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Occupational therapy from the start : five case studies on the experiences and needs of parents in the Neonatal Intensive Care Unit

Wendelyn Gail Veder
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**Occupational Therapy From the Start:
Five Case Studies
on the Experiences and Needs of Parents
in the Neonatal Intensive Care Unit**

**A Thesis
Presented to
The Faculty of the Department of Occupational Therapy
San Jose State University**

**In Partial Fulfillment
of the Requirements for the Degree
Master of Science**

**By
Wendelyn Gail Veder
December 1994**

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Abstract

Occupational Therapy From The Start: Five Case Studies on the Experiences and Needs of Parents in the Neonatal Intensive Care Unit

Wendelyn Gail Veder

This study involved five mothers whose children were in the Neonatal Intensive Care Unit (NICU) at Lucile Salter Packard Children's Hospital at Stanford (LPCH). Subjects participated in semi-directed interviews regarding the mother's background, the infant's start, the impact of the infant's hospitalization on the family, the mother's specific experiences and needs during that time, the relations with the NICU staff, the role of the occupational therapist in the NICU, and the baby's present status.

As a result of the interviews, recurring themes in the participant's experiences were identified. Four themes were especially pertinent to this research and to the field of occupational therapy. These recurring themes were: the need for support, the need for information, attitude as an asset to parents and to professionals, and the role adaptation that was necessary for participants during this unique experience.

With their background in development and holistic and meaningful approach to treatment, occupational therapists can provide an invaluable service to this population. Implications confirming the role of occupational therapists in the NICU and recommendations for future research were identified.

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The participants, for opening their homes and their hearts.

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to take calculated risks, have the strength to unleash our hearts, and have the
blessing of friendships that will last a lifetime.

My family, for instilling in me confidence, determination, and a quest
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the greatest modality.

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CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was twofold:

1. To explore the experiences and needs of parents who have had a child in the Neonatal Intensive Care Unit (NICU) at Lucile Salter Packard Children's Hospital at Stanford (LPCH) and
2. To suggest additional methods for use by occupational therapists to assist parents during their NICU experience.

Statement of the Problem

As the survival rate of premature and medically fragile infants is increased by medical advances, the needs of the parents who must bond with and ultimately care for these children must be addressed. Research is needed to learn about these unique parents and to suggest ways in which occupational therapists can increase the effectiveness of their interactions with these new parents in the early stages of their infant's treatment.

Research Questions

This study was designed to answer the following questions:

1. What were the perceived experiences of parents about the time they and their child spent in the Neonatal Intensive Care Unit?
2. What are the parents' perceptions regarding the methods used by the Neonatal Intensive Care Unit staff for assisting parents to operate within the Neonatal Intensive Care Unit environment?
3. What can occupational therapists do to most effectively assist the parents of infants in the Neonatal Intensive Care Unit?

Definitions

The following definitions were generated for this study.

Conceptual Definitions:

Perceived Experience: Subjective description of one's involvement in the NICU and any or all of the feelings, emotions, and activities which might have been included in the daily experiences during this time.

Premature: Infants who are born under 37 weeks gestational age (Ensher & Clark, 1986).

Operational Definitions:

Lucile Salter Packard Children's Hospital (LPCH) at Stanford University

Medical Center, Stanford, CA: "Internationally recognized pediatric health care institution dedicated to excellence in patient care, education, and research.

1. Patient care: To provide the highest quality health care for children in an environment that supports the special needs of children and their families;
2. Education:
 - A. To support the training and education of physicians and other health care professionals in primary and specialty care for children;
 - B. To serve as an advocate for improving the health status of children;
3. Research:
 - A. To support basic and clinical research in the interest of children;

B. To transfer advances in science and technology into the practice of caring for children" (LPCH at Stanford Strategic Plan, 1994).

Neonatal Intensive Care Unit (NICU): Located at Lucile Salter Packard Children's Hospital at Stanford University Medical Center, Stanford, CA. Designed to provide optimal care to infants and their families when hospitalization in an intensive, critical care nursery is necessary.

NICU Staff: All health professionals who work within the NICU (Includes neonatologists, residents and interns, nurses, social workers, occupational therapists, physical therapists, respiratory therapists, nutritionists and others.)

Parents: Men or women who have had a child in the NICU at Lucile Salter Packard Children's Hospital at Stanford.

Therapists: Within the culture of the NICU at Lucile Salter Packard Children's Hospital at Stanford, the occupational and physical therapists share a common body of knowledge regarding evaluation and treatment of premature infants, allowing either to complete the initial assessment. After the initial evaluation, the primary therapist is chosen according to essential qualities of the patient's need and the specialties of the two disciplines. Roles that are primarily filled by occupational therapists include upper extremity splinting and fabrication, feeding evaluation and treatment, and positioning for safe transport home after discharge. Roles that are primarily filled by physical therapists include lower extremity splinting, evaluation and management of soft tissue damage, and dermatome and myotome testing. However, a large portion of the services provided, such as conducting developmental assessments,

consulting with NICU staff regarding positioning, provision of developmentally appropriate activities, discharge planning, and staff and caregiver training may be provided by either the occupational therapist or physical therapist in order to limit the number of staff to whom infants and parents are exposed.

Assumptions

In proposing this study, the researcher made several assumptions.

1. The needs of parents whose children were in the NICU were not being met as effectively as possible. This assumption was based upon informal discussions between the researcher and parents in the NICU and between the researcher and the occupational therapists who served this population.
2. Occupational therapy offers valuable and unique services to the research population.
3. Therapists who work with this population would benefit from closer examination of the experiences and needs of the parents who participated in this research.
4. The parents who participated in this study would be willing and able to reveal their needs and explore their experiences during a recorded interview with the researcher.
5. Valid questions would be asked during the interview, since the interview instrument was designed with the assistance of therapists who are experienced in the field.

Limitations

Limitations of this study include:

1. Participants were limited to English-speaking mothers in order to eliminate the confounding variables of ethnicity and gender. Clearly, further research is indicated on the perspectives of fathers and of parents who do not speak English;
2. The subjects provided information by self-report in a semi-structured interview. Therefore, accuracy of responses may have been limited; and
3. Since the interviews were conducted and transcribed by the researcher, it must be acknowledged that although precautions were taken to reduce or eliminate bias, some bias may have occurred in reporting the data;
4. The small sample size limits the ability to generalize the findings.

Significance

Parents who have a child in the NICU will ultimately be responsible for the long term care of their child with special needs. Information compiled in this study will provide additional insight into the parental perspective and ways in which the NICU experience can be improved. This insight can serve to guide health professionals as they interact with and plan treatments for this population. Results may include more effective treatment with a larger amount of carryover, and the commitment of the parent to the child which is an invaluable asset. The children with committed and involved parents will have a greater potential to reach their maximum level of functioning, and later be able to participate in and contribute to society. Although occupational and physical therapy are unique professions, because of the cooperative team approach utilized in the NICU at LPCH, this study could provide beneficial

information to professionals in both fields.

CHAPTER 2

LITERATURE REVIEW

Review of the literature was organized into the following categories: occupational therapy in the NICU, professional partnerships, parental experiences and needs, the impact on the mother, and a perspective on partnership.

Occupational Therapy in the NICU

The American Occupational Therapy Association (AOTA) Commission on Practice (1993) acknowledged that parents and other family members are the most important and consistent influence in the infant's life. When parents are faced with the crisis of a premature birth, the medical needs of the infant take priority over the needs of the parents. Health care providers and parents alike may confuse the tremendous professional investment and roles of various hospital staff members with the unique role of parents (Schraeder, 1980). Parents may feel guilt, anger, fear, and rejection as they see the medical staff taking on the role of caring for the child whom they had assumed would be theirs alone (Smith, 1986). As one parent remarked, "I had a hard time believing that strangers would care for and love my child as much as I could" (Kolovitz, 1989, p. 54). In turn, hospital staff may experience difficulty relinquishing responsibility for the care of medically fragile infants, even to parents.

The occupational therapist's concern with the interactions of biological, developmental, and psychosocial aspects of human function makes him/her an ideal member of the treatment team to assess the wide range of needs of the developing infant and family (AOTA, 1993). Additionally, with the implementation of Public Law 99-457 (Education of the Handicapped Act

Amendments of 1986), occupational therapists may also be well suited to act as case managers (Case-Smith, 1989). This law specifies that a case manager must be named in the individualized family service plan (IFSP) who is "from the profession most immediately relevant to the infant's and toddler's or family's needs who will be immediately responsible for the implementation of the plan and coordination with other agencies and persons" (p. 5).

Therapists should involve parents in treatment planning and facilitate parental role adaptation. The family may thus become a focus of the occupational therapist's intervention, utilizing "the important role of the family as nurturer and agent of change" (Humphry, Gonzales, & Taylor, 1993). Similar conclusions were drawn by Case-Smith (1989) when she included the roles of family support, parental training and education, and promotion of positive parent-child interactions as those which the occupational therapist was well suited to perform. Case-Smith believed that the primary goal of the intervention program is for parents to become as independent as possible in adapting the environment to their child's developmental needs and goals, admitting that most families need education, assistance, and support to help them facilitate their child's development. Case-Smith stressed the importance of empowering parents to maintain control of their situation while the occupational therapist acts as a consultant to facilitate independent decision making. Greenwell (1992) also believed that "occupational therapists have the opportunity to explain premature or delayed infant development to the parents," thereby empowering them with knowledge that will lead to healthy interactions with their infant.

According to King's theory of Adaptive Responses, the action of a person accommodating to environmental demands is an adaptive response

(Levine & Brayley, 1991). The central focus of occupational therapy, according to King, is to elicit adaptive responses (Christiansen, 1991). When a parent is faced with the birth of a premature or "at risk" child and the ensuing NICU experience, functional patterns must be developed to meet the new demands. An occupational therapist in the NICU can assist parents of their patients with the development of positive adaptation, thereby improving the quality of the child's and family's life under adverse, devastating circumstances.

According to Mosey's theory of Role Acquisition (cited in Christiansen, 1991), occupational therapists can also be instrumental in assisting these parents who are in role transition with using activities and relationships to learn role skills. Successful role adaptation by parents in the NICU can be encouraged and assisted by occupational therapists through empowerment, enablement, and education.

The results of limited parental involvement may include poor role adaptation, poor infant-parent attachment, and significant mothering disorders (Faranoff, 1972). An associated result may be limited follow-through with occupational therapy treatment. Kovach's study (cited in Kilgo & Raver, 1991) found that parents only followed through with half of the treatment strategies when they were not involved in treatment planning. However, when parents were actively involved in the treatment planning process, implementation was 80% to 100%. Parental empowerment can therefore affect the quantity and quality of treatment implementation, and ultimately affect attainment of the infant's potential for development.

As a result of her study on the needs of parents when their infant is a patient in the NICU, Bass (1991) concluded that "Costs are incurred when

providing support for families. However, when families do not adapt well to parenting their infants, the potential costs to hospitals treating the neglected or abused children may be greater. Failure to provide support to families at risk may impose on society the greatest cost of all" (p. 32).

Professional Partners

The difficult task that faces the occupational therapist who works in the NICU is evident in the unavoidably tenuous relationship in which parents and professionals participate. Stein (1992) acknowledged some of these difficulties when she said, "The early weeks of any parent-professional collaboration are crucial to the development of trust and communication. It is a time, however, when hope and possibility clash with the limitations inherent in the system. Limitations may include the parent's inability to understand or even accept their child's diagnosis. Limitations may involve the service provider's time, resources, and knowledge" (p. 19).

Kolovitz (1989), a parent whose child was placed in a NICU, provided a glimpse of the parental perspective and a plea for parental involvement in the NICU. She believed that "every effort should be made by both parents and the hospital to ensure that babies who must be hospitalized receive parental attention" (p. 55). Admitting that the "NICU has an extremely intense atmosphere," she found that the physical therapist's positive, pleasantly stimulating interactions with her child provided the balance that was beneficial both to herself and to her child. Kolovitz did not offer suggestions for facilitating parental adaptation.

In Cole's (1990) work on the parent's view of quality health care, the parent-professional partnership was identified as a key factor in providing quality health care. "Professionals offer the most relevant professional

expertise, and, in turn, parents use that expertise, along with what they know about their child and about resources and services. Parents must combine their knowledge with their vision of the child and family, and make a decision for which they are ultimately responsible. This is the process by which quality care is achieved. It involves communication, negotiation, and team decision making" (p. 372).

Parents told Harrison, author of *The Premature Baby Book* (1983), of their concerns regarding the difficulty and frustration caused by parental exclusion from the treatment planning process and in actual implementation of their baby's care. These concerns were further discussed in Harrison's (1993) article which outlined principles for family-centered care. Among the principles for family-centered care were that care should be based on "open and honest communication between parents and professionals, on medical and ethical issues," and that "parents and professionals should work together to. . . promote parenting skills and encourage maximum involvement of families with their hospitalized infant (p. 644)". Harrison's strong opinions clearly reflect compassion and advocacy for parents in this unique situation. This is especially evident in her statement that "Neonatologists, pediatric surgeons, and others who care for imperiled newborns must recognize the life-long impact of their treatment decisions on their patients and their patient's families. They must have a realistic understanding of the resources that are (and are not) available to infants with disabilities and their families. The presence or absence of such resources should not be irrelevant to treatment decisions in the NICU" (p. 647). Unfortunately, decisions on whether to save a human being in today's American medical system are not based on "a realistic

understanding of resources," but rather on rules and regulations which encourage physicians to prolong life, rather than allowing it to terminate.

In a study of mother-preterm infant pairs and the supportive acts which nurses provided, the most frequently performed supportive acts included "active listening," "sounding board," "information exchange," and "validation" (Kirgis, Godfrey, & McNeal, 1991). The aim of this type of intervention was facilitation of the developing relationship between the mother and her infant, and incorporation of the child into the family structure. It was also acknowledged that interventionists must be sensitive to the unique needs and styles of each infant-parent pair, and interventions must be adjusted accordingly.

The team approach to treatment was cited as the most effective way to treat a patient in the NICU (Greenwell, 1992), with the perspective that "In this situation, you not only have the infant as your patient, but also the parents, since they must be the voice of and advocate for their child" (p. 16).

In their work on the experiences and needs of caregivers for children with medically complex needs, Diehl, Moffitt, and Wade (1991) utilized a focus group interview as a method to collect data. One parent said, "We had no idea [of] the impact. . . what [having a sick child] was going to do to our family" (p. 173). Among the topics which arose during the discussion was frustration over the difficulty caregivers experienced with understanding physicians. Information was often delivered quickly, only once, and in unfamiliar terminology. The process left parents feeling confused, frustrated, and helpless. The authors found evident the need for parental training from the onset of their child's treatment. Again, parents wanted to be included in the

decision-making process. Rather than viewing members of their child's treatment team as "professional partners," the relationship was viewed as "them against us." Unfortunately, results from the study indicated that "professionals who did a good job were viewed as the exception" (p. 174). Interestingly, it was also reported that "the professionals most frequently viewed as very supportive and informative were the occupational therapist and the private physical therapist" (p. 174).

Parental Experiences and Needs

Jean Kasper's (1986) thesis on the perceived needs of parents in the pediatric intensive care unit inspired follow-up work by Bass (1991) that focused on the needs of parents in the Neonatal Intensive Care Unit (NICU). Bass's study was unique because parents were the sources of their own need statements. This was different from previous research in which data collection tools were used through which parents chose from a list of needs generated by the researcher. Using tools modified from Kasper's study, Bass used a chart information form, a demographic questionnaire, and a flexible, semi-structured interview guide. Bass found needs in six categories. The needs were for information, person-related support (excluding NICU staff and clergy), attachment/parenting support, physical support, spiritual support, and staff support. This study was limited by its small, non random sample. The sample consisted of white, married adults (husbands and wives), and excluded other racial groups, unmarried parents, and teenage parents. Findings were consistent with previous research which identified infant appearance, sights and sounds in the environment, parental role alteration, and staff communication as the major stressors for parents.

One common thread throughout Bass' study was the need, ranked as "extremely important," for parents to receive positive, encouraging information. Bass reported that parents wanted even negative possibilities to be presented in a more positive way, and they wanted to receive positive information from staff members whenever possible. One parent in Bass' study said, "If it is possible to give positive feedback, then I think they should." This concept was echoed by Greenwell (1992) when she stated, "It is important that the staff regularly communicate to the parents in a clear, positive manner" (p. 16).

The Impact on the Mother

The issue of focusing on the mother rather than the father throughout a majority of the research efforts on infants and children was addressed by Sabbath (1984) in an article entitled "Understanding the impact of chronic childhood illness on families." Sabbath stated, "It is assumed, correctly or incorrectly, that the birth of a defective infant is more of an insult to the mother than to the father" (p. 50) and further that "the mother must mourn for the loss of her wished-for perfect infant and accept and care for the real child who was born" (p. 50).

In a study of 23 couples whose children were in the NICU, Miles, Funk and Kasper (1992) explored the stress response of mothers and fathers of preterm infants. The study concluded that both parents perceived their altered parenting role as causing the most stress during this experience, although mothers perceived all aspects of the NICU environment to be more stressful than did fathers.

In an effort to determine the degree of stress related to the NICU environment perceived by parents, Perehudoff (1990) distributed

questionnaires to 31 parents whose children were in the NICU. The authors reported that altering the parental role caused the most stress for mothers while the sights and sounds of the NICU were more stress-inducing for fathers. Additionally, mothers were significantly more stressed by the entire NICU experience than were fathers, as was demonstrated by their scores on the NICU Parental Stress Scale. This reinforced the findings of Miles et al. (1992). Perehudoff believed that one implication of this research was that nurses should communicate with parents in a manner that prevents or reduces stress.

The importance of maternal involvement in child care was explored in a study of 65 mothers of preterm, low birth weight infants (Generro, Grisemer, & Musci, 1992). This study emphasized the lifestyles of the mothers and the expectations which they held for their children. It was found that mothers felt a sense of pride as a result of the ability to care for their low birth weight infants.

A Perspective on Partnership

The patient's perspective is crucial in the treatment process, as was discussed in Mattingly's (1991) work on the narrative nature of clinical reasoning. The occupational therapist who applies specialty skill in the NICU treatment of premature infants must address the psychosocial needs of parents in order to facilitate the necessary commitment of a parent to his or her critically ill child and to the therapeutic process. A powerful technique for this process described by Mattingly (1991) is "storymaking." This "storymaking" involves cooperation and creative vision as the therapist consults with the parent to write "stories" of potential scenarios which may be enacted in the future. In doing so, they come together and share a common view on the purpose of engaging in a particular treatment strategy for the

infant. Ultimately, a successful intervention develops when the parent takes over authorship of the "story" and, with a new perspective, begins to edit chapters which the therapist might never have envisioned.

Clark (1993) also encourages the use of "occupational storytelling" as a means by which therapists may develop better understanding of the spirit of their patient. She found that "every patient has important stories of childhood occupations that influence who they are today" (p. 1074). Although young patients in the NICU have not yet had the opportunity to envision or enact their childhood occupations, the actions and dreams of their parents will undoubtedly influence the way in which their child's story will unfold.

Peloquin (1993) wrote an article entitled "The patient-therapist relationship: Beliefs that shape care" as a part of "a larger inquiry into the challenge of creating a climate of caring" (p. 935). Peloquin's work serves to remind health professionals that patients frequently believe that "helpers fail to see illness and disability as emotional events charged with personal meaning" (p. 936). This failure adversely affects the patient-professional partnership.

Summary

The literature has emphasized the importance of parental involvement in the form of a professional partnership, the significance of giving parents the opportunity to have their experiences heard, the unique role of the mother in the NICU, and the pivotal role that occupational therapists are suited to play in assisting parents to adapt to and cope with their unusual parenting situation during the NICU experience. The literature has not adequately reported the specific experiences and needs of parents of children in the NICU. The literature suggests that parents of children in the NICU need to be

given the opportunity to have their stories told, their tales acknowledged, and their needs met. This storytelling ritual can be a first step in the rite of passage from the childhood they remember to the childhood they envisioned for their own child and finally to the unexpected, unscripted future which their child now faces.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The purpose of this study was twofold:

1. To explore the experiences and needs of parents who have had a child in the Neonatal Intensive Care Unit (NICU) at Lucile Packard Children's Hospital at Stanford (LPCH) and
2. To suggest methods for use by occupational therapists to assist parents during their NICU experience.

Research Questions

This study was designed to answer the following questions:

1. What were the perceived experiences of parents about the time they and their child spent in the Neonatal Intensive Care Unit?
2. What are the parents' perceptions regarding the methods used by the Neonatal Intensive Care Unit staff for assisting parents to operate within the Neonatal Intensive Care Unit environment?
3. What can occupational therapists do to most effectively assist the parents of infants in the Neonatal Intensive Care Unit?

Design and Methodology

This exploratory study was conducted using case study methodology to study a phenomenon. Phenomenological methods for the assessment of trustworthiness were employed.

Yin (1986) defined case study methodology as involving

an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the

boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used (cited in DePoy & Gitlin, 1994).

Thus, speaking with multiple participants to explore a phenomenon of similar experiences falls within the realm of the case study methodology.

Krefting's (1991) description of phenomenological methodology provides for "the assessment of trustworthiness" which was utilized in this study. This study provides a description of the perceptions of a specific experience, without the ultimate purpose of generalizing these findings to theories or models. Krefting analyzed Guba's model for evaluation of research. Guba's strategies were combined with Krefting's personal experiences to allow Krefting to offer suggestions for future researchers as they evaluate their work. Evaluation criteria were recommended to establish truth value, applicability, consistency, and neutrality. In quantitative research, these criteria are known as internal and external validity, reliability, and objectivity. In qualitative research, these criteria are known as credibility, transferability, dependability, and confirmability. Efforts were made throughout this study to meet these qualitative criteria and thereby establish trustworthiness in this research.

The researcher made an effort to establish trustworthiness by consulting with participants about the findings of data collected during prior interviews with other participants. It was found that the experiences had been interpreted and described in such a way that the participants recognized and agreed with the descriptions as valid and accurate to their own experiences as well. Additionally, variations in the perceived experiences

could be ascribed to an identified source, whose history or approach to issues was unique. Thus, dependability was established.

As the interviews were conducted, the subjects frequently addressed the majority of topics planned on the interview instrument without the researcher needing to guide them to these topics. At the close of each interview, inquiries were made of the participants as to additional areas they wished to address. Participants consistently reported that they perceived the interview to be thorough and requiring no additional components. These factors add to the dependability of the interview instrument.

Confirmability, the neutrality or objectivity of the data, may have been compromised as interviews were brief and conducted with participants with whom the researcher had not developed a relationship. If participants and the researcher had been better acquainted, deeper introspection by the participants and more aggressive questioning by the researcher may have occurred. These types of interactions may have resulted in additional or varying data from that which was collected during this study.

Transferability is the responsibility of those wishing to transfer the findings of this work to another situation. Therefore, it will be the responsibility of future researchers during replication and expansion of this work to establish transferability.

Sample

The subjects for this study were five mothers of children who were discharged from the NICU at LPCH two to twenty months prior to the study and for whom English is the primary language. This range of time following discharge was selected to provide variable perspective on the experiences that these parents have had and to avoid placing additional pressure on new

parents during the difficult transition period immediately following hospital discharge. All participants have children who are "graduates" of the Neonatal Intensive Care Unit at Lucile Salter Packard Children's Hospital (LPCH) at Stanford and who were seen by occupational therapists during their child's hospitalization. Participants were purposely not selected on the basis of such characteristics as frequency of visits to the NICU, length of their child's hospitalization, or degree of prematurity in order to provide a rich base of information from mothers whose experiences may have varied.

The selection of participants for the pilot study and the formal research were determined by the researcher with assistance from the primary occupational therapist in the NICU at LPCH. Criteria for exclusion from the study included fathers, non-English speaking mothers, mothers who lived more than 40 miles from LPCH, mothers whose children are no longer living, and mothers who declined to participate.

Instrument

The interview instrument (Appendix A) was developed from review of the literature and with assistance from occupational therapists and the Director of the Rehabilitation Services Department at LPCH. Revisions of the instrument followed review by the thesis advisor and readers and the occupational therapists at LPCH. Final revisions followed use of the instrument during the pilot study, and subsequent discussion and re-evaluation of the instrument by an instructor and the researcher's peers in a course on Advanced Clinical Problems at San Jose State University.

Procedures

From the medical records at LPCH, a list was compiled of all mothers who met the criteria for inclusion. These mothers were then contacted by

telephone when a determination was made of study eligibility. Following introduction, each mother was asked about her willingness to participate and to sign an agreement (Appendix B) indicating this willingness to become a participant in the study. This agreement allowed the researcher to audio tape the interviews and report the findings in this study. Interviews were designed to last 60-180 minutes. If the mother agreed to participate, mutually convenient times and locations were established for the interviews.

Data from each participant were collected during one semi-structured interview. The infants who had been cared for in the NICU were present at all interviews. This allowed the researcher to observe the child's present status, as well as the interactions that occurred between mother and child. Following the interview, participants were asked if they would like support from psychological or social service professionals to relieve psychological distress which may have developed as a result of their participation in the interview. No requests for referrals were made. After completion of each interview, participants were mailed a note of appreciation for their contribution to this research.

At the conclusion of the study, approximately 600 minutes of interview data had been recorded. The researcher then transcribed the audio tapes onto a Macintosh computer. These transcribed interviews were then dissected and examined for emergence of themes, using the "storyboard" approach.

CHAPTER 4

DATA, COMMON THEMES AND RESULTS

Presentation of Data

In this section, responses are presented to answer the research questions posed for this study. Each case is presented individually to provide the reader with an opportunity to view each case distinctly. The responses have been organized according to the structure of the interview, and include general information regarding the mother, the baby's start, the impact of the infant's hospitalization on the family, the mother's specific experiences and needs during that time, the relations with the NICU staff, the role of the occupational therapist in the NICU, and the baby's present status.

Case A

Introduction

Mother A is a 34 year old woman with a college education. She came from an intact family and has one brother. She has been married for 10 years. Mother A has two sons and one daughter. Her daughter, Baby A, spent 17 days in the NICU at LPCH immediately following her birth. Prior to the birth of Baby A, Mother A had no experience with children with special needs.

Baby's Start

Mother A had not intended to have another child and had even modified her health plan to eliminate prenatal care and delivery coverage prior to the conception of Baby A. This would prove significant with the birth of Baby A, as additional insurance was required for intervention with this special child, and bills mounted quickly. At twelve weeks gestation, a sonogram reflected abnormally developing hands on the fetus. At 24 weeks, an additional

sonogram reflected no resolution of the apparent deformity, and suggestions were made to Mother A that splints might be necessary after the baby was born. However, when Baby A was delivered at term, weighing 9 pounds, 2 ounces, it was quickly evident that deformed hands were the least of the challenges that she might face. Concerns mounted approximately 12 hours after delivery when Baby A still had not shown any feeding suck or gag, and had severely decreased tone. After extended testing procedures, a diagnosis of Cerebral Ocular Facial Skeletal (COFS) syndrome was made. Mother A was informed that severe neurological impairment was present, and that this syndrome was fatal. Mother A recalled being told, "This kid isn't going to live a year." When asked how she felt when she was first told that her child was not going to live, Mother A responded,

It was awful. It was like out of a bad movie. It was in a small room, windowless and airless and there were nurses, social workers, neonatologists. . . there were about ten people. They all went around and said, "It looks grim. I don't think she is going to make it." You name it. . . they said it. Whatever bad there was to say, they said it. Things couldn't get any worse than that. . . . We said that we wanted to go on Code Blue. We had her christened in the hospital that night. Then we went home and waited for the phone call for them to tell us that she was dead.

Family

At the time that Baby A was in the hospital, Mother A reported that her parents (Baby A's grandparents) were "blithering idiots."

They thought that this was the worst thing that could happen to me. They did not deal with it well at all. They were a detriment at that time. They have since come to terms and are helpful, but in the beginning, I felt like I was holding them up rather than the other way around. But I am so grateful that I have the husband that I do. He has always been 100%. You need that, because it is hard to do it all anyway, let alone with extra problems.

Mother A was happy to already have two sons prior to the birth of Baby A because they were helpful with providing stimulation to their new sister and they gave Mother A reason to continue her daily life.

Thank God we had two boys, because we had soccer practice, birthday parties to go to. . . .They are so protective and loving of her. I really credit their involvement. . . the noise, the chaos, the touching, to her good progress. . . . We had to just keep on living. Just because we had a crisis did not mean that the rest of the world was going to stop for us. It was hard, but we kept our routine. I think that made all the difference.

Mother's Experiences and Needs

When asked how she felt about her experience of having a child with special needs, Mother A spoke of the difficulties in this experience and the importance of a positive attitude.

The picture keeps changing. In the beginning, I was devastated, of course. But, I never saw myself being punished by God or something like that. I felt that obviously I needed to learn something. And I tried to think about the whole thing

in the most positive light. But, [caring for Baby A] is a lot of work. And, it is a lot of work to be positive. Her story is not finished. She is not done writing it. There are times when I wonder if she is going to be retarded. At other times, I have this fantasy that she is going to be a geneticist or something like that. She has surprised me before. So, I try to keep my hopes up and positive. . . . tempered with some realism.

Mother A's religious foundation has helped her through this experience. She believes that she has gained an understanding and some degree of peace about her role in controlling her child's destiny.

[When she was being christened in the hospital] I said to myself, "God, it is in your hands. If you are going to take her, then take her. I can accept it. If not, I can accept it too. I know that I am not in charge. I know that I have no control over the situation. I am not even going to try to think about it."

When looking back on her experience 17 months after bringing her child home, Mother A's clearest memory of her time in the NICU was of a doctor examining her newborn in a manner that was disturbing.

The head honcho in the NICU was examining her in a cursory fashion before the big meeting. . . . and just picking her up and holding her like a rag doll. It stands out. . . . and then the meeting [where they told me about my child's poor prognosis].

When asked about her worst experience during this time, Mother A replied,

Well, other than the meeting, I think the worst thing connected with the nursery was when they called to schedule a follow up appointment with the High Risk Clinic. When they wanted me to come in for more evaluations, I said, "Why? If you are going to tell me that she is delayed, then don't bother. I already know that." But, they led me to believe that there were going to be 12 doctors standing in there when I walked in and that they were going to tell me that she was strong in this area and weak in that area. And then, because it is a teaching hospital, you wait and wait and wait. Then the intern comes in [sic] and you tell her everything again. The whole thing was really irritating. It was a total waste of my time and money.

The best aspect of Mother A's NICU experience was her uplifting interactions with certain members of the staff in the NICU.

They were more like "the glass is half full." Our pediatrician would call and tell us, "She only drank a few milliliters of milk," but the O.T. would say, "She took 5 milliliters today!" Every thing they did was like that.

Having support from friends, family, and professionals at the hospital was a strong need of Mother A's during her NICU experience. She said, "I guess one thing that helped was that I didn't try to hold it all inside. I cried, I talked to anyone who would listen. I never bottled anything up inside. That was the best thing."

Mother A found it very difficult to leave the hospital without her baby, and equally difficult to return to see her baby with the knowledge of the poor

prognosis. When asked about her schedule for visiting her newborn during hospitalization, she replied,

When she was born, the first two days I could pop in and out because I was still in the hospital. But once I came home, it was just too hard. It was a time commitment to go there. . . 45 minutes each way. For the first two weeks, my husband and I would alternate every other day. But it was just too hard to go there. Sometimes I would get there and then turn around and go back even before entering the nursery.

Mother A described the NICU environment as "cold and austere." She realized ". . . there is not much of a way you can fix it up." However, Mother A appreciated the efforts toward this end that nurses made when they decorated a name tag, and encouraged Mother A to bring stuffed animals or toys and clothing to decrease the clinical tone of her infant's immediate surroundings. She said,

It was really nice that they dressed her up in clothes in the [Intermediate Intensive Care Unit]. It was like she was a real baby, not just wrapped up in a blanket. It made her more of a person. It made it less awful.

Relations with NICU Staff

Mother A recognized that she held mixed feelings about her interactions with the doctors in the NICU. Although sympathetic to their difficult position that included revealing devastating news about a parent's child, Mother A yearned for a more "human approach."

I would not want to have to tell any person horrible news like that. On the other hand, if they had only said something

personal. . . . For example, one of the doctors in the main meeting said, "I looked at your daughter and I cried." She had real feelings. I guess often they try to hold themselves in check so much that they come off as cold and unfeeling. I am sure they really are not.

Another perspective on how a doctor might interact with a family in this situation was given during a visit to a neurologist for a second opinion on Baby A's prognosis.

He was a funny man. He was refreshing in the sense that he did not sugar-coat anything. He was really blunt. He said, "I am going to tell you the truth. I don't think that she is going to die." Whereas I felt like we never got a straight answer from the doctors at Packard. They said, "We don't think she is going to make it, and we think she has COFS." If they had just said to me right from the beginning, "We don't know" then I would have felt better. They would have been more human. I have mixed feelings. I guess that sometimes you just have to have time. I have learned to be patient through this whole ordeal.

In addition to doctors, many health professionals were involved in Baby A's stay at LPCH. Mother A was especially pleased with her interactions with the ancillary staff. She reported,

The social worker was great. She plugged us into the system and also told us about the pitfalls right away. . . . She was wonderful. She jumped right in with both feet and was calm

and smooth and knew all of the right answers. She was just wonderful.

An open line of communication between Mother A and her pediatrician helped to keep Mother A informed of her child's progress, and allowed opportunities to ask questions as they arose.

Our pediatrician would call us every morning at 7:30 to let us know how our baby was. She would spend 10 or 15 minutes each day, and keep us informed. I guess part of the reason we did not want to spend a lot of time there was that there wasn't anything we could do. We could look at her and we could hold her, but it was just too raw. Maybe some people can do that, but it was just too hard for me. I guess if it was one of the boys and they had a horrible accident, I would probably be right there night and day, but that is different, because I have a relationship with them. . . a history with them. Just because someone is in your stomach for nine months doesn't mean that you know how you are going to feel.

When asked for her suggestions for health care professionals when interacting with parents in the NICU, Mother A spoke of the need for a personal touch in interactions and the maintenance of hope.

My only suggestion [for the health care professionals] is to be more in touch with their feelings. If a doctor said, "We are really frustrated. We really don't know. . . " right from the beginning, they would have felt more human. But I am certainly sympathetic to their situation. I guess that some

parents demand an answer right away. For once, time has been on our side. They kept saying, "We have to wait and see."

Role of Occupational Therapy

The Occupational Therapist in the NICU reportedly had a positive attitude which made Mother A feel that her baby was important and cared for. "The O.T. always seemed to be there. I don't know, maybe the nurses called her. She always just seemed to appear when I was there. If we had questions, we could ask her. She was always available."

Baby A is heavily involved in therapy at this time. Mother A reported, She is a full time project right now. She has four appointments each week. Two come here and I go to the other two. We see speech therapists, occupational therapists, physical therapists, and an infant educator. She just had two sessions today, and she did quite well.

Baby's Present Status

Baby A is now 18 months old. She appears to have cognitive involvement, although the extent or definitive presence of impairment is not confirmed at this time. Mother A and Baby A's therapists are trying to encourage Baby A to pull up to standing and begin to "cruise". Mother A reports,

She is just taking micro steps right now. She is doing really well in her therapy. I think that when she starts walking that she is going to get into a lot of devilment. . . that is for sure. . . for which I will do a handstand. We are lucky that it turned out that the doctors were wrong. I mean, she is delayed, and I am not naive. I know that she is not anywhere

near where an 18 month old should be. But she is such a sweet child. She really is surrounded by angels or something. Everyone loves her and she has affected so many people in a positive way. She is here for a reason.

Case B

Introduction

Mother B is a 35 year old woman who was born and raised in San Jose. Mother B attended a junior college for three years prior to marrying her husband and has now been married for 12 years. Mother B is a housewife who also assists her husband with his private business. Mother B has a daughter who is now 7 years old, and Baby B is now 10 months old.

Mother B's parents were divorced when she was a young child, and her mother cared for her and her three sisters. Mother B cherishes the close relationship which she has with her sisters, and aspires to raise her children in the loving and supportive style with which she was raised by her mother. It was evident throughout the interview that Mother B's upbringing positively influenced her approach to motherhood. She stated,

I would love to take after my mother in how she raised us girls, to see that there was the closeness we had. I really like how I was brought up. I want to do the same with my children. We had a very close relationship with our mom and with each other.

Prior to Baby B's birth, Mother B had no previous experience with children with special needs. Mother B is definitely interested in having more

children, but is ambivalent in light of her continued time commitment to her child with special needs.

When we had just had [Baby B] my husband got all "gung-ho" on having another baby right away. Then they could be born in the same year! He thought it would be neat. . . almost like twins. I don't think he was thinking logically. I talked with one mother who had done [sic] that, and her kids were nine months apart. Her advice was to absolutely not do it. She said that I would just have a newborn baby that I didn't have time for. I would be happy to get pregnant now, though. But it is still hard to say what the future holds for Baby B.

Baby's Start

Although Mother B was interested in becoming pregnant years ago, she battled infertility. She experienced great frustration as doctors told her that her "timing was just off" and she watched friends become pregnant easily. After three years of trying to become pregnant, Mother B was elated to conceive. Unfortunately, repeated successive incidents led to frequent doubt as to the potential outcome of the pregnancy. Two months into her pregnancy, Mother B developed a cough for which doctors found no apparent cause. After numerous courses of antibiotics, the cough persisted. Having to take antibiotics during her pregnancy was very disturbing for Mother B, as she rarely took any medication, and would have preferred to remain "drug free" during her pregnancy.

Additional complications arose, and bedrest was ordered. A difficult string of incidents closely preceded the premature delivery of Baby B.

I will never forget the record-breaking 104 degrees here in San Jose that week. I was laying in my bed in June thinking, "How am I going to make it to October?" Then on the sixth night of bedrest, I was getting little cramps. I called my doctor and he put me on some contraction-stopping medicine. I thought, "Here I go again. . . another medicine in my body." But I took the medicine and I was watching the Giants-Dodgers game. It was the ninth inning and the Giants were leading by three points, and the Dodgers hit a grand slam to win it. I screamed, because I was mad, and then this big contraction came. I said to myself, "I am having this baby tonight!" I really thought that, but I wasn't thinking clearly. I mean, how was this baby going to survive? I will never forget that grand slam!

I woke up in the middle of the night in complete labor. There was so much water and so much blood. I thought I wasn't going to survive. At this point, I was more worried about me dying than anything about the baby.

When she was born, she looked like a black baby. All I could see were her feet, and then they wheeled her out. A few minutes later, they brought me pictures of her. In looking back, that was the smartest thing they could have done to prepare me for all of the tubes and how she looked. Then, we saw her for about [thirty minutes]. She was so tiny and frail. But, to this day, I never thought I was going to lose her.

After delivering Baby B, Mother B struggled to determine which steps needed to be taken in informing friends and family about the unexpected turn of events. She remembers, "I was an emotional wreck. I wanted to call people and say that I had a baby, but I wasn't sure. Right when I had the baby, I didn't know if she was going to make it."

Baby B was born at 24 weeks gestational age, and weighed slightly more than one pound. She spent three and one-half months in the NICU and two months in the IICN.

Family

Mother B was very pleased with the role that her husband played in their infant's hospital stay. She described that visiting twice a day and assisting with feeding the infant by bottle appeared to assist father and infant with attachment. Mother B observed,

With bottle feeding, a father can interact so much more and have so much more to do. When she was in the hospital, it was such an accomplishment for her to take a bottle. It made you feel like, "I am a special person because she took a bottle from me." She did great with him.

Father B reportedly reacted emotionally to having his child in the NICU. Crying together and sharing fears of losing their daughter, Mother and Father B solidified their bond with each other and their mutual commitment to their newest child, according to Mother B.

Father B had instances of conflict with the staff. At one point, he arrived to visit his infant and no one was attending to her. His complaints resulted in improved care for his child, but Mother B feared that this incident would negatively affect her child's care.

Afterwards, I went home and told my husband, "You have got to make these people like us [in the NICU], or they are not going to like [our baby]. They might not take as good of care!" We got in an argument, because he said, "[Baby B] could have died because no one would have been there to save her." I know he was right, but I also felt like we had to be nice to those people. It was a bad situation.

Mother B received a lot of support from members of her family throughout this experience. After Baby B's birth, Mother B received a telephone call from her sister during which her sister cried uncontrollably. Mother B realized ". . . she wasn't crying for [Baby B], but for me and what I was going through. . . . She has two kids, but she came to stay with me anyway. She took care of my older daughter and kept my house together."

Mother's Experiences and Needs

Seeing her baby in the NICU for the first time was very difficult for Mother B. After delivering her baby at another local hospital where there were only two critically ill children, entering the NICU at LPCH was "a real shock. . . seeing baby after baby." She stated, "I was just blown away when I saw the bubble wrap (applied because Baby B had not yet developed skin)!" When one doctor attempted to deliver information about the status of Baby B, this supportive act even seemed overwhelming. Mother B remembered, "I just stood and looked at her all curled up in the plastic."

Later, Mother B conquered her fears about hearing the reality of her child's condition, and met with the doctors for an informative meeting. After this point, Mother B became very involved in her child's care and researched topics related to her child's situation to increase her knowledge and

understanding. She remembered, "The books would be scary at times, but they were really helpful. I would look up everything the doctors said. It was also helpful to know that other kids had gone through what my baby was going through."

Memories which are most clear in Mother B's mind include entering the NICU on a daily basis, stopping to talk with the friendly receptionist, and looking at a picture board filled with "success stories." Mother B reported, "One day, my nurse told me that she had told my baby's story to another mom who had a similar situation and that mother had given me a picture of her baby, now a healthy one year old. . . I was very touched."

Relations with the staff were the best part of Mother B's NICU experience. She felt they acknowledged and admitted when negative issues arose, and their honesty was difficult but helpful. The NICU staff also provided an abundance of positive information, which encouraged Mother B. Hearing the "success stories" of other children who were in the NICU was especially encouraging to Mother B. Mother B hoped to encourage other mothers in the future and gave a photo album to each of the nurses in the NICU to share with parents in the future. Mother B intends to continue to mail updated pictures to the nurses, to further demonstrate to other parents that a baby who was once very ill was able to develop and grow into a beautiful child.

Mother B's worst experience centered around an obliteration of her sense of hope for her child when one doctor confronted her unexpectedly with devastating news. Information was generally delivered to Mother B during scheduled meetings or during impromptu meetings in a conference room. Thus, delivering a poor prognosis to Mother B at her baby's bedside and without warning was shocking and upsetting.

He led me to believe that my child was not going to survive the next few hours. I can not tell you what he said, as far as why he thought she was going to die. I think I blocked it out. I have really bad feelings toward him. . . to this day. He didn't treat me right. Maybe that was the way he treated all of his patients. I don't know if I was spoiled. . . but I needed my doctors to always have some positive with the negative. They would never say all positive or all negative. They always showed me both sides. That was super-helpful. So, I just couldn't handle it when he only gave me negative [information].

When asked which word would best describe her experience, she equated it to going on a roller-coaster ride. She explained,

I think that is the perfect way to put it. You hit a hill that you have to climb over. You get to the top and are really worried and concerned, and then things get better and you go down. And then you have to start climbing back up again. One time, they told us that she was the sickest baby there and that we should prepare ourselves for her not to make it. Two hours later she had a big turn-around where all of her vital signs were back up. She was really doing good. She must have heard us doubting her. . . .It is just such a roller coaster all of the way through.

Mother B reiterated the need for support throughout this experience when she said,

Support is what you need most when you have a child in the hospital. Luckily, I had that. . . my sisters are my three best friends. They got me through this whole thing. . . I did not have to find a baby-sitter for my older daughter through this whole thing, because friends were always taking care of her. It was really helpful to have support from family and friends to get you through it. I am so lucky. This whole experience has made me believe in the "trickle down theory." Since someone was pulling me through it, I could pull my baby through it.

Additionally, Mother B emphasized the important role members of the NICU staff played in her support system. "My big thing. . . the whole way I survived was with primary nurses. I give them a lot of credit. They really got to know my baby and what was going on." Her interest in having consistent nursing care was a major issue with Mother B. She recognized that different nurses have different styles, and she was determined to negotiate a schedule which would facilitate interactions with nurses who appeared gentle and caring with her child. Mother B said, "I wanted her to have more of a 'family' relationship with the nurses."

During the time immediately following Baby B's birth, Mother B especially appreciated the support she received from her sister who had come to live with her temporarily. This enabled Mother B to visit her newborn, while being assured that her older daughter was being cared for. Mother B remembered,

It was very hard to have a child in the NICU and go up there every day. At first, we had a lot of help from relatives, so I

was able to get up in the morning, go to the hospital for two or three hours, and have someone to care for my older daughter. But once everyone left, it got really hard. She (older daughter) was going to the hospital with me. . . I knew that was okay once in a while, but not every day. I would also go back at night after my husband was home and able to care for my older daughter. But, I felt like we were just out of synch. My older daughter's behavior changed in a bad way, and she was just trying to tell me that she needed me. It took me about a month and a half to realize that we were having problems in the family. Then, I stopped going to the hospital at night and stayed home to do the "family thing." We read books, made dinner. . .

Although Mother B was raised in an organized religion, she no longer participates on a regular basis. She stated,

So many people lately are telling me how I am going straight to heaven, and all of these weird things. I believe in God, and I definitely think that positive thinking and someone from above brought [Baby B] through this. But, first was her strong will to survive.

Mother B told of many instances where her child's progress seem to defy medicine and appeared to be caused by positive thinking and miracles. In one instance, Mother B was highly concerned because it appeared as though heart surgery would be necessary to close the ductus in her child's heart. Mother B was extremely wary of this operation and was struggling to convince

herself to give consent. She was told the surgery would be needed and would be performed the following day. She remembered,

That afternoon, I had taken [sic] my older daughter and her friend swimming at a community pool. I suddenly became very tired. I knew that I was responsible for my child and her friend, and tried to open my eyes to watch them, but I just couldn't. All I saw was a black circle that just kept closing and closing. Finally, it was solid. My eyes opened up and I suddenly felt perky again. When I got home, I called to check on [Baby B]. The nurse said, "You won't believe this, but her ductus has spontaneously closed." I really think that there was some connection between my baby and that situation. I am not usually spiritual, or one who believes that things like that can happen, but I think that she was using my energy. She was still connected to me. I wasn't purposefully visualizing it. . . . I was really happy. Since that situation I do have more positive energy within me. Positive thinking definitely gets you further. I am so glad that I have learned that, through all of this.

As a result of her experience with having a child in the NICU, Mother B reported having gained a new appreciation for life and for the closeness of her friends and family. She believes that she will never forget how people helped her during her time of need.

Relations with NICU Staff

Establishing consistency with primary nursing staff was a difficult yet important endeavor. Mother B reflected the difficulty in achieving this goal when she said,

We really had to push the system to get primary nurses consistently with our baby. . . We really had to speak up. . . It took us about two months to finally get primary nurses. Establishing primary nurses was very important to us because we could get to know each other's personalities, and it just made it easier. Even for [Baby B] to have the same nurses dealing with her. . . I was afraid of having all of those different nurses. . .

As they arose, questions were quickly answered by nursing staff, and more lengthy issues were addressed during a scheduled weekly meeting with all members of Baby B's treatment team. Mother B reported that her peers in similar situations were not given weekly meetings, and she was thankful that they were a consistent part of her experience. She remembered, "Sometimes we would dread those meetings, but at least we knew where we stood, and could begin to accept it."

Role of Occupational Therapy

Mother B started working with an occupational therapist for assistance with feeding issues. Mother B described her interactions with the occupational therapist as a "very good experience." When Baby B's milk intake remained low due to her decreased ability to suck, the occupational therapist intervened. When mother B reflected upon her NICU experience, she said,

I thought for sure I knew how to do it all. The O.T. kept telling me that it might not work that way. The O.T. was very supportive, and not at all pushy. I am very impressed about how she is still a part of [Baby B's] life. She frequently calls, even now, to see if there is anything I need for [Baby B] and if I have any questions.

Present Status

Presently, Baby B is 10 months old and weighs 8 pounds, 15 ounces. She is experiencing some difficulty with maintaining sufficient nutritional intake orally, but is working with an occupational therapist to improve eating skills.

Case C

Introduction

Mother C is a 38 year old woman with a bachelor's degree and a career in computer programming. Prior to Baby C's birth, Mother C worked full time. Presently, she works three days per week, and hopes to maintain this schedule. She feels it allows her time with her child while also admitting, "It is nice to get out of the house and talk to other adults and do something else." She has been married for 14 years. Baby C is her only child, and she and her husband do not intend to have additional children. Prior to this experience, Mother C did not have any experience with children with special needs.

Baby's Start

Mother C tried for years to become pregnant. When asked how she felt when she learned she had finally conceived, Mother C responded, "My husband and I were both ecstatic. Before I had [Baby C], I had one miscarriage. So, we tried artificial insemination, and it worked!" The pregnancy appeared to be progressing well until the sixth month. An emergency Cesarean section

was indicated after Mother C began to have seizures. At delivery, Baby C, a boy, was 24 weeks gestational age and weighed less than two pounds. As a result of seizures and kidney failure, Mother C's health was a primary concern after her child was delivered. Because he had not been expecting his child to be delivered for an additional three months, Mother C's husband was away on a business trip. Upon receiving the unexpected news of his child's premature birth, Father C immediately returned to be present with his child and to help his wife during her five day hospitalization.

Baby C required ventilation for 8 weeks due to his poorly developed lungs. In total, Baby C spent 2 months in the NICU and 2.5 months in the IICN, totaling 4.5 month of hospitalization.

Family

Mother C's husband was very upset about having a child in the NICU. She stated,

I think it bothered my husband more than me. He worried a lot, especially about future development. He kept saying, "What are we going to find? What problems will we see later?" I was just concerned about him being healthy and happy and coming home. I think my husband is less worried now than when [Baby C] was in the hospital, but he is still concerned. I am concerned, too. But I think of it a little differently. I do not see it as being "horrible." If it happens, then it happens. We will deal with it when we get there. Hopefully it won't happen. I think I am pretty optimistic. To me, he is a miracle already.

Baby C's grandmother came to the hospital to see her grandson one hour after he was delivered. Mother C described the new grandmother's attitude as "cheerful" and "upbeat" about how wonderful the new baby was. Grandmother C continues involvement with her grandson, as she baby-sits with him on the days when Mother C now works.

Mother's Experiences and Needs

Mother C described her experience of premature delivery as "kind of strange." She thought, "I was supposed to be pregnant for three months more. . . but here he was!" Prior to seeing her child, she was brought a picture of him. She admitted,

I guess I had a picture in my mind that did not match the picture of my baby. I was glad to see that he had arms and legs and fingers and toes. He was really tiny, and did not even look like a baby yet. Not everything was ready to be out in this world.

Seeing her newborn for the first time sent Mother C into shock. She described him as looking like "a little frog."

His little rear end wasn't formed yet, so there were no cheeks or a butt there. They just had his legs folded under and he was laying there with tubes and all. My husband saw our son before I did. He was very cheerful too. No one came in crying or saying, "What a shame!" or acting as if [Baby C] would not live. That was important to me. We were just glad that he was here and doing okay. I think starting off that way helps a lot.

Mother C described this experience as tiring and draining. Leaving her child in the hospital seemed unnatural to Mother C. Yet, she believes that

having someone else care for her child helped her to get the rest she needed to recover from her ordeal as well.

The worst part of the NICU experience for Mother C was not being able to hold her child. She stated, "All I could do was stick my hands in the isolette and touch his fingers or put my hands around him. But, I could never pick him up and hold him." Seeing other babies enter and leave the hospital for their homes was trying for Mother C. She frequently found herself thinking, "When is it our turn?"

The best part of the NICU experience for Mother C was the helpfulness of the support staff. Mother C reported that she felt that staff members were available to assist her and her son whenever needed. She especially appreciated having the same nurse assigned to her son. Regarding primary nursing, Mother C stated,

I think [maintaining a primary nurse] is very important. You are already going through a stressful situation, and it helps you to build a relationship with the nurse and feel comfortable with her. It makes you not mind leaving the baby at night. You just can't be there twenty-four hours a day!

Mother C reported feeling that she comes from a family in which members are relaxed and do not tend to react strongly to any situation. She said, "We don't over-react or get super-stressed, so that probably helped." Mother C went to church as a child, but has not attended in the past 20 years.

When asked if this experience has impacted her outlook on life, Mother C responded that it has broadened her perspective, but has not caused substantial alterations on her outlook.

I don't think that I have changed. A lot of people say, "It must have been a very hard and horrible experience." But for some reason it doesn't feel [that way]. . . . It wasn't easy, and there were bad times. . . sometimes every day felt like forever.

Mother C has gained a new understanding of prematurity and its implications. She said,

Before being there, you don't even think about babies being born early, especially as early as [Baby C] surviving at all. Before this, I thought of early as two weeks, and those babies still went home with their mom.

Mother C described the NICU as "noisy, busy, and full of activity." She recognized the fragile status of the children there, and was surprised by the noise created by both monitors and staff to which the children were exposed. Also, she was startled by the crowded quarters of the NICU. "They probably have twelve kids in each room. That is a lot! If they could break it up to put four kids in each room, then it might be quieter."

During the first eight weeks after her child's birth, Mother C visited her child for half of each day. When she had to return to work, visiting became more difficult. Mother C tried to visit her child after work daily, but the excessive time commitment to driving was an impediment. Mother C's husband worked near LPCH, and was therefore able to visit his son daily at lunch time and participate in feeding and holding his son as he developed.

Relations with NICU Staff

Mother C felt that staff members were involved and caring about her child and his progress, as well as how she and her husband were feeling. When a serious issue arose, a team meeting would be called and it would take

place in a meeting room, away from the nursery. Mother C appreciated the honesty of the doctors and how difficult it must be for them to admit that they did not know the route to pursue in her child's care. For more routine questions, Mother C felt at ease about approaching her son's nurse, or asking a doctor when he was in to see her son. Mother C was especially pleased with two doctors she encountered. She remembered,

They just had a very good bedside manner, and showed a lot of concern for me. They made me feel like they were almost there only for me. They were not rushed, and they didn't seem uncomfortable talking with me. Also, they didn't talk over my head.

Similar to the importance of primary nursing staff was that of primary doctors. In the midst of Baby C's hospitalization, doctors began to rotate more frequently. This rotation was disturbing to Mother C. She recalled,

It seemed like all of the sudden we had a new doctor every week. It was like constantly starting over. They were not aware of the history, and they did not seem to read all of the reports. I felt like I was always retelling the story from the start. It got old. I thought to myself, "Well hey! You are the doctor! You should know! The other doctors should have turned the information over to you. The parents shouldn't have to go through this over and over again to bring you up to date!"

Role of the Occupational Therapist

Mother C received support and guidance from the occupational therapist in the area of feeding. Also, the occupational therapist provided

Mother C with ideas of what she might expect of her baby with regards to development and temperament. Mother C remembered,

I guess a lot of preemies are very touchy and irritable, so we were expecting to come home with a baby who was crying all of the time, and who would not want to be touched or cuddled. Luckily, [Baby C] was not like that at all. It was a very nice surprise. He is a very good baby.

The occupational therapist also played an invaluable role as liaison between the mother and the doctor with regards to discharge planning. Through her work with Mother C and her husband, the occupational therapist was able to gain perspective on the parents' ability to effectively feed their child and was thus able to recommend an earlier discharge date. This might not have been possible without her involvement in this important area of the infant's development.

Baby's Present Status

Baby C is now twenty months old and is delayed in development of gross motor skills. He is currently attending physical therapy to assist him with starting to walk. Baby C also appears to be delayed in language skills, and is therefore seeing a speech therapist. Although he is not using words, Mother C believes that he is beginning to understand more. Baby C is not currently seeing an occupational therapist.

Case D

Introduction

Mother D is a 34 year old woman who attended junior college for one year and worked for many years as a medical assistant. She is presently a

homemaker and describes herself as "permanently retired" from work outside the home. Her current occupation is "full time mom," a position from which she jokingly states she will never retire. She has been married for six years. Mother D's husband works in the computer industry.

Mother D comes from an intact home and says that she had a "great" childhood. With her mother as a homemaker, Mother D developed a deep appreciation for having a mother home with her children. Mother D has a brother and a sister with whom she maintains a close, loving relationship.

Baby D, a boy, is an only child. Mother D intends to have additional children in the near future.

Baby's Start

Mother D was very excited to learn that she was pregnant. After an uneventful pregnancy which extended ten days beyond the due date, Mother D needed to have labor induced. She described this experience as "pretty awful" and remembered

I was a first time mom, so I wanted to do the best that I could.

It took fifteen hours of labor with two hours of pushing. Once he was born, he was fine, except for his clubbed feet. We knew they were easily corrected, so it was all just great.

At delivery, Baby D was of average weight (7 pounds, 2 ounces) and, apparently healthy, went home with his parents. After eleven days, Mother D returned to the hospital with her child because he appeared to be turning yellow. After determining that his bilirubin level was extremely high, E Coli Sepsis was diagnosed. Eventually, kidney failure and a leak in the gallbladder were diagnosed. Doctors did not know the prognosis, and warned Mother D that her child might die. Mother D said,

I just couldn't believe it. The doctor told me that if he survived, he would need to stay in the NICU for two weeks. I thought to myself, "Oh my God! I can't deal with that. . . not having my baby for that long." In the end, [Baby D] spent seven weeks in the hospital.

Family

Mother D and her husband share a close relationship filled with sentiment and humor. Although very sad and full of disbelief at the start of his son's illness, a positive attitude and strong sense of hope guided her husband's behavior. Mother D reported,

I really wanted to believe my husband and believe that my son would be okay, but it was really hard. I kept thinking that if things turned for the worse, then I would be up for a very big disappointment and a lot of pain. But, we both tried to be as positive as we could.

Mother D and her husband helped each other to maintain perspective and provide feedback as needed.

We have always had the kind of relationship where we can talk to each other and we are not afraid to say what is on our mind. We do a lot of talking, which is nice, because we need to communicate and let our feelings out.

Mother D's own mother and sister were a constant source of support throughout the NICU experience.

[My mother] and my sister were always there for [my husband and I], giving us support and seeing if there was anything they could do for us. Just being there for everything and

anything that we needed. I don't want to say that it brought us closer, but I guess you get to know a person in a different way when something like this happens. You don't know how they are going to react. You really see how genuine people can be.

Mother's Experiences and Needs

When asked how she viewed the experience of having a child in the NICU, Mother D stated,

I guess a lot of people would look at it as a real negative experience. I see it as a very scary time in our lives, but it is hard for me to see it as negative. I am not angry at God or whomever, like "Why did this happen to my child?" A friend of mine was asking how I could deal with it without constantly thinking, "Why me?" I replied, "Why not? Why am I so special?" I really am not.

Mother D viewed the conception and development of a child as a "creative miracle." She acknowledged that in all complicated processes, difficulties are bound to arise. "You are just going to have to deal with it. . . and make the best of it."

When looking back on her experience in the NICU, Mother D is thankful for the support and encouragement that she received from her family, friends and NICU staff. Coming from a nurturing family with a strong religious foundation served as an invaluable assistance throughout this experience.

I am a born-again Christian. Praying and having people pray for us helped. Knowing that someone was looking out for us, and that we weren't alone was a good feeling.

Mother D recognized that her positive attitude was her best asset in coping with her son's stay in the NICU.

It was an experience. . . I am not glad that I had it, but it makes me feel that if there was any other mother who had to go through it, then I could talk to her and let her know it would be okay. Again, she would have to have a positive attitude also, or maybe if she didn't then I could help her to get one. Things work out, and if they don't then there is a reason. You have to look at the broader spectrum. [How it all goes for you] has a lot to do with your attitude and the attitude of those around you. Also, I can't overemphasize the importance of support. If you have a faith, whatever that might be, then you need to tap into it, because you just don't know from one day to the next.

One of Mother D's worst and best situations during the time her child was in the NICU occurred concurrently. Due to her son's clubbed feet, casting was necessary. Mother D had requested to be present during the procedure, and was distraught to learn that it had been done in her absence. She knew the procedure would be painful and wanted to be able to comfort her child. However, she was relieved to know that he had been cared for during the procedure when a nurse approached her and mentioned that she sat and rocked him while he cried, and found herself crying because she knew how painful it must have been. "That made me feel really good, to know that she cared so much and that he had someone there to comfort him and hold him when I couldn't be there."

Seeing her infant in the NICU was "really heartbreaking." She remembered,

It looked like he was hooked up to everything. At one point he had IVs on his feet, a catheter on his penis, dialysis, IVs in his arms, a cannula in his nose, and a nasogastric tube. It was like I was watching one of those movies of the week. Every time I went there, I just couldn't stop crying. I tried to be really strong. I guess I felt like I didn't want the nurses to think I was a big cry baby, but my husband would reassure me not to worry and that they understood.

Supplying her child with breast milk was a time consuming endeavor during Baby D's hospital stay, yet was symbolic of her commitment to her child.

I was pumping and pumping [my breast milk] around the clock. It was inconvenient at times, but it didn't matter. I wanted him to have my breast milk, because I knew that it was the best thing for him. I pumped my milk every three hours. I would wake up in the middle of the night [to pump] and then take it into the hospital every day. I would pump everywhere I went.

At times Mother D felt guilty that she wasn't at the hospital all of the time. She was able to reconcile her concerns because,

First of all, I know the Lord was taking care of him. Secondly, I know that the staff was doing all that they could. And by me being there, he wouldn't get better any faster. But, I know he

could tell when I was there. I would hold him and talk to him and read to him, but it was. . . very hard.

Mother D spent an average of eight hours each day at the hospital with her son. Although devastated by the appearance of her ill child, Mother D was able to maintain a sense of humor.

When I saw [Baby D] with IVs in his head, I thought it looked so traumatic. They had to shave parts of his head, so it looked like a mohawk. He looked like he had horns, too. Actually, we thought he looked like a martian!

Relations with NICU Staff

Mother D described members of the NICU staff as "extremely compassionate and very helpful." Keeping Mother D informed of upcoming procedures, results, and progress were especially important to Mother D.

They always seemed to say the positive first. We have the highest respect for [the nurses and therapists] and the doctors. They were just wonderful. I feel like we made a lot of friends. . . You get close to a person in that situation. You just have to when it is your life or your child's life.

Most of Mother D's memories surrounded not the surgical procedures or the physical environment of the NICU, but rather

. . . the people and how much they wanted to help, and how informative they were. They were always answering questions. . . they were always courteous, not curt at all. We had the same nurses. That sure was nice because I felt like I knew them.

When difficult situations arose, an overwhelming sense of teamwork and emphasis on a common goal (improving Baby D's health and sending him home) guided the group's decision-making process. Recognizing the difficult job of health care professionals in the NICU, Mother D said,

I am sure it must be hard for them to act positively, especially if they know that something is not right, or if they know that it could go either way. We have had really good experiences with them. Just being there, we needed them. They were great, just great people. We will never forget them.

Role of Occupational Therapy

Feeding Baby D was a struggle throughout his hospitalization which presently continues. Working with the occupational therapist was described as a "great experience" by Mother D. She described the occupational therapist as very patient, caring, and creative. "She was very good at working with us."

Baby D is not receiving any therapy services at this time.

Baby's Present Status

Baby D is now seven months old and weighs 11 pounds, 2 ounces. Mother D is not concerned about her son's small size, because she is confident that his cognitive development is not delayed. She finds him to be very alert and social.

Case E

Introduction

Mother E is a 37 year old woman who has a college education and manages a recreation department. Mother E is married and her husband is employed in sales.

When speaking of her childhood and previous experience with people with disabilities, she reported,

I am the youngest of twelve children, and was raised by my older sister. With that many people, there is always going to be some kind of handicap. My niece is married to a guy in a wheelchair. We have dealt with it all along. It is common to us.

Mother E has worked with children and adults with disabilities in a recreational setting prior to her son's birth and described it as "a great experience."

At a current age of seventeen months, Baby E is the youngest of Mother E's two children. Mother E does not plan to have additional children, "Two is enough. Twelve taught me that you don't want to have all of those children in the house. Two has always been the goal." If Baby E had not survived, Mother E would have had another child, ". . . but he did survive, so we don't need any more."

Baby's Start

Mother E was in the 24th week of a "normal" pregnancy when the delivery process spontaneously began. In the hospital, Mother E was told, "We can save this one. This one can survive." Mother E recalled, "One special thing that did happen, was that the NICU staff was there to take him right away, and I think that is why he is alive. There was no delay in his care."

The medical issues which Baby E struggled to overcome included meningitis, a hernia that required a surgical procedure to correct, and a birth weight of slightly more than one pound. Baby E was placed on the respirator for 66 days and spent a total of 6 months in the NICU and IICN at LPCH. Due to

the tremendous medical expense of this prolonged and intensive hospitalization, Mother E jokingly referred to him as her "2.5 million dollar baby," as this was the total cost of his hospitalization.

Family

Mother E reported that her husband is "still terrified of [Baby E]." She notices that Baby E has a pronounced preference for women.

He doesn't like men, and gives my husband a hard time. . . I don't know if it is because of the hospital where a lot of the doctors and respiratory therapists or the people who put in the IVs were men. . . But, my husband is very close with our daughter, so he is just going to give [Baby E] a little more time before trying to push the relationship [with our son].

Family members refer to Baby E as "the miracle baby." After numerous miscarriages by women in Mother E's family which also occurred during the 24th week of gestation, Mother E feels a real appreciation for the miracle of Baby E's survival. Mother E repeated her appreciation for his life when she said, "He had some bad times, but he is meant to be here, so he fought back. . . I am so glad they saved him, because he is such a good kid."

After being discharged from the hospital, Baby E was readmitted to the NICU secondary to respiratory complications on Christmas Eve. This regression was difficult for Baby E's parents, but was especially difficult for his sister. Apparently, she had been looking forward to being with him on Christmas ". . . for Santa Claus and all of that." When Mother E asked her daughter if she wanted to go and visit her brother in the hospital, she replied, "No. If I can't bring him home, then I don't want to see him."

Mother's Experiences and Needs

Mother E found that maintaining stability in her life through work was helpful during the early days of her son's hospitalization. "When I realized that he was going to be here for awhile, the best thing that I did was to go back to work. I didn't take maternity leave until he came home." Luckily, because Mother E was in a supervisory position, she was able to alter her schedule and hire assistants to cover for her. She recognized that this was a big advantage, as other mothers in this situation were forced to quit their jobs. Mother E also stressed the importance of a positive attitude and patience, advising that "patience is the best way out of everything."

Mother E was the recipient of an outpouring of support from friends and family members throughout her experience. She reported,

I still have baby gifts that I have not opened. He is the special kid in the house, no matter how many kids are there. He is the center of attention. I think it will ruin him in the end. . . a spoiled kid!

Mother E credits her family with providing the support that she needed when she said, "We are all so close and supporting of each other that if he had made it or hadn't made it, there would be someone there for me. That is just the bottom line."

Upon reflection, Mother E viewed her NICU experience positively. Able to recognize the positive aspects of her experience, she said, "The experience in the NICU, changed me because I gained more friends. I would never have come in contact with a lot of the people that I know now. The NICU is the common thread."

Maintenance of some degree of control and authority in relation to her child was important to Mother E. She found,

The only bad thing was with a really young nurse, when my son was about a pound and a half. He was pulling on his tubes and I said, "He is going to pull it out." She didn't think he could because he was too little, and sure enough he did. I let them know what I wanted. . . was someone who knew what they were doing there at the bedside, and who would listen to me when I knew something in particular about my child.

One of the most difficult things for Mother E was maintaining a relationship with her older child during the time in which her infant was hospitalized. "When [Baby E] came early like that, something had to give. It was hard to meet both of my children's needs." Mother E eventually was able to design a schedule in which she was able to more effectively meet the needs of both children.

When describing the NICU environment, Mother E highlighted, "The best room had less children, and more space for parents. The nurses seemed more at ease also. In the largest room, there were just too many babies. It was packed." When Mother E first saw her child, he looked "transparent." Being able to see her son's organs was startling and tough for Mother E. She remembered, "They had to bubble wrap him and put him under a heat lamp, because he was loosing so much heat without skin."

With regards to visiting her child, Mother E typically came to the NICU in the afternoon and stayed until early evening, with occasional visits later in the night. Mother E was confident that her son knew when she was present, because his levels of oxygen saturation always rose when she was there.

I realized that in order for me to get him home, I would need to spend between 9 and 12 hours per day with him. . . So, I started to do that. I knew that I would have to prove to the doctors that his [oxygen saturation levels] would stay high enough for me to be able to take him home. I told the nurses, "You are going to be tired of seeing me, because I am moving in until we can get this kid home!"

Words used by Mother E to describe her NICU experience included "great," because "we got him home." Qualities which made the situation easiest included Mother E's perception of being well informed regarding her child's plan of care and confident in the doctor's abilities. However, she recognized the uniqueness of her situation and how her child's present status may effect her reflections of the experience. She said, "Bottom line is that it turned out fine for me, but not so great for someone else."

Being in the same room with another mother when she lost her baby was a frightening experience for Mother E. This experience has helped to reinforce how fortunate she is that her child survived and that she was surrounded by support from family and friends. She remembered,

I spent the next six hours with this mother, and no one arrived to help her out. . . No family. No staff. Finally, my son's nurse came looking for me and realized what had happened. She arranged for a social worker to come and help this mother. . . but it was just awful.

Relationships with NICU Staff

Mother E enthusiastically offered praise for the NICU staff, remembering,

The staff in the NICU was great! They treated me like a friend, like a person. . . Everyone was really nice, not pushy or anything, but everyone had different styles. Some wanted me in the room during procedures with IVs, and others didn't. Other than that, it wasn't bad at all, considering the reason why I was there.

Mother E acknowledged that her experience was especially positive, and that her peers may not have been as fortunate. She said,

I hear stories from other parents about bad things that happened, but none of them happened with [Baby E]. I never got in an argument with a doctor. . . none of that type of stuff.

When questions arose, Mother E felt comfortable asking a nurse who was at her son's bedside for information. She realized that this was a politically sound method and advised,

I think a lot of the mistakes that happened [for other parents] were because instead of asking a nurse when they had a question, they would pick up the chart and begin to read it, and that would put them on a bad start [with the nurses].

She recommended that mothers introduce themselves to the nurses and become friendly with them. Mother E felt very well informed from the doctors as well. She admitted,

There was only one doctor who used a lot of jargon, but he is an intern. . . so he will get over that. They were very clear as to what I might expect. It was very clearly and nicely done. They would come and tell me what was happening, and I appreciated that a lot.

Mother E reiterated the important role that consistent nursing care had in her experience when she said, "One of the best things that they did was give us primary nursing care. We had four nurses the whole time."

Role of Occupational Therapist

When describing her experience with occupational therapists, Mother E said, "Working with the O.T. was easy. . . they explained purposes of therapies."

Present Status

Baby E presently weighs 20 pounds and is described by his mother as "a happy kid" who ". . . passed all of his O.T. tests." She reports,

Everything is right where it should be, and in some points, he is ahead of where he should be. He still has poor endurance and frequent shortness of breath, but his ["at risk" status] has been dropped. Our doctor told us, "Forget the special classes in school. Put him in with the other kids. He is very bright." We have been lucky. I don't care if he never plays any ball. I got him up and walking. He is healthy, and I don't care if he never does anything in his life.

Common Themes

For the analysis of the data acquired during the interviews, a "storyboard" method was utilized. This method was employed for similar research as was described in "Going to the source: The use of qualitative methodology in a study of the needs of adults with cerebral palsy" (Kibele & Llorens, 1989). With the reorganization and grouping of data, it became apparent that several themes recurred. Four themes emerged from this researcher's analysis of this research and provided the information necessary

to address the research questions. These common themes were: the need for support, the need for information, attitude as an asset to parents and to professionals, and the role of adaptation which was necessary for participants during this unique experience.

Need for Support

Participants identified the need for support from family members, friends, and the staff in the NICU as an extremely important need during the time in which their child was in the NICU. The participants emphasized its importance by labeling support as "invaluable" and the "best part of the experience." Participants identified various methods in which support was delivered, including psychological/emotional support and support in the form of service. An example of support in the form of service was when friends provided assistance in the participant's home, thereby permitting the participant to attend to her child in the NICU. One parent stated,

I was surprised by the support I got. We did not try to shoulder it all ourselves. If friends wanted to cook us dinner or watch our kids, we said, "Fine." We did not try to keep a stiff upper lip. . . . What person is prepared for parenthood, let alone parenthood with a crisis? You can't be. You need help, and you need to ask for help, and we were never afraid to ask.

Among the participants was a group of mutually supportive husbands in addition to other supportive family members and friends. The parents assisted each other to maintain a sense of hope and determination through frequent discussion.

Information Needs

The need to be well-informed was among the most important issues for the participants during their child's stay in the NICU. Additionally, the need for information that was delivered in a positive, sensitive manner was prevalent throughout all interviews. When participants perceived information to be misleading, frustration mounted and dissonance developed. Participants spoke of the importance of an appropriate setting and timing for delivery of the information. Further, the participants expressed the need to be psychologically prepared for the information to be delivered. One mother said, "The doctor came over to me and wanted to explain stuff, but I asked him if we could do it the next day. I just wasn't prepared, mentally, to hear about it yet."

Attitude as an Asset

The positive attitude of staff members in the NICU and of the participants themselves provided a clear screen upon which the NICU experience could be played. Along with the delivery of information, reinforcing positive aspects of the child's status was deemed equally influential upon the parent's reaction as the quality of the information itself. Wanting to be presented with positive as well as negative realities, participants were adversely affected when hope was dashed by the delivery of information which was perceived as entirely unbalanced toward the negative.

Concerned that a negative attitude on behalf of the NICU staff would adversely affect their child's care, many parents expressed ambivalence over their relationship with staff members. After a conflict between the NICU staff and one of the fathers, this concern was evident when one mother said to her

husband, "You have got to make these people like us [in the NICU] or they are not going to take as good of care [of our baby]!"

When inquiries were made about the best and worst experiences which occurred while in the NICU, the researcher learned that the focus of the answers was not related to the child's medical status, but to the way parents were treated by the NICU staff. "Poor bedside manners" were reported to cause significant stress and anguish, while the positive interactions among staff members who treated their patients and families with respect served to mark the high points in the overall experience.

Yearning for a "more human approach," parents were discouraged when they perceived medical staff to be cool and unfeeling about the patient who was their child. However, the overall consensus of the participants was one of pleasure with the attitudes of the staff in the NICU due to their positive attitude and approachability.

Possessing the ability to "make the best" of their unusual situation and to view things as "scary, but not negative," mothers were able to maintain a sense of hope. Optimistic thinking after learning that other neonates had survived similar experiences provided additional motivation for participants to cope with this experience. Patience was also cited as an important asset, being referred to as "the best way out of everything."

A deep appreciation for their child's survival was evident in all interviews. One mother reported,

After someone tells you that your kid is going to die, anything doesn't seem that bad. So, she needs glasses. . . lots of kids need glasses. So, she walks a little funny. . . I can still spend a

lifetime looking at other people and seeing how much luckier I am than them.

Role Adaptation

Regardless of the level of prematurity of the child's birth or the severity of the child's medical condition, all participants discussed numerous incidents in which role adaptation was necessary. The descriptive word, "unnatural" clearly indicated the need for adaptation. For the mothers whose children were born prematurely and were then removed to the care of neonatal specialists, being shown a photograph of their newborn in the NICU was an unusual event. One participant described her reaction to the photograph as "a real shock" and that her infant "did not match" what she had in mind. Additionally, being unable to hold the new baby caused distress and sorrow for many of the participants.

The issue of feeding was the source of the initial referral for occupational therapy services for all of the parents. Mixed feelings secondary to the need to pump one's breast milk and bottle feed their children was evident in all cases. One mother was discouraged about pumping breast milk, and stated,

They encouraged you to pump your milk. I used the machine and I felt, "What is the point? They told me she is going to die. Why do I need to pump breast milk?" I was to believe [sic] that she was going to die any minute, so it seemed kind of contradictory. I tried breast feeding her, but she couldn't even take a bottle, let alone my breast. I did that about three weeks. Then, I just stopped. It was just too hard.

Another mother responded to this issue with intense dedication, viewing her ability to provide nutrition to her child as her most important avenue for contributing to her infant and to assuming the role of mother. Interestingly, one mother noted the unique opportunity that bottle feeding presented to her husband in his role development as a father as he was able to contribute so directly to his child.

The importance of maintaining control and being validated as an important person in her newborn's life was discussed repeatedly by the participants. Especially highlighted was the need for parents to be empowered in this unique situation so that they may act as advocates for their children when necessary.

Results

1. What were the perceived experiences of parents about the time they and their child spent in the Neonatal Intensive Care Unit?

Parents found the experience of having a child in the NICU to be unnatural, difficult, shocking, and concerning. With the reflection provided by this experience, parents reported feelings of enlightenment. They reported gaining a deep appreciation for the support of their friends and family. Maintenance of hope and determination were crucial factors for all participants, and all found their positive attitudes to be their most valuable asset.

2. What are the parents' perceptions regarding the methods used by the Neonatal Intensive Care Unit staff for assisting parents to operate within the Neonatal Intensive Care Unit environment?

The "human approach" was the most acceptable approach for interaction between NICU staff and participants in this study. Timing and methods of information delivery were highly influential in the perceptions of the participants. Additionally, positive support from staff was reported by all participants as very helpful during the time their child was in the NICU.

3. What can occupational therapists do to most effectively assist the parents of infants in the Neonatal Intensive Care Unit?

The data demonstrated that involvement of occupational therapists in the early stages of the infant's hospitalization may provide parents with an additional resource for support and education, as well as specific treatment in the domain of occupational therapy as issues such as feeding difficulties and positioning needs arose. Approaching parents with a positive attitude and facilitating the necessary role adaptation are treatment methods used by occupational therapists that can be invaluable interventions.

CHAPTER 5

DISCUSSION, PROFESSIONAL IMPLICATIONS, IMPLICATIONS FOR FUTURE RESEARCH, AND SUMMARY

Insights regarding the implications and impact that themes identified in this study might have upon health care providers in the NICU environment are discussed and recommendations for future researchers are provided.

Discussion

The findings of this study are congruent with many findings in the review of the literature. The statement of one parent in Kolovitz's (1989) work which indicated that a parent felt she was the one person who knew her child best and could most effectively care for her child was echoed in the early concerns of participants in this study. However, other participants appeared resigned to allowing NICU staff to care for their children, commenting that ". . . by me being there, he wouldn't get better any faster."

The occupational therapist did indeed appear to assume the roles recommended by Case-Smith (1989). Providing support, training, education, and promoting positive parent-child interactions were among the services provided. However, most parents reported the role of the occupational therapist to be minimal in comparison to other members of the NICU treatment team. It is important to note the large ratio between occupational therapists and the medical staff involved in this setting, as only one occupational therapist worked in the NICU at LPCH, as compared to numerous nurses, doctors, and other medical personnel. It is possible that research on a larger sample might indicate greater utilization of the occupational therapist, or additional roles which occupational therapists are assuming in this type of setting when interacting with families with varying needs.

Adaptive responses, as outlined by King (cited in Levine and Brayley, 1991) were described by all participants in this study. These adaptive responses included altering time schedules to permit visiting their child in the NICU, adjusting the image of how they believed their newborn child should appear and act, and adapting to the "unnatural" role of a mother in the NICU. These adjustments occurred over time as parents continually modified their patterns to develop the functional pattern which would most effectively meet the demands which they now faced. For example, it was one mother's intent to spend as much time as possible at her baby's bedside in the NICU. However, this action resulted in complications in continuing her roles of wife to her husband and mother to her older child. Therefore, the mother adapted to this new need by diminishing time spent in the NICU and increasing time spent nurturing her family members who were outside of the NICU.

Mosey's theory of role acquisition (cited in Christiansen, 1991). provided a helpful frame through which the actions of the occupational therapists could be viewed. Clearly, occupational therapists who worked with these participants empowered, enabled, and educated them. These actions by the occupational therapist may have assisted parents in acquiring and adapting to their new role.

Family-centered neonatal care (Greenwell, 1992; Harrison, 1993; Kirgis et al., 1991) was not frequently described by parents. In one example, a nurse rebuffed advice from a parent about her child's needs. This quickly became detrimental to the child. Cooperation and team decision making would have been beneficial in this and similar circumstances.

Information delivery was an important theme in all interviews. Consistent with the findings of Diehl et al. (1991), parents in this study

reported incidents in which the style of information delivery was perceived to have a stronger effect than the content of the information itself. The receiving and deciphering of information was influential throughout the experiences for all participants.

Results of this study confirm the findings of Bass (1991) in which support needs, information needs, and the need for role adaptation also ranked highly on self-generated lists of needs. The need to receive "positive, encouraging information" was an additional commonality between work by Bass (1991), Greenwell (1992), and the findings of this study.

The findings confirmed that the NICU experiences, overall, had a greater impact on mothers than on fathers (Miles et al., 1992; Sabbeth, 1984; & Perehudoff, 1990). However, contrary to the findings of Perehudoff (1990), one mother reported a level of stress which was significantly less than that of her husband. This may be attributed to her perceived lifelong pattern of being "easy going" and "not stressed out." Clearly, it is difficult to accurately compare the reactions of mothers and fathers in this study, as all data were collected by the mother's self-report.

The sense of pride in caring for their children was especially evident in parental reports on feeding. One mother's intense dedication to providing breast milk for her child and thus increasing her involvement in his care confirmed the findings of Generro et al. (1992).

The researcher attempted to create a "climate of caring" throughout this research, as was also attempted by Peloquin (1993). Striving to strengthen the bond of the parent-professional relationship, it was confirmed that the hospital experience was indeed a series of "emotional events charged with personal meaning."

The process of retelling the story of their experiences and scripting stories of their hopes for their child's future (Clark, 1993; Mattingly, 1991) appeared beneficial to all participants. When asked how she felt at the close of the interview, one parent realized sentiments which were echoed by all participants. She said,

I have told this story [of my child's birth and NICU experience] hundreds of times. . . but this was different. No one ever took the time to spend 3 hours really listening to what I had to say and how I felt about it all. Now I feel a great sense of relief.

Professional Implications

Results from this research indicate that an important role exists for health care providers in the NICU experience. Whether providing support or information, the method of delivery has been found to be extremely influential. Occupational therapists have the unique opportunity to interact with parents and staff, encouraging a view of our youngest patients and their families which is sensitive and holistic. With a background in development, occupational therapists can educate parents on their child's developmental level, and on methods for adapting to changes in their roles, as was also found by Greenwell (1992) and Case-Smith (1991).

The results of this research may benefit hospital administrators who may have underestimated the significance of continuity of sensitive care. This new understanding may affect staffing patterns which would allow for infants to receive care from primary nurses, a strong desire for many of the participants in this research, and allow for an automatic continuity in nursing staff which has thus far been difficult to arrange.

Occupational therapists are not involved in the life-and-death issues that infants in the NICU face and for which nurse and doctor involvement is necessary. Thus, utilizing occupational therapists in a supportive role that involves education and service coordination can most effectively meet the wide range of parental needs.

Implications for Future Research

Results of this study generated additional needs for research into the roles of parents whose children are in the NICU. Observing and interviewing parents during the time in which their infant is still in the NICU or immediately upon discharge could allow the researcher to gather information on the immediate reactions and experiences, but may cause undue hardship on the new parents and lack the benefit of reflection which was afforded to participants in this study. Involving participants from various cultural backgrounds, socio-economic levels, those for whom English is not a primary language, and fathers as well as mothers would also generate more information.

Additionally, studies which are conducted in more depth and with more participants would provide a greater fund of knowledge and sense of trustworthiness for the data. When analyzing data collected during further research, variations on the format of the research and qualities of the participants must be acknowledged in order to accurately establish transferability of findings and maintain a sense of trustworthiness.

As the focus of many mothers' experiences was on the manner in which they perceived they were treated, further research is indicated to determine if these findings are consistent between sites, and the implications if findings differ.

Summary

This study involved five case studies of mothers whose infants spent time in the NICU at LPCH. Subjects participated in semi-structured interviews regarding the course of their infants stay in the NICU, their experiences and needs, and the roles which health care providers played during this time.

Common experiences and needs were identified. The most common needs identified were the needs for support and information. The influence of parental and professional attitudes on the experience were explored, as well as the role adaptation that occurred in the participants as a result of their unique mothering situations.

Results from this study indicate a need for a positive, holistic approach to treatment. Occupational therapists have been valued as able to meet these needs, although study participants generally spoke less about interventions with occupational therapists than they did about staff (physicians, nurses) who provided critical medical care to their fragile and technologically-dependent infants.

This study confirms the important role of the occupational therapist. Successful occupational therapy interventions with parents whose infants require intensive care includes easing the transition into community-based services as indicated, effectively facilitating parental role adaptation early in the NICU experience, and ensuring a holistic approach in the care of the child and the family.

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APPENDICES

APPENDIX A: INTERVIEW INSTRUMENT

INTERVIEW INSTRUMENT

Introduction

- Tell me about yourself (age, marital status, education, etc.)
- Tell me about your parents.
- Tell me about yourself as a child.
- Tell me about your family structure now.
 - How many members in your family/home?
- Do you have other children?
 - If so, did having other children make a difference in how you coped with your experience with this baby?
 - Do you plan to have additional children?
 - Did you have any experiences with children with special needs or those who were born prematurely prior to the birth of this baby?

Your Baby's Start

- How did you feel when you first learned that you were pregnant with this baby?
- Tell me about your child and his/her birth.
 - age at birth
 - length of stay
 - present status

Your Experience with this Baby

- Generally, how do you see the experience of having a child born prematurely and/or with special needs?
- What words would you use to describe your experience in the NICU?
- What one memory stands out most clearly from your time in the NICU?
- How did you feel when you first saw your baby in the NICU?
- What was the best part of your NICU experience? The worst part?
- Are there things about your upbringing or culture which you believe have influenced your experience?

Family

- How did you think your baby's father felt about this baby having to be in the NICU?
 - How did other members of your family (your mother, father, in-laws, grandparents) feel about what was happening to this baby?
 - How do you think they feel about the baby now?
 - How do you think they feel about their experience with the NICU?
 - What have they told you about their feelings or experiences with having a baby in the NICU?
 - How were your relationships with the various members of your family affected by having a baby in the NICU?

Your Needs During That Time

- What was the most difficult for you?
 - For your husband?
 - Other children?
 - How did you resolve these difficulties?
- Were there other areas of your life and/or complications outside the hospital which made being present with your child in the NICU especially difficult?
- What can you tell me about your experience with the physical environment of the NICU?
- What did you need most in the NICU?
- Can you tell me what a typical day was like for you while your baby was in the NICU?
- What is a typical day like for you now?

Your Relations with NICU Staff

- How would you describe your interactions with the NICU staff (O.T./P.T., nurses, doctors, etc.)?
- How did members of the NICU staff communicate with you (Ex: good/bad news, clearly/technical jargon, which methods, etc.)?
- Was there a particular individual (professional or other) or experience that helped you to cope with the experience of having a child in the NICU?
- When you had questions about your baby, was there anyone whom you felt you could approach?
- What advice or support did you receive from NICU staff that was helpful in meeting your needs? Can you give an example?
- What would you suggest that could help staff in the NICU to better help parents in the future?

The Role of Occupational Therapy in Your NICU Experience

- Have you worked with an O.T. either during your baby's time in the NICU or since discharge?
- What are your current goals for your baby?
- Did someone help you set these goals?
- Is your baby receiving any follow-up services?
- If you work with an O.T./P.T., do you know if the O.T./P.T. with whom you are working has goals which are different from yours?

Conclusions

- When looking globally and retrospectively at the experience, how did having a baby in the NICU impact your life? What changed?
- What other questions should I be asking you?

APPENDIX B: SUBJECT CONSENT FORM

A campus of The California State University

College of Applied Sciences and Arts • Department of Occupational Therapy
One Washington Square • San Jose, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

Responsible Investigators: Wendy Veder, OTS and Alice Kihle, MS, OTR

Are you participating in any other research studies? yes no
2/15/94

**Occupational Therapy From The Start:
Five Case Studies of the Experiences and Needs of Parents
in the
Neonatal Intensive Care Unit**

You are invited to participate in a study of the experiences and needs of parents in the Neonatal Intensive Care Unit (NICU) at Lucile Packard Children's Hospital at Stanford (LPCCH). You were selected as a possible participant because you have had the experience of having a child in the NICU at LPCCH. I hope to learn about how the experience affected you and what your needs were during this experience. I hope that the results of this study will increase the knowledge of how parents in the NICU feel about their experience and how health providers within this unique environment might better meet the needs of parents in the future.

If you decide to participate, I will meet you at a mutually agreeable time and location, and ask you questions about your experience and for suggestions which you might have towards improving the experience for parents in the future. Because I am anxious to learn about your experiences and feelings, I will listen to and tape record our meeting. I will use an interview instrument to direct my questions to those which pertain to your experiences. The interview process will take 60-180 minutes of your time. Your interview will be transcribed and, along with the interviews of other parents, analyzed and interpreted in my master's thesis.

No risks or costs are anticipated as a result of this study. No payment will be provided for participation in this project. **WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY.**

While participating in this study, you should not take part in any other research project without approval from all of the investigators. This is to protect you from possible injury arising from such things as extra blood drawing, extra x-rays, interaction of research drugs, or similar hazards.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential as required by law. If you give your permission to participate by signing this document, I plan to disclose the information you have given me regarding your experience of having a child in the NICU and your suggestions for meeting the needs of parents in the future to San Jose State University, LPCCH, and professional journals. However, your name will not be disclosed, and I do not anticipate that it will be possible for anyone to identify you as distinguished from others who are participating in the study. Patient information may be provided to Federal and regulatory agencies as required. The Food and Drug Administration, for example, may inspect research records and learn identity if this study falls within its jurisdiction.

* Please initial to indicate that you have read and understand the above information.

A campus of The California State University

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The results of this study will be presented to the Department of Occupational Therapy at San Jose State University and will be submitted for publication in a national, professional journal.

You may refuse to participate in this study. Your non-participation does not impact or effect your relationship with the NICU or LPCH. No service of any kind will be lost or jeopardized if you decide not to participate in this study. If you decide to participate, your consent must be given voluntarily. You are still free to withdraw your consent and discontinue participation at any time without prejudice to you or effect to your relations with San Jose State University, LPCH, or any other participating institution.

Please ask me any questions at this time. If you have any additional questions later, you may contact me, Wendy Veder, OTS, at (408) 923-0876. Alice Kibele, MS, OTR at (415) 497-8218, LPCH Director of Rehabilitation Services, will also be happy to answer your questions.

If any complications arise, the researcher will assist you in obtaining appropriate treatment but this study does not provide financial assistance for additional medical or other costs. Additionally, Stanford is not responsible for research and medical care by other institutions or personnel participating in this study. You do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write the Administrative Panel on Human Subjects in Medical Research at Medical School Office Building, Room X-107, Stanford, California, 94305. In addition, if you are not satisfied with the manner in which the study is being conducted or if you have any questions concerning your rights as a study participant, please contact the Human Subjects Office at the same address and telephone number.

You may also present any complaints to Amy Killingsworth, MS, OTR, Department Chair of San Jose State University's Occupational Therapy Department, at (408) 924-3070. Questions or complaints about research, subject's rights, or research-related injury may be presented to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies and Research at San Jose State University, at (408) 924-2480.

As a human subject you have the following rights. These rights include but are not limited to the subject's right to:

- be informed of the nature and purpose of the experiment;
- be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized;
- be given a description of any attendant discomforts and risks reasonably to be expected;
- be given an explanation of any benefits to the subject reasonably to be expected, if applicable;
- be given a disclosure of any appropriate alternatives, drugs, or devices that might be advantageous to the subject, their relative risks and benefits;

"_____ Please initial to indicate that you have read and understand the above information.

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- he informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise;
- he given an opportunity to ask questions concerning the experiment or the procedures involved;
- he instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice;
- he given a copy of the signed and dated consent form;
- and he given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject's decision.

• YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

Subject's Signature_____

Date_____

Investigator's Signature_____

Date_____

Wendy Veder, OTS
14940 Penitencia Creek Road
San Jose, CA 95132
(408) 923-0876

APPENDIX C: LPCH HUMAN SUBJECT'S REVIEW BOARD APPROVAL

STANFORD UNIVERSITY
Stanford, California 94305
(415) 723-2883

CERTIFICATION OF HUMAN SUBJECTS APPROVAL

DATE: February 1, 1994

TO: W. Ueder
A. Kibele, M.S., OTR and M. Thorn, OTR
Department of Rehab Services

FROM: Chairman, Medical Committee for the
Protection of Human Subjects in Research

PROTOCOL ENTITLED:

Occupational Therapy from the Start: Five Case Studies on the Experiences and Needs of Parents in the Neonatal Intensive Care Unit.

The Panel approved human subject involvement in your research project on February 1, 1994.

The expiration date of this approval is January 31, 1995. If this project is to continue beyond that date, please submit an updated proposal in advance for the Panel's re-approval. If this proposal is used in conjunction with any other human experimentation or if it is modified in any way, it must be re-approved for these special circumstances. In addition, the Panel requests prompt notification of any complications which may occur during any experimental procedure.

All continuing projects and activities must be reviewed and re-approved at least annually by the Panel. Panel approval of any project is for a maximum period of one year. It is the responsibility of the investigator to resubmit the project to the Panel for annual review.

Donald C. Dafoe, M.D., Acting Chairman

cc Sponsored Projects

Funding Agency: (Un-sponsored) (N)
Period of Time: 02/01/94 through 01/31/95
Investigational New Drugs: N
Investigational New Device: N
Cooperating Institution: N
Expedited Review
Assurance Number: M1272
IRB 801