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Attitudes of families towards their children's illness and hospitalization.

BOSTON UNIVERSITY
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ATTITUDES OF FAMILIES TOWARDS THEIR CHILDREN'S ILLNESS AND HOSPITALIZATION

A thesis

Submitted by

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CHAPTER I

INTRODUCTION

Statement of the Problem

This is a descriptive study of the attitudes of eleven lower class, urban families towards their children's illness and hospitalization. Each of these families had a seven to thirteen year old child with a physical illness requiring hospitalization on a medical, pediatric ward of Boston City Hospital. The study was designed to answer the following research questions with regard to these families:

1. What is the social setting in which illness takes place?
2. What are the events and circumstances which surround illness?
3. How does the family perceive and deal with illness?
4. What are the effects of illness and hospitalization on the family?

In relation to the social setting of illness, the study focuses on the family composition and relationships. These include personal characteristics of the child and family, relationships among family members, and relationships between family members and the extended family. It also includes the child's diagnosis and the number and length of his hospitalizations.

The events and circumstances surrounding illness include crises situations which occurred in the six months prior to hospitalization. Emphasis was placed on changes in the number of people in the household, on the quality of interpersonal relationships, and on some of the meaning of these to the family. When the social setting and the events and circumstances surrounding illness are known, it is possible to gain a greater understanding of why the family perceived the illness in the way they did, and why the illness affected the family in the way it did.

The perception of the illness includes when and how the parents recognized the child's illness, what they said concerned them most about this, and when and where they sought help. The mother's reasons for choosing Boston City Hospital and her attitudes towards it are described as well as her awareness of the diagnosis and her concepts of the etiology of the illness. If more is known about when and how a medical facility is used and what the attitudes of the patients are towards this facility, it may be possible to educate the patient - population to a more appropriate use of the facility if necessary. It may also be possible to add new services or revise old ones to make them appropriate to the needs of the people.

In relation to the effect of illness on the family the study focuses on changes in routines, changes in relationships and changes in the affect of a family member. More information about these can also result in improved service.

Theoretical Considerations

There have been several studies on the attitudes of a child towards hospitalization and illness, but there have been few studies from the family's point of view. Most of the latter seem to concentrate on the impact of the family upon illness, or on how the impact of illness on a family will in turn affect the patient. It is the opinion of the writer that although these are certainly important areas of concern, it is also important to know the impact of illness on the family members for their own sakes. The more that is known about the meaning of illness to a family, the more possible it will be for social workers and other professional people to help by methods of prevention or treatment.

Gerald Caplan and Erich Lindemann feel that each individual has an equilibrium of functioning in relationship to his environment. This equilibrium is kept stable by a series of homeostatic mechanisms which operate within his personality and within the social system of his network of close interpersonal relationships. During a

crisis, these homeostatic mechanisms are overpowered, and the individual can no longer solve the problem by his normal methods. Old conflicts which are symbolically linked with the present problem are revived during the period of disorganization of a crisis.[1]

Illness may arise in an environment in which the equilibrium has already been disturbed by other factors. Illness and hospitalization may be crises that cause disequilibrium, or both of these may be so. Whether illness arises from a disequilibrium and/or causes it, may influence the perception of the illness and the way with which it is dealt. These may also be influenced by the nature of the old conflicts which are revived at this time, and the extent to which they were resolved in the past.

Some people have studied the effect of the family or environment upon the onset of illness. Doctor Hinkle says:

> The weight of the evidence is that man's interaction with his "social" and "interpersonal" environment is relevant not just to his "emotional state" or to his "mental health", but to all of the illness that he experiences.This relationship is, in the last analysis, a "life and death proposition" for him. Man's interaction with his

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[1] Gerald Caplan, "An Approach to the Study of Family Mental Health," in The Family a Focal Point in Health Education, pp. 58-59.

> social environment affects the course of all his illness, sometimes to a great degree, and sometimes to only a small degree. How much, in what manner, and under what circumstances are the questions to be determined in each instance.[2]

Doctor Arthur Z. Mutter, professor of psychiatry at Boston University School of Medicine, has been conducting an exploratory study to identify crucial psycho-social variables in disease onset and to work out a method to study these. He found no particular variable in the psycho-social setting which is related to the onset of illness. It is the quantitative and qualitative nature of the events rather than the events per se which are important. An event must be viewed by the individual as causing some change in himself or his family before it can be related to the onset of illness. Depending upon biological and psychological factors the event will be important in maintaining health or illness.[3]

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[2] Lawrence E. Hinkle, "Ecological Observations of the Relation of Physical Illness, Mental Illness, and the Social Environment", Psychosomatic Medicine, vol. 23 (July-August, 1961), p. 295.

[3] Arthur Z. Mutter, "The Psycho-Social Setting in Which Illness Takes Place and Its Impact on the Family", paper presented at Psychiatric Grand Rounds of Massachusetts Memorial Hospitals, Boston, 1962.

Illness and hospitalization of a child may be a crisis situation not only to the child, but also to the family. Caplan has said,

> Not only will the support or lack of support of the family during crises have a marked effect on the outcome, but that outcome which may be most significant in terms of the future mental health of the individual may be expressed in terms of improved or worsened emotional relationships among family members,[4]

It is the feeling of the writer that these improved or worsened emotional relationships among the family members should be explored further not only because of the future mental health of the patient, but also because of the future mental health of the other family members.

In a workshop on the management of the parent in pediatrics, management of the parents of the chronically ill, acutely ill, and ambulatory patients were discussed. Although the discussion was mainly geared to the pediatrician's role, there are implications for social work. Veronica Tiza said that parents can adjust to a child's chronic illness if they can give up the fantasies and goals they had for the child before the illness, work through their grief over the loss, and accept the altered goals realistically. Once

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[4] Ibid., pp. 61-62.

they have done this, they can help the child strive toward optimal functioning.[5]

Melvin Lewis points out the importance of understanding the crisis that confronts the parents and the child. It is also important to understand the ward staff's feelings either as individuals or as a group and the impact of the interaction between the parents and staff.[6]

During the period of a crisis, especially at its peak, the emotional forces inside the individual and his interpersonal network are off balance. Help at this time, by family, close associates, and caretaking agents in the community, can weigh the equilibrium down in a positive direction in regard to mental health and produce lasting effects quite out of proportion to the effort expended.[7]

The workshop on the management of the parents in pediatrics and the study presented in this thesis are related to the concept of prevention as it is used in public health as well as to treatment. There is a current interest

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[5] Veronica B. Piza, et al., "Management of the Parent in Pediatrics Practice - Workshop, 1960", American Journal of Orthopsychiatry, vol. 32 (January, 1962), p. 54.

[6] Ibid., p. 66.

[7] Caplan, op. cit., p. 60

in applying this concept to a social work framework. Werner Boehm states that the prevention of social dysfunctioning is one of the three functions of social work. It entails "early discovery, control, and elimination of conditions and situations that potentially could hamper effective social functioning." He divides this further into the prevention of problems in the area of interactions between individuals and groups and prevention of social ills.[8] Illness, or negative after effects of it, could certainly hamper social functioning, and thus would be suitable areas for concern under the terms of this definition.

Lydia Rapoport discusses primary, secondary, and tertiary prevention. This study seems to relate to her concepts of secondary prevention and especially to specific prevention, a form of primary prevention. Secondary prevention includes case finding and emphasizes early diagnosis and treatment so that the duration of the distress will be shortened, the symptoms reduced, and the sequelae limited. Specific prevention implies some knowledge of causation and includes such things as provision for reducing the secondary effects of stress.[9]

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[8] Werner W. Boehm, "The Nature of Social Work," Social Work, vol. 3 (April, 1958), pp. 16-17.

[9] Lydia Rapoport, "The Concept of Prevention in Social Work," Social Work, vol. 6 (January, 1961), pp. 4-11.

It would seem that, when necessary, during a period of crisis, social workers could help parents work through their grief and adjust to a child's illness, could serve as a liaison between the ward staff and the parents, and could provide other tangible services and support to the parents to help relieve the secondary effects of illness and prevent further disequilibrium. However, knowledge of the meaning of illness to the family would be necessary in order to carry out these functions most effectively.

CHAPTER II

METHODOLOGY

Selection of the Sample

The sample was selected from the parents of seven to thirteen year old children who participated in the social group work program at Boston City Hospital. The program is designed to help children to adjust to hospitalization and illness and to minimize negative after effects of these. The groups may vary in size and membership from day to day. The most common reasons for choosing a group member are the nature of the illness or problems a child is having on the ward, either acting out or withdrawing. Sometimes, a well adjusted child is chosen if the worker feels this will be helpful to the other group members.

Boston City Hospital is a large, general, municipal hospital which also serves as a teaching center. It provides a wide variety of in-patient and out-patient services for both adults and children. Because of its location in the South End of Boston, a low income area, and because of its flexible payment plans, the hospital frequently draws its patients from low socio-economic classes.

An eight story building contains all the pediatric in-patient services. These include both medical and surgical services for boys and girls from infancy through age thirteen. Psychiatric consultation and evaluation,

when necessary, may be obtained from the child guidance clinic. There are almost no casework services, although there are plans to implement the casework program in the future.

This sample was limited to eleven families of children on two medical pediatric wards of Boston City Hospital. One is a girls' ward, the other a boys' ward. The names of the families were given to the writer by the two social group workers on those wards. Each worker chose them from the groups of children whose reactions to illness and hospitalization she was studying in detail.[10]

Methods of Data Collection

Data were collected from hospital records and from interviews with the mothers of the hospitalized children. Permission for this was obtained from Doctor Sydney Gellis, Director of Pediatrics at Boston City Hospital, and from Miss Marian Chuan, director of the social group work program.

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[10] Miss Judith Bailey studied the girls' reactions in an unpublished master's thesis, Boston University School of Social Work, 1962. For cross reference, the code letters referring to the child in her thesis are given here, followed by a dash and the letter given to the corresponding family in this thesis: B-B, C-A, D-F, E-D, F-E, G-C.

Miss Audrey Montesi studied the reactions of the boys in an unpublished master's thesis, Boston University School of Social Work, 1962. The relationships are presented as above: A-G, D-J, L-H, M-I. The K family was not included in her paper as he was seen individually, but not in a group.

The data from the hospital records were collected with the cooperation of the social group workers who made their records available. These data include identifying information about the child, the child's medical diagnosis, and the reason the child was selected to join a group. (See Appendix, Schedule A.)

The mothers were contacted by letter or telephone. The study was then explained to them and an appointment was made for a home visit. The mothers were told that the study was connected with Boston University. They were also told that its purpose was to study attitudes of families of hospitalized children towards the child's illness and hospitalization, but were not told of any direct relationship to the social group work program. In this way it was hoped to reduce the possibility of parents being unable to express negative or ambivalent feelings towards the hospital.

Seven of the home visits were made while the child was in the hospital. The other four were made within ten days of discharge. The visits lasted approximately an hour and a half.

A structured questionnaire designed by Doctor Arthur Mutter after two years of exploratory research was used in the home visits. (See Appendix, Schedule B). It consists of a series of open-end questions dealing with

the areas discussed under the statement of the problem. At the beginning of the interview, the purpose of the study was again explained. The mothers were then told that a questionnaire would be read and the answers written down. If the meaning of a question was not clear to a mother, the wording was changed. The order of asking the questions was changed when a mother brought up an area that appeared later in the questionnaire. If a mother was hesitant to answer questions at the beginning of the interview, these were usually repeated later.

Sometimes, in answering these questions, the mother mentioned other crises or feelings. These were usually related to special feelings for this child or changes in the quantity or quality of family relationships prior to the last six months. When it was felt these were relevant, they were explored, either at the time they were mentioned or at the end of the interview, to get a better understanding of the mother's attitude towards the child and his hospitalization and illness. The questions for these periods were not specific, but were unstructured and adapted to the individual situation.

Limitations of the Study

The study was limited by the small number of families which were interviewed. This makes it inadvisable to generalize the results to a larger population. Since the children in these families were all in group work groups,

it is possible that the parents' attitudes towards the groups or contacts with the group workers influenced the perception of the child's illness and/or the hospital.

It has been demonstrated that children who showed the most successful adjustment on a ward were those who seemed to have the most satisfying relationships with their parents and whose parents were most able to adapt to their child's hospitalization and illness.[11] Since the children in the groups were often those with problems of adjustment on the ward, it is probable that the sample was biased in the direction of more disturbed families.

This study was limited to parents of latency age children and to a low socio-economic group. The results may differ for other ages or socio-economic classes.

The method of interviewing was in some ways a limitation for this study. In some interviews mothers would volunteer information which was not directly asked for on the questionnaire but which was related to their attitudes towards the child and his illness. However, in other cases where there may have been equally relevant information, this was not brought out. If these interviews had been preceded

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[11] Dane G. Prugh, et al., "A Study of the Emotional Reaction of Children and Families to Hospitalization and Illness," American Journal of Orthopsychiatry, vol. 23 (January, 1953), pp. 70-104.

and followed by a focused, but unstructured interview on social history, this would have provided a more complete picture of each family.

Because it will not be possible to follow-up these families, it is impossible to assess anything but their immediate reactions. The more lasting effects, if any, of illness on the family may not become apparent until some time later.

CHAPTER III

SOCIAL AND PERSONAL CHARACTERISTICS

This chapter will deal with the personal characteristics of the child and family and the social setting in which the child lived at the time he became ill. Table 1 shows the sex, age, race and religion of the child and whether or not the parents, without being asked, verbalized a feeling that this child was a special child in the family.

TABLE 1

PERSONAL CHARACTERISTICS OF THE CHILDREN

Child	Age	Sex	Race	Religion	Special child
A	12	F	N	Prot.	Yes
B	13	F	N	Prot.	Yes
C	9	F	N	Prot.	Unknown
D	11	F	N	Prot.	Unknown
E	10	F	N	Prot.	Unknown
F	11	F	N	Prot.	Yes
G	10	M	W	Cath.	Yes
H	10	M	N	Prot.	Yes
I	7	M	W	Cath.	Yes
J	12	M	N	Cath.	Unknown
K	11	M	N	Cath.	Unknown
Total	11	5 M 6 F	2 W 9 N	4 Cath. 7 Prot.	6 Yes 7 Unknown

From the table it can be seen that the group is almost evenly divided between boys and girls. The ages of this group of children vary from seven to thirteen, the median being eleven. Nine out of a total group of eleven

children were Negro. This high proportion of Negroes is not consistent with the normal proportion of Negroes at Boston City Hospital, nor in the group work program, but seemed to be a coincidence occurring at the time this population was chosen. Four of the boys were Catholic, the rest of the children were Protestant. Both white children were Irish Catholics.

All but one of the Negro children came from Southern Negro families. That is, the parents and/or the children, usually both, came from the South. The other Negro family came from Ohio. This is in contrast to the two white families both of which had their roots in this area.

The number of children in these families ranged from one to twelve with a median of five.

As can be seen in Table 2, there were four main reasons why the mothers said they felt these six patients were special or different in some way. In both cases where there was only one boy in the family, he was considered special. Some children were considered special because of their ordinal position in the family. This included an oldest or youngest child in a family, and one girl who had remained the youngest child longer than her siblings had. One child (H) was considered special for two reasons. Three mothers (A,B,H) felt these children were also special to the fathers.

TABLE 2

VERBALIZED REASONS WHY CHILD WAS CONSIDERED SPECIAL

Reasons	Male	Female	Total
Sex	2 (G,H)	-	2
Only child	-	1 (A)	1
Position in family	1 (H)	2 (B,F)	3
Behavior	1 (I)	-	1

Table 3 shows the child's diagnosis, the number and total length of his hospitalizations and the reason he was chosen for the social group work groups. The children had a wide variety of medical diagnoses and were chosen for the group work groups for many reasons. Most of the children had only one hospitalization between October, 1961, and February, 1962. However, one of the girls and two boys were in the hospital two or three times. The sexes varied in the length of the hospitalization. Most of the girls remained in the hospital less than two weeks while all of the boys but one remained three to eleven weeks.

The ages of the mothers ranged from twenty nine to thirty eight years with a median age of thirty four and one-half years. The ages of the fathers or stepfathers ranged from twenty four to thirty nine years with a

median age of thirty seven years. The twenty four year old was a stepfather (A) who did not live with the family.

TABLE 3

CHILD'S ILLNESS AND HOSPITALIZATION

Child	Medical Diagnosis	No. of Hospitalizations between 10/61 and 2/62	Total Length of Hospitalization	Reason for Being Chosen for Group
A	Vomiting, failure to thrive	1	14 days	Nature of illness, needed experience in socializing with peers
B	Hemogronia (undiagnosed at time of interview)	1	15 days	Length of hospitalization, oldest child on ward
C	Convulsive disorder? spasms of mouth and hand	1	9 days	Diagnostic observation
D	Pneumonia	1	8 days	To provide others with normal peer relationship
E	G.U. infection and enuresis	1	12 days	Nature of illness
F	Arthritis	2	17 days	Chronic home situation
G	Asthma	3	40 days	Nature of illness, no. of hospitalizations

TABLE 3 cont.

CHILD'S ILLNESS AND HOSPITALIZATION

Child	Medical Diagnosis	No. of Hospitalizations between 10/61 and 2/62	Total Length of Hospitalization	Reason for Being Chosen for Group
H	Glomerulnephritis and hypertension	2	17 days	Acting out on ward
I	Rheumatic fever	1	77 days	Length of hospitalization, "perfect patient"
J	Rheumatic fever	1	52 days	Length of hospitalization, acting out on ward
K	Toxic synovitis	1	14 days	Acting out on ward

The marital status of the parents is shown in Table 4.

TABLE 4

PARENTS' MARITAL STATUS

Status	Male	Female	Total
Married	2 (H,K)	4 (A,B,C,D)	6
Separated	2 (G,I)	2 (E,F)	4
Widowed	1 (J)	-	1
Total	5	6	11

About one-half the children came from intact families. A higher proportion of girls than boys came from intact families. However, two of the girls' mothers who considered themselves married were not now living with their husbands. One of the husbands (A) was overseas in the army. His wife could have gone with him, but decided against this. The other husband (B) was in Deer Island, a prison, because of non-support. Thus, the total number of mothers not now living with their husbands was seven out of a total group of eleven. Five of the six "special children" came from these seven families.

The families were supported by various means as can be seen in Table 5. The one pension mentioned was a widow's pension from a merchant marine firm. In one of the families supported by both parents, and in the family

supported by the father and A.D.C., the father supported the mother but not the ill child.

TABLE 5

FAMILIES' MEANS OF SUPPORT

Means of Support	Male	Female	Total
Father	2(H,K)	2(C,D)	4
Mother-Father	1(G)	1(A)	2
A.D.C.	1(I)	2(B,F)	3
Father-A.D.C.	-	1(E)	1
Pension	1(J)	-	1
Total	5	6	11

In the study discussed in Chapter I, Doctor Arthur Mutter devised rating scales to help measure the psychosocial setting in which the illness takes place and the impact of the events in this setting on the family. The criteria for the following four scales were taken from Doctor Mutter's scales.

Doctor Mutter's criteria for rating the social composition of the family were based on the Glueck Scale. They were:

Poor: disintegrated, "home just a place to hang one's hat", self-interest of members exceed group's interest; extreme emotional and/or physical deprivation.

Fair: elements of cohesiveness but some evidence of some family members pulling away from the family unit.

Good: strong "we" feeling as evidenced by cooperativeness of group interests, pride in home, affection for each other.

Table 6 shows the social composition of these families.

TABLE 6

RATING OF SOCIAL COMPOSITION OF FAMILIES

Rating		Number of Families
Poor	1	1 (A)
	2	2 (G,I)
Fair	3	2 (B,E)
	4	4 (C,F,H,J)
Good	5	2 (D,K)
	Total	11

It seemed that this was not a disentegrated group of families. Only one family received the lowest rating, and eight received a rating of fair or better. Both white families (G,I) received a rating of 2. Both families with working mothers (A,G) received low ratings on this scale. However, it seemed in both instances that the families were disintegrated before the mothers went to work.

The families' relationships to their extended families were rated in Table 7 according to the following criteria:

Loose: rare contact with kin (less than once every six months) and kin not readily available physically or emotionally.

Medium: contact less than once a week

Tight: personal or telephone contact with kin at least once a week; kin readily available

This information relates mainly to the mother's relatives.

TABLE 7

RATING OF KINSHIP TIES

Rating		Number of Families
Loose	1	2 (A,G)
	2	1 (I)
Medium	3	2 (B,F)
	4	1 (K)
Tight	5	5 (C,D,E,H,J)
	Total	11

From this it can be seen that eight families received a rating of 3, 4 or 5 and almost half the families have tight kinship ties. Families A, G, and I received the lowest ratings on this scale as well as on Table 6. All three of these families had close relatives living in the Boston area. The mothers of Mrs. G and Mrs. I died when they were quite young. Both of these women spent some time in foster homes as well as time with relatives.

Although Mrs. I retained a close relationship with her sister until a year ago, both women seemed to have had loose ties with other family members for a long time.

It was not possible to evaluate the fathers' roles because of a lack of information in many families. The mother's role as a wife was not evaluated because of the large number of families which were not intact. The mother's role as a mother was rated as:

Poor: lack of awareness of needs and interests of children, deprives children emotionally and/or physically.

Fair: some awareness and some ability to act appropriately.

Good: aware of and acts appropriately on her awareness in respect to needs of children.

TABLE 8

RATING OF MOTHER'S ROLE AS A MOTHER

Rating		Number
Poor	1	1 (A)
	2	3 (E,G,I)
Fair	3	
	4	5 (B,C,F,H,J)
Good	5	2 (D,K)
	Total	11

Since no detailed information was received about other children in the family, this table refers mainly to the mother's role as a mother to the patient. Nine families received the same rating on this scale as on Table 6. The other two (B,E) shifted one point in either direction. Seven of the mothers received a rating of 4 or 5 on this scale while the other four mothers received a rating of 1 or 2.

The A family consistently received the lowest rating on the three preceding scales. The child (L) was a twelve year old girl who was hospitalized for two weeks for vomiting and failure to thrive. She lived with her thirty year old mother and the mother's girl friend in a small apartment in a very substandard neighborhood. Her twenty four year old stepfather had been overseas for one year in the service. L was an illegimate child and had never seen her own father. She was brought up in Alabama by her maternal grandparents until the grandmother's death two years ago. At that time she came to live with Mr. and Mrs. A neither of whom wanted her. Mr. A continued to support Mrs. A, and she went to work to support L. When Mr. A was sent overseas, Mrs. A decided to stay in Boston. The friend moved in two months ago as Mrs. A was lonesome. Mrs. A's father, who, at the time of the interview, lived in Boston, came to visit her about twice a year. She had almost no contact with her sister or

brother. Mrs. A felt that although she could get in touch with her family, they would be of no help to her.

Mrs. A said she "don't know nothin' about kids," although she got along with L sometimes. These times were apparently infrequent as she felt L was "not friendly", but wanted a lot of Mrs. A's time and attention. Mrs. A felt she was too tired at night to spend time with L, and she had other things she would rather do. She did not know the name of the school L attended, although she knew where it was, and she was very vague about L's interests and activities. Mrs. A summed their problems up by saying, "L needs a mother", and shrugged her shoulders. She gave the interviewer the impression she wished she could care more.

The mother's role as a housekeeper was rated as:

Poor: not able to cope with household chores

Fair: some ability, inconsistent

Good: able to manage her household duties

TABLE 9

MOTHER'S ROLE AS A HOUSEKEEPER

Rating		Number
Poor	1	-
	2	2 (G,I)
Fair	3	2 (A,F)
	4	1 (B)
Good	5	6 (C,D,E,H,J,K)
	Total	11

More than half of the mothers received a rating of 5 for housekeeping. Two of these (D,K) also received that rating on Tables 6 and 8. The mothers (G,I) who received a rating of 2 on this scale received that rating on Tables 6 and 8. One of them (I) also received a rating of 2 on Table 7. With the exception of these four families, there was no consistently close relationship between the families' ratings on this and Doctor Mutter's other scales which were used here.

CHAPTER IV

HOW THE FAMILY PERCEIVES AND DEALS WITH ILLNESS

There were three kinds of physical symptoms which were recognized by these families: pain, loss of appetite, and external physical change. External physical change includes those symptoms which could be seen by the parents; such as, stiffness in walking, convulsions, swelling, blood in urine, breathing difficulty, and vomiting.

Table 10 shows the symptoms recognized by the parents.

TABLE 10

PHYSICAL SYMPTOMS RECOGNIZED BY PARENTS

Symptom	Male	Female	Total
Pain	3(I,J,K)	4(A,B,D,F)	7
Loss of appetite	1(I)	1(A)	2
External physical change	4(G,H,I,K)	5(A,B,C,D,F)	9
No symptoms recognized	-	1(E)	1

Two (I,K) of the five mothers noticed more than one symptom in their sons. Four (A,B,C,D) of the six mothers noticed more than one symptom in their daughters. One mother (E) took her enuretic daughter to the hospital when an A.D.C. worker told her to do this. The mother was unaware that a diagnosis of G.U. infection had been made. She said her child was wetting the bed, and this was not an illness.

Nine of the mothers stated they had no difficulty in recognizing symptoms in their children. Two mothers (H,J) however, felt this had been difficult until their sons' symptoms had become severe because the children did not complain.

Table 11 shows the symptoms which the parents said concerned them. The mother (E) who was not aware of any illness was not concerned.

TABLE 11

SYMPTOMS CONCERNING THE PARENTS

Symptom	Male	Female	Total
Complaints	4 (G,H,J,K)	2 (B,F)	6
Apparent physical symptoms	2 (H,I)	4 (A,C,D,F)	6
No concern	-	1 (E)	1

The parents of the girls expressed most concern about apparent physical symptoms. The parents of the boys expressed most concern about their children's complaints. Nine of the families noticed no previous change in the child's behavior which may have been related to the illness. The other two families (B,I) felt the children became more demanding and impatient.

The illness and/or hospitalization often had an effect upon the child's usual interests and activities. As can be seen in Table 12, all of the boys and seven of the total group showed some change in their usual interests or activities which were noticed by the mother.

TABLE 12

EFFECT OF ILLNESS ON CHILD'S USUAL INTERESTS AND ACTIVITIES

Effect of Illness	Male	Female	Total
Some activity change	4 (H,I,J,K)	2 (B,F)	6
Loss of interest in all usual activities	1 (G)	0	1
No change	0	4 (A,C,D,E)	4
Total	5	6	11

Most of the mothers tried to do something to help the child before going for medical treatment. Two of them (A,E) asked advice from a friend or relative. As can be seen in Table 13, eight of the eleven mothers tried at least one form of home treatment. This included bed rest and medication. The most common forms of medication were aspirins or rub-downs with patent medicines. The other form of treatment was mentioned by the mother of the enuretic girl (E). The mother awakened her each night before the mother went to bed.

TABLE 13

HOME TREATMENT BEFORE PARENTS SOUGHT MEDICAL ASSISTANCE

Treatment	Male	Female	Total
Rest	2 (G,H)	2 (B,F)	4
Medication	4 (G,I,J,K)	4 (A,B,E,F)	8
Other	-	1 (E)	1
None	1 (H)	2 (C,D)	3

The length of time between the parents' recognition of the illness and the hospitalization ranged from the same day to several months. However, nine of the families sought medical aid within a week after noticing symptoms. Three families (C,D,G) sought medical assistance the same day the symptoms were noticed. Six families (A,F,H,I,J,K) sought medical assistance within two days to one week, and two families (B,E) waited more than one week.

All the mothers with one exception went first to Boston City Hospital for medical assistance. The one exception (F) used a private doctor because it was more convenient, but was not satisfied with his treatment. As the mother found Boston City Hospital helpful in the past, she then took her daughter there.

The other mothers chose Boston City Hospital because it was convenient, helpful, inexpensive or a combination of these. Table 14 shows the parents' reasons for choosing Boston City Hospital and their attitudes towards it. These attitudes are related only to this illness.

TABLE 14

REASONS FOR CHOOSING BOSTON CITY HOSPITAL AND ATTITUDE TOWARDS IT

Reasons	Positive	Ambivalent	Total
Convenient	2 (H,K)	-	2
Helpful	1 (J)	1 (E)	2
Inexpensive	3 (A,B,C)	-	3
Convenient-helpful	1 (D)	2 (F,I)	3
Convenient-inexpensive	-	1 (G)	1
Total	7	4	11

Whatever their original reasons for choosing Boston City Hospital, most of the parents ended up with positive feelings towards it. Three (E,F,I) of the four people who expressed ambivalent feelings towards the hospital had chosen it, at least in part, because it had been helpful in the past. Three (E,G,I) had not based the negative part of their ambivalence on the way the hospital had dealt with the illness necessitating this admission. Mrs. E felt they had not cured her daughter's enuresis,

although she had been hospitalized for a G.U. infection. Mrs. G objected to the way her son had been treated on the accident floor, and Mrs. I objected to their postponing her son's tonsillectomy. He had been hospitalized this time for rheumatic fever. These three families (E,G,I) all received low ratings (2) on Table 8 which rated the mother as a mother. Although Mrs. F received a higher rating (4) on that scale, it is possible that due to the many crises which had recently occurred and the special feelings she had for the patient (see Chapter VI), she felt she was not as able to fulfill the patient's needs as she should have been.

In eight of the nine cases (A,C,D,E,G,H,I,J,K) where there was a definite diagnosis, the parents were aware of at least the name of the child's diagnosis. Mrs. A was aware of the enuresis, but not of the G.U. infection which was the reason for the hospital admission. In both cases where no definite diagnosis was made (B,F), the children were "special children". Both mothers seemed to over react to the child's illness. This was possibly due to their own feelings about the child combined with a realistic sense of uncertainty as to what was wrong. The two mothers (A,E) whose children had lived most of their lives with their grandmothers seemed to have a very limited awareness of the child's

illness.

The mother's conception of the etiology of the illness can be seen in Table 15.

TABLE 15

MOTHER'S CONCEPTION OF ETIOLOGY

Etiology	Male	Female	Total
Internal	-	1 (E)	1
External	1 (H)	2 (A,C)	3
Both	2 (G,I)	2 (D,F)	4
Unclear	2 (J,K)	1 (B)	3
Total	5	6	11

Some examples of external factors were a virus, cold weather, food, or being hit. Internal factors were physical or psychological. Some examples of these were susceptibility to illness, bad tonsils, a cold or bronchitis which a child had at the time of illness, being lazy, or working too hard. Mrs. I, who mentioned both internal and external factors, said that her son's rheumatic fever had been caused by a strep throat, bad tonsils, a virus, lack of green vegetables, and the fact that the mother had had shortness of breath when the patient was born.

All the mothers whose concepts of etiology had an external component (A,C,D,F,G,H,I) recognized

external physical symptoms in their children. With one exception (G), they expressed most concern about external physical symptoms. With the exception of Mrs. G, the mothers whose concepts of etiology had an internal component (D,E,F,G,I) recognized either pain or no physical symptom at all.

CHAPTER V

EFFECT OF ILLNESS ON THE FAMILY

The illness had three known types of effects on these families: changes in routines, changes in relationships, and changes in the affect of a family member.

As can be seen in Table 16, the illness had an effect on the housework of the mothers of all of the boys and three of the girls. One mother's (H) work was affected by doing less work and by departing from her usual time schedule.

TABLE 16

EFFECT OF ILLNESS ON HOUSEWORK

Effect	Male	Female	Total
Less done	4 (G,H,I,J)	2 (B,F)	6
Work times changed	2 (I,K)	1 (C)	3
No known change	-	3 (A,D,E)	3

Illness had a known effect on the work routine of only one father (H). He said that he rushed through his work so that he would finish on time to visit his only son and favorite child in the hospital. However, this was the only father present during an interview. It is impossible to know if other fathers reacted this way or

had their work routines changed in other ways without their wives being aware of it.

Table 17 shows the effect of illness on the relationships between the parents.

TABLE 17

EFFECT OF ILLNESS ON PARENTAL RELATIONSHIPS

Effect	Male	Female	Total
Increased friction	-	1 (C)	1
Relationship strengthened	2 (H,I)	1 (B)	3
No clear effect	3 (G,J,K)	4 (A,D,E,F)	7
Total	5	6	11

In four cases (A,E,F,J) the mother's husband did not know of the child's illness. If these cases are omitted, it can be seen that in four of the remaining seven cases the illness had some effect upon the parents' relationships. Two of these were intact families (B,H); in two, the parents were separated (C,I).

The relationships were strengthened when two mothers (H,I) felt their husbands were going out of their ways to be nicer and more helpful. The third mother (B) did not see her husband, but they began to write to each other more frequently. In these letters she asked for and received support for other issues as well as for

her feelings about the illness.

There was increased friction in the relationship between Mr. and Mrs. C at the time of the patient's hospitalization. In the early years of their marriage there had been conflict over authority and the amount of service Mr. C could expect from his wife. They resolved this by Mrs. C's allowing her husband to make all major decisions. He allowed her to work as a cook during the summers and to work part time during the rest of the year. Except for the summers, she was always home to serve his meals, and she kept the apartment as neat as he wished. They got along very well; and during the two years before their daughter's hospitalization, Mrs. C voluntarily, gradually decreased and then stopped her working. Mr. C worked in the late afternoon and evening. When their daughter was hospitalized, some of the old conflicts were revived. Mrs. C would prepare his dinner, but could not serve it to and visit with him before he left for work. She visited the patient in the afternoon, so she would not have to leave her younger child alone in the evening. Although these and similar conflicts never became extremely serious, they did create more tensions in the home.

Although all of the mothers mentioned the time spent visiting at the hospital, only two mothers (G,I)

felt the illness or hospitalization affected their looking after the other children. Mrs. G felt that because of the illness and hospital visiting, she did not have much time to spend with the other children. Mrs. G is one of the two working mothers included in this study. The other working mother (A) had no other children. Mrs. I said that the illness and hospitalization had made it necessary for her to give all the children a little less attention and to give her eleven year old son more responsibility.

In one case (F) it was felt the father's relationship with the other children changed when the patient became ill. The patient had a great deal of special meaning to the father. Since the patient had been ill, the father talked with the other children and expressed interest in and concern for them. However, he no longer played with them or shared in activities with them.

All the mothers except one (E) expressed worry or concern about the patient's hospitalization. All but one (G) felt that those fathers who knew of the illness also were worried or concerned. At least one and usually all of a patient's siblings were known to be worried or concerned except in the E. family.

In eight families, the illness had no known effect on the relationships of the family to close

friends or relatives. Three families of boys (H,I,J) had less contact with close friends or relatives because of the illness.

None of the parents felt that the patients wanted less attention from them when they became ill. Five children (A,B,F,G,I) wanted more attention, and there was said to be no change in the relationship between the parents and the other six patients. Two parents (C,H) mentioned being afraid to discipline the child because it might aggravate the symptoms.

In all of the families but E, there was a known effect in at least one of the areas discussed in this chapter.

CHAPTER VI

PSYCHO-SOCIAL SETTING AND CRISIS

In seven of the families there were known events in the psycho-social setting close to the time of illness which seemed to influence the way that the family perceived and dealt with the illness or its effects on the family. Those events involved: loss by death or separation of a close family member (families B,G,I,J); addition of a new person into the household or return of a family member (A,B,F); changes in family relationships (F,H,I); changes in the behavior of a family member (I); illness of a close friend or family member (F,H,J); affective change in a family member (B,F,J); onset of development of secondary sex characteristics (F); and change in housing or schools (A,F,H,I).

This can possibly best be understood by briefly examining the events in each family and some of the meaning of these events to the family. Patient A was a twelve year old girl who was hospitalized for vomiting and failure to thrive. Within the last six months there was an addition of a new member to the household, and a school change for the patient. The family consisted of the patient, her mother, and the patient's stepfather who was overseas in the service. The patient had been brought up by the maternal grandmother until the

grandmother's death two years ago. Although the step-father supported Mrs. A, she worked to support the patient. Her employment was resented by the patient who felt Mrs. A should have been home as the grandmother was. About five months before the illness, the family moved to an unsatisfactory apartment. The patient had always had difficulty in getting along with people and was a slow learner, so the necessary school change was also difficult for her. Those factors seemed to have increased the tension in the home.

Two months before the illness Mrs. A's girl-friend who worked in the laundry with her moved in with the family. Mrs. A liked having another person around, as she was not so lonesome. Unlike Mrs. A, the friend liked children and played with the patient. The patient began to eat better when the friend moved in. It is possible that the friend helped to slightly increase Mrs. A's understanding of the patient and her awareness of the child's needs. This may have had some influence on the mother's ability to act as soon as she did when she noticed the child's symptoms. This illness was the first time she had ever worried about the patient.

Patient B was a thirteen year old girl who was hospitalized with hemogronia which had not been diagnosed at the time of the interview. This case illustrates

loss of a family member, return of a family member, and an affective change in a family member. The B family consisted of Mrs. B, Mr. B who had been in prison for eleven months, and their eight children. The patient was the third oldest child, and both parents felt especially close to her. Within the six months before the hospitalization, both oldest daughters were married, moved out of the household, had children, and the oldest daughter and her family moved back in. Mrs. B felt that the older girls' leaving the household were positive events for the patient who could then have more control over the younger children. She became closer to Mrs. B and tried to be more helpful. The parents had mixed feelings about these events. They were glad the girls had married and moved to homes of their own. It gave Mrs. B more room and more time to spend with the younger children. However, they were upset that the girls were pregnant when they were married, and Mrs. B wondered how they were getting along.

The addition of her two nephews to the family had no known effect upon the patient's relationships to her family and friends. She said she would not have babies until she was old enough, but played with these babies and enjoyed them. None of the family liked having the oldest daughter and her family move back into the

household. The daughter worked, and Mrs. B had the responsibility of caring for the baby. It was necessary to rearrange the household to make sleeping space for them.

Mrs. B had felt she could rely on the patient for help during these crises. Now that the patient was ill, not only had another crisis been added, but Mrs. B had lost a major source of support. She felt that she and the patient missed and needed Mr. B during this illness and the other crises. This may have stirred up feelings of guilt which Mrs. B had when he was sent to prison because of non-support. She tried not to let her family know just how upset she was, but this illness seemed to have increased her awareness of and concern about the other crises. Also, the other crises seem to have affected and intensified her feelings about the illness.

The patient in the F family was hospitalized twice because of a question of arthritis. A definite diagnosis was not made. Addition of a new family member into the household, changes in family relationships, illness of a family member, affective change in a family member, onset of development of secondary sex characteristics, and change in housing all occurred in the six months prior to the illness.

The patient was the oldest of seven children.

There was no father in the home, and Mrs. F had no contact with her former husband or the other four fathers of her children. Six months before the interview, the youngest child was born and three months later sent to the hospital because of diarrhea. She was at Boston City Hospital at the same time the older patient was. The affective environment in the home had changed somewhat as the patient was physically uncomfortable and cranky, and Mrs. F was quite upset. The family discovered soon after moving that the new apartment was unsatisfactory, as it was drafty and could not be properly heated.

Although the baby was not wanted by Mrs. F or the patient, Mrs. F said once she was born she loved her as much as she loved the others and cared for her the best she could. The patient liked her when she was sure she would not have to wash the diapers. When this baby became ill and was separated from the family, Mrs. B was upset. She also became more aware of the patient's illness and absence because ordinarily the patient would have cared for the other children while Mrs. F was visiting the baby.

The physical development of the patient was regarded as a crisis situation. It was a source of great concern to Mrs. F as it made her more conscious of the fact that the patient was an illegimate child

and would soon find this out. It also made her more aware of her special feelings towards the patient. This combined with the fact that no definite diagnosis had been made and her general worry about recent events seemed to make Mrs. F especially concerned when this child became ill.

The patient in the G family suffered a loss by separation of a close family member. He was a ten year old boy who had asthma, an illness which had a lot of meaning to his mother. His parents were separated between his second and third hospitalization after a long period of incompatability. Mr. G also had asthma. The patient's illness, coming at the height of the marital friction, seemed to increase the mother's tendency to identify the patient with the passive and unpleasant qualities of his father. Some of the doctors had told Mrs. G that asthma comes from some emotional factors. This was an extremely frightening idea to Mrs. G whose father was mentally ill and very regressed.

There was a change in family relationships in the H family as well as illness of a family member and a school change for the patient. A cousin of the ten year old patient was ill with glomerulnephritis a few months before the patient was. Although the illness had little effect on the H's at the time, his recovery

later gave the H's confidence that their son would also recover. When the patient developed hypertension as a secondary effect of the glomerulnephritis, it may have seemed even more complicated because the cousin did not have this. The change in family relationships came because the father would not enter into activities with the other children while the patient was ill. The school change seemed to be a positive event for the patient who had not related well to the teacher in the old school. This teacher had hit him, and this event was associated by the parents with the etiology of the illness. The child and family were happy with the change.

In the I family there was a loss by separation of a family member, change in the behavior of a family member, and change in housing and school. The patient, the second of five children, was hospitalized for seventy seven days because of rheumatic fever. His older brother was sent to a state training school about a month before the patient's hospitalization after a period of severe acting out. The loss of this child seemed to increase Mrs. I's special feelings for the patient who was quiet, affectionate, and "good". These feelings plus the fact that she could not rely upon him for support at the time of the illness or the change in

housing which they made while the patient was ill, seemed to have contributed to the general anxiety which Mrs. I had and to have increased her concern about this child's illness.

The twelve year old patient in the J family was hospitalized because of rheumatic fever. There was a loss by death of a family member, illness of a family member, and affective change in a family member. In the six months preceding the patient's hospitalization, Mrs. J's sister died and her brother underwent a serious operation. His condition was still critical at the time of the patient's hospitalization. She felt that she had been quite depressed since her sister's death. Her daughter, who was then in California in the Air Force best realized how Mrs. J felt and kept in close touch with her, but was unable to come home. These events probably influenced Mrs. J's attitudes towards the severity of illness in general and towards the patient's illness.

From the preceding examples it can be seen that the ways in which the families perceived events in the environment could effect their attitudes towards illness and hospitalization and/or the impact of these on the family.

CHAPTER VII

SUMMARY AND CONCLUSIONS

This was a descriptive study of eleven lower class urban families who had a child hospitalized on a medical, pediatric ward of Boston City Hospital. The attitudes of families towards their children's illness and hospitalization were studied by interviewing mothers regarding the social setting in which illness takes place, the events and circumstances which surround illness, how the family perceives and deals with illness, and the effect of illness and hospitalization on the family.

Although there has been much work on the attitudes of children towards illness and hospitalization, few studies have considered this from the family's point of view. Most of the latter seem to concentrate upon the impact of the family upon onset of illness, or how the effects of illness on the family in turn affect the patient. Interest in studying the effects of illness on family members for their own sakes stemmed from the feeling that a child's illness and hospitalization may be crises situations for the family as well as for the child. Some of the work on adapting the public health concept of prevention to a social work framework is also relevant.

It was felt that a study of this kind was important because if more is known about families' attitudes

towards their children's illness, it may be possible to improve services to these families when necessary. They could be helped to reduce secondary effects of illness and to prevent further disequilibrium.

The sample was selected from families of seven to thirteen year old children who participated in the social group work program at Boston City Hospital. The names of these families were provided by the two social group workers on the male medical and the female medical wards in the pediatrics building.

Data were collected from hospital records and from interviews with the mothers of the ill children. Home visits were made to conduct the interviews. A schedule designed by Doctor Arthur Mutter of Boston University was used with the mothers. This consisted of a series of open-end questions which were read to the mothers. When the mothers mentioned special feelings towards the ill child or past crises which seemed to influence their attitudes towards the illness, they were explored further without the use of a structured schedule.

The sample was almost equally divided between boys and girls. The proportion of nine Negro to two white children was higher than in the average population at Boston City Hospital. Six of the group were known to have special meaning to one or both parents. Seven of the

eleven mothers were not living with their husbands at the time of the interviews. Five of the six special children came from these families. Most of the families were supported, at least in part, by the parents.

Doctor Mutter's rating scales for the social composition of the family, the kinship ties of the families, the mother's role as a mother, and the mother's role as a housekeeper were used in this study. The ratings were made after only one contact and might have been different if more were known about the families. However, the home visits seemed to be a valuable tool in assessing these ratings of families. It provided the interviewer with an opportunity to see the physical conditions of the home, and some family interaction.

Although there was a range of ratings, most of these families did not seem to be disintegrated; the mothers seemed to retain close kinship ties, and were able to manage household chores. There was a close relationship between the ratings of the mother's role as a mother and the ratings of social composition of the families. Families D,G,K received consistent ratings (D, [illegible] rating 5;G,2) on all of Doctor Mutter's scales except for kinship ties. Family A received consistently low ratings (1) on all scales except for the mother's role as a housekeeper. Family I received consistently low ratings (2) on all four scales.

All the families with the exception of E recognized the child's illness and were concerned about it. The physical symptoms which they recognized were pain, loss of appetite, and external physical change. Six families noticed more than one symptom in their children. Most of the mothers stated they had no difficulty in recognizing symptoms of illness.

Those ten families that recognized physical symptoms were concerned about the illness. Although almost equal numbers of parents of boys and girls noticed external physical symptoms, the parents of the girls tended to express most concern about them. The parents of the boys tended to express most concern when their sons complained. Two families (B,I) noticed previous change in behavior which they felt may have been related to illness. The children became more demanding and impatient. The illness, and/or hospitalization had an effect on the usual interests or activities of seven of the children.

Most mothers tried to do something to help the child before going for medical treatment. This included asking advice of others or some form of home treatment. The length of time between the parents' recognition of illness and the hospitalization ranged from the same day to several months. Nine of the families sought medical

aid within a week of noticing symptoms.

The mothers chose Boston City Hospital because it was convenient, helpful, inexpensive, or some combination of these. Whatever their original reasons for choosing Boston City Hospital, most mothers had positive feelings towards it. All but one (G) of those with ambivalent feelings chose the hospital, at least in part, because it had been helpful in the past. Three (E,G,I) had not based the negative part of their ambivalence on the way the hospital had dealt with the illness necessitating this admission. None of the mothers expressed negative feelings towards Boston City Hospital. It is not known if any mothers hesitated to express these because they associated the writer with the hospital.

In all the cases but one (E) where there was a definite diagnosis, the mothers were aware of at least the name of the child's diagnosis. Mrs. E was aware of the patient's enuresis, but not of the G.U. infection which was the reason for the hospitalization. Mrs. E was the one mother who did not recognize the child's illness, but was told by an A.D.C. worker to take the child to the hospital. Mrs. E felt the child did not have an illness; she recognized no symptoms of illness, expressed no concern, and recognized no concern on the part of the other children. She expressed ambivalent feelings towards the hospital, because it had not cured the

enuresis.

It would seem that this case points out the need for social services beyond those which a social group worker working with the child should be able to provide. In this and similar situations, some clarification of the role of the hospital may be helpful to the mothers because of the present ambivalent feelings. Also, since present attitudes towards the hospital may influence future use of Boston City Hospital or other medical facilities, some clarification now may prevent a future hesitation to use the hospital when necessary.

All the mothers whose concepts of etiology had an external component recognized external physical symptoms in their children. With one exception (G) they expressed most concern about external physical symptoms. With the same exception, the mothers whose concepts of etiology had an internal component recognized either pain or no physical symptoms at all.

Illness had three known types of effects on these families: changes in routines, changes in relationships, and changes in the affect of a family member. Eight mothers felt their housework was affected. The one father who was seen felt his work routine was affected. It is impossible to know if other fathers felt their work was affected without their wives being aware of it.

There was a change in the parental relationships in four of the seven cases where both parents were aware of illness. In one of them (C) the relationship was weakened. In the others (B,H,I) the relationships were strengthened. In two cases (G,I) the mothers felt the illness or hospitalization affected their caring for the other children, and in the H case the father's relationship with the other children was affected. Three families had less contact with close friends or relatives because of the illness.

All of the mothers but one (E) expressed worry or concern. All but one (G) felt that those fathers who were aware of the illness were worried or concerned. At least one and usually all of a patient's siblings were worried or concerned except in the E family.

The E family was the only one in which there was no known effect in any of the areas discussed here.

In seven of the families (A,B,F,G,H,I,J) there were known events in the psycho-social setting close to the time of illness which seemed to influence the way that the family perceived and dealt with the illness or the effects of illness on the family. These events involved: loss of a close family member, addition of a new person into the household or return of a family member, changes in family relationships, changes in the

behavior of a family member, affective change in a family member, onset of development of secondary sex characteristics, and change in housing or schools. With the exception of the J family, the situation was further complicated by the fact that the patient was a special child in the family.

Because of the small number of cases, it is difficult to make recommendations. However, the findings do suggest that the illness of a child does have an effect upon the family. A study using a larger sample and providing for some follow-up could yield more information about the meaning of illness to families and what can be done to lessen the stress of the crisis situation.

The meaning of the patient to the family in relation to their reactions towards illness would seem to be an area deserving further study. If more could be known about those kinds of families in which illness has an effect upon family relationships, it may be possible to provide services to help these families maintain strengthened relationships, lessen increased friction, and prevent further breakdown of relationships. The relationships between the symptoms recognized by the mother and her concept of etiology may also be worth further

study. Although only two mothers mentioned difficulty in caring for the other children, it would seem important to be concerned with this and find out how severe this is and what services can be provided to help the mothers and/or the children.

It would seem that because of the crisis nature of illness, the knowledge that this can often stir up old conflicts, and the knowledge of how effective help at the time of crisis can be in reestablishing or strengthening the normal family balance, it would be important for all families of hospitalized children to be interviewed. A social worker, trained in dealing with problems within a family as well as between the family and its environment would be in a position to assess whether or not professional help is needed, to provide direct service, to refer the family for more appropriate service, or to serve as a liaison person between the family and hospital staff. In this way it may be possible to reduce the stress and to prevent further breakdown of the family equilibrium.

Accepted 5-14-62
Katherine Spencer

APPENDICES

APPENDIX

SCHEDULE A INFORMATION FROM MEDICAL RECORDS

1. Name: 2. Sex: 3. Age:

4. Address: 5. Telephone:

6. Diagnosis:

7. Dates of Admission and Discharge:

8. Reason for Being Chosen for Group:

APPENDIX B

QUESTIONNAIRE

Date:

Interviewer: _____ Name: _____

Address: _____

Tel: _____

I. ILLNESS OF CHILD

A.

1. When did you realize one child was ill:

2.

a. What did you see in the child that made you think he was ill (symptoms):

b. Is this usually how you tell when the child is ill and, if not, what is it that usually makes you decide child is ill:

3. Was there any previous change in behavior that might have been part of the illness (specify):

4.

a. When was the child previously ill:

b. Describe the previous illness:

5. Is it difficult to tell when this child is ill (why and describe):
a. This illness:

b. Past illnesses:

6.

a. At what point in this illness did you become concerned, how and why:

b. Is this usually so and if not how different:

7. How serious do you think this illness is (duration, incapacity, hospitalization, treatment, complications, outcome):

8.
a. When did you seek medical assistance and why:

b. Is this usually when you have a doctor in and, if not, how different:

9.
a. What did you do before calling for medical aid (medication, bed rest, seeking advice from family or neighbors):

10. What do you think caused this illness:

11.
a. What are the usual medical facilities you use:

b. Why do you usually use these facilities (convenience, helpful, expense).

c. Is this one different, why so:

d. How helpful do you feel this facility is:

e. How helpful are medical facilities in general:

B.
12. How did this illness effect (open-ended question):

a. You (mother):

b. Your husband

c. The ill child

d. The other children:

e. Extended family members:

f. Is this the usual way and, if not, how differs:

13. How did the illness effect you as far as:

a. Routine housework (cooking, cleaning, shopping, laundry):

How do you usually run your household if different from above:

b. In looking after your children (amount of time with them, affection for them, interest and participation in their activities, discipline):

What is the usual situation:

c. In time spent with your husband (amount of time spent together, doing things for and with him, getting along with one another):

What is it usually like when there is no illness:

14. How did the illness effect father as far as:

a. his work routine (absent from job, going in late, home early):

What is it usually like:

b. His getting along with you (helping you in housework, time spent with you, helping in any special ways, feeling between the two of you):

What is it usually like when no illness:

c. His getting on with the children (time spent with them, participation and interest in their activities, concern for them, affection for them, discipline):

What is the usual when there is no illness:

15. Was there any change in any of the children when patient became ill and/or hospitalized (worried, jealous, helpful, difficult to manage):

16. Did the illness require any special rearrangement in the household:

17. Did this illness effect what you ordinarily do with your close relatives (visiting, phoning, calling on them for help):

What is the usual situation when no illness:

18. How did the illness effect the child himself:
    a. Was there any change in how he gets on with you (demandingness, affection, obedience, ability to care for himself--more babyish or more independent):

    Is this how he usually responds to illness and if not, how different:

    How does he usually behave with you when not ill:

    b. Was there any change in how he gets on with father (obedience, affection, demandingness):

    Is this usual when he is ill and if not how:

    How does he usually get on with father:

    c. How does he get on with brothers and sisters during this illness (sharing affection, fighting, playing):

    Is this usual when he is ill and if not how:

    How is it when he is not ill:

d. Was there any change in how he gets on with his friends (interest in them during his illness, range of friends, visiting from them, playing, sharing, activities, fighting, being leader or follower):

Is this usual during illness and, if not, how:

How does he get on with friends when not ill:

e. What are his usual interests and activities:

Did these change during illness and how:

II FAMILY STRUCTURE (include name and age of parents)

MGM MGF PGM PGF

M F

Children

A. Physical Composition

1. Race
2. Religion
3. Marital status
4. Ethnic
5. Occupation:
   Father:
   Mother:
6. Means of support (father, father-mother, mother, ADC, etc):

7. Work history

8.
a. Who are yourclosest relatives (name and relationship):

b. How often are you in contact with them (visiting, phone):

c. How available are they when necessary:

d. How helpful are they:

9.
a. How is your (mother's) health now?

b. How has your past health been:

10.
a. How is father's health now:

b. How has it been in past:

11. How has the patient's past health been:

12.
a. Current health of other children:

b. How has their past health been:

III SETTING

If any of the following events have occurred, for each event describe the impact on the parents and children (see page 10, Item C)

(For the following, specify nature and timing of event and whether or not event is usual):

A.

1. Does this month have any special meaning to the family (anniversary of marriage, death, illness, birth, moving):

B. Did any of the following events occur in last six months?

2. Were there any deaths (of relatives, close friends or neighbors):

3. Did any family member, relative, close friend leave (permanent or temporary and distance):

4. Were there any births in family?

5. Did anyone move into the household?

6.

a. Has there been any change in the way the family gets along together (closer, happier, more fighting, more or less worried, more or less demanding, more or less affectionate):

b. Was there any change in the way get on with relatives (seeing more or less of them, closer or more distant):

c. Was there any change in way get on with friends or neighbors:

7.

a. Were there any illnesses in family, relatives, close friends or neighbors:

b. Did anyone's behavior change (more independent, more childish, more of a problem):

c. Were there any pregnancies:

d. (If any of children in age range) Did any of children begin to develop:

8. Was any member of family or anyone close to family upset in past six months (unhappy, fearful, excited):

9.

a. Child's current grade and school:

b. How does he get on in school (marks, promotions, behavior) in past six months and is this usual:

10.

a. How long have you lived in this house?

b. How long in this area?

c. How do you like it here?

d. Do you plan to move and if so why?

e. Has there been any change in neighborhood itself?

11. Have there been any changes in job or income?

C. These are to be filled in for each event that did occur. (Same points of reference as under Illness--pages 3,4,5, and 6; #13,14,17 and 18).

Event #1 (Specify)

1.

a. How did this event effect the child (patient) (open end):

b. How did it effect how he usually gets along with you (mother):

c. How did it effect how he usually gets along with father:

d. How did it effect how he got along with his brothers and sisters:

e. How did it effect how gets on with friends:

f. Was there any change in how got on at school and how:

g. Any change in his interests and activities and how:

h. How did it effect his mood or spirits:

2.

a. How did this event effect you (mother) (open end)

b. How did it effect how you run the household?

c. How did it effect how you usually get on with the children?

d. How did it effect how you get on with husband?

e. How did you feel about it?

3.

a. How did the event effect father (open end):

b. How did it effect his work?

c. How did it effect how he gets on with children?

dd. How did it effect how he gets on with you?

e. How did father feel about it?

4.
a. How did event effect the other children (open end)

b. How did they feel about it?

5. How did it effect how the family usually gets on with relatives or close friends:

Event #2 (Specify)

1.
a. How did this event effect the child (patient) (open end)

b. How did it effect how he usually gets along with you (mother):

c. How did it effect how he usually gets along with father:

d. How did it effect how he got along with his brothers and sisters:

e. How did it effect how gets on with friends:

f. Was there any change in how got on at school and how:

g. Any change in his interests and activities and how:

h. How did it effect his mood or spirits:

2.

a. How did this event effect you (mother)(open end)

b. How did it effect how you run the household?

c. How did it effect how you usually get on with the children?

d. How did it effect how you get on with husband?

e. How did you feel about it?

3.
a. How did the event effect father (open end):

b. How did it effect his work?

c. How did it effect how he gets on with children?

d. How did it effect how he gets on with you?

e. How did father feel about it?

4.
a. How did event effect the other children (open end)

b. How did they feel about it?

5. How did it effect how the family usually gets on with relatives or close friends:

Event #3 (specify)

1.

a. How did this event effect the child (patient) (open end)

b. How did it effect how he usually gets along with you (mother):

c. How did it effect how he usually gets along with father?

d. How did it effect how he got along with brothers and sisters:

e. How did it effect how gets on with friends:

f. Was there any change in how got on at school and how:

g. Any change in his interests and activities and how:

h. How did it effect his mood or spirits:

2.

a. How did this event effect you (mother) (open end)

b. How did it effect how you run the household?

c. How did it effect how you usually get on with the children?

d. How did it effect how you get on with husband?

e. How did you feel about it?

3.

a. How did the event effect father (open end):

b. How did it effect his work?

c. How did it effect how he gets on with children?

d. How did it effect how he gets on with you?

e. How did father feel about it?

4.

a. How did event effect the other children (open end).

b. How did they feel about it?

5. How did it effect how the family usually gets on with relatives or close friends:

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