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An exploratory study to determine the needs of the mother who has given birth to a child with a physical abnormality

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AN EXPLORATORY STUDY TO DETERMINE
THE NEEDS OF THE MOTHER WHO HAS
GIVEN BIRTH TO A CHILD WITH A
PHYSICAL ABNORMALITY

By

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CHAPTER I

INTRODUCTION

In motherhood woman enters directly into the process of human creation. Her position finds no substitute and, while awaiting the birth of her expected child, a woman has every reason to look forward to her accomplishment, viewing it with admiration.

Of the four and one half million newly delivered mothers in America in 1960, two hundred and fifty thousand found discrepancy between the child which was expected and the child which was produced.¹ At some time during the creative process something went wrong, resulting in children being born with a defect of some kind. Fortunately the number of children being born with some type of defect, to the total number of children born, is low. When such a birth does occur the family finds itself unprepared. The relative state of equilibrium is suddenly altered and the family must find ways to cope with the unexpected.

The importance of the strengths which the family have developed in the past, together with the support and guidance given during and immediately following the birth, can very

¹Albert Maisel, "We're Winning the Battle Against Birth Defects," Readers Digest, LXXVIII, (January 1961), pp. 89-93.

well determine whether the family adapts itself in a manner which will fruitfully benefit both parent and child. The nurse working with the family of the physically abnormal child shares in the responsibility of giving the necessary support and guidance to assist the family.

STATEMENT OF THE PROBLEM

The purpose of this study is to determine how the nurse can best help a mother who has given birth to a physically abnormal child. To accomplish this objective, it is necessary to obtain as much information as possible directly from mothers of these children. Direct contact with the mother is important in the study in order to understand their felt needs. Proceeding from this we can determine what can be done to assist in coping with whatever reaction may result following the birth of an abnormal child.

IMPORTANCE OF THE PROBLEM

To know what to say, when to say it, and what not to say to the mother who has delivered the child with a physical abnormality is very difficult. To gain some insight into being able to intelligently meet a situation which is difficult has the compensation of being doubly rewarding, if accomplished. As a result, it should increase the helping effect of the nurse to her patient as well as to aid the nurse in recognizing her own feelings. Both results (here applied to the response to the mother and her child) could be beneficial in acutely stressful situations met in all areas

in the field of nursing. This is the import of this inquiry and study of the mother herself and her feelings after her child was born.

Was she satisfied with the extent of the care, information and support received within the hospital setting, or did she return to her home only to have questioning thoughts which went unanswered? Does the transition from the hospital to the home necessarily terminate the nurse's continued and concentrated support of these families? Is there adequate evidence to show that these mothers would want and benefit from immediate followup care by professional help? By finding answers to these questions we can determine what a mother experiences, and by examining and evaluating these answers we can provide useful information which can be used in caring for these mothers.

SCOPE AND DELIMITATION

Behavioral sciences have the distinction of being both the most fascinating and the most unpredictable. Individual personalities and individual reactions are shaped and influenced by different forces. For this reason there is a major limitation in the extent of analysis which can be done on a mother's reaction without knowing something about her past history.

A given mother's reaction is shaped by the type and degree of the defect found in the child, her own past experiences with parents, siblings, and others, along with

conflicts in her relationship to her mother regarding her own femininity. Awareness of all these factors is a major process in the total approach to be taken toward each mother. While it is impossible to control these variables, we profess to an awareness of their importance and recognize that they influence a mother's reaction.

It should also be recognized that the nurse-patient relationship has two aspects which must be considered in order to effectively evaluate the interaction between them. These are the needs of the mother and the feelings of the nurse as she reacts to these needs. Only the former are being examined, with the understanding that by not examining the latter, a second limitation on this study is imposed.

A third limiting factor to be considered is the small number of cases included in the sample from which data is available. Any generalizations concerning the reactions to the birth of a physically abnormal child should be made cautiously.

These three limitations, however, did not provide sufficient reason to discontinue the investigation. It is believed that useful information can still be gained by examining a small number of cases which may disclose certain responses and needs that these mothers have in common. Perhaps a study done on this small scale can in some way assist the nurse in helping this family. Current literature in maternal and child health indicates that society is becoming

more and more aware of the needs of these families. Much is yet to be divulged, however, concerning how the nurse can help these families and what a mother's perceived needs are after she delivers her baby.

DEFINITION OF TERMS

For purposes of this study a "need" will be defined as "any requirement, whether on a physical, emotional, or intellectual level that contributes to the patient's well-being, whether expressed explicitly or implicitly in words."²

A "physical abnormality" will be defined as any observable deviation from the normal found in the child immediately after birth.

PREVIEW OF METHODOLOGY

The study design is exploratory in nature. The area being explored is the needs of the mother who delivers a child with a physical abnormality. It was felt that the best one to express these needs would be the mother herself. To this end a guided interview was devised for purposes of obtaining this information. Interest was concentrated upon the reaction of the mother to the birth of the child, the effect of the care given by the nurses, and the feelings, attitudes and impressions of the mother during hospitalization and upon returning home.

²Marion S. Lesser and Vera R. Keane, Nurse-Patient Relationships in a Hospital Maternity Service, (St. Louis, Missouri: The C. V. Mosby Co., 1956), p. 17.

Where possible the initial contact was made with the mother while she was hospitalized following her labor and delivery. This contact was introductory in nature and information pertaining to the guided interview was not sought at this time. The mothers who were not contacted immediately following delivery were contacted in their home.

All of the mothers had delivered their children within a period of two months of the interview. It was decided to carry out the interview following hospitalization with the thought that her past needs and anticipations of future needs could be reported more objectively, and with greater perspective than at an earlier point. However, the contact made with the mothers while they were hospitalized was thought to be valuable in that a contrast could be made between feelings while in the hospital and after returning home. For this reason it was considered beneficial to include all pertinent information, whether obtained during hospitalization or in the home.

A content analysis of the interviews provided the tool for summarizing the data. Emphasis was placed upon common responses, as expressed by the mothers, to their physical, emotional and informational needs.

CHAPTER II

THEORETICAL FRAMEWORK

The worker in the field of maternal and child health is not unaccustomed to dealing with stressful situations. There are few situations having as much potential stress, in which expenditure of professional time, care and energy would be more beneficial, than that period of time immediately following the birth of an abnormal child.

Unlike many situations which have the ingredients of acute distress, the people directly involved are known immediately and are available for assistance. This is perhaps the only fortunate aspect of the entire situation. It is vitally important. The question is, do we in the role of helpers (in this instance "nurses") recognize the opportunity which is ours to serve in the lives of these families who have sustained such an unexpected blow?

"The birth of a physically abnormal child constitutes one of the most real and definite crises that many individuals in this world have to meet."¹ The crisis presents itself at a time of pronounced vulnerability. The mother, physically and psychologically exhausted from her labor and delivery, must face an irreversible and realistic hardship.

¹George Gardner, M.D., "Helping Parents of Handicapped Children-Group Approaches," Proceedings of Conference, (Boston, Mass., October 15-16, 1956).

The outcome of a crisis situation at this time, is largely dependent, not only upon the long standing personality patterns of the participants, but also upon their current choice among the many alternative ways of solving the problem which upsets them. The latter factor is capable of being radically influenced by the intervention of key helping figures, both from their own family and from outside community 'caretaking agents' such as nurses, obstetricians, pediatricians and social workers. As in any crisis, prevention intervention during the period of upset has a much greater effect in terms of influencing the attitudes of the participants in the family drama, than it would have at periods of stability of emotional functioning.²

Expediency must not take precedence over a cautious and careful intervention at this time. The entire situation is fraught with emotional involvement for the family, with the mother in particular sustaining whatever feelings are evoked by the child she has created, an extension of her very being. Therefore, it is very important to be aware of the types of reactions which may be involved, in order to determine the most helpful approach in caring for the mother who has given birth to the physically abnormal child.

It may be argued that the nurse is not adequately prepared in psychological principles to become an influential figure in assisting the mother and her family at this time. However, it is my contention that if she is not prepared, she should be. She should be since she works very closely with these mothers. She is present at each phase of the

²Gerald Caplan, M.D., "Psychological Aspects of Maternity Care," American Journal of Public Health, XLVII, (January, 1957), pp. 25-26.

hospitalization, including the time when the impact of the crisis takes place. Because of this closeness to the event itself, the nurse shares in the responsibility of helping the mother, and can make this help more effective by extending her services into the home environment. If she finds herself unable to meet the situation effectively, she should at least not proceed along lines which may compound the difficulty. Therefore, it is essential for all nurses to be aware of, and to understand the many behavior patterns which may be manifest in the mother at this time.

After speaking with the young mother of a baby girl, who had been born with a badly deformed right ear, one wonders if nurses fully understand a mother's needs. The child, now nearly one and one half months old, is to be hospitalized for possible correction of her deformed ear. The mother, anxious at not knowing what is to happen, relates that, "After the baby was born, the nurse in the hospital told me not to worry about the ear since the baby is a girl, the hair can be combed so as to hide the ear." This ear was not only misshapen, but there was no external opening so that the child's hearing was impaired.

One wonders further when it was discovered that this mother was vitally concerned when discharged from the hospital yet she was not seen again by professional personnel until an entire month had passed. At this time the public health nurse visited the mother and shortly afterward she started

attending the clinic. One month had elapsed, however, with the mother worrying about what was to happen.

In my opinion we get off on the wrong track in regard to these children within the first few weeks of their birth. That's the time when we ought to provide services, and that is the time where we have no services. The reason we go off on a wrong track is that it's a very difficult thing for a family, a mother in particular, to deal with a child who has a congenital anomaly or a birth injury. This is an extremely difficult problem, and if she's left on her own she will often move along the wrong path and will get a disturbed relationship with the child and so increase the difficulty. Then he has the physical disability and also does not have a healthy emotional environment in which to grow. These two interact with each other. So a lot of difficulty can be traced back to this particular period.³

Personal feelings and availability of professional services are both influencing factors which should be considered in the above case. Both are, of course, realistic causes for inadequate responses to the problem.

In caring for the mother following her delivery, it is difficult for the nurse to resist/trying to make the mother "feel better" about her child. She, just like the mother in this instance, meets the event unprepared. Her feelings have had no time to become resolved, and so she talks to the mother in terms of "it isn't so bad - it can be hidden." In so doing, the one person who could do so much to assist this mother at a very important and critical time, is only

³ Gerald Caplan, M.D., Mental Health Aspects of Social Work in Public Health, ed. Ruth Cooper, A Report based upon an Institute (University of California, Berkley, Calif., June 6-8, 1955), p. 26.

reinforcing an inadequate response (denial) which the mother already has.

Though it is virtually impossible to do, let us assume for a moment that the nurse's personal feelings played but a minor role in her response to this mother. Was she intellectually aware of what this mother may be experiencing in response to her child? Had she, the nurse, in preparing for her professional role been made aware of how much good she could do at such an opportune time?

Nursing education in the field of maternal and child health finds itself concentrating upon the normal aspects of childbearing and childrearing. Textbooks which are being used reflect this philosophy and proceed to the abnormal only after the normal is understood. One such widely acclaimed text used in many schools of nursing, emphasizes in its preface:

The subject of health teaching, including anticipatory guidance, is discussed as an integral part of total patient care. Basic principles with universal application are stressed, rather than specific procedures which may vary from hospital to hospital. Mental health concepts are highlighted at every opportunity.

Later in the book the authors state:

The graver congenital malformations are always a cause of keen disappointment to the family and sometimes produce serious psychological disturbances in the mother. Such cases demand the utmost in sympathy and understanding on the part of the nurse, who will do well, as a rule, to endeavor tactfully to direct the

mother's thoughts to other interests.⁴

Is there not more which could be done to better prepare the nurse to meet the event in a way which would be more beneficial to the nurse as well as the patient? Would not additional awareness prepare the nurse for what she could do, help her to recognize her limitations and in so doing make her helping relationship more effective?

It is true that there is an implication here that the nurse should do something. Perhaps this implication is ill-conceived at this particular time, if one thinks of "doing something" as the active give and take of verbal communication or manipulative skills. Furthermore, it may lead one to believe that the nurse should interpret the mother's behavior and discuss this interpretation with the mother.

Interpretation of unconscious feelings or thoughts, or attempts to make connections for the patient between past experiences of loss and the current subjective responses, should not be done. This should not be done because of narcissistic involvement during the mourning period.⁵

⁴Elise Fitzpatrick, R.N., M.A., and Nicholson J. Eastman, M.D., Zabriskie's Obstetrics for Nurses, (10th ed. rev.; Philadelphia: Lippincott Company, 1960), pp. vii and 485.

⁵Albert J. Solnit, M.D., and Mary H. Stark, M.S.S., "Mourning and the Birth of a Defective Child," The Psychoanalytic Study of the Child, Volume XVI, ed. Anna Freud, Heinz Hartmann, and Ernst Kris (New York: International Universities Press, 1961), p. 531.

Instead, let us understand that a helping relationship between the mother and the nurse is a relationship in which each finds comfort in the other's presence. Such a feeling for the nurse would be manifested by a wish to help the mother, to talk to her if she wants you to talk, to listen if she wants you to listen, to simply let her know that you care by not avoiding her. The mother will feel this concern and in this way she too will find comfort.

No matter how extensive her experience, it is difficult for any nurse to find some semblance of comfort with a mother who has realized one of her greatest fears. There is no one right approach to use. All individuals, nurses as well as mothers, must fashion their own responses to meet this task. These responses should be guided and influenced by previous knowledge and understanding of the types of behavior which may be manifested by the mother at this time.

Such knowledge and understanding is provided in the previously cited article, "Mourning and the Birth of a Defective Child."⁶ The word "defective" in the article refers to any child deviating from the normal, with particular attention on the mentally defective. It is pointed out, however, that the reaction of mothers is similar, differing only in the degree of the seriousness of the defect. The article is psychoanalytical in approach and written by those individuals

⁶Ibid.

prepared to help the mother on this level.

Recognizing the nurse's responsibility as limited at this level, it still provides her with an excellent picture of what the mother might be experiencing. For this reason, the resume which follows, seems to be a worthwhile base from which the nurse could begin to prepare herself to serve the patient and family more effectively.

The psychological preparation for a new child involves the wish for a perfect child and the fear of a damaged child. It is very likely that there is always some discrepancy between the mother's wishes and the actual child; to work out this discrepancy becomes one of the developmental tasks of motherhood that are involved in the establishment of a healthy mother and child relationship. However, when the discrepancy is too great, as in the birth of a defective child, or where the mother's wishes are too unrealistic, a trauma may occur.⁷

The image of the expected baby is a composite of self and other love objects. The birth of a defective child abruptly interrupts this preparatory and adaptive process. The mother's reactions will be shaped to a significant extent by the degree and the type of abnormality, along with the mother's past experiences. The course of motherhood, a developmental process, is influenced by the characteristics of the baby, first by his appearance and then gradually by his responses. It is further stated that "significant deviations, such as gross retardation or obvious congenital defects, may limit or interrupt the mother's developing

⁷ Ibid., p. 524.

capacity to accept the new child who is totally dependent upon her."⁸

Grief is the characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job, status, home, country, an ideal, a part of the body, etc. Uncomplicated grief runs a consistent course, modified mainly by the abruptness of the loss, the nature of the preparation for the event, and the significance for the survivor of the lost object.⁹

In place of the typical grief syndrome there may appear distorted pictures, each of which represents one special aspect of the grief syndrome. By appropriate techniques these distorted pictures can be successfully transformed into a normal grief reaction with resolution.¹⁰

Accordingly, the mother's reaction to the birth of a defective child is synchronized to the mourning process which in this instance would involve three stages.

The first is characterized by numbness and disbelief. The disappointed, highly charged longings for the expected child may be recalled, intensely felt and gradually discharged. This phase requires time and repetition and serves to liberate the mother's feelings. The mourning process makes it possible to progress to the second phase, that of awareness, of the disappointment and feeling of loss with the accompanying affective and physical symptoms; to the last phase of the grief reaction in which intense re-experiencing of the memories and expectations gradually reduce the hypercathexis of the wished for

⁸ Ibid., p. 525.

⁹ Ibid., p. 526, quoting G. L. Engel, "Is Grief a Disease? A Challenge for Medical Research," Psychosomatic Medicine, XXIII, 1961.

¹⁰ Erich Lindemann, M.D., "Symptomatology and Management of Acute Grief," Paper read at the Centenary Meeting of the American Psychiatric Association (Philadelphia, Pa., May 15-18, 1944).

idealized child.¹¹

The reaction of individual parents can involve elements of both denial and guilt. The defenses represent the modes of warding off depression and guilt and are selected according to the individual's characteristic patterns. These are greatly influenced by the predominance of feelings which the child has evoked within the parent.

In order to facilitate the work of the mourning process, the mother needs: physical rest; an opportunity to review her thoughts and feelings about the wished-for child; a realistic interpretation and investment of the feared, unwanted child by doctors and nurses; an active role in planning for and caring for the newborn child as she is able.¹²

Taking into account these psychological reactions, physicians, nurses and social workers can aid the mother in working through her grief to help her overcome the trauma of giving birth to a defective child.

The above study makes us aware of a mother's reactions to the birth of an abnormal child and tells us specifically what these reactions are. In addition, another equally important element is the effectiveness with which this knowledge would be used. This involves the personal feelings of those whose responsibility it is to help these parents. These feelings are important, and though they are not the primary subject of this work, they cannot be eliminated as

¹¹ Solnit and Stark, Op. Cit., XVI, p. 526.

¹² Ibid., p. 535.

influencing the relationship between the patient and those caring for her.

In a study done on "The Parent's Reaction to the Birth and Early Care of Children With Cleft Palates,"¹³ forty-two of the fifty-five mothers spoke of their experiences at the child's birth, and two-thirds recalled bewilderment and great anxiety.

Professional personnel illicited general apprehension which surrounds the birth of a malformed baby. Frequently, not knowing what to do, the doctors and the nurses in charge did nothing. They delayed the painful moment of revelation until they felt that the mother could 'take it,' or perhaps until they were able to handle their own unhappiness, that instead of giving the mother a perfect baby, they had to present her with an imperfect, disfigured one... Parents suffered the most when information was delayed - under the impact of stress, unchecked by reality and being perceptibly avoided by the very people, the doctors and the nurses, from whom she expects information and support, old fears and fantasies become alive in the mother again.....early, thoughtful and sincere communication between the doctor and the parent is the best.¹⁴

At the beginning of this chapter it was mentioned that expenditure of professional time, care, and energy, directed toward assisting the parents of the physically abnormal child, would be wisely invested. What investment could reap

¹³Veronica B. Tisza, M.D., Betty Silverston, M.D., and Elizabeth Gumpertz, M.S., "The Parent's Reactions to the Birth and Early Care of Children With Cleft Palate," A Report of a Study Conducted by the Psychiatric Services for Children, New England Medical Center, Tufts University School of Medicine, and the Cleft Palate Institute, Tufts University School of Dentistry (Boston, Mass.).

¹⁴Ibid.

a dividend greater than being able to say, "I was able to help this mother when she wouldn't look at her child because he had been born with a cleft lip. I was able to offer some support as she gradually extended her love and affection to this child."

Certainly we cannot eliminate the great stress of the situation, but we can help by recognizing:

.....that people are much stronger in dealing with difficulty than we usually give them credit for. A good deal of our work should be in removing the blocks and obstacles which prevent them from finding the right path.....I think if we have set ourselves the goal of trying to remove suffering from the world, we set ourselves an impossible goal. There will always be stress. There will always be problems. People will always suffer. I think our goal, which is a practical goal, should be to try to help people deal with these problems in as effective a way as possible.¹⁵

In the case of the mother who has given birth to a child with a physical abnormality, there is both an adaptive and a maladaptive way of meeting this problem. The future parent-child relationship may very well depend upon which response the family follows. There will be obstacles which need to be overcome, and blocks to be removed. It will take time. The nurse who is aware of the impact of the entire situation upon the new parents, who is aware of her own feelings as she approaches the new mother, and who recognizes the great good she can do in helping, will not fail in her

¹⁵Caplan, Mental Health Aspects of Social Work in Public Health, p. 138.

responsibility in this nursing situation.

ASSUMPTIONS

- (1) The nurse's awareness of the mother's needs following the birth of a physically abnormal child, will lead to a more effective helping relationship.
- (2) Nurses tend to avoid those things which make them uncomfortable.
- (3) The mother who gives birth to the physically abnormal child has needs which are many times unexpressed.

CHAPTER III

METHODOLOGY

Data for this study was obtained by interviewing mothers, as soon as possible, after they had been informed that their newborn baby had a physical abnormality. The study was conducted in a large Metropolitan hospital in the Boston area.

The maternity section of the hospital recorded 3,500 births in 1961. Patients in the maternity section occupy beds on open wards on three different floors. The nursery on each of these three floors has a nursing staff separate from that of the ward. A registered nurse is in charge of both areas at all times with student nurses, in their senior year of a three year basic nursing program, who rotate within the area.

The initial plan in selecting mothers to be interviewed was dependent upon the rate of abnormal births within this hospital, during the three month period between the last week of February, 1962 to the last week of May, 1962. As soon as the writer became informed of the birth, the mother was contacted in the hospital. At this time the study and its purpose was described to the mother. If the mother consented to participate, an appointment was made to visit with her four or five days later.

During this time only five mothers gave birth to a child with a physical abnormality. The five mothers who experienced this crisis during this time were contacted in the hospital, and a home visit was arranged in order to interview them about the needs which they experienced after being informed of their children's defect.

Because of the low birth rate of physically defective children at this hospital, it was necessary to expand the three month period to five months by including the two months preceding the last week of February, 1962. This was done by reviewing the birth records for the months of December, 1961 and January, 1962. This two month period was selected in order to assure some control upon the mother's ability to adequately recall initial feelings and attitudes following the birth of her child.

A review of the birth recordings for this two month period disclosed that there were two children born with a physical abnormality. One child was born on the twenty-sixth of January, 1962 and the other on the third of February, 1962. During the first week of March, 1962, the mothers of both children were contacted by written correspondence. An appointment was then arranged to visit the mothers in their homes within one week.

During the course of collecting data for this study, a fellow student informed the writer of a mother who had given birth to a child with an abnormality. This mother had

returned to her home from another Metropolitan hospital the previous week. The physician who had taken care of the mother and the baby, was contacted. He was told of the study and its purpose and through his interpretation to the mother, consent was granted to visit with her and an appointment was arranged. This increased the sample to eight mothers.

It was recognized that, although a larger sample would provide a better basis for validating findings, exploring the feelings of these eight mothers would be worthwhile and could still prove beneficial to all interested parties. All interviews were conducted with the mother under the assumption that she is the major influencing factor in setting the emotional tone within the family constellation. What would affect her would affect the entire family in some way. The total number of individuals making up the eight family units was thirty-nine. This would include the newborn child. All would be affected by the feelings of the mother herself. The study continued with the idea that to be able to explore the needs of these eight mothers, and more adequately understand how to help them, all thirty-nine members of these families might be helped in some way.

A maximum of five weeks and a minimum of one week had elapsed between the time of the birth of the child and the time the interview was held. All of the mothers except one, had their newborn children in their homes and were caring for them. This one mother had lost her child five weeks after

birth and had at no time cared for him within the home environment. It was decided to include this mother in the sample because the initial reaction to meeting this unexpected situation was not unlike the others within the sample. All of the families were in the lower economic level in the social class structure.

The method used for data collection was that of a guided interview. (See Appendix A) Probing type questions were used in each individual case, whenever it was considered necessary. Following the interview the interaction and information were recorded at the first convenient place away from the home. This method was selected because it was felt that the mother would feel more free to express her feelings if the information was not recorded in her presence.

The data was compiled, information pertinent to the purpose of the study drawn out through analysis of the content, and categorized under specified headings.

CHAPTER IV

FINDINGS

The purpose of this study is to identify the needs of the mother following the birth of a physically abnormal child. The data gathered from the guided interviews conducted with the mothers of eight children, sought to bring out what these needs might be.

Noting the quantity of material which resulted from these interviews, a method was sought to extricate those responses which seemed unique for these mothers. A content analysis of the data was done with the intention of discerning common elements in each situation, which would lend itself to categorization. The seven categories resulting from this analysis are as follows:

- (1) The need to find something good about the experience.
- (2) The need for information. (Simple and realistic interpretation and reinterpretation as soon as possible and with consistency).
- (3) The need for reassurance and support. (In the hospital as well as after returning home).
- (4) The need to express fears evoked by the child.
- (5) The need to express feelings of self-blame.
- (6) The need to find acceptance, for herself and her baby. (By society)
- (7) The need to express feelings in regard to care given to her during and following the birth of her baby.

These categories are not inexhaustible, but were thought to cover the main areas in relation to the purpose of the study.

The mothers who were interviewed were of varying backgrounds, some with children at home, some without. The abnormalities found in their babies were also of varying kinds and degrees and were of some influence upon what was expressed within the interview. The following chart illustrates characteristics of the mother, their families, the newborn child, and the time interval between hospitalization and the information-gathering interview, all of which are pertinent to the study.

CHARACTERISTICS OF THE FAMILIES BEING INTERVIEWED

Family	Age of Mother	No. of Children (not incl. this child)	Sex of child with anomaly	Type of anomaly	Interval between delivery and interview
A	16 yrs.	0	Male	Congenital absence of digits on both hands	8 days
B	20 yrs.	0	Female	Anomaly of right ear	5 weeks
C	30 yrs.	0	Male	Unilateral club foot	1 week
D	25 yrs.	3	Male	Unilateral cleft lip and cleft palate	5 weeks

CHARACTERISTICS OF THE FAMILIES BEING INTERVIEWED (cont.)

Family	Age of Mother	No. of Children (not incl. this child)	Sex of child with anomaly	Type of anomaly	Interval between delivery and interview
E	24 yrs.	3	Male	Myomen- ingeoma	5 weeks
F	34 yrs.	5	Male	Naevous Flammeus over left side of face, shoulder and arm	2 weeks
G	24 yrs.	2	Male	Congenital dis- location of left hip	1 week
H	25 yrs.	3	Female	Congenital dis- location of right hip	8 days

The data is presented under the aforementioned categorical headings. The responses are identified according to the defect found in the child. It was felt that the severity of the defect was the major influencing factor in the degree of reaction shown by the mothers. Comments and discussion of the findings follow each category.

(1) THE NEED TO FIND SOMETHING GOOD ABOUT THE EXPERIENCE

Mother of child born with congenital absence of digits:

My husband said it could be an arm or a leg which was not right. Then he couldn't walk and that would be worse.

If Jesus wanted it this way,

Mother of child born with anomaly of right ear:

I know she hears because she jumps when a loud noise is made. If only I knew what they were going to do for her.

then that's the way it has to be. It could be much worse.

You should see how he grips the bottle with his hands even though he doesn't have all of his fingers. He is so strong.

Did you see how well he uses his hands?

.....

Mother of the child born with a myomeningeoma:

I saw my baby move his legs and he moved his bowels okay. I know he did. I could see him when I went to the nursery to look.

This baby was prettier than my other two kids.

Mother of the child born with "birthmark:"

I don't know, it doesn't show up too much on his face, only when he gets mad.

My whole life is my children. This is the nicest baby I've had. I like big babies and I showed the doctors that I could have a big baby.

Mother of the child born with a congenital dislocation of the right hip:

Yes, the doctor told me about the baby. She told me that it was something which could be fixed.

This new baby is just the apple of my husband's eye. He wanted a girl so badly. The other two are boys you know.

The need of the mother to see something good seems to indicate a striving to seek some security (a basic need) in a situation which she was not prepared to meet. Implicit within the preceding statements is a common defense

mechanism, denial, which can serve a worthwhile purpose, as well as a harmful outcome, if it should persist and cause the family to move along a maladaptive course of action.

The first phase of a normal grief reaction usually involves numbness and disbelief. Disappointed, highly-charged longings for the expected normal child may be recalled, intensely felt and gradually discharged. This would necessitate denying the reality in order to work through the feelings necessary to go on to the next phase, that of awareness.

Since the interviews were carried on at a relatively short time after the birth of the child, it could be assumed that this "first phase" was still being worked through. Until the mother expresses her readiness to face the realistic aspects of the child's condition, clarification may fall upon deaf ears.

(2) THE NEED FOR INFORMATION

Simple and realistic interpretation and reinterpretation as soon as possible and with consistency.

Mother of the child born with congenital absence of digits:

I wasn't asleep in the delivery room. I heard the doctor say there was something wrong with the baby's hands. When they didn't bring the baby out for me to see for twelve hours, I thought there was something terrible wrong even though they told me that all babies are not brought out for twelve hours. My mother had a ten pound baby

Mother of the child born with a club foot:

In the delivery room right after the baby was born, the doctor told me, "Now look Mrs. C., I don't want to alarm you but your baby has a club foot." He showed me the foot. He told me it could be fixed. I'm glad he told me right away.

that lived only fifteen minutes and my mother never did find out what was wrong. I was afraid my baby was not going to live.

.....

Mother of the child born with a cleft lip and cleft palate:

I saw the doctor who was going to operate on the baby's lip only once. It was the aide who told me that the doctor was very good.

All I know is they will fix the inside of his mouth when he's fifteen months old. I never could get any information when I went to see the baby.

I found out about the baby in the delivery room. No, the doctor did not show the baby to me. It did not sink in. I just went off to sleep.

Mother of the child born with a myomeningeoma:

I didn't know anything was wrong with him until the next day when I woke up and saw a slip on my bedside table saying they had baptized the baby. I knew something was wrong in the delivery room, the way everyone acted. Then the next morning when I saw the slip, I had the nurses call the doctor.... he told me there was something wrong with his spine and that the baby may not be able to use his legs or move his bowels. Later a lady doctor came and told me he would be alright. The other doctor said that she shouldn't have said that.

The doctors used such big words that I couldn't understand what they were saying most of the time and I didn't want to ask them.

.....

Mother of the child born with a congenital dislocation of right hip:

The doctor was very nice. She explained everything to me and I know what she said but I don't know how

to tell anyone. She explained to my husband too and I was glad of that because I don't know how to explain it in a way that he would get anything out of it.

The two mothers who "thought something was wrong" immediately following delivery, expressed anxiety at not knowing what was going on. In the first instance we see an example of old fears and fantasies being brought to the conscious, as the mother awaited information concerning her baby. Is the twelve hour interval still warranted in this instance, or should regulations be secondary to helping this mother at a critical time in her hospital stay? One wonders if the anxiety, unchecked by reality, is necessary in the above instance.

Explanations, made simple, and as soon as possible, seem to illicit the most favorable response. Even in the case of the mother who gave birth to the child with the cleft Palate and the cleft lip. Though her reaction was severe when the shock allowed full recognition of her child's condition, this mother did not say that the information given to her in the delivery room should have waited. For this mother, interpretation and reinterpretation was necessary because of the numbing shock resulting from her child's defect.

We note also, how important it is to the mother to have her husband informed just as she has been informed. In this

way the two can start from the same vantage point as to the child's condition, and find security in not being alone.

Specific techniques of how and when the child's defect could be repaired, were important to the mother. One had the impression that when this information was accompanied by the feeling that someone understood their problem and cared about them, the information was more readily assimilated.

Consistency in what was told to the mothers was another very important part of how the mother was able to cope with the information given to her. Anxiety was still expressed a month later by the mother who had been given conflicting information concerning her child born with a myomeningeoma. It should also be noted that this child had expired two weeks before the writer talked with the mother. This mother still had questions concerning the information given to her. Until these questions were answered, she would have obstacles in working through her feelings effectively.

(3) THE NEED FOR REASSURANCE AND SUPPORT

In the hospital as well as after returning home

Mother of the child born with an anomaly of the ear:

The baby had to stay in the hospital for four days after I came home. I was so worried when I had to leave the baby, because I did not know what they were going to do with her. The doctors didn't know either, maybe that is why they couldn't tell me more.

Mother of the child born with a club foot:

I have to take the baby back in one week and the doctor told me how to soak the cast off before I come in. I'm scared to do it, but the doctor said it will just peel off when I soak it. I know I'll be all nervous when the time comes.

.....

Mother of the child born with a cleft lip and cleft palate:

I was shown how to feed the baby twice before we brought him home. The first time the nurse walked out of the room and left me.

No, I don't want any nurses stopping in. To tell you the truth, I don't care to have them around. My mother can help me. She knows more than any of them.

It's going to be quite a job feeding the baby. I'm so afraid that he will choke. It takes me all morning to feed him.

.....

Mother of the child born with a birthmark over face:

I don't know, since I'm home the eye is beginning to swell up on that side where the birthmark is. My husband is very nervous about it and he wants me to take the baby into the clinic.

Mother of the child born with a myomeningeoma:

Ever since this happened my husband and I have been quarreling. I just don't care for him like I used to.

The nursery nurses never had anything to say either. They wouldn't let me feed the baby. I felt awfully bad about it. Just to see all of the other mothers having their babies made me feel so bad.

It is so good to have someone to talk to. You just don't know. I'd be glad to have you come back.

Mother of the child born with congenital dislocation of left hip:

See, this is what they told me to do. Do you think it is alright?

I don't know how I'm going to be able to keep him like this when he gets older, if it takes three months. (maximum time quoted for repair of defect)

I think I'd like to have a nurse visit if they could tell me if it was getting better or not. What do you think? Do you think it would get better quicker if they put a splint on it?

.....

Mother of the child born with
congenital dislocation of
right hip:

See how she rests on her
stomach. This way I can keep
her on her stomach and at the
same time keep her legs out
like they're supposed to be.
See I put the diaper on like
this, do you think it is
alright?

Sometimes I look at her and
feel, my gosh it must be awful
to have your legs out like that
all of the time. I know when I
have my legs in the stirrups for
a short time in the delivery
room, how awful it is.

I was so nervous when I started
taking care of the baby. The
doctor showed me how to put on
the diaper, but I couldn't put
it on like she did. I've
arranged my own way to do it.

All of the mothers interviewed gave evidence of having
been visibly upset by the defect found in their child. Five
of the eight mothers had been contacted initially in the
hospital. At this time all of the mothers talked optimisti-
cally about their child and the possibility of having the
defect corrected. They talked of their confidence in the
doctor and all were anxious to go home.

During the home visit with the mothers, the writer
found these mothers requesting advise, looking for approval
for the care they were giving their children, and anxious to
express their feelings about the hospitalization and the
birth of the child. They seemed to want a chance to be

heard. They expressed optimism at their child's eventual well-being and at the same time verbalized fears at the validity of this optimism. Internal conviction of external acceptance had not yet been worked through. They seemed to be asking, "Won't you help me accomplish this?"

The mother of the child born with the cleft palate sought her support within the family. The entire experience of the birth of the child in this instance, was viewed in highly negative terms. She wanted no additional help from a visiting nurse and yet she expressed a need for support in feeding her baby.

Save for this one instance, all of the other mothers gave evidence of a need for assistance to help them find the most effective way to meet this unexpected situation.

(4) THE NEED TO EXPRESS FEARS EVOKED BY THE CHILD

Mother of the child born with congenital absence of digits:

You know I knew a lady in New York who had a baby who looked just like a monkey. She kept him locked in a room and she wouldn't let anyone see him, it scared me so much, I was only thirteen years old when I saw the baby. You know, my baby's hands look like a little chicken's. You know those little chickens you get at Easter time.

Mother of the child born with a club foot:

All I could think of was, a club foot means that my baby is going to have one leg shorter than the other, and he'll have to wear one of those built-up shoes.

.....

Mother of the child born with a cleft palate and lip:

.....then when I got back to

Mother of the child born with a myomeningeoma:

I'm afraid to have any more

my room and realized, I cried for two days. I didn't see the baby for two days. I didn't want to see it. When I finally did go up to see it, I took one look and screamed. I couldn't look at it. Finally, I kind of got over it and I told the student nurse that I'd like to hold it and she asked the nursery nurse and I got to hold it. children because of this baby.

I don't want to have any more children.

To have reality confirm fears which may have been experienced during her pregnancy, confronts the mother with a difficult psychological task. Many are unable to express the fears evoked by their child. Reluctant to speak in these terms, and not given the opportunity by a permissive atmosphere, the mother suppresses her disappointed feelings. Is it here that one seed is first planted for future difficulty as the mother seeks to successfully assume her new role?

The second phase of the effective mourning process usually involves the expression by the mother of the disappointment at having produced a defective child. To recognize the importance of such expression could be beneficial to those 'caretakers' interested in helping this mother.

The smallness of the sample and the lack of more than one extensive interview, are both limitations in bringing forth such delicate feelings. The fear of the mother in the first instance is a striking contrast to her relative uncon-

cerned behavior in the hospital.

The fear of having another child is a realistic response of these mothers. It cannot be dismissed as unimportant if the mother is to find assistance at a difficult time. The family stability may very well rest upon effective resolution of this one reaction of the mother who has given birth to a defective child.

(5) THE NEED TO EXPRESS FEELINGS OF SELF-BLAME

Mother of the child born with a club foot:

Oh God, why couldn't it have happened to me instead of the baby.....all I could think of was, what did I do that might have caused this.

Mother of the child born with a cleft palate:

I thought maybe I had done something but the doctor told me that something happens in the first three months. He said that it wasn't anything that they could find a reason for.

.....

Mother of the child born with a myomeningeoma:

I asked the doctors if it was anything that I had done because my husband beats me and I thought maybe he could have caused it. They told me that there wasn't any real explanation for it.

Mother of the child born with anomaly of the ear:

The doctor told me that the baby's ear could have been caused by the way she was lying inside of me. I don't know, maybe I did something.

.....

Mother of the child born with congenital dislocation of the right hip:

I didn't know if maybe it was the way I carried the baby or what - or maybe it was the way the baby was born.

.....if I have to keep her legs out for six years, I'll do it if that is what it takes to help her. I'll do anything.

One of the most common questions asked by the parents is, "Why did this have to happen?" The mother, identifying the child as an extension of her physical being, looks to herself for the cause of having produced an imperfect child. While she searches her mind, trying to discover the cause of this misfortune, she is apt to recall and lend special significance to the fears and fantasies mothers have during pregnancy.

Four of the mothers looked to themselves as the cause of their child's deformity. They had been told by the doctor that they (the mother) had done nothing which could have caused the baby's condition. The writer was of the opinion that these mothers had intellectually accepted this information, but had still not "digested" it. They still needed reassurance and a chance to talk about their responsibility in what had happened.

The mother who sought an answer by "blaming" her husband, demonstrated another common method of meeting a difficult situation. Unable to cope with her own anxiety, she seeks to work it out by projecting the blame onto someone else. In the same manner, the mother who sought an answer to why her child was born with a congenital dislocation of the hip, looked to the birth process as the cause.

Guilt is one of the most common feelings found in these mothers. Most of these feelings are scientifically unfounded, but for the mother they are very real, and she must be allowed to express them without being dismissed as talking foolishly.

if these mothers' expressed feelings were not motivated by their own inability to "feel alright" about their child's condition. It is quite unfair to interpret a mother's reactions from one visit. However, awareness of what might be the reason for what the mother expresses can be of great assistance for those seeking to help the mother through a difficult time.

(7) THE NEED TO EXPRESS FEELINGS IN REGARD TO CARE GIVEN TO HER DURING AND FOLLOWING THE BIRTH OF HER BABY

Mother of the child born with congenital absence of digits:

All of the nurses were pretty nice to me. My mother says if you treat people nice, they'll treat you nice.

I'll tell you one thing, they didn't give you enough pills.

Mother of the child born with an anomaly of ear:

The nurses helped me by giving me medicine. I think it was the doctor who helped me the most, except for giving medicines.

.....the nurses did come to talk to me a couple of times. We didn't talk about the baby.

The nursery nurse did tell me that I shouldn't worry about the ear. That when the baby is grown, (since she is a girl), you can just comb her hair down and it won't show.

.....

Mother of the child born with a club foot:

The doctors were very good to me and the student nurses and the aides too.

The way some of those graduate nurses look down on you is the thing I liked least.

Mother of the child born with a cleft lip and palate:

The ones who pass trays really helped me the most. [aides] At least I could talk to them. I don't know what I would have done without my roommate. She's the one who took care of me.

The nurse who dressed my baby made me feel so bad. She kept saying, "Oh you poor thing - I feel so sorry for the little thing." Honestly, she made me feel so bad. I was all upset when I took him home.

The only ones I liked were the student nurses, especially one. Not those others who treat you as though they don't care. [R.N.] The students aren't like that. You can talk to them without being afraid that what you're saying isn't exactly right.

.....
Mother of the child born with a myomeningeoma:

No, the nurses never had anything to say to me. I don't think they knew too much about the baby.

.....
Mother of the child born with a "birthmark":

I never asked the nurses about the baby. I didn't think they knew too much about it.

.....
Mother of the child born with a congenital dislocation of the left hip:

The nurses came around and talked to me when they had time. They were very nice.

.....
Mother of the child born with a congenital dislocation of the right hip:

Well, I think they did everything they could for me. I don't care I'm very satisfied with X Hospital.

The doctor helped me the most. She was good to come and tell me everything right away instead of letting me find out on my own.

The nurses are always so busy. The ones taking care of the mothers, I hate to ask for anything. If I need a pill or anything like that, I'd ask for it. For anything else, I just figure they have enough to do without my asking for something.

I don't know, I don't like to bother them. They're

underpaid just like
teachers.

For the most part the mothers spoke of being pleased with the doctors care given to them during hospitalization. The one exception was the mother who delivered the child with a cleft lip and cleft palate. She was pleased with nothing concerning the birth of her child. The satisfaction expressed for the care given by the doctor was not repeated when the mother was asked how she felt about the nursing care.

As all of the negative responses began to emerge, the writer had misgivings at recording "only one side of the story." I felt as if these mothers were being unfair, but were they? Unfair or not, this is how they felt, and if we as nurses are to initiate our functions from the patient's frame of reference, it is our role which must be adapted to effect a helping relationship. Theoretically this is how it must be. Practically, we cannot overlook the nurse's personal feelings. Maybe some of the nurses caring for these mothers wanted to help but didn't know how, and so did nothing.

Most of the mothers spoke with satisfaction of the student nurse's care. When asked why they felt this way, the mother spoke in terms of "they seemed to be so concerned about me as a person, not just one in many."

Generally speaking, the mothers looked to the nurses

for medication, bedpans, and physical care. Expecting no more and hesitating to ask for more, they returned to their homes with unanswered questions, unexpressed feelings, and an unfortunate lack of a clearcut picture as to the great good we in nursing can do.

CHAPTER V

SUMMARY AND RECOMMENDATIONS

This study sought to explore the needs of the mother giving birth to a physically abnormal child. Proceeding from the premise that there is an effective way (substantiated through review of the literature) and an ineffective way for a mother to respond, interviews were arranged to determine the specific needs arising from specific situations. The primary interest of the investigation focused upon the nurse's role in helping the mother work through this difficult time as effectively as possible.

Three assumptions established the frame of reference from which the study proceeded. There were:

- (1) The nurse's awareness of the mother's needs following the birth of a physically abnormal child will lead to a more effective helping relationship.
- (2) The nurse tends to avoid those things which make her uncomfortable.
- (3) The mother who gives birth to the physically abnormal child has needs which are many times unexpressed.

The data resulting from the investigation established these assumptions as having some validity.

Eight mothers were interviewed following the birth of their physically defective children. Seven had been contacted through a large Metropolitan Hospital in the Boston area.

One had recently been discharged from a second hospital in the same area and was included in the study through the intervention of her physician. Five of the mothers had other children at home, none of which were physically abnormal. For three mothers, this was their first child. Seven of the children were being cared for in the home at the time of the interview. The eighth had expired in the hospital and had never been cared for by the mother within the home.

Upon reviewing the mother's reactions, it was found that they expressed many of the same feelings concerning their children, themselves, and the people who cared for them during their hospital stay. These feelings seemed to vary in degree, correlating positively with the severity of the child's defect. They were exposed only after indirect probing was used during the interview.

The severe reaction of the mother who gave birth to the child with the cleft palate and cleft lip can be compared and contrasted to the mother who gave birth to the child with the club foot. The striking difference was in degree, not in kind. Both gave evidence of needing reassurance and support beyond the hospital setting. The former, because of a traumatic hospital experience, did not seek this support from professional people. The latter was very responsive to suggestions of professional assistance. Both illustrated feelings of guilt, fear, and the need for themselves and their babies to be accepted. The remaining six mothers

responded in various degrees between these two extremes.

An interesting aspect of the eight interviews, was to try to form a sort of "barometer reading" as to which stage in the mourning process these mothers could be placed. In this way the helping person would be provided with a gauge with which to judge how well the mother was doing in working through her feelings. Fixation in any one phase would be an indicator that more help should be given to this mother, and an attempt could be made to prevent future difficulty before it begins.

For the mother whose child was born with congenital absence of digits, awareness and realistic appraisal of the child's condition was still not on the conscious level. She still seemed to need time to deny the defect in order to discharge the disappointed longings for the expected child.

The mother of the child born with an anomaly of the ear displayed affective symptoms which could be attributed to a realistic awareness of her child's defect. She was not willing to accept the nurse's comment that the ear could be hidden. She wanted it fixed. It should be noted that the interview was carried out five weeks following the birth, whereas in the preceding interview, only one week had elapsed.

The mother giving birth to the child with the club foot was interviewed one week after the child's birth. The child's leg was in a cast. The mother had been informed of the proposed treatment but it became apparent during the

interview that realistic awareness had not been accomplished. She felt "just terrible" when the nurse offered her sympathy as the child was being dressed to go home. She also needed time to discharge her disappointed longing for the expected normal child before she could feel secure enough to accept this child with a defective foot.

The mother of the child who had died illustrated a double burden of fear at having produced a defective child, and the grief of losing this child. Deterioration of the family constellation gave evidence of this mother's ineffective resolution of her feelings concerning her child's birth and death.

From all indications, the mother giving birth to the child with the cleft palate and cleft lip, had gone through marked reactions while still in the hospital. A period of complete denial and severe affective symptoms preceded her offer to hold the child. At the time of the interview, five weeks after the birth, this mother still seemed as though she needed time to fully work through her disappointed longing for a normal child.

The "birthmark" on the baby's face was being dismissed by the mother as somewhat incidental. Again we see a mother in the process preceding realistic awareness.

Similarly we can also describe the two mothers whose children were born with a congenital hip. Both were upset by neighbors asking about their children. Still insecure in

their own feelings and disappointed because their expected normal child was not produced, they would need time to re-invest their feelings into this unexpected child.

The sample of this study is small, but there are definite indications that special care is needed for these mothers as they try to effect the equilibrium within the family, suddenly altered by unexpected circumstances.

The responses illicited from the mothers gave no indication that the nurse served as a major factor in removing the obstacles to help her (the mother) work through this period. The graduate nurse was viewed as a busy woman in white, overworked, underpaid, intellectually superior and available for physical care only. The mother, reticent at bothering this person, found informational needs satisfied by the doctor and emotional needs subjected to nonverbalized suppressed feelings.

Implicit within the mother's responses is the feeling that nurses are not aware of the patient's special needs. Likewise, the patients are not aware that the nurse is available to serve as a sounding-board for needs other than physical needs. The result is a lack of effective communication and a less than satisfactory nurse-patient relationship. An exception is found, however, when the mothers mention the student nurses. They remember them well and speak affectionately of them. The mothers seemed to view the student nurses as intellectually fallible and humanly kind.

Awareness of the reactions found in these eight mothers, and reactions in similar cases could provide a framework for action in effecting a consistent, intelligent and successful response of the mother to her baby. With this as a basis, both mother and child could look optimistically to a healthy, happy relationship.

Based upon the findings of this study it is believed that the following recommendations would be beneficial in helping to develop a "healthy" mother-child relationship, and would provide a better understanding from which the nurse can effectively meet her responsibility:

- (1) In the case of the birth of a physically abnormal child, hospital regulations should be flexible, used with discretion, and adapted to the best interest of the patient.
- (2) The family who has a physically abnormal child should be followed from the hospital to the home by a "helping person" who is aware of the best way to assist the family.
- (3) This "helping person" should be:
 - (a) the nurse who cared for the mother in the hospital following the birth of her child, and whose services can be extended into the home within the first week following the mother's discharge, or
 - (b) the visiting nurse who had consulted previous to the visit with the doctor and nurse who had direct contact with the mother in the hospital. The visit should be made within the first week following discharge.
- (4) Nursing education, in the field of maternal and child health, should include theoretical principles concerning grief situations such as that found when a mother is told her child has a physical abnormality.
- (5) Provision should be made for the nurse to be able

to discuss her feelings in caring for the mother who has given birth to the physically abnormal child.

- (6) A follow-up study could be done (preferably by the writer) on the eight mothers included in the sample of this study, to determine their progress, or lack of progress in working through the "mourning process."
- (7) A study similar to this study could be done on a larger scale with an attempt to control such variables as:
 - (a) number of children in the family
 - (b) type of physical defect
- (8) A study could be done to determine those qualities found in the student nurse which the patient speaks of so favorably.
- (9) In the case of the mother who gives birth to a physically abnormal child, information should be given as soon as possible and in simple, understandable terms.
- (10) If the doctor is unavailable to give this information, and if the mother is aware of "something being wrong," the nurse should not deny the reality.

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APPENDIX A

Appendix A

INTERVIEW GUIDE

- (1) Recalling your hospitalization, can you tell me, was there anything more that you felt could have been done for you?
- (2) Did you get as much information about your baby as you felt you needed during your stay in the hospital? (if not, what more would you have liked to know about?)
- (3) What did you like most about your hospital stay?
- (4) What did you like least?
- (5) Who seemed to be of greatest assistance to you during your stay in the hospital?
- (6) In what way did this person help you?
- (7) What, do you feel, is the main job of the nurse at this time?
- (8) What's the most valuable thing that nurses do for mothers?
- (9) Do you ever think of the nurses as having a comforting role?
- (10) Is there anything the nurse might have done that might encourage you to turn to her for comfort, when you were upset?
- (11) Do you think it would be helpful to have a nurse visit you now that you are home?

APPENDIX B

Appendix B

INTERVIEWS OF FOUR MOTHERS FROM
THE SAMPLE OF EIGHT

Family A

Male Infant - Firstborn

Abnormality - Bilateral claw hands; both hands functional

Conversation within the hospital setting:

My husband said it could be worse. It could be an arm or a leg. I wasn't asleep in the delivery room. I heard the doctor and he said there was something wrong with the baby's hands. When they didn't bring the baby out for me to see for twelve hours, I thought there was something terrible wrong - even though they told me that all babies are not brought out for twelve hours. My mother had a ten pound baby that lived only fifteen minutes. My mother never did find out what was wrong. I was afraid my baby was not going to live. If Jesus wanted it this way then that's the way it has to be. It could be much worse. The doctor explained it to my husband and me. He said that it could probably be fixed. You should see how he grips the bottle with his hands even though he doesn't have all of his fingers. He is so strong. Did you see how well he uses his hands? My mother said if you're nice to the nurses, they'll be nice to you. My baby eats pretty good. I just love to hear him cry. I'm going to have him circumcised before he leaves the hospital, because I couldn't bear to have him leave home once I had him home. I'd like to have thirteen children but my husband said just three or four. A specialist is coming around later on to talk to me about the baby. I'm anxious to get home but I don't know much about taking care of the baby.

Conversation recorded following a home visit eight days following the birth of the child:

Oh the doctors helped me the most. They came around, about four or five of them, and talked to me. I think they told me as much as they could. I won't be able to find out anything for sure until after the fifth of April. They took X-rays

of the baby's hands yesterday at the clinic and then on the fifth of April they'll be able to tell me more. The nurses were all pretty nice to me. I'll tell you one thing, they didn't give you enough pills. You had to ask for them and then go up and get them. The nursery nurses took care of the baby. They told me about bathing him and feeding him and they said I'd have to leave the baby in the hospital. I said that I wasn't going home unless I took my baby with me. They said then, that it was alright with the doctor if I promised to bring him back to the clinic on the 6th of March. (I suppose this whole thing has caused you a lot of concern) Oh yes, but it could have been much worse. The doctor said that no matter how many more children you have, the first one is always special. You know I knew a lady in New York who had a baby who looked just like a monkey. She kept him locked in a room and she wouldn't let anyone see him. It scared me so much, I was only thirteen years old when I saw the baby. You know the baby's hands look like a little chicken's. You know those little chickens you get at Easter time. I don't care what's wrong with my baby, I love him anyway.

Honestly, I told my husband, sometimes I think I'll go crazy thinking about everything. (Do you mean concerning the baby?) Yes, yesterday after the doctors took X-rays of the baby's hands the nurse at the clinic told me that she wouldn't have anything done with the hands, that to cut into them may do more harm than good. My father says that too. (How do you feel about it?) Well, I don't know I think I'd like to have them fixed, but still when he's up walking around and everything, maybe you won't even notice his hands.

I'd like to have you come back to see me. I won't be going out myself until the baby and I are both well.

Family D

Male Infant - Fourth child (second son)

Abnormality - Unilateral cleft palate and cleft lip (the latter had been repaired two weeks previous to interview; the child had been discharged one day previous to interview)

Child born by Caesarean Section (the Mother's third)

Conversation recorded following home visit five weeks following the birth of the child:

Come in. Don't mind how I look. (The mother was in her pajamas at 2:30 P.M.) I haven't been dressed since the baby came home yesterday. (A visitor came out carrying the baby) He looks pretty good doesn't he? (Purpose of the visit was reviewed) Oh Lord, don't talk to me about nurses. If you want to hear about them you came to the right person. My stay in the hospital was the worst experience I have ever had in my life. I'll never go back to that hospital again. I can't think of one thing good about it except that they fed the baby good and one nurse, a student nurse, was awfully nice.

I found out about the baby in the delivery room. The doctor told me but it didn't even sink in. I just went off to sleep. Then when I got back to my room and realized I cried for two days. I didn't see the baby for two days. I didn't want to see it. When I finally did go up to see it, I took one look and screamed. I couldn't look at it. Finally I kind of got over it and I told one of the student nurses that I'd like to hold it, and she asked the nursery nurse and I got to hold it.

The ones who pass trays really helped me the most. At least I could talk to them. Another thing, I don't know what I would have done without my roommate. She's the one who took care of me. I never was in such pain before, and they wouldn't give anything. I was vomiting after my operation and was so sick I couldn't hold the pan. The nurse came in and handed me the pan and went out. My roommate held it for me. I don't know what I would have done without my roommate.

The nurses were awful. The ones with caps that kind of look down on you. The only ones who I liked were the students, especially one. Not those others who just treat you as though they don't care and like you're just one more that they have to watch. The students aren't like that, you can talk to them without being afraid that what you're saying isn't just exactly right. Those others make you feel as though they're above you.

(Do you ever think of nurses as having a comforting role?) Lord no - comfort, my gosh, they didn't help me at all. (Did you talk to the nurses about the baby or ask them any questions about the baby?) No, I didn't feel I could ask any questions, anyway, the nurses were never around. I don't know where they were, having a card game or something I guess.

I was not able to rest in the hospital. The sleeping pills did not work and I asked for something stronger. Another thing you can tell those nurses, if you want my opinion, tell them not to put mothers who are breast feeding their babies in the same room as those who are not. You're awake all night long with those babies coming in.

I don't want to have any more children.

I saw the doctor who was going to operate on the baby's lip only once and it was the aide who told me that the doctor was very good. I didn't want my baby to be operated on in this hospital because I hated it so much but the operation would have had to be postponed if the baby would have been taken to another hospital. I was shown how to feed the baby twice before we brought him home. The first time the nurse walked out of the room and left me.

I don't want any nurses stepping in. To tell you the truth, I don't care to have them around. My mother can help me. She knows more than any of them. Anyway, my baby was not circumscized and my mother said that they're supposed to push the skin back every day and they didn't do it once. They didn't have a bellyband on the baby either. I don't want any nurse stopping in here.

(Did you have any questions as to what could have caused this thing in the baby?) Yes, I did. I

thought maybe I had done something but the doctor told me that something happens in the first three months of the pregnancy. He asked me if I'd had any viruses or anything at that time and I told him I had not. He said that it wasn't anything that they could find a reason for.

All I know is that they will fix the inside of the baby's mouth when he's fifteen months old. I never could get any information when I went to see the baby in the hospital. It's going to be quite a job feeding the baby. I'm so afraid that he will choke. It takes me all morning to feed him.

Family E

Male Infant - Third child (second son)

Abnormality - Myomeningeoma (Child expired one month after birth)

Conversation recorded following homevisit five weeks after the birth of the child and one week after the child expired:

They let me have a glimpse of the baby in the delivery room. I didn't know anything was wrong with him until the next day when I saw a slip on my bedside table saying that they had baptized the baby. I knew something was wrong in the delivery room, the way everyone acted. Then that next morning when I saw the slip I had the nurses call the doctor and I talked to the doctor at that time, and he told me that there was something wrong with his spine and that the baby may not be able to use his legs or move his bowels, and then later a lady doctor came and told me he would be alright and the other doctor said that she shouldn't have said that.

I saw my baby move his legs and he moved his bowels okay. I know he did. I could see him when I went to the nursery to look. I don't understand why he got so he couldn't move his legs after the infection. The fluid started leaking out and the doctors thought that they would operate but then they couldn't because of the infection. They just put a few stitches in. They were afraid that he would die if they operated.

I didn't understand all of the words that they used.

I asked the doctors if it was anything that I had done because my husband beats me and I thought maybe he could have caused it. They told me that there wasn't any real explanation for it. Ever since this happened my husband and I have been quarreling more and I don't take it like I used to. I just don't care for him like I used to.

No, the nurses never had anything very much to say to me. I don't think they really knew too much about it. The nursery nurses never had anything to say either. They wouldn't let me feed my baby. I felt awfully bad about it. Just to see all of the mothers having their babies made me feel so bad.

I'm afraid to have any more children because of this baby. This baby was prettier than my other two kids.

It is so good to have someone to talk to. You just don't know. I'd be glad to have you come back.

Family H

Female Infant - Third child (first daughter)

Abnormality - Congenital dislocation of the right hip

Conversation recorded following home visit eight days following the birth of the child:

I got home last Thursday and everything seems to be going pretty good. See how she rests on her stomach. This way I can keep her on her stomach and at the same time keep her legs out like they're supposed to be. See I put the diaper on like they showed me in the hospital.

I think they did everything they could for me in the hospital. I don't care I'm very satisfied with X Hospital. I know one thing, I'll keep my appointments, that's for sure.

The doctor was very nice, she explained everything to me and I know what she said, but I don't know how to tell anyone. She explained to my husband too and I was glad of that because I don't know how to explain it in a way that he will get anything out of it.

The doctor didn't tell me what caused it but maybe they don't know and anyway I didn't want to bother them by asking them a lot of questions. I didn't know if maybe it was the way I carried the baby or what, or maybe it was the way the baby was born.

Well, I think the doctor helped me the most. She was so good to come and tell me everything right away instead of just letting me find out on my own. She came right out and told me. She seemed to be concerned about me and the baby, and whenever anyone is concerned about my kids they're tops. The nursery nurses, especially one, was very good. She helped me a lot by talking to me about the baby and trying to help me understand.

(What do you think is the main job of the nurse at this time?) Well, I don't know they're always so busy. The ones taking care of the mothers, that I hate to ask them for anything. If I needed a pill or was hurting I'd ask them for it, but for anything else, I just figure they have enough to do without my asking for something. They were out on the floor when someone would need anything. I don't know, I don't like to bother them. They're underpaid just like the teachers. I did have more confidence in the doctor and what she said. The nurses on the floor just seemed to have too much to do and I didn't want to bother them.

I think my baby will get along alright and if I have to keep her legs out for six years, I'll do it if that is what it takes to help her. I'll do anything. Sometimes I look at her and feel, my gosh it must be awful to have to have your legs out like that all of the time. I know when I had my legs in the stirrups for the short time in the delivery room, how awful it was.

Then I think, what if her legs grow out like that. When I have her diaper off her legs just stay out like that. I have every confidence that she's going to be alright. That she'll walk alright.

One thing I get so darn mad at, I had a neighbor come in and she started saying, 'poor baby, poor baby' - just as if my baby wasn't normal and this makes me so darn mad. These people just don't understand and it makes me mad. I'm nervous anyway. I know the baby is going to be alright and sometimes I don't even think about her leg.

This new baby is just the apple of my husband's eye. He wanted a girl so badly. The other two are boys you know.

I was so nervous when I started taking care of the baby. The doctor showed me how to put the diaper on but I couldn't put it on like she did. I've arranged my own way and it holds her legs out like they're supposed to be. They told me if I have any trouble that I should come into the clinic.

I think she's going to be okay. She'll be out playing ball and I'm going to take her out horse-back riding. I know she will be okay.