
<td>28</td>
</tr>
<tr>
<td>B. Consent of the Siblings</td>
<td>29</td>
</tr>
<tr>
<td>C. The Parent as Gatekeeper</td>
<td>30</td>
</tr>
<tr>
<td>D. The Researcher's Responsibility to Consent Givers</td>
<td>30</td>
</tr>
<tr>
<td>The Interview as a Data Collection Tool in Qualitative Research with Children</td>
<td>31</td>
</tr>
<tr>
<td>Collecting the Data</td>
<td>32</td>
</tr>
<tr>
<td>The Circumstances of the Interviews</td>
<td>35</td>
</tr>
<tr>
<td>A. Interviews with the First Family</td>
<td>35</td>
</tr>
<tr>
<td>B. Interviews with the Second Family</td>
<td>37</td>
</tr>
<tr>
<td>C. Why a Second Interview with the Same Population was Conducted</td>
<td>40</td>
</tr>
<tr>
<td>Analysis of the Data</td>
<td>41</td>
</tr>
<tr>
<td>Summary</td>
<td>43</td>
</tr>
<tr>
<td><strong>CHAPTER IV:</strong> THE CONCEPTUALIZATION OF THE DATA</td>
<td>44</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>Introduction.</td>
<td>44</td>
</tr>
<tr>
<td>The Nature and Sources of Information</td>
<td>45</td>
</tr>
<tr>
<td>A. The Seriousness of the Illness.</td>
<td>45</td>
</tr>
<tr>
<td>B. Medication Taking</td>
<td>47</td>
</tr>
<tr>
<td>C. Diagnostic and Treatment Procedures</td>
<td>49</td>
</tr>
<tr>
<td>The Concepts and Their Indicators</td>
<td>52</td>
</tr>
<tr>
<td>A. Special Status for the Ill Child.</td>
<td>52</td>
</tr>
<tr>
<td>1. Creation of Special Status for the Ill Child by the Parent</td>
<td>52</td>
</tr>
<tr>
<td>2. Conferring of Special Status on the Ill Child by the Siblings</td>
<td>56</td>
</tr>
<tr>
<td>3. Siblings' Requirements for Outsiders to Confer Special Status on the Ill Child</td>
<td>59</td>
</tr>
<tr>
<td>4. Maintaining Special Status of the Ill Child</td>
<td>59</td>
</tr>
<tr>
<td>B. A New Normality</td>
<td>60</td>
</tr>
<tr>
<td>1. Changes in Responsibility</td>
<td>61</td>
</tr>
<tr>
<td>2. Concerns About the Ill Child</td>
<td>63</td>
</tr>
<tr>
<td>3. Stress Associated with Illness and Treatment Variables</td>
<td>65</td>
</tr>
<tr>
<td>4. Mortality of the Ill Child</td>
<td>69</td>
</tr>
<tr>
<td>5. What is Normal?</td>
<td>70</td>
</tr>
<tr>
<td>6. Why Redefine Normal</td>
<td>72</td>
</tr>
<tr>
<td>The Relationship Between the Concepts and the Proposal of a Core Variable</td>
<td>73</td>
</tr>
<tr>
<td>Summary</td>
<td>74</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CHAPTER V:</strong> DISCUSSION.</th>
<th>75</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction.</td>
<td>75</td>
</tr>
<tr>
<td>Comparing Themes Identified in the Literature to Themes Found in this Study.</td>
<td>75</td>
</tr>
<tr>
<td>A. Negative Feelings Such as Anger and Resentment.</td>
<td>76</td>
</tr>
<tr>
<td>B. Isolation and Deprivation</td>
<td>77</td>
</tr>
<tr>
<td>C. Change.</td>
<td>78</td>
</tr>
<tr>
<td>Comparing Concepts Identified in this Study to Similar concepts Discussed in the Literature.</td>
<td>80</td>
</tr>
<tr>
<td>A. Special Status of the Ill Child.</td>
<td>80</td>
</tr>
<tr>
<td>B. Redefining Normality.</td>
<td>81</td>
</tr>
<tr>
<td>Relating the Methodology to the Literature.</td>
<td>83</td>
</tr>
<tr>
<td>Summary of the Discussion</td>
<td>87</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CHAPTER VI:</strong> SUMMARY AND CONCLUSIONS</th>
<th>88</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of This Study.</td>
<td>88</td>
</tr>
<tr>
<td>Suggestions for Further Research.</td>
<td>89</td>
</tr>
<tr>
<td>Implications for Practice.</td>
<td>91</td>
</tr>
</tbody>
</table>
REFERENCES ................................................................. 93
APPENDICES ................................................................. 100
    A. Parent's Consent Form ............................................. 100
    B. Children's Consent Form ......................................... 102
    C. Interview Schedule ................................................ 103
ACKNOWLEDGEMENTS

I am deeply grateful to several people without whose participation and encouragement this thesis could not have been completed.

First of all I would like to thank the children who shared their experiences with me and their parents for encouraging them to do so.

I would like to thank my committee members, Helen Elfert and Virginia Hayes-Morris for their guidance and contribution in the research and writing of this thesis.

I appreciate the help of Dr. Mavis Teasdale who facilitated the process of obtaining a study population.

And finally, I owe a special thanks to Joe, Kevin, and Megan who have been supportive and accommodating throughout my graduate studies.
CHAPTER I: INTRODUCTION

INTRODUCTION TO PROBLEM AND PURPOSE

The change in the survival rates of children affected with cancer has resulted in the goal of a "cured" child. With the achievement of this goal a possibility, the social, psychological, and developmental requirements of the child assume the same degree of importance in the treatment schedule as physical well-being. Hopefully, the results of treatment will be a mentally healthy child functioning in an age appropriate manner (van Eys 1977).

In North America, society has conferred on the family much of the responsibility for helping the individual to meet his social, psychological, and developmental requirements. Where siblings are a component of the family system, sibling relationships and interactions have been identified as important variables in the development and socialization process (Schaveneveldt 1979). Nurses who view the family as a system indicate that an illness in one family member will affect members of the system in some way (Horton 1977). Understanding the impact of childhood cancer on the siblings thus assumes increasing importance in attempting to achieve the goal of a "cured" child.

Coddington (1971) identified serious illness of a brother or sister requiring hospitalization as a stressful life experience for the sibling. Within a system's context, because this kind of experience is stressful, understanding the impact of childhood cancer on siblings assumes a signi-
significant importance in attempting to achieve the goal of a cured child.

How siblings are affected by the presence of childhood cancer has been reported in only a limited fashion to date, and the literature relating to siblings of chronically ill children indicates a need for further study. Burton (1975) interviewed parents of chronically ill children who had well siblings living at home. The parents related their views of the effect of this situation on the siblings. They described feelings of jealousy of and resentment toward the ill child for the extra attention being given to him/her. Communication between well sibling and parent about the illness appeared to be limited.

Cairns, Clark, Smith and Lansky (1979); Lavigne and Ryan (1979); Gayton, Friedman, Tavormina and Tucker (1977); and Carandang (1979) have all studied sibling's reaction by assessing particular psychological variables. Gayton and colleagues suggest that the long-term effect on the sibling living with a child who is chronically ill is related to the success of the coping strategies of the sibling.

Inherent in the process of coping is the individual's perception of the problem (Murphy 1974; Mechanic 1974; Lazarus 1975). The sibling's perception of day to day living in a family when another child is being treated for cancer will influence how (s)he is affected. The research on siblings of pediatric cancer patients to date has concent-
treated on parents' reports and assessment of specific psychological variables. There appears to currently be a lack of research reported which focuses on the sibling's perception.

Developments in cognitive psychology have contributed to current views of perception. Bruner (1973) established through his research the importance of motivational interests, purposes, and expectations as determiners of perception. He demonstrated that there is not a simple correlation between external events and actions, but there is some mechanism or function of choice that directs behavior. Piaget (1969), in one of his many dissertations on perception, suggests that it is determined by a constructive problem-solving process. The individual is constantly accumulating information to build into the perception, thus, there is a developmental aspect also. Because the scope of the present study was limited, it was not possible to explore all of these aspects of perception in depth. However, the report of the findings of this study is an attempt to contribute additional data about sibling's perception of the specified illness experience.

Diers (1979) says that when there is a lack of information about a phenomenon, or when a researcher wishes to take a new look at a situation, a factor-searching study is appropriate. Glaser and Strauss (1967) have described a method of gathering and analyzing data in a factor-searching study whereby it is possible to conceptualize rather than describe a situation. The method involves constantly com-
paring, coding, and analyzing data. This method allows the researcher to generate theory or to "discover" theory. It is not a method for testing of theory but it is more specific than description of a situation. This study utilized this method to conceptualize the sibling's perception of day to day living when another child in the family was being treated for cancer.

BACKGROUND TO THE PROBLEM

In a review of the literature related to the role of nursing in pediatric oncology, this researcher found a significant number of studies and articles related to the response of the family to childhood cancer (Binger, Albin, Feurstein, Kushner, Z'oger, and Mikkelsen 1969; Lascari and Stehbens 1973; Pearse 1977; Embleton 1979). However, on closer examination the subjects constituting the "family" were the parents and ill child with the responses of siblings being presented not by themselves but by the parents. In the more recent literature there are reports of psychological testing of siblings with the study variables being decided by the investigator based on his or her perception of the effect of chronic illness on the siblings (Cairns et al 1979; Carandang 1977; Gayton et al 1977; Lavign et al 1979).

In existing literature that describes, but again not by the siblings themselves, working with families of pediatric cancer patients, there appears to have been little direct
contact between health professionals and the siblings other than on a social basis. Parents occasionally expressed concern regarding the siblings and these would be discussed, with interventions suggested. The parent thus seems to be very much the intermediary between siblings and health workers.

Lavigne (1980) found in a survey to which twenty pediatric cancer centers responded that six reported individual therapy was available for siblings, five reported siblings were rarely seen, and nine reported individual therapy was available as needed. Lavigne posed the question "Does our current level of knowledge indicate that more rigorous intervention is routinely needed for siblings of childhood cancer patients?" (p. 46). This investigator's review of the literature suggested that there is not enough information available at present to answer that question.

The child's reaction to, and interaction in, a situation is related to his/her perception of that situation and its requirements. Within a developmental paradigm, the child's view of the world is not the same as the adult's (Lerner 1976). The child's view must be studied in depth to determine if there is a need for more structured and systematic intervention with siblings of childhood cancer patients. This study was designed to explore one way of studying the child's view.
STATEMENT OF PROBLEM AND PURPOSE

The purpose of this study was to conceptualize the sibling's perception of day to day living when another child in the family is being treated for cancer.

The specific questions which the report of this study will address are:

1. What concepts which relate to the siblings perception can be derived from the sibling's description of the experience of day to day living when a child in the family is being treated for cancer?

2. What is the relationship between these concepts?

DEFINITION OF TERMS

The terms following are defined to assist in clarifying the purpose of the study and the problem statement.

Being treated for cancer: The child with cancer is currently receiving radiation therapy, taking chemotherapeutic medication, undergoing or scheduled to undergo a surgical procedure.

Concept: "Abstractions grounded in the data, but set off with specific definitions" (Diers 1979, p. 101).

Conceptualize: To identify concepts and their relationships.

Perception: The process by which we obtain, transform, organize, and structure information arising from the world in sense data or memory, and respond to that data in a selective and discriminative manner (adapted from Gibson 1969).
SIGNIFICANCE OF THIS STUDY FOR NURSING

Orem (1980) has stated in her general theory for nursing that a need for nursing exists when an individual is unable to meet his requirements for self-care. Underlying this is the premise that people have specialized capabilities conditioned by age, experience, and culture, which enable them to take self-care actions. From time to time, the requirements for self-care may exceed the capability of the individual. If the increased demand is health related, a nursing system may be required. One of the functions of the nursing system is the calculation of the therapeutic self-care demand. Conceptualization of the sibling's perception of day to day living when a child in the family is being treated for cancer will give guidance to the nursing profession in the calculation of the therapeutic self-care demand for that population. It would seem to be possible, using the constant comparative analysis method of Glaser and Strauss (1967), to generate theory which can be applied in calculating the therapeutic self-care demand for children whenever the reason for the increase in demand is substantively similar to those siblings which form the sample in the study.

Family theorists indicate that an illness in one family member will affect all members of the family in some way (Horton 1977). To understand why living with a child being treated for cancer is disturbing for some siblings and not for others, it is necessary to know more about how the
sibling views the situation. This information is essential for designing programs of anticipatory guidance for families of children with cancer.

LIMITATIONS OF THE STUDY

Limitations of the study arose from the limited number of experiences that were be sampled within the scope of this study.

Limitations also arose from data collection being limited to the interview and consequently to remembered experience rather than current experience. This issue is addressed in the discussion.

In the two families which composed the study sample, the ill child was the youngest child. If the position of the ill child in the sibling order is a significant factor in the sibling's perception of family experiences, this could be a limitation.

SUMMARY OF THE INTRODUCTION

It appeared that a study to conceptualize the sibling's perception of day to day living when a child in the family is being treated for cancer would be timely and that such a study could contribute to nursing research and to nursing practice.
CHAPTER II: REVIEW OF THE LITERATURE

INTRODUCTION

The purpose of the literature review in this study is twofold. The review of the literature demonstrates the need for a study about day to day living when another child in the family is being treated for cancer, undertaken from the point of view of the sibling's perception. It also identifies research and theoretical orientations which aid in conceptualizing that perception.

Health professionals speak of cancer as being a chronic although life-threatening illness with acute exacerbations. The literature referring specifically to siblings of children with cancer is very limited. Therefore, a portion of the literature referring to siblings of chronically ill children has been included in this literature review on the assumption that it will help to clarify the impact on the healthy siblings, of long-term illness of a child in the family. This literature review excludes those studies of siblings done following the death of the ill child. Death itself introduces a new set of experiences, emotions, and behaviors that alter the sibling's perception of the illness experience. Literature is reviewed which could be helpful relative to constructing a theory of sibling behavior. Finally, literature is reviewed which gives direction to the methodology to be employed for data collection and analysis.
SIBLINGS OF CHRONICALLY ILL CHILDREN

The study of specific psychological variables has been one way of gaining information about the effect of chronic childhood illness on siblings of the ill child. As part of a larger investigation of the psychosocial aspects of cystic fibrosis, data were collected comparing 23 children with cystic fibrosis and 26 siblings between the ages of 5 and 13 using the Piers Harris Self-Concept Scale, Missouri Children's Picture Series, and the Holtzman Inkblot Test (Gayton, Friedman, Tavormina & Tucker 1977). The total self-concept score for siblings on the Piers Harris Scale was higher than that reported by Piers for normal children. The results indicated no significant differences between the means of the patients' and siblings' scores on the first two tests, and personality functioning for both groups within normal limits on the inkblot test. This study does not support the researchers' hypotheses of an increased incidence of emotional disturbance in children with cystic fibrosis nor does it support a negative psychological impact on sibling development. In the discussion of their findings the authors do not negate the concept of chronic illness as a stressor but suggest that the utilization of coping devices may result in healthy adaptations for the ill child and members of his family. The author suggests it is possible that the instruments used were not adequate to measure the negative impact of the chronic illness.
A second study using the Piers Harris Scale along with the Bene-Anthony Family Relations Test and the Thematic Apperception Test was conducted in which children diagnosed as having cancer were compared with their siblings (Cairns, Clark, Smith and Lansky 1979). Forty-seven parents and 55 siblings comprising 27 patient-sibling pairs between 6 and 16 years of age were involved. No significant differences between patients and siblings were found on the Piers Harris Scale. Differences were found in 14 patient-sibling pairs on the Bene-Anthony Family Relations Test. Siblings viewed the mother as over-protective and over-indulgent. The authors suggest that this finding may be valid only during the time the patient is hospitalized. The findings also suggested male patients and female siblings did not feel other family members had good feelings toward them. Seventeen patients and 20 siblings took the Thematic Apperception Test. There were enough differences between the two groups that respondents could be identified on the basis of the TAT story. Siblings appeared to have a significant degree of anxiety, fear for their own health, social isolation, as well as sharing with the ill child a negative body image.

In the two preceding studies, the testing was carried out in a clinic or hospital setting. Cairns et al suggests this could serve to increase the anxiety of the siblings relative to their ultimate mortality and susceptibility to illness.
Carandang (1977) investigated the effects of the stress of sibling illness on cognitive formulations about illness by a non-ill sibling. Her sample consisted of 72 children aged 6½ to 15 years and their mothers. They were divided into two groups of 36 children each, one-half had healthy siblings. The two groups were matched in terms of sex, Piagetian cognitive level, grade level and socio-economic status. All subjects were interviewed in their own homes with the task of the interview being to measure the level of illness understanding, stress, and frequency of discussion of illness. The author found that the more worry the mother expressed, the less sophistication a child showed in illness conceptualization and understanding. Also, the less frequently the family discussed illness, the more worry the child expressed.

In an attempt to get an overall view of the effect of long-term illness on the healthy siblings, Taylor (1980) interviewed 25 siblings of children with asthma, congenital heart disease, and cystic fibrosis ranging in age from 7 to 12 years eliciting descriptions of the effects of long-term childhood illness from them. Five aspects of the ill child that affected the well-sibling were identified. These included play and socialization, medical care and treatment, parent-ill child relationships, physical condition, and child's reaction to his illness, with the first three having the greatest effect. She did not include siblings of chil-
dren with cancer in her sample nor did she attempt to correlate findings with disease entity.

Lavigne and Ryan (1979), in examining discrepancies in findings between studies done by Gath (1972) and Tew and Laurence (1973), thought that perhaps the discrepancies in findings could be specific to each disease process. They designed a study which looked at incidence of sibling adjustment problems in groups composed of 37 siblings of children having plastic surgery, 57 siblings of children with congenital heart disease, and 62 siblings of hematology clinic patients (all but two patients had leukemia or other cancerous conditions). The Louisville Behavior Checklist was completed by parents who rated the patient's youngest and oldest sibling between the ages of 3 and 13 years. In the control group, parents were asked to rate the youngest and oldest sibling between 3 and 13 of a specified child. They found that analysis of covariance indicated no differences between illness groups and healthy controls on aggression, hyperactivity, or learning disability scales. However, on the social withdrawal scale, the siblings of the chronically ill children as a total group were significantly more withdrawn than siblings of healthy children, and within the former group siblings of plastic surgery children were most withdrawn. This pattern was repeated on the scale measuring sibling's irritability.

When the siblings of hematology patients were compared directly with healthy siblings they were shown as a group to have a tendency to be more withdrawn, inhibited or fearful,
and irritable, but not more learning disabled or aggressive. Male siblings of the hematology patients between the ages of 7 and 13 appeared to have more adjustment problems than females in the same age group. However, the study did point out that not all and probably not most of the siblings of hematology patients were having troubles coping. Rather, more siblings of plastic surgery patients were having problems. Is it possible that there is a significant factor relative to the illness that is affecting the siblings perception of the illness experience and consequently his coping capacity? This study while giving additional data about a population at risk does not address the experience from the point of view of the sibling's perception nor attempt to give any information about his attitudes to or understanding about the illness experience.

Iles (1979) conducted a pilot study interviewing siblings of five children aged 9 to 11 years whose brother or sister had cancer, each in a different state of the illness. Although the stages were defined as onset of treatment, first remission, first exacerbation, subsequent remission, and terminal status, the results are not reported with reference to the stage of the illness. However, change appears to be the most consistent finding with siblings identifying change in interpersonal relationships and the external environment.

The review of the literature as outlined above would indicate that siblings are definitely affected by the pres-
ence of pediatric cancer. How they are affected, and the long-term ramifications are less clear. The siblings definition of the experience has not been addressed in any of the studies. The literature reviewed contains some direction to aspects of the illness experience which may be relevant to sibling perception.

SIBLINGS

Schvaneveldt and Ihinger (1979) state:

It is reasonable to assume that the experiences children share with siblings have a profound influence on their socialization and personality development processes (p. 453).

Although this must be true, there is little research available about sibling relationships which will help in the understanding of the impact on a sibling of living with a brother or sister who is being treated for cancer.

There is a large body of research attempting to establish a relationship between ordinal position of siblings and a variety of variables. Schvaneveldt and Ihinger (1979) conducted a critical review of the literature for the purpose of theory construction related to siblings. They concluded as a part of this review:

It is too simplistic to hope that a structural variable such as ordinal position could possibly have effects on such a diverse set of child and adult behaviors (p. 456).
They have identified sample problems, lack of theoretical framework, lack of theoretical interpretation, and measurement problems as being factors in making this body of research less useful than it could be in contributing to constructing theoretical formulations about sibling relationships.

They propose the following assumptions which this investigator finds useful in viewing the sibling group within the family:

1. The family can be viewed as having three separate subsystems: spousal, parental-child, and sibling-sibling. All of these subsystems function as semiclosed systems within the family group.

2. Siblings are both recipients and instigators of socialization. Family interaction is a dynamic arena in which spouses affect each other, parents affect children, children affect parents, and siblings affect each other.

3. Sibling interaction is a continuous developmental process not limited to the early "critical" years.

4. The nature of family composition and interaction are determining factors in personality development and social behaviors of members.

5. Sibling groups have distinctive group properties and characteristics as do other small groups.

Addressing sibling interaction more specifically, Bank and Kahn (1975) have, on the basis of a literature review and their own clinical experience, suggested ways of conceptualizing sibling influence. They have identified the
following functions that siblings serve for one another:

1. Identification and differentiation - these processes provide for vicarious learning and living with a child determining through another's behavior ways in which (s)he would or would not like to be like a sibling.

2. Mutual regulation - this allows the opportunity of trying new behaviors and roles with the regulatory process taking place in the relationship between equals.

3. Direct services - these may occur inside or outside of the family and include such things as lending money, teaching skills, manipulating friendships for each other, acting as buffers for each other and so on.

4. Dealing with parents - including such things as balancing the power of parents, joining together to negotiate, maintaining or betraying confidences about each other's behavior, mediating between one another and between themselves and their parents, mediating between the outside world and their parents, mediating between their parents, and finally pioneering which occurs when one sibling does something new, thereby giving other siblings permission to do the same thing (pp. 319 - 324).

It would appear that relationships which siblings have with other family members are both structural and functional. Structural relationships occur because of physical proximity of a sibling to a sibling, or a sibling to a parent. Functional relationships are related to maintaining or promoting some type of behavioral interaction with another family member. The family member may or may not be physically in the presence of the sibling for a functional relationship to be occurring. These relationships have as one of their goals achieving one or more of the functions siblings serve for one another as identified above.
Following through on the assumptions of Schvaneveldt and Ihinger, the above interactions are by and large habitual both at the individual and at the group level. If, however, some environmental change occurs, the habitual ways of behaving and relating may or may not be effective. The individual siblings will be affected, and the sibling group will be affected. The ramifications of this are that the communication network, power, affective relationships, and clique alignments can all be altered. How they will be altered will depend on the world view of the individual.

METHODOLOGY

Diers (1979) suggests problems similar to the one which the study being reported poses - conceptualizing the sibling's perception of day to day living when another child in the family is being treated for cancer - can be approached from the perspective of a factor-searching study. Factor searching studies are appropriate for categorizing, classifying or conceptualizing situations. In the study being reported, the task is conceptualizing. Diers further states the method introduced by Glaser and Strauss as discovery of grounded theory has as its goal conceptualization of an event or situation as opposed to describing it. This is done by deriving abstractions or concepts from the data collected (Glaser and Strauss 1967; Glaser 1978).
This method was first detailed by Glaser and Strauss (1967) in the report of their study of death and dying with the focus on the experience of dying in hospitals. Since then others have used the method to better understand a situation or experience in conceptual terms. It was used by Wilson (1977) as she attempted to gain understanding of the existence of a radical institution in a conservative society. Stern (1980) described the use she made of this method to understand how stepfathers were incorporated into a family. Glaser (1978) elaborated on the method giving more specific procedures for researchers to follow.

The reports of the use of this method indicate that it is process oriented being concerned with the movement of life through time as opposed to being concerned with such factors as social class, sex, status, group, organization and so on. Glaser (1978) identified two basic types of processes which he termed social-psychological and social-structural. Examples of the former include socialization, becoming, normalizing and examples of the latter are bureaucratization, codification and formalization.

SUMMARY OF THE LITERATURE REVIEW

The literature indicates that siblings of children being treated for cancer are affected by the illness experience. It is less clear whether the effects are positive or negative, transient or permanent. The sibling's per-
ception of the experience is not addressed other than in one pilot study which indicated change was the dominant factor identified by the siblings.

The constant comparative method of Glaser and Strauss appears to be appropriate to accomplish the purpose of this study which is to conceptualize the sibling's perception of the experience of day to day living when a child in the family is being treated for cancer, by seeking answers to the questions posed:

1. What concepts which relate to the siblings perception, can be derived from the siblings description of the experience of day to day living when a child in the family is being treated for cancer?

2. What is the relationship between these concepts?

The precise methodology employed in the conduct of the study is described in Chapter III.
CHAPTER III: METHODOLOGY

INTRODUCTION

The purpose of this study was to conceptualize sibling's perception of day to day living when another child in the family is being treated for cancer. As described in Chapter II, a review of the literature indicated the qualitative paradigm would be appropriate for the conduct of such a study. This chapter details how the research data were obtained including the selection of participants, contacting the families, making contact with the siblings, ethical considerations, the data collection tool, collecting the data, and the analysis of the data.

OBTAINING THE SAMPLE

The researcher found obtaining a sample for a study in which the population was composed of siblings of children with cancer to be complex.

The process in this study was first to contact the Nursing Research Committee of the large general hospital where the oncology clinic was located for permission to discuss with the physician in charge of the clinic the possibility of conducting the study in question. This was done by submitting to the committee a written request and a copy of the study proposal. When this permission had been
obtained the researcher then met with the physician in charge of the oncology clinic to discuss the study in detail. The physician met with members of the multidisciplinary oncology team and obtained consent for the study to take place. The members of the team determined the procedure the researcher would follow to gain access to a suitable population.

It was decided that the researcher, in conjunction with the social worker, would select families which met the criteria established by the researcher. Permission would then be obtained from the physician in charge of the ill child's medical care to contact the family. The first person to contact the family about the study could be the physician, the social worker, or the researcher.

The social worker agreed to act as a resource person to the researcher should there be any psychological sequelae for any sibling as a result of the study. Talking with children about such a potentially emotionally charged topic as is the subject of this study may arouse feelings of anxiety within the siblings with which they have difficulty coping (Rich 1968; Spinetta 1978). The parents were told of this potential problem and asked to contact the researcher if they had any concerns.

The oncology team had some reservations about such a study being conducted. They have a very close, long-term relationship with the children with cancer and with the parents. This in turn appears to be translated into an
expression of protective behavior toward the whole family. Other researchers had been interested in gaining access to the families in question and the oncology team were reluctant to expose their clientele.

Viewing the oncology team - family relationship in terms of systems theory, a subsystem consisting of the oncology team members and the family is formed. As such, the subsystem possesses the characteristics of a system including a boundary (Bertalanffy 1968). In this case the physician as a member of the system is controlling access to members of the system, the family, by clearly defining the boundary and the procedure for penetrating that boundary.

CRITERIA FOR SAMPLE SELECTION AND UNDERLYING RATIONALES

The sample which was selected could be defined as a judgement sample (Honigman 1970, p. 268). That is, the informants were selected to conform to certain criteria. Specifically:

1. There were two or more children in the family, one of whom had been diagnosed as having an oncology related disease.
2. One or more siblings of the ill child agreed to participate.
3. The child with the oncology related disease was currently being treated but was past the initial hospitalization
4. The siblings of the child with cancer were between the ages of 8 and 18 years.
5. The siblings were living at home.
6. The siblings were fluent in English.
7. The families lived within a one hour drive of the oncology clinic.

The rationales underlying the criteria included the following. There must be at least one child in the family other than the child with cancer for a sibling relationship to exist. There did not seem to be any reason for limiting the numbers of siblings agreeing to participate as, consistent with the definition of perception recorded in Chapter I, each individual's perception of a situation is unique although some components may be shared. Because the study was concerned with the perception of day to day living and not with the adjustment of siblings to hospitalization of the ill child or the initial reaction to the presence of cancer the criterion was included that the initial hospitalization period be over. Hospitalization of a sibling is a recognized crisis event in the life of a child (Coddington 1972, p. 207) and an adjustment period must be allowed following a crisis before studying the ongoing business of day to day living (Aguilera and Messick 1978, p. 67).

The literature indicated the treatment episode is a significant time in the ongoing life of the child with cancer (Bluebond-Langner 1978). Systems literature supports that factors affecting one family member affect others (Horton 1978). It can be concluded that treatment episodes may be significant in the ongoing life of the sibling therefore, the requirement for the child to currently be under-
going treatment was included.

The method of data collection, the interview, presupposed the child be able to communicate with the researcher verbally. This imposed the restriction of being fluent in the language of the researcher and suggested some age parameters. Eight was arbitrarily selected as the minimum age at which children are more likely to be able to communicate verbally, recognizing that some latitude could be allowed in meeting the criterion. This age coincides approximately with the stage of concrete operations defined by Piaget (Piaget and Inhelder 1969). This period beginning about age 6 is the stage when cognitive abilities of the child are expanded so that the child need not actually see operations performed to know about them. The child now has the cognitive structures enabling him or her to think about activities without having to experience them. This ability must be present for the child to be able to participate in a straightforward interview.

Eighteen was set as the upper age limit with the reasoning being that past that age the child would quite likely be involved with leaving the parental home. This is the age of man, that of late adolescence and young adulthood (Erikson 1963), when peers have prime importance and the young adult is ready for intimacy with another outside of the family boundary. As the day to day living with a child with an oncology related disease was the focus, living with the same family as the ill child was considered an essential criterion for regular association.
MAKING CONTACT WITH THE SIBLINGS

Parents act as gatekeepers in the family and access to a study population of children is through them (Bogdan and Taylor 1975, p. 31). Kantor and Lehr (1976) found parents act to limit the penetration of the boundaries of the family system. They do this by restricting movement of information into and out of the system and by limiting access to family members. The researcher found evidence of this kind of behavior in gaining access to the siblings. The researcher's initial penetration of the family boundary is described in this section.

The first family selected was approached initially by the physician who asked a parent during a regular clinic appointment if the researcher could contact them. The parent agreed. The physician then gave permission for the researcher to make the contact. This was done by a telephone call to the family home explaining to the mother the nature and purpose of the study, requesting permission to meet with the family for further discussion aiming at eventual participation of the siblings in the study. The parent indicated she would discuss the proposal with the children and an appropriate time for the researcher to call back was suggested. On call back, the parent indicated three children were willing to participate in the study to the extent that they agreed to a first interview. The timing of the first interview was to be decided in several weeks because of other commitments that the family had.
The second family selected was approached first by the researcher who after obtaining permission from the physician met the mother in person at the oncology clinic and described the nature and purpose of the study. The mother then spoke to the children. The researcher followed up the initial contact by telephone and was told five children had agreed to participate. This interview took place within two days of the first contact.

Following the initial contact with the first two families selected, eight children had agreed to participate. This became the study population.

A qualitative study is based on the premise that "all settings and subjects are similar while retaining their uniqueness" and general social processes can be studied in any single setting or through any single subject (Bogdan and Taylor 1975, p. 12). The sample size required is dependent on the emerging data and the study design allows for flexibility in adding subjects as required (Glaser 1978). Due to constraints in terms of time available for conducting the study, no additional subjects were added. If the data had not yielded a core variable additional interviews or additional subjects would have been necessary.

ETHICAL CONSIDERATIONS

Ethics is concerned with the rightness or wrongness of actions (Schachtel 1978). The ethical considerations in
this study center primarily around the issues of obtaining informed consent from parents permitting their children to participate in the study, obtaining informed consent from the children themselves, and the parents' right to act as gatekeeper of information entering and leaving the family system (p. 36 of this study), and the researchers responsibility to the consent givers on completion of the study.

A. The Parental Consent

Originally the researcher had intended to use a letter to introduce the study to parents. As the process of sample selection proceeded, that did not seem appropriate. The contents of the letter were subsequently incorporated into the parental consent form (Appendix "A").

When sanctioning access to a population for the purposes of doing a study, the consent givers and the population have a right to know that the researcher is competent to conduct the research, why the study is being done, and what the role of the subject will be (MacElveen 1978). With this information as a guide, the subject can determine, on an informed basis, whether or not he or she wishes to participate. The consent form specified the qualifications of the researcher, the purpose of the study, the potential subjects, and the nature of the data gathering technique. The form that was used also inquired as to whether or not the parents had shared the diagnosis of cancer with the siblings and guaranteed not to disclose it if they had not done so. This was important to protect the parent's right
to be the information giver. Permission was requested to audio tape record the conversations with the children with anonymity being preserved by identifying the recording with a code number and restricting access to the tapes to those directly involved in the study. The researcher's intention was to destroy the tapes at the conclusion of the study. However, the subjects and parents in both families asked if they could have them and the researcher agreed. The tapes were given to the children. The parents were assured that any or all siblings in the family could withdraw from the study without jeopardy to the child undergoing treatment for cancer, at any time. One parent from each family signed this form.

B. Consent of the Siblings

None of the children were of legal age to sign consent forms. However, recognizing the child's right to not be a research subject (MacElveen 1978) and the right of informed consent (van Eys 1978), a form was designed explaining to the child the kind of information the researcher was interested in obtaining and requesting permission to audio-tape record the conversation (Appendix "B"). The form also indicated to the child permission to refuse to answer any questions and permission to terminate the conversation at any time. The children each signed this form, as an indication that they understood the procedure to be followed and their part in it.
C. The Parent as Gatekeeper

Granting a researcher access to children in the family cannot be construed as parental abandonment of the right to control information flow. This researcher was very conscious of the parents not giving up that right. It was evident in the request to be given the tapes at the end of the study.

A parent of one set of siblings was present for the first interview encouraging the children to participate and in and out of the setting during the second interview. In conversations before and after the interviews the parents sought assurance that the researcher had a clear understanding of usual family relationships. The researcher felt it was necessary to reassure the parents that the comments made by the children were, in the researcher's experience, similar to the comments made by other children as in fact they were.

D. The Researcher's Responsibility to Consent Givers

The conducting of research related to human behavior seldom results in the discovery of new information (Holt 1978). Researchers should help the consent givers to understand this. The research can contribute to the organization of knowledge, and in this spirit, a copy of the report of this study will be made available to the oncology team which granted access to the families. A summary of the findings will be sent to each of the participant families. The researcher will be available to discuss the study with both groups.
THE INTERVIEW AS A DATA COLLECTION TOOL IN QUALITATIVE RESEARCH WITH CHILDREN

The interview is used in this study to collect data. An interview has been described as a "human being talking to another human being" (Rich 1968, p. 1). The phenomenological perspective recognizes the social nature of the research act. The view of the human subject-as-object is not valid in this paradigm as it considers knowledge as subjective and recognizes the fusion of the observer and the observed in the act of observing (Davis 1978). Cicourel (1964) reminds interviewers and those interpreting data obtained from an interview that a basic social process is involved. He suggests "the interviewer, through his intuition, must develop a community with the respondent that will enable him to elicit frank answers." (p. 75).

In interviewing children, it is important to give them time to talk. There is a great danger of obtaining only limited data if procedure is very structured as the child may simply answer questions and not feel secure enough to elaborate or may not have a wide enough knowledge range to be more accurate in responses. However, the child does respond truthfully from his/her point of view. That is, the child's answers represent the truth. However, since the child's frame of reference and the interviewer's may not be the same, the interviewer's interpretation of the truth as related by the child and the child's may not be the same. It is therefore necessary to take time to explore a topic
from several points of view and possibly even at different times to ensure the interviewer understands what it is that the child is trying to share (Rich 1968).

COLLECTING THE DATA

The interview can be compared to a measuring tool (Cannell and Kahn 1968) and what is being measured must be specified. In this study, it is the sibling's perception of day to day living when another child in the family is being treated for cancer. This is being measured by seeking answers to the questions:

- What concepts which relate to the sibling's perception can be derived from the sibling's descriptions of the experience of day to day living when a child in the family is being treated for cancer?
- What are the relationships between these concepts?

An interview schedule was constructed to act as a map in the process of seeking answers to the research questions (Appendix "C"). The general areas to be covered were derived from the literature on the family and on chronic childhood illness. Included were the sibling's activities, relationships and feelings with reference to the subject in question, how the presence of the child being treated for cancer interfered with the sibling's activities, the positive and negative aspects of having a child being treated for cancer in the family, and information about specific illness variables.
A group interview comparable to the rap sessions described by Bogdan and Taylor (1975, p. 130) was utilized for the first interviews in each family. The technique used in the interview was to introduce a subject from the interview schedule if in the course of a conversation the children did not introduce one. Then, using the response of the child as a guide, to pursue that topic, trying to clarify the child's view. When the family group was together, the oldest child in the family tended to respond most quickly to the follow-up questioning. This led to the decision to interview the children separately. However, in both families, when this was suggested as a plan for the second interview, the younger children indicated a preference for being interviewed as a group. As younger children appeared to be more relaxed in the group setting, and more willing to talk in that situation, the researcher agreed. With the oldest child absent, it was possible to follow through on a theme with the younger children. Had this not been the case, a third interview, to be held individually with each child would have been requested. The oldest child in each family was interviewed individually.

The research interview was conducted primarily as a series of open-ended and probing questions seeking to clarify the meaning of the experience for the sibling. During the interview itself the researcher attempted to identify concepts that were occurring in the data and to center questions on these. This kind of questioning occurred more
frequently in the second interview of the study and in subsequent interviews as data analysis had begun and the focus of the interviews became more particular. This is in keeping with the inductive approach of grounded theory where the theory emerges after data collection begins and as it emerges the researcher constructs the conceptual framework (Glaser 1978).

The process whereby the nature and the analysis of the data determine the subject matter to be sampled or even the population to be sampled is termed theoretical sampling by Glaser (1978). It consists of assigning codes to raw data at the start of data collection, using these codes to guide additional data collection, continually looking for information regarding the properties and relationships of the codes. The outcome of this activity as described by Glaser is that:

> the analyst progressively sees more in his data of relevance and fit as he explains how the basic social process resolves the basic social psychological problems of the participants in the substantive area under study (p. 36).

As the comparison, coding and re-coding continues, the categories become saturated. That is, no new information is being added. At this point data collection can cease. The direction for data collection and the extent of it, thus comes from the data.
THE CIRCUMSTANCES OF THE INTERVIEWS

Because the interview is a social encounter constructed by the interviewer and the interviewee, and the data are products of that encounter (Cicourel 1964), it is important that the reader have access to information about the actual circumstances of the interviews. This will be combined with a brief description of each family.

A. Interviews with First Family

The first family contacted is composed of a mother, father, male child age 14 years, male child age 12 years, female child age 10 years, and the child with the oncology related disease age 8 years. They live in a small community about one hour's drive from the oncology clinic. The ill child goes to school within the immediate community and the other children, being in higher grades, in a community about a half hour drive away. This means that some of their social activities occur in the neighboring community.

When the researcher spoke with the first parent, she was not sure her children would be interested in being interviewed, however, she agreed to ask them. She indicated her children all verbalized well, especially the older one, but thought the younger two siblings might have difficulty talking with a stranger. On call back she indicated the children had consented. She did say she hoped there would only be one interview. The reluctance which appears to
underlie parental agreement is in keeping with the function the family serves of controlling access to children and children's access to experiences outside the usual family boundary (Kantor and Lehr 1976).

The logistics of organizing the interview time then presented somewhat of a problem as the children were engaged in many outside activities. Also, this mother wanted the ill child occupied in such a way that he would not be aware of what was going on. Eventually, an appointment was arranged. The plan was that the family would have an early supper on an evening that the child with the diagnosis of cancer had a soccer practice. When the interviewer arrived as arranged, the family was just about to sit down to dinner and the soccer practice had been cancelled. The interviewer waited in a separate setting while the family ate. The mother then took the youngest child away. The oldest child was not yet home. The two younger children chose to be interviewed together. The setting selected by the children was one of their bedrooms. One of the siblings closed the door. We sat on the floor and began to chat. About 10 minutes into the interview the oldest child joined in. The children of this family were eager to share their experiences with the researcher. This is in keeping with the findings of Green (1982). At the conclusion of the interview, they agreed to be interviewed again.

Six months later the second interview time was arranged with the parent. The researcher requested separate inter-
views with each child. On arrival of the researcher, the oldest child was not at home and the other two asked if they could be interviewed together. This was agreed to in the interests of maintaining cooperation. The child with cancer was at home during this interview, but apart from a little social conversation at the beginning of the interview, was occupied playing with a friend. The setting this time for the interview (again chosen by the children) was an open play area located between the bedrooms.

As the oldest child did not return while the researcher was there, another time was set to meet with him. This time there was no hesitancy on the part of the mother in arranging the meeting time. It subsequently took place at a neighbor's, as when the researcher arrived the child was there looking after the neighbor's house and animals for the day. He was also baby-sitting with his younger brothers and sister, two of whom were at the house during the interview. The interview setting selected by the child was at a table in an eating area next to the kitchen. One sibling was in another room unable to hear the conversation. The child with cancer wandered in and out throughout the interview occasionally participating in the interchange and occasionally making demands on his older brother.

B. Interviews with Second Family

The second family was composed of mother, female child age 14 years, male child age 12 years, male foster child age 9 years, male foster child (brother of the other foster
child) age 7 years and male child with an oncology related illness age 7 years. They lived in an urban area about 15 minutes drive from the oncology clinic. The two foster children attended school directly across the street from the home, the ill child and the 12 year old attended a church related school nearby, and the 14 year old attended the nearby junior highschool.

The parent of this family agreed immediately to having the children participate, and upon confirmation of the children's willingness, an appointment was set up within two days. When the researcher arrived, the children were all gathered and the mother organized the interview setting around the table in an area adjoining the kitchen. On a subsequent visit the researcher found that this seemed to be the common place for the family to congregate and for conversations to occur with outsiders.

The children seemed wary of sharing with the researcher. They required time to assimilate information about the purpose of the interview and the roles of participants. The requirement for this kind of clarification is included by Rich (1968) as he describes expectations and their influence on communication with children. Children, because of their limited experience tend to see an adult, not simply as a person but as a person with a role attached such as a teacher, a parent, a nurse. This means, for example, that the child may be more at home with a teacher in a classroom than in a living room. The children in this family had viewed
and participated in interview settings before with a social worker who had been involved in the placement and ongoing supervision of the two foster children. The individual brings to each experience the sum total of previous experiences and extracts data from current experiences to construct each new situation in such a way as it makes sense to him (Schutz 1966). Because the interview setting is a social setting involving interaction between human beings (Cicourel 1964), the interviewer plays a part in the way the interviewee constructs the experience of being interviewed. The interviewer cannot construct the experience for the interviewee, but must be aware of the way in which the interviewer is constructing the experience.

In this instance the children required time to assess the interviewer, decide what her role was, and decide if they would share with her and what they would choose to share. For part of the interview with this family, the child with cancer was present. When he found the process was lasting too long he and the youngest sibling went out to play. The other siblings chose to stay until the end of the interview. The mother was also present for a part of the interview, encouraging the children to participate. On reviewing the interview content with the mother present, and comparing it to the content of interviews done when she was not present, her presence did not appear to inhibit the children sharing their experiences. The oldest child appeared to be the leader in the information giving. She also
appeared to be actively trying to cope with grieving. Therefore, in the second interview she was seen separately. The other children wanted to be together and again they wanted to include the ill child. This time the 12 year old boy initiated the information giving and was much more involved in sharing his perception.

Following each interview, field notes were made about the interviewing setting, experience, conversations with the parents and so on. These notes were of contextual significance in placing the interview and some comments being made by the subjects.

C. Why A Second Interview With The Same Population Was Conducted

Following the first interview in each family analysis and coding of the data was begun. This is consistent with the methodology being used (pp. 49-51 of this report). The purpose of the second interview was to explore in greater depth some of the topics introduced in the first interview, and to collect additional information pertinent to the concepts which were emerging in the process of data analysis. Qualitative methodology also allows for this kind of interview to occur with a different subject population (Glaser 1978). However, since this population had agreed to the additional interviews, and the researcher felt obligated to expose as few families as possible to the research process a second interview with the same population was the option chosen.
ANALYSIS OF THE DATA

Analysis of the data in a qualitative study such as this begins as soon as the researcher and the subject make contact. Although, the data collection tool was the interview, the interview data were analyzed within the context of the social encounter (Cicourel 1964).

The data were analyzed by the process of constant comparative analysis (Glaser and Strauss 1967; Glaser 1978; Maxwell and Maxwell 1980). The analytic unit in this study was the sibling's perception of a specified experience or any indicators of this concept.

Each interview was transcribed from the audio tape. The transcription was studied line by line following the instructions of Glaser (1978) to carry out open coding asking the following questions:

- What is this data a study of?
- What category does this incident indicate?
- What is actually happening in the data?
- What basic social-psychological problem is being faced by participants?
- What processing of problems is being done by participants to make life viable? (Glaser 1978, p. 57)

Each piece of data was transferred to a three inch by five inch index card and then assigned through a filing process to as many categories as possible. Duplicate cards were made so that a separate card could be filed in each category. As it was filed it was compared to other data in
the same category and to data in other categories. Glaser (1978) terms this process "fracturing" the data. Fracturing the data allows the analyst to consider the data at a conceptual level rather than becoming embroiled in the detail of the experience being related by the subject. Notes regarding possible relationships and other ideas occurring to the analyst during this process were written. After the initial coding and categorizing was done for the first interview, the procedure was repeated for subsequent interviews. As subsequent data were categorized and compared some of the original categories were altered in light of the new datum being added. Categories were added, categories were deleted, and some data were recategorized with notes about relationships and ideas continually being recorded. The process of open coding and categorizing is termed substantive coding (Glaser 1978, p. 56). Substantive coding is a means of conceptualizing the substance of the area of research.

Following this procedure, the notes about relationships and ideas were categorized, the data compared and recategorized. This type of coding is theoretical coding (Glaser 1978, p. 72). This coding indicates the relationship between the substantive codes indicating hypotheses which may be integrated into theory. At this point, the coding has moved from the sorting of data to conceptual sorting or the sorting of ideas. As a core variable, or construct which appears to account for the major portion of variation in
behavior pattern begins to emerge, then all other categories and properties are sorted as they relate to the core variable. In this study, a construct began to emerge at this time. This construct can only be considered an hypotheses. It is not a fact.

This data analysis process can be summarized in the words of Glaser (1978, p. 55). It involves "fracturing the data, then conceptually grouping it into codes that then become the theory which explains what is happening in the data".

SUMMARY

This chapter has described the procedure followed to arrive at a conceptualization of the sibling's perception of day to day living when a child in the family is being treated for cancer. In the next chapter, the nature of information available to the sibling which is integral to his/her perception and the conceptualization of that perception will be presented.
CHAPTER IV: THE CONCEPTUALIZATION OF THE DATA

INTRODUCTION

The process used to conceptualize the sibling's perception of day to day living when another child in the family is being treated for cancer as described in Chapter III involved interviewing siblings, comparing and categorizing the data for the purpose of considering them at the conceptual level, identifying concepts, and finally looking for relationships between the concepts. This chapter will present the data at the conceptual level. The concepts and their relationships as derived from the data will be described. Preparatory to this a summary of the nature and sources of information available to the siblings about the illness is presented.

Two premises underly the presentation of the data:

1. "All settings and subjects are similar while retaining their uniqueness" thus general social processes can be studied in any single setting or through any single subject. "At the same time some processes that appear in bold relief under some circumstances appear only faintly under others" (Bogdan and Taylor 1975, p. 12).

2. The process of fracturing the data then conceptually grouping it into codes results in a theory which explains what is happening in the data (Glaser 1978).

These two premises allow the researcher to present the data from multiple sources in a combined form rather than as individual accountings. Verbatim accounts of interactions
are included to give the reader access to the data upon which the researcher's conceptualizations are based.

THE NATURE AND SOURCES OF INFORMATION AVAILABLE TO THE SIBLINGS

In Chapter I perception was defined for the purposes of this study as the process by which we obtain, transform, organize and structure information arising from the world in sense data or memory, and respond to that data in a selective and discriminative manner (p. 8). The information available to the siblings about the illness and their interpretation of that information thus becomes a component in their perceptions. In this section segments of conversations with the siblings are used to illustrate the nature and sources of information about the illness experience which are available to the siblings. Siblings participating in conversations have been identified as "C", the researcher as "R". If more than one sibling participated in the conversation this has been indicated by designating the speaker as C1, C2 and so on in the order in which they first spoke in the conversation being reported.

A. The Seriousness of the Illness

Analysis of the data indicated that all of the children in the study population knew the ill child's diagnosis and that the illness was potentially very serious. The possibility of a fatal outcome was not alluded to by the re-
searcher, however several children did mention death either directly or indirectly as a possibility.

The mother in one of the families related that the seriousness of the illness had been discussed with the children but she was not sure that the two youngest children really appreciated the implications. The researcher had the impression that the possibility of death had not been discussed with those two children. The siblings of that family referred to a death of another child that took place during the initial hospitalization of their brother indicating to the researcher that death was something they had thought about.

C1: The sad thing was like he shared his room with four other people - four other little kids and one of the little guys died. But I don't think he ever found out about it. We knew about it.

C2: He did? I didn't even know.

C3: Yeah, you know down at the end of the hall where it said no unauthorized personnel beyond this place. The last room.

The above interchange is most likely an example of a sibling gaining another piece of information to add to the repertoire of knowledge. The conversation continued as follows:

C2: The other little kids were really cute, really nice actually.

C3: Yeah we met some kids who were really cool, kind of nice. Some of them are bald.

C1: Yeah, its just a matter of really relating to them you know. Its hard to talk. You see a bald person on the street and you can't talk to him you
know. You feel out of place. But if you overcome that everyone's a friend pretty well.

C2: Except mean people.

At this point C2 moved outside of the talking circle. The researcher introduced a new topic and she moved back in. The topic of death was not pursued nor did it come up again with the two younger children in this sibling sub-group.

The siblings in the other family had discussed the possibility of the ill child's death with the mother and spoke about death in direct relationship to their brother during the interview. This statement was made in the presence of the ill child and the mother. The sibling making the statement was visibly upset and the others looked sad but it appeared to the researcher that this kind of expression of feeling was sanctioned in this family.

C: Whenever I hear "leukemia" I always think about — and things like that. Sometimes when I look in the newspaper that lists sort of where the dead peoples are sometimes I hope he never gets in — in — in the paper where people that die — I hope he never gets there. That's how I feel about it.

A more common referral to the ill child's mortality was a statement made by one of the siblings.

C: He's ok now. He'll make it.

B. Medication Taking

The siblings knew their brothers received medication. The conversations indicate their knowledge of details of this as hazy.
C: He has to take all those shots and pills. All those awful pills.

C1: On Friday he used to take six of those little yellow ones.

C2: He took them all at once.

C1: He took three at a time.

C2: Four at a time.

C: We're never around when he takes his pills cause he always hates when anybody's around.

C: Every once in a while. I think Monday. Mostly Monday and Tuesdays.

R: Does he take pills on other days?

C: I don't know. I don't see him.

Some of the siblings knew the names of some of the drugs and one knew how they tasted.

C1: Once he made me bite in one of his pills.

C2: Like it was ok that we bit. It wouldn't hurt us.

C1: My brother once, I think it was prednisone or something he said "I dare you to bite into one of those". And I had to. It was yick. I hate it. I had to take about ten cups of milk.

The siblings knew the drugs caused some unpleasant side-
effects.

C: And when he's taking his prednisone for a week he's in a really bad mood. You don't get in his way then.

R: Are his sore feet part of leukemia or is that from being hit by the van?

C: I think its because of his medicine mostly.

C: ____ is just sick on those days. Like he just sleeps it sort of away and he's ok the rest of the week.

Some of the side-effects were hard for the siblings to get used to.

C: When he didn't have any hair I couldn't get used to it.

C. Diagnostic and Treatment Procedures

The siblings had all witnessed some part of the diagnostic or treatment procedure. The language they used and the descriptions offered suggest that health professionals were not involved in interpreting what was happening or in helping them to understand the experience.

Their descriptions of treatment procedures witnessed included such things as:
C: I saw ____ having a needle in his bum.

C: I remember when they stuck this silver thing under his tongue.

R: So tommorrow he just goes for a regular little check-up?

C: Uh huh.

R: What happens when he goes for one of those?

C1: He just gets a couple of shots.

C2: And, uh, they take his weight and things. All that, you know.

R: So those are all the kinds of things that happen to him and he doesn't mind?

C1: Yeah. And his l.p. kind of thing.

When observing treatments the children did not always see what a trained eye would see.

C: When he was in the hospital last year and he didn't have all those wires and things we'd get him in the wheelchair and we'd push him.

The wires and things presumably refer to the intravenous tubing.

Some of the children's descriptions of what they saw reflect emotional involvement in the experience including psychosomatic symptoms, sadness, fear, empathy and sympathy.
C: I started to feel sick.

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R: What did you see?
C: I saw _____ having a needle in his bum.
R: Did you see them put it in?
C: Yeah.
R: What did you think about it?
C: Sad.
R: Sad?.
C: Yeah

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C: It's kind of hard to watch it. I wouldn't be able to do it. I don't really like watching it. I guess he just likes me being there.

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C: Whenever I go to the hospital sometimes and he screams when he gets a needle that makes me feel like crying when he screams and that.

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C: You can't do anything you know. You can hold his hand but he's really nervous and he pushes it away. You know you can't do anything. It's scary.

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C: ... with the spinal tap or the bone marrow lying on that bed and the nurses are all swarming around him. And I think that's one of the things that really scares him. Like there's 10 people all looking over him. He can't look anywhere. And we try to assure him but you know it's kind of - not really assurance it just puts more pressure on him.
The siblings reacted to the hospital itself.

C1: The hospital atmosphere is pretty nice but sometimes it's so dismal.
C2: And everybody is talking and everything.
C1: It's all grey and everything.
C3: Whenever you go into a building like a hospital it's got a different kind of smell and everything.

The expression "and everything" appears to imply a larger experience than the child is able to articulate (Foss and Hakes 1978).

THE CONCEPTS AND THEIR INDICATORS

The first concept to emerge from the data was that of special status for the ill child. This concept and the indicators supporting it will now be described.

A. Special Status For The Ill Child.

1. Creation of Special Status of the Ill Child by the Parent.

As the substantive coding progressed, the data indicated that the siblings' perceived that the child with cancer was treated differently than the other children by the parent. This had begun with the initial diagnosis.

The illness trajectory for the children with the oncology related illness in both of the families comprising the study population began with an acute illness requiring hospitalization which resulted in disruption of normal
individual and family activities. Hospitalization of a family member thus became one of the first variables associated with the illness to which the siblings were required to react. This period of time was characterized by the parent(s) spending long hours at the hospital with the ill child. The children, retrospectively, referred to the absence of the parent(s) from the home in a matter of fact way. As described by the children of one family:

C: My mom and dad - either of them was usually always at the hospital. Sometimes we'd have to stay at the hospital until about 11 o'clock and then my mom would drive us home and stuff.

C: Yah, every night my dad or mom stayed there for the night.

Within the family subsystem this created a special status for the ill child. He was receiving more than his usual share of parental time and attention. At the same time, other children in the family were required to give up their usual activities to also spend more time concerned with the ill child. When discussing the intention to participate in an organized sport one child said with reference to attendance at games:

C: I'd get to some. Sometimes I'd get a ride with someone but most of the time I'd miss it.... It was kind of a waste of money to join it but we didn't know he was going to get sick.
When the child came home from the hospital, the siblings and the parent(s) continued to support the concept of special status for the ill child within the sibling subsystem. This support is reflected in such statements with reference to the ill child as:

C: He always gets his way. He gets treats.

C: He'd get in trouble but I don't think he'd end up paying.

C: It's because my mom gives him special attention you know.

The special attention of one parent was reflected in the concern for the general health of the ill child and the ways in which the parent attempted to see that his nutritional intake was adequate. The siblings saw this concern demonstrated as follows:

C: A while ago he was hooked on marshmallows and after the hospital my dad made the mistake of kind of getting him the marshmallows. You know he's kind of in a bad mood and you might as well cheer him up. We got him off that habit. He'd also get a big chocolate bar. So now you know after the hospital my dad brings him to Kentucky Fried Chicken for some chips and pop and everything to get him something good to eat.
C: He gets better yogurt - things like that.

C: My mom went down to the store and bought some Super Socco, chocolate milk and some grapes that I had to drop into him.

C: He gets treats like that. Extra drinks, my mom didn't usually buy chocolate milk, pop and stuff.

Ensuring adequate rest was also a concern. The siblings' statements reflected how they saw the parents handled that problem area.

C: If he's sleeping my mom just lets him sleep.

C: He sleeps a lot.
R: What do you do?
C: Play outside - out of the way.

From the siblings point of view, the ill child was dealt with in a special way.

Creation of this special status by the parents was not only related to concerns about particular illness variables. It also occurred with regard to acceptable behavior of the ill child and his interactions with his siblings. Siblings reported:
C: I usually have to put away his clothes - yesterday Mom made him do it - he just sat there for awhile.

C: He screams a lot too.

R: Do you mean you have to give in to him all the time?

C: Yeah - not all the time but most of the time.

C: Like usually I don't like letting him get his way. I don't like it and then if I don't I usually get in trouble cause he gets mad and screams and stuff.

The words of one sibling indicated how he saw this behavior as beginning early in the illness trajectory and being related to the special status accorded the ill child because of hospitalization.

C: He's learning that he has a lot of authority because you see when he was in the hospital and everyone takes special attention - give him special attention.

The relationship appeared to be circular in that the parent accorded the ill child special status and the ill child in turn demanded special treatment requiring the parent to respond.

2. Conferring of Special Status on the Ill Child by the Siblings

Continuous comparing of data and deriving of substantive codes indicated that granting special status within the
family system to the ill child was done not only by the parent, but also by the siblings. In one incident one of the siblings related how he would offer to pay the ill child to eat a bowl of salad, or go to bed. He did not do this with other siblings in the family as it did not matter so much if they ate properly or got enough sleep. This behavior on the part of the sibling was reinforced by the parent when the sibling had no money to pay the debt and the parent paid it.

Siblings appeared to confer special status on the ill child because they felt that was something tangible or concrete they could do for the ill child. To refuse a request of the ill child was difficult.

C: If I want to go to Stanley Park, he says it's not fair. Can I come? And I can't say no so I usually take him.

C: I usually take him out to the movies and treat him. That's how I try to keep him happy.

Siblings referred to the mortality of the ill child in rationalizing why they conferred special status:

C: To make his life better.

C: He hasn't got long on this earth.
C: To make me forget, forget about him, you know.

C: When we have a cold we have to stay away from him. Like one of the big things is Saturday morning cartoons. And like you walk in there and if you have a cold like you do a lot of times during the last week of school. Like if he's sitting here you kind of have to go over to the edge.

The following interchange indicates one of the siblings was much more tolerant of the behavior of the ill child within the family, than of a child of another family who had the same diagnosis. This sibling was not prepared to confer special status on all children with an oncology related illness.

R: You feel that she's really spoiled and hard to get along with?

C: I think she's more spoiled than ____. ____'s not that bad. Like I think she's too much spoilt. She always wants her way when I'm here. And if she doesn't get her way she starts sticking her tongue out at me and stuff like that.

R: What happens when ____ doesn't do what you want him to do?

C: He just slaps me on the leg or something or he just starts screaming but he doesn't hit or anything. Just sits there and cries. That's what he does. He runs in his room and shuts the door.

R: He shuts the door?

C: And locks it. He doesn't always. He just closes it. Sometimes he locks it when you tell him to come out.

R: He won't come?

C: If I get the door open he throws something at me. He tells me to get out. That's only sometimes.
He hardly ever loses his temper. He's good to get along with I think. Not all the time but sometime.

3. Siblings' Requirement for Outsiders to Confer Special Status on Ill Child

The data indicated that siblings wanted outsiders to confer special status on the ill child. This was expressed as a direct requirement in the following statement.

C: He misses (school) sometimes when people have chicken pox. A lot of people are totally stupid. Most of the people'd phone up my Mom and say well - ah - somebody's got chicken pox. But some people'd send their children to school and then everybody gets it.

The requirement was also demonstrated in the ways in which the sibling sought to protect the ill child.

R: Do your friends know about ____?

C: Yeah. I told them if they touch him I'd kill them.

4. Maintaining Special Status of the Ill Child

The data indicated that over time, the siblings no longer viewed as unusual the special status of the ill child within the family. Rather, they began to incorporate the creation and maintenance of special status for the ill child into their daily activities and relationships. When this happened, the process appeared not to be an irritant in sibling relationships. During the second interview, siblings of one family were discussing the eating habits of the
ill child. The discussion centered around the ill child refusing food which was served to the whole family.

C: He says, "No I don't want that." So we make him something different.

R: What do you think about that?

C: I don't care.

One of the siblings summed up the new relationship with the ill child in this way:

C: You kind of have to treat him as you used to treat him but also keep an eye out for him. Like you give him special attention but not so he really knows, you know.

The siblings appeared to accept the new requirement to treat the ill child in a special way.

R: Do you think if he hadn't been sick you would have given into him that way?

C: No, I don't think so. It just turned out he was sick and it's just the way it went I guess.

Special status for the ill child came to be viewed by the sibling as normal. Through the process of conferring special status on the ill child, and then acting to incorporate the creation and maintenance of the special status into their daily activities and relationships, the siblings seemed to be constructing a new subjective normality.

A NEW NORMALITY

At this point, a second concept appeared to be emerging from the data, that of a new normality. The indicators of this concept will now be described.
1. Changes in Responsibility

A part of the siblings' perception of living in a family where a child was being treated for cancer included changes in their responsibilities. The siblings identified being responsible as being related to the illness experience.

R: Do you feel _____'s illness has made a difference in your lives?

C1: Yeah. We're more responsible.

C2: A lot of my friends are more spoilt. We had to get our own stuff. We have to earn and work. Like we have to baby-sit and stuff. Not all my friends but some.

In one family siblings related increased responsibility for household chores that began while the ill child was in hospital and continued to the present.

R: Is that when you learnt to cook?

C1: Yeah. We didn't want to eat that (referring to a casserole brought in by a neighbor).

C2: I'm still a pretty good cook. I make your breakfast every morning.

Some of the increase in assumed functions related to caring for the ill child.

C: She has to make his bed everyday. Put away his clothes.

The above comments were made very matter of factly with no obvious indication of annoyance on the part of the siblings.
One of the ill children required his oldest sibling to go with him to the clinic when he was having bone marrow aspirations done.

R: You made him go with you?
Ill Child: Yah.
R: What did he do for you?
Ill Child: Just sat and watched.
R: What did you do? (Directed at the sibling)
C: Just sat and watched. I don't know he just likes me being there. Somebody staring at him.
R: Can you hold his hand or anything?
C: My Dad does.

This sibling had been accompanying his brother to the clinic appointments from early in the illness experience. When asked if he went to all of the clinic appointments he said:

C: I go to some, don't go to some. Just play it by ear I guess. I go if we've had a fight.

During the first interview this sibling described the helpless feeling he had when bone marrow aspirations were being done. In the second interview the investigator had the impression that the experience was now much less traumatic for the sibling. He said:

C: It's kind of hard watching it. I wouldn't be able to do it. I guess he just likes me being there.
Assuming some functions normally associated with parents such as making breakfast every morning for other children in the family, and accompanying the ill child to the clinic became a part of the new normality for the siblings in this family.

2. Concerns About the Ill Child

The siblings indicated concern about the ill child's nutritional status, requirement for rest, and protection from infection. Whereas these are common parental concerns it would appear to be unusual for siblings to feel responsible for seeing that these requirements are met (Bank and Kahn 1982).

The sibling's concerns are indicated in the following quotations:

C: I say to him, "You better eat or else you'll get in trouble."

C: Sometimes I pay him 50¢ for each bowl of salad he eats. It's the only way.

C: We have to stay away from him. Like one of the big things is Saturday morning cartoons and like you walk in there and if you have a cold like you do a lot of times, like during the last week of school like if he's sitting here, you kind of have to go over to the edge.

Cl: Also at dinner we had (undecipherable). He didn't like it so I made him a cheese sandwich and my mom
was going to make him something else. Like you have to keep him healthy. It does affect him. Like us, if we get sick, we stay in bed for a couple of days but for him it can be a little more serious. Like if one of us was to get chicken pox I think we've all had it right? Yea. Well we would have to move out.

C: You kind of have to treat him as you used to treat him but also just keep an eye out for him. Like give him special attention but not so he really knows you know like, oh you can stay up really late tonight is not really going to help him.

C2: Yeah then he'll be really sleepy and won't be able to get up.

C3: If he's going to keep sleeping my Mom just lets him sleep.

R: When _____ sleeps in you don't mind?

C1: No. It's also better that he goes to the school closer. If need be my Mom can just whip over there and they can bring him home.

The siblings were concerned about other aspects of the ill child's general health state. One of the siblings asked the ill child to give some of his gum to his sister. The ill child responded:

IC: I need them.

C: What for? So you can get a couple more cavities?

The ensuing conversation demonstrates another facet of concern about general health.

C: It's still a big responsibility to worry about him. When he goes out he has to wear two sweaters and stuff.
R: Does he listen to you when you tell him he has to wear two sweaters?

C: Yeah, he usually listens. When he doesn't we have one of our occasional little fights.

3. Stress Associated with Illness and Treatment Variables

When the child was acutely ill siblings' thoughts were often on that child and his predicament. It was an uncomfortable time. Said one of the siblings:

That's the time I didn't like. I had my mind too much on ____.

To reduce the stress of the concomitants of the illness, the treatments, the hospitalizations, siblings used a variety of means. One of these involved reducing the authority of the hospital and clinic through play. The sibling in the following conversation described a visit to the clinic:

Actually he's pretty fun at the hospital. Except when he has to get his bone marrows. When he's on l.p. or when he's just getting his shots he's ok. We play soccer after inside. We sneak jelly beans and stuff you know. Watch T.V.

Eventually this use of play worked to reduce the stress involved with bone marrow aspirations as was exemplified in this conversation from a later interview:
R: I hear you went with _____ when he had a bone marrow.

C: Yeah. I had a lot of fun after. We snuck upstairs to the kitchen and stole a bunch of stuff. We didn't really steal it - just kind of borrowed it. We each had a couple of ice creams and popsicles and stuff and jellos. Got jelly-bean-freaked-out.

Some siblings were not successful in reducing the distress associated with being present at treatment procedures. One of the siblings described his reaction to being present during a session.

C: I started to feel sick.

R: What did you see?

C: I saw a whole bunch of blood going into a tube.

Another sibling included a description of the room in his reaction to being present:
This little room is where _____ always goes to get needles. It's white and he gets treatments and he starts crying. Well, I would cry too.

Siblings used laughter to reduce stress associated with the discussion of illness variables. Siblings demonstrated this when laughter accompanied descriptions of unpleasant experiences the ill child was undergoing.

C: I probably wouldn't be able to take it but he goes in and fights it out. (Laughter) He screams a
lot though. (More laughter)

C: He has to take blood tests and things. Eek! (Followed by laughter)

C: (Regarding taking pills) They tried to grind them up and mix them with ice cream. But he could still taste them. But he's got used to it I guess. Anyway, you check to see if he's taken them. (Laughter)

siblings expressed that verbalization with the parent(s) was helpful in understanding the illness of their brother. In a discussion about this topic siblings revealed:

C1: If you don't know what's happening and everything you get confused.
R: When do you get confused?
C2: Well like if you don't know what's happening. They (the parents) don't really say that gets sick or something or about all these pills or anything.
C1: That's what a lot of people do and that really wrecks up their kids. You know they don't understand what's happening. Their little brother or sister or something they're taking all these pills and every week they go in for an examination you know and they don't understand it. So I think it's better like to be open with the kids. And it also helps out because we could understand him and we treated him like he was that kind of person. He was a little sick but we never really hinted to it.

siblings appeared to inform their peers about the ill
child and required certain behaviors from them regarding maintaining of special status of the ill child but beyond that verbal exchange appeared to be limited.

R: Do the kids at school know that _____ goes to the hospital and has treatments?
C: Yeah. They don't think about it though.
R: Did you tell them about it?
C: Yeah.
R: Do they want to know about leukemia and what happens?
C: They don't bother talking about it.
R: Do you talk to them about it?
C: No.
R: Have you ever talked to any of the kids at school about _____?
C: No. They won't understand. They just go, oh. They might feel sorry for you but inside they are really saying oh who really cares.

C: A lot of people felt sorry you know. They'd say that it's too bad, you know, my friends, you know. Like I was in grade seven and you can be more open with them. They were pretty friendly about it. Nobody really talked about it.
R: Did you talk to your friends about it?
C: I only told one person at the beginning.

Verbalization of concerns among the siblings or between siblings and the ill child also appeared to be limited. At no time in the interviews did any information come forward to support that extensive verbalization with reference to
the illness experience took place in the sibling subgroup. The lack of such conversation was confirmed by one mother. When questioned specifically about conversations the children might have among themselves about the ongoing treatment procedures and sequelae she said, "They don't talk about it. They just all do their own thing."

4. Mortality of the Ill Child

As part of the new normality siblings were confronted with the essentially mortal nature of man. Consideration of the mortality of the ill child seemed disturbing for the sibling. One of the siblings indicated that thoughts of the ill child's potential fate were close to the surface.

Whenever I hear "leukemia" I always think about and things like that. Sometimes when I look in the newspaper that lists sort of where the dead, peoples are, sometimes I hope he never gets in - the paper where people that die - I hope he never gets there. That's how I feel about it.

Denial seemed to be used to help to reduce the anxiety associated with the thought of the leukemia not being controlled. This is reflected in such statements as:

He had leukemia. He doesn't have it now. It's just a matter of staying healthy.

Well I don't know. I just don't see him as having leukemia anymore.
However, when discussing with the sibling who made the last statement the kinds of things that concerned her about the ill child this interchange took place.

R: What kinds of things do you worry about?
C: About death.

siblings expressed concern about their own mortality.

C: I'm afraid to get cancer. I think I would die. I hate cancer.

C: I hardly ever think about it and when I do I just feel like running away cause I don't want to think about it.

They could reconcile for themselves the fact that the ill child had to undergo unpleasant diagnostic and treatment procedures.

5. What is Normal?

Normal appeared to be a subjective construct. It appeared to be related in part to the amount of disruption siblings perceive in their daily lives.

R: So you say that things have changed. That it's changed your whole life.
C: Like we couldn't do sports then. But right now it's getting back to usual.
And another sibling said:

> Usually everything is normal now. Like I play sports and stuff.

Normality also seemed to have structural connotations. Siblings described the situation as being normal when everyone was at home. It was related in part to the resumption by the parent of usual roles. One sibling indicated this by the statement that usually when the ill child was in school the mother, who was a teacher, was subbing.

In one family, normality was associated with the ill child resuming his activities. In the second interview, when talking about the state of the ill child's health and the family situation the siblings volunteered:

C: He's played with his friends a lot.
R: Does he?
C: He's played the piano.
R: Does he?
C: He took lessons. He did that before he went into the hospital.

The ill child in one of the families had not been walking properly for several months. An interesting phenomenon took place as this too became incorporated into normality.
R: You don't see him as having leukemia anymore?

C: I just see him - I don't know - he's just slow - and I have to carry him everywhere I go.

Incorporation of this event as being normal occurred when a "cause" which was normal occurred. The child had been struck by a van. One of the siblings gave that as the reason the child could not walk, indicating that it had happened awhile ago. In actual fact it had happened within the proceeding two weeks and the child had not walked for several months. The examination after the accident attributed no damage as a result of this accident. Much later in the interview this same sibling related that the child had not walked for some time because of the medicine he was taking. The younger siblings gave clues about how they were incorporating this lack of mobility into normality as well. One of the children in the neighborhood had asked about the ill child's limp. The ill child said to the sibling who was telling of this event, "Why didn't you tell her I was hit by a van?". The sibling replied, "I did," and all of the siblings seemed happy with the solution.

6. Why Redefine Normal?

Two statements which siblings made became important to this researcher in considering the concept of normality as a component in the conceptualization of the siblings' perception of the experience under study. The first was made with reference to undergoing diagnostic tests.
He's got used to it I guess.

The second was made with reference to the necessity to undergo chemotherapy and suffer its unpleasant side-effects.

It's just a natural thing - everyone has to do things. Like a chore.

It appeared that by redefining normality siblings were more effectively dealing with the concomitants of day to day living in a family where a child was being treated for cancer.

THE RELATIONSHIP BETWEEN THE CONCEPTS AND THE PROPOSAL OF A CORE VARIABLE

The concept of special status for the ill child appears to be integral to the concept of a new normality. It appears that over time beginning with the creation of special status and in support of the maintenance of that concept the siblings construct a new definition of what constitutes normal. It is proposed that the process of redefining normality is the core variable in this data. The redefinition of normality appears to make it possible for the siblings to accept as normal the special status of the ill child, the necessity for the ill child to regularly undergo unpleasant diagnostic tests and treatments, and the periodic incapacitation of the ill child as a result of treatments.
The mortality of the ill child was not incorporated into the redefinition of normality in this data.

SUMMARY

This researcher's conceptualization of the sibling's perception of day to day living when another child in the family is being treated for cancer has been presented. In the next chapter the discussion will focus on relating this conceptualization to the literature.
CHAPTER V: DISCUSSION

INTRODUCTION

Chapter IV identified special status for the ill child and a new normality as concepts that emerged from the data. Redefining normality was identified as a core variable. In the following discussion, this conceptualization of the research data will be related to the literature from three perspectives. First, themes found in studies which reflect the sibling's perspective of life with a chronically ill child will be compared with themes found in this study. Second, the concepts identified in this study will be compared to similar concepts discussed in the literature. Finally, methodology used to arrive at the described conceptualization will be discussed.

COMPARING THEMES IDENTIFIED IN THE LITERATURE TO THEMES FOUND IN THIS STUDY

In this section, themes identified in studies reported in the literature are compared to those of the present study. The limited number of studies referred to reflects the scarcity of studies reported which address the siblings perspective.
A. Negative Feelings such as Anger and Resentment

The presence of negative feelings in the siblings, including anger and resentment with accompanying guilt at experiencing these feelings, is referred to in the literature by several authors (Share 1971; Spinetta, Kung, and Schwartz 1976; Kagen-Goodheart 1977; Burton 1975). Most of the data of these authors were based on parental reports. Although it was anticipated that a theme similar to these suggestions would be found in this study, that anticipation did not materialize. Perhaps the operative factor here was "not only do people interpret things differently, they focus their attention on different things" (Bogdan and Taylor 1975, p. 10). Furth (1980), using a methodology similar to that employed in this study, has demonstrated that a child's conception of society is vastly different than that of an adult. There is reason to believe that the view of siblings about living with a child with a life-threatening illness would be different than the adult's interpretation of the sibling's view.

In support of parental reports of the negative feelings demonstrated by siblings, S. Taylor (1980) found siblings admitted to occasionally having death wishes for their ill siblings and saying or doing things to the ill child which they could identify as being cruel or angry. The data in the present study did not show anger and resentment as being prominent themes. This is not to say they may not have formed a part of the siblings' perception. The interview
may not have elicited this aspect of perception or these feelings may not have been a component of perception at the time of the interview.

B. Isolation and Deprivation

S. Taylor (1980) found feelings of isolation on the part of the siblings to be the largest single effect of the ill child, with siblings feeling isolated from family relationships as the parent(s) and ill child formed a dyad which excluded them. Feelings of deprivation in terms of parental time and attention were prevalent. The present study does not seem to support this finding, but that may be a factor of the time period in the illness trajectory which was sampled, or a factor related to specific treatment or illness variables. The children in Taylor's study included a population with asthma and cystic fibrosis both of which can involve an extensive dedication of parental time in treatment procedures. In this study there was not daily involvement of parental time in treatment procedures.

The study of Harder and Bowditch (1982) also does not support the concept of isolation of the siblings. They found siblings reported that the family was drawn closer together as a result of the illness of one child. At the same time, however, some of the siblings complained about decreased parental attention as parents spent more time with the ill child.
C. Change

Two of the studies reviewed found change to be a theme (S. Taylor 1980; Iles 1979). However, the conceptualization of change by the two researchers was different.

Iles identified losses as the primary component of change. The losses related to quantity and quality of relationships with parents and with the ill child. In the present study loss was present as a theme particularly exemplified in concerns regarding possible death of one child but it was not a dominant theme in perception. This may reflect the stage of the illness existing at the time of the study, as Iles' sample included only two cases where the ill child was in remission. The others were in a more crisis-oriented period, that is, newly diagnosed, first exacerbation, or terminal. There is no indication that the length of the remission period had been established. In the current study, both ill children had been in remission for more than eight months and remained in remission throughout the study. There had been time for relationships to stabilize. Also, neither child had been hospitalized apart from the period associated with the initial diagnostic and treatment period. The data collection method may also account for the difference, as Iles asked children to draw a picture about the family to facilitate symbolic communication of perception. This method may have resulted in an expression of feelings not elicited by the interview technique used in this study. This reasoning is supported in the findings of
M. M. Taylor (Taylor 1980) which indicate that interview descriptions of families were cohesive, but family drawings depicted feelings of isolation.

S. Taylor (1980) identified change in relation to positive effects of the illness experience for the siblings. She commented on the siblings' acceptance of changes in the family caused by the illness, and the increased responsibility of the sibling with reference to participating with other family members in the treatment of the illness or improvement in the ill child's condition. Siblings performed chores for the ill child and assumed some parental functions regarding treatments, and monitoring the ill child's diet and medications. She states:

Some children were remarkably in tune with their parents and the ill siblings' feelings and tried to adjust their own behavior accordingly (p. 115).

The following statements which were made by siblings in Taylor's study, would have been identified in the present study as being related to the special status of the ill child.

I cut the grass for him so he won't wheeze.

I help her with her school work when she has to miss school so she won't get behind (pp. 60 - 62).

Harder and Bowditch (1982) also indicated that in their study the siblings referred to change in commenting on the increased number of chores for which they were responsible.
In the present study the overall concept of change has been incorporated into redefining normality.

COMPARING CONCEPTS IDENTIFIED IN THIS STUDY TO SIMILAR CONCEPTS DISCUSSED IN THE LITERATURE

A. Special Status of the Ill Child

The creation and maintenance of special status for the ill child has been described in this data as occurring cybernetically as an active process as siblings respond to the world around them.

The concept of special status of the ill child has been supported in the literature. Harder and Bowditch (1982) report siblings of children with cystic fibrosis as being aware of their brother's or sister's need for more time with their parents and accepting this requirement. The siblings also seemed to understand and support the importance of giving priority to the ill child's needs. They report siblings made the following statements with reference to family finances.

Mom always told me if it came down to no furniture or new clothes it doesn't matter. So long as we can help her have medicine anytime she needs it.

It's probably that little bit of extra money. I can't think of anything specific, just extra money we could use. But I really don't mind because its to help Joshua. (p. 118)
Burton (1975), although not naming the concept of special status, found indicators of it in parental reports of siblings showing lowered aggression, increased protection and extra care towards the child in families with cystic fibrosis particularly when the sibling was older than the ill child.

In a study which addressed the construction by the parent of social reality for the sick and the well child, Anderson (1981b) found well children were encouraged to develop social and psychomotor skill, whereas normal play and normal social relations for the ill child were discouraged. Social interaction was not emphasized but the mother-child interaction was intensified. This type of parental activity would contribute to the process identified in this study as construction and maintenance of special status for the ill child.

B. Redefining Normality

The analysis of the data in this study indicates that creation and maintenance of special status for the ill child are part of a larger process which has been termed redefining normality or constructing a new normality.

Normalization of the illness experience has been addressed in the literature from two points of view. Strauss (1975) describes this process from the point of view of the ill person, identifying normalizing as a basic strategy used by the ill person in the course of living with a chronic illness. The actions associated with the strategy are
dependent on such factors as the individual's symptoms, treatment regimens, and knowledge of others about the illness. Strauss includes an illustration of an application of this strategy by a child with a cardiac impairment.

... used to be especially fond of playing cow-boys and Indians. He was much in demand as an Indian because they were always getting shot and he could rest while he lay down and played "dead". (p. 58)

This behavior was illustrated in this study when the children were discussing reasons for the ill child not being able to walk and the ill child said "Why didn't you tell her I was hit by a van?".

Anderson (1981 b) describes the process of normalization as a component of the way in which parents of chronically sick children understood and described their child's illness, and a component of their interactions with the child. She stated families perceived normalization of the sickness was important in helping the ill child to accept the therapeutic regime. They did not consider the disease process as normal but they:

... constructed the illness experience with the child and for the researcher in such a way as to normalize the experiencing of a pathological process (p. 430).
RELATING THE METHODOLOGY TO THE LITERATURE

The grounded theory approach has been documented in the literature as useful in the study of clinical nursing problems. It has been utilized in nursing research to gain an understanding about the client's view of the situation (Stern 1980; Fagerhaugh and Strauss 1977). Two terms that appear frequently in literature in relation to this approach are ethnography and grounded theory. Aamodt (1982) succinctly differentiates between these two approaches indicating that ethnography refers to culture and cultural processes whereas grounded theory refers to social processes. This study being concerned with social processes has utilized grounded theory.

The data collection process was centered around eliciting descriptions of behaviors and feelings relative to specified experiences. Eliciting similar data from the same subjects at time intervals of six months can be cited in support of the validity of the data. Prior to the second interview with siblings of each family being conducted initial coding had been carried out. When topics which appeared to be related to previously identified codes, themes, and concepts occurred, the researcher concentrated on asking questions aimed at confirming their existence and clarifying their meanings. This is consistent with theoretical sampling (Glaser 1978) and with the suggestions of Aamodt (1982) to return to the scene to recheck observations.
The ideal method of data collection for this study would no doubt have been living with a family for a period of time as a participant observer. This being impractical, interviews were conducted during which the investigator prompted the siblings to discuss the experience of day to day living. Consequently, remembered experience was explored (Oiler 1981). The individual is thus interpreting "experience in reflection" (p. 179) having made sense of the experience or making sense of it in the process of interpretation. The researcher's task is then to answer the question "What is really going on here?", or in the words of Glaser (1978 p. 57) "What is the basic social psychological process or social structural process that processes the problem to make life viable in the action scene?".

The concepts of truth and reality take on a different perspective within the context of a qualitative study (Bogdan and Taylor 1975). Reality becomes subjectively defined by the participants and the researcher must attempt to present the subject's view of the world as seen by the subject at that moment in time with the following qualifications being added.

Just as different people may interpret the same things differently, so too may the same person interpret things differently at different times.

(Bogdan and Taylor 1975, p. 11)

The study of the sibling's perception of day to day living when another child in the family is being treated for
cancer is in part a study of relationships and factors affecting those relationships. The method used in data collection and analysis in this study has been directed at overcoming a method error identified by Sholter (1974) as existing in socio-psychological research.

Personal relationships and other human groupings do not exist and function as matters of fact, but are maintained by the intention of members to maintain them... Personal relationships need to be described in a way exclusively human; in terms of what the people in them are trying to do. (p. 223)

The intimate involvement of the researcher in the research process is documented as a frequent criticism of qualitative methodology (Bogdan and Taylor 1975; Cicourel 1976; Rist 1979). Oiler (1982) suggests bracketing as a means of controlling observer bias. Bracketing involves bringing an experience into clearer focus by controlled reflection, considering opposing views of the same situation, questioning, and being receptive. This process was employed in this study at several levels. Examples include the literature review being conducted as the data was being analyzed, the process of problem identification, the data collection procedure, and finally the data analysis procedure.

Fracturing the data and then putting the concepts back together as relationships are postulated goes beyond asking the individual to identify what is going on or to identify factors to which they are sensitive. In fact, Nisbett and
Wilson (1977) found people unable to identify the causes of their behavior. Bowers (1981) extends this conception to argue people have an ability to respond productively to information not fully specified or represented in consciousness. They argue this is consistent with a theory of tacit knowledge and implicit responsiveness. This researcher argues that the latter lends credibility to the research method followed in this study.

This research has demonstrated the utility of the described methodology for conceptualizing an individual's perception of a situation. It is recognized that reliability of the findings is a function of the number of experiences sampled and would be enhanced by additional data collection including extensive theoretical sampling.

The use of the approach of grounded theory does create a dilemma in terms of the traditional approach to replication of the study. The data collected for a second study would be different and the interaction between the coder and the data will be unique to that coder and that data as the researcher is an integral part of the data and the analysis. In grounded theory the analyst must do his/her own coding as the codes arise from the data and the memos written by the analyst during the coding process are integral to the development of emergent theory (Glaser 1978). This researcher did not find examples of replicating studies using grounded theory in the literature.
SUMMARY OF THE DISCUSSION

There is support in the literature for the concepts of special status and a new normality, and their relationship to the sibling's perception as postulated in this study. There is also support in the literature for the methodology used to identify the concepts. The implications of the findings of this study for nursing practice and nursing research are considered in Chapter VI.
CHAPTER VI: SUMMARY AND CONCLUSIONS

SUMMARY OF THIS STUDY

This study presented a qualitative approach to the conceptualization of the sibling's perception of day to day living when a child in the family was being treated for cancer. This study differed from previous research in that concepts were identified using the approach of grounded theory to identify social processes.

The purpose of the study was to conceptualize the sibling's experience of day to day living when another child in the family was being treated for cancer. Interviews were conducted with school-aged siblings of pediatric cancer patients. The data were subjected to a process of constant coding, comparison, and recoding to derive the concepts present in the data and to derive relationships between the concepts. Redefining normality was identified as the core variable in the data with the concepts of normality and special status of the ill child being identified as related to the redefinition of normality. The special status of the ill child was identified as an integral component of the new normality. A review of the literature indicated support for the presence of the stated concepts and for the methodology by which the concepts were derived.

This has been a preliminary study and as such its primary contribution to theory development is to raise
questions which indicate some direction for future research. Some implications for nursing practice arise from the data.

SUGGESTIONS FOR FURTHER RESEARCH

This study was approached from the point of view of social processes and grounded theory. An alternative approach to the conduct of this study would be that of ethnography which is concerned with culture and cultural processes. It is suggested that such a study be conducted for the purpose of comparing the utility of each in contributing to the development of theory in relation to perception of day to day living by siblings of children with life-threatening illnesses.

Comparison of the conceptualization of the data in this study with findings of studies reported in the literature suggest factors associated with the illness trajectory as well as experiences over time are salient in the sibling's perception. Research in the form of longitudinal studies and/or studies sampling a broad spectrum of day to day experiences over time would help to clarify the nature of the relationship of these variables to the sibling's perception of day to day living.

The data in this study indicate siblings' articulation of their knowledge about the illness condition is poor. Taylor (1980) found siblings demonstrated an inadequate knowledge. Health care workers do not appear to be seen as
a source of information by siblings. Research should determine the nature and source of the sibling's information about the illness condition and the part this information plays in the sibling's perception of day to day living in a family where a child is being treated for cancer. The adequacy of the information relative to its intended function should also be explored.

The population of this study was limited to siblings of children with cancer but the research related to children with other long-term illnesses was included in the comparison of the findings with the literature. These long-term illnesses generally came under the rubric of lifethreatening. Research which addresses the validity of grouping cancer with other long-term illnesses or chronic illnesses is in order at this time.

This study has demonstrated that the sibling is sensitive to much more information communicated to him about childhood cancer than that which is related verbally. This would suggest that studies which conceptualize communication as broader than verbal exchange are important in the understanding of the effect of the presence of the ill child on siblings.

Creation of special status for the ill child within the family system constitutes a change in the pattern of sibling relationships. Study should be directed at disclosing the comparative nature of sibling relationships in families where a child has a life-threatening illness and those where one does not exist.
The identification of redefining normality as the core variable which accounts for the majority of the behavior in this data suggests a relationship between the individual's definition of normality and the coping process. The nature of this relationship should be explored.

IMPLICATIONS FOR PRACTICE

In the introduction to this report referral was made to Orem's self-care concept and the necessity of understanding the sibling's point of view in calculating the therapeutic self-care demand as a part of determining the requirement for nursing. The conceptualization of the data in this study has reinforced that necessity.

The data has indicated the inadequacy of the sibling information about the illness condition. Interpreting this within the framework for nursing described by Orem (1980), a situation has arisen which is health-related, and within, which the sibling is required to function differently terms of his/her self-care actions. He/she may have inadequate information to meet the new requirements. Consequently a self-care deficit will exist. If the nurse has the ability or knowledge to assist the individual to meet his/her self-care requirements a need for nursing will exist. The data collected in this study has demonstrated a need for nursing exists for siblings of children with cancer in relation to assessing a knowledge base and acquiring knowledge which is a component of self-care ability.
The data has indicated that siblings of the ill child are active participants in physical care as well as in the process of helping the child to live with his illness. If the time spent with the ill child is an indicator of the quantity of care-taking and support activity, they have a much more important role to play in maintaining the quality of life of the ill child than do health care workers. Nursing has a responsibility to enhance the sibling's ability to fulfill this role by direct contact with the sibling and by working with the parent(s).

This study has reinforced that the presence of a life-threatening illness impacts on the whole family and the family members react individually and as a unit. The focus of nursing must then include the family as a unit as well as individual members.

The success of the group sessions as a technique for eliciting sibling perceptions would suggest group sessions might be utilized to encourage siblings to share experiences. Siblings may learn new caretaking and supporting techniques in such sessions as well as having an opportunity to clarify concerns.

The value of this study rests not in the specific findings which are particular to this study but in the admonishment to nurses which arises from the conceptualization of the data to expand the scope of practice and research to include the whole family of the child with cancer.
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APPENDIX "A"

PARENT'S CONSENT FORM

I am a registered nurse and a graduate student in nursing at the University of British Columbia. I am working on my master's thesis which is concerned with children's perception of day to day living when another child in the family is being treated for cancer.

If you agree that your child (children) may participate in this study, I would like to talk to those who are between 8 and 18 years of age and living at home, excluding the child who is under treatment. I would like to talk to your children individually or together, if there is more than one, depending on their preference. I would anticipate that our talk would last between 30 and 60 minutes. If the children are in agreement and you are too, I may ask to speak with them again at a later date.

If you have not shared the diagnosis of cancer or leukemia with your children, please let me know, and I will be careful not to give them this information.

Through this study, I would hope nurses can gain more information about the impact of serious illness on other children in the family that they can share with parents. This information would be useful in understanding and in
APPENDIX "B"

CHILDREN'S CONSENT FORM

Kathie McLaughlin has explained to me that she would like to talk to me about what it is like to live with a brother or sister who is sick, or has been sick, and still has to see the doctor from time to time. I have agreed that she may tape our conversations. I understand that I don't have to answer questions that I don't want to answer and that I can stop our talks at any time.

SIGNATURE: ____________________________

DATE: ____________________________
APPENDIX "C"
INTERVIEW SCHEDULE

"As we have previously discussed, I am a nurse, interested in knowing about how you see things from day to day during the time that _____ is sick, needs to go to the doctor, or even be in the hospital, taking medicines and so on."

The remainder of the interview will be conducted as a series of open-ended and probing questions, the content of which will depend on the interviewee's response with an effort being made to cover the general areas listed below. The first question will relate to a currently significant event in the sibling's experience.

GENERAL AREAS TO BE COVERED IN IDENTIFYING SIBLING'S PERCEPTION OF DAY TO DAY LIVING:

1) Activities;
2) Relationships;
3) Feelings;
4) Interferences and Activities;
5) Positive and negative aspects of having a child with cancer in the family;
6) Illness Variables.