THE NEEDS AND CONCERNS OF PARENTS WITH DYING NEONATES: COMPARISON OF THE VIEWPOINTS OF NURSES AND PARENTS

by

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Fam-i-ly/'fam-(ə) lē /n: A system comprised of subsystems that interact around collective concerns and purposes.

This thesis is dedicated to my Family who made my graduate education a collective concern:

To David for his endless encouragement and support. His love and understanding have been the fuel that kept me going these past two years. I thank him for all the personal sacrifices he made and for being my sweetheart.

To Mom and Dad who have shared the best years of their lives and shown me the joys, sorrows and strengths of family love.

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To Bill who has helped me see the beauty of being "me".

To Joseph who has taught me the importance of peace of mind.

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Lastly, this thesis is dedicated to the littlest Robinson, the soon-to-be-born first grandchild. May the innocence and love of this child fortify and strengthen the love we already share as a family.

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CHAPTER I

INTRODUCTION

The birth of an infant under normal conditions follows a natural process of conception, pregnancy, delivery and establishment of new relationships for all members of the family. The birth of a dying infant is unexpected and leaves the parents feeling inadequate and ill-prepared to love, touch and care for their infant during his short life span. Faced with sudden and acute illness and panicked by thoughts of losing their infant, parents often feel alone and confused, and do not know to whom to turn for help and comfort. Besides feeling empty and sad, and physically exhausted, one or both parents may feel at fault for the tragedy (Giles, 1970).

For health professionals there are few situations more arduous than trying to help the parents of a newborn with an illness that is fatal. They can do nothing to change the reality of the situation, and often avoid the family because of their own feelings of helplessness, inability to comfort the family, worry of saying the "wrong thing" and their own views of death as a defeat (August-Miller, 1978). They may feel totally unable to lessen the parents' suffering.

The scope of the problem of neonatal deaths is considerable. Many infants are born with, and die from, congenital heart defects, genetic defects, asphyxia, respiratory distress syndrome, and prematurity. Many of these babies receive care in neonatal intensive care units. However, to date, little research has focused on the needs of families experiencing the death of their newborn infants. Still less has dealt with the attempts of professionals working in neonatal intensive care

settings to help the families of such babies through their crisis. Health professionals have been forced to follow traditional patterns of care which lack documented validation. Alternative and possibly more helpful interventions have not been explored.

This study will attempt to identify both the most important needs of parents when their newborn is dying, and those behaviors which offer greatest support, comfort and ease of bereavement. It is one small step toward examining and validating health practices in the neonatal setting. It may lead to further understanding of the care that families need to help them come to terms with and accept the death of their newborn.

Review of the Literature

According to available statistics, the neonatal period is marked by a higher incidence of mortality than any subsequent time in childhood (Kennel, Slyter & Klaus, 1970; Pierog & Fanaroff, 1978; Schneider & Daniel, 1979). Six percent of all babies born in Canada have problems after birth which require care in a Neonatal Intensive Care Center (NICC) (Perrault, Collinge & Outerbridge, 1972). Every pregnant woman experiences some fear that her baby will not be born normal or may even die, but still the baby is joyfully awaited. When a baby is stillborn or dies as a neonate, the family must deal with the reality of death plus the fact that the pregnancy was unsuccessful (Parrish, 1980). This literature review will address the stages of grief following the death of an infant, parental grief responses, parental needs and crisis intervention.

Stages of Grief

An understanding of grief and grieving is basic to any study of perinatal death. Although individual responses to death vary, most people exhibit a recognizable grief process. George Engel (1964) first described four stages of this process under the conditions of sudden death. The initial stage is one of Shock and Disbelief as a result of the inability to acknowledge reality. Minutes to hours later the second stage of Developing Awareness occurs as the pain of the loss begins to be felt. The mourners may feel they have in some way failed and commonly react with guilt, anger and sorrow. The third stage of Restitution is achieved as family members work through their feelings of loss. It is a time for family members to acknowledge their need for support and usually lasts months before the final stage of Resolution occurs. Successful mourning can take up to a year or longer to complete.

A few years after Engel, Elizabeth Kubler-Ross (1969) published her widely read book "On Death and Dying" in which five stages of grieving are described. These five stages are denial and isolation, anger, bargaining, depression and acceptance. More recently Schneider and Daniel (1979) have expanded on the work in this field, by describing the grief process specific to the death of infants. Schneider and Daniel do not see the parents' grief as necessarily progressing sequentially through the five stages of Ross, but rather their presence (in whatever order) may serve as an indication of an ongoing grief process which culminates in the acceptance of the death. Thus, parents may manifest denial and isolation. Here they intellectualize the death,

and continue in their usual non-grieving patterns of behavior. Commonly they express sentiments such as "The doctors don't really know" and "Everything will work out." Or they may cling to the myth of the switched baby. "The armbands are wrong, my baby is OK in the nursery." In this stage, parents seem not to grasp the facts presented, but hear only what they want to hear. Or they may express feelings of numbness and disbelief, as "This isn't really happening." Finally, denial may take the form of a feeling of distance from the situation and from other persons, and a sensation of observing one's own behavior from without.

In the stage of anger, anger may be either directed or generalized. Anger may be directed toward the spouse, other family member, or health care provider. "It's all your fault." Anger may be generalized. "Nobody knows anything." "Why are they doing this to me?"

In the stage of bargaining, the parents may attempt to strike a bargain with the supernatural, as God or Fate. "If you will let my baby live, I'll go to church more often," or behave in a different manner, etc. Another behavior is described as a "fantasy barter". "If I close my eyes, everything will be OK when I wake up."

Schneider and Daniel describe the stage of depression as generally manifested through body language rather than verbalization. When verbalized, depression is often diffuse. "I feel down." Sometimes, depression is directed inwardly, and is accompanied by self-blame and guilt. When expressed outwardly, the symptoms are sad expressions, tears, listlessness, and fatigue.

The fifth and final stage is acceptance or adjustment to the fact of death.

Parental Grief Responses

The death of a newborn places a severe stress on every family member, their friends and the professional staff working with that family (Kennell, Slyter & Klaus, 1970; Schneider & Daniel, 1979). Responses to this stress are as varied as the individuals affected but some commonalities have been observed. Common family grief reactions within 24 hours of an unexpected death of an infant include shock, disbelief and denial; hostility, negativism and anger; strong guilt; verbalization of previous fears of loss and demonstration of past unresolved grief; and occasionally feelings of relief (Smialek, 1978; Goldson, 1979). Similar feelings are experienced by parents of stillborns and infants who die within a few days or weeks of birth (Dillard, Auerbach & Showalter, 1980; Morris & Beard, 1978; Waechter, 1977; Waller, Todres, Cassem and Anderten, 1979).

Schneider and Daniel (1979) have listed additional physical and emotional symptoms in parents following a perinatal death. Physical symptoms include loss of appetite, sleep disturbances, tightness in throat or chest, choking sensation, shortness of breath, fatigue, exhaustion and "aching arms." (Some mothers say their arms "hurt" from not being able to hold their baby.) Emotional symptoms include depression, an empty, lonely feeling, increased emotional distance from others, inability to return to usual patterns of conduct, a sense of a loss of femininity by mothers and a sense of futility.

The death of an infant may have a permanent effect on the parents,

as they internalize their feelings of helplessness, acting them out in their social life and marriage (Parrish, 1980). Marriages may be damaged and interpersonal problems increase between husband and wife. Spouses may blame each other and may be unable to forgive and relate to each other as they did before the death of their child (Bourne, 1979; Parrish, 1980).

With regard to the reactions of mothers, specifically, their reactions have been likened to the "acute emotional disorders" which result from attempts to cope with a threatening event without sufficient psychological preparation (Kaplan & Mason, 1960). Cullberg (1971) has documented the main reactions of mothers after a perinatal death as apathy and feelings of emptiness and inadequacy as well as more serious psychosexual and mental disorders, anxiety attacks, cancer and/or uteri phobia, obsessive thoughts and deep depression.

The reactions of fathers, also, have been described. Benefield, Lieb and Vollman (1978) studied the grief responses of parents when their critically ill newborn was admitted to a regional NICC. They found that fathers had more difficulties than mothers in expressing their grief because of their many and conflicting responsibilities to place of employment, home and hospital. The totality of fathers' roles as supporter, provider and manager impose role overload and engenders role conflicts which often inhibit healthy coping responses.

A similar difficulty in expressing grief was reported by fathers whose infants died of Sudden Infant Death Syndrome (SIDS) at a few months of age. According to Mandell, McAnulty and Reece (1980), fathers attributed their difficulty to the increased burdens placed on them.

They reported spending more time at work to meet a need to keep constantly busy. Many fathers blamed themselves for the death of their infant because of the limited amount of time they spent in the actual physical care of the baby before his or her death. A majority of fathers expressed diminished feelings of self-worth and a diminished ability to seek help from staff. Paternal patterns of behavior and grieving appeared to be influenced by the traditional expectations of masculine behavior.

In summary, it can be said that the death of a newborn, whether the result of a premature birth, stillbirth or neonatal problem, or the result of sudden and unexplained causes, places the family in a serious crisis situation. Grief reactions may vary from individual to individual, from mother to father and from family to family in form, intensity, duration and lasting effects.

Parental Needs and Crisis Intervention

Whenever a person encounters a stressful event such as a death, certain "balancing factors" (August-Miller, 1978) can effect a return to normal functioning: (1) a realistic perception of the events leading to the death; (2) adequate situational supports and (3) adequate coping mechanisms. Health professionals must learn to facilitate mourning after a neonatal death in order to help the family better adjust to its loss. Crisis intervention techniques will allow effective intervention in a crisis so as to produce a more adaptive outcome. According to August-Miller, crisis intervention requires that the intervening agents as a first step assess the infant's illness and family background as well as family attitude toward death. After assessment, the helping

professional should promote the "balancing factors" mentioned above, by giving anticipatory guidance and preparing the family for the infant's eventual death. When parents deny the impending death of their infant they may lose some of their energy and resources as a response to this threat. When this happens the process of crisis intervention must be utilized (Wegman & Ogrive, 1981).

Recent studies have attempted to define the ideal nursing and medical care of the sick neonate and his family. One recent program (Dillard et al., 1980) was developed using crisis intervention techniques to help parents deal with neonatal illness. Two full time social workers coordinated the program which stressed early contact with both parents, assessment of parents'ability to cope, and determination of available support systems, emotional support and guidance from physicians, nurses and social workers and the fostering of frequent parent-infant touch and interactions. Mothers participating in the program, when compared to mothers of healthy term newborns, had at the time of their hospital discharge similar attachment feelings and perceptions of their sick infants, as well as similar attitudes toward their pregnancy and medical care. In a second study, Perrault et al. (1979) promoted family support in the NICC setting in an effort to minimize the lasting effects of parental stress and anxiety on their future interactions with their infant. The investigators found it best to encourage relatives, friends and siblings to visit anytime during the day. They claimed open and honest communication and explanations of equipment and procedures were essential in reducing the parents' stress.

Still, a third study, by Hiley and King (1975) examined communication patterns in a neonatal unit. Most of the parents they interviewed felt that they had not been told enough about the neonatal unit of their babies' condition and treatment. All would have welcomed more information.

Other research has been concerned with interventions appropriate when newborns succumb, to help bereaved parents through their crisis. Studies by Furman (1978), Parrish (1980), Shosenberg (1980) and Morris & Beard (1978), all have stressed the need for bereaved parents to talk with similarly bereft families; the need for non-judgmental counseling regarding the planning of subsequent pregnancies; and the importance of giving parents something that belonged to the newborn such as a bracelet or bootie.

Smialek (1978) examined the common grief reactions of 351 families who lost an infant suddenly and unexpectedly from SIDS and catalogued the main needs of families soon after. Some of these needs included: (1) time to say goodbye to the baby, see it and/or hold it; (2) clarification of misconceptions about the cause of the death; (3) conscious efforts to help fathers express their felt loss; (4) help in arranging funeral services; (5) guidance in the care of surviving siblings; and (6) opportunity to express feelings without criticism of their grieving reactions.

One more investigation by Freihofer & Felten (1976) is worth mentioning in this connection. Twenty-five pairs of terminally ill patients and their loved ones were asked to rank nursing behaviors with regard to bereavement from most-desired behaviors to least-desired

behaviors. Although the study was not designed for application to the neonatal setting, many of the behaviors that families desired from nurses are also mentioned in the neonatal literature as types of care that parents want for their infants. Most desired behaviors included giving pain medication as often as possible, keeping the patient physically comfortable, answering questions honestly, and keeping family informed of the patient's condition. Least desired nurse behaviors were giving encouragement to cry, holding family members' hands, trying to get the family's mind off patient's condition, and reminding family that the suffering will soon be over.

In summary, very little research has been reported in the literature on the health care needs of the dying neonate and his family. This review of the literature has highlighted the stages of grief and the emotional and physical responses of parents following a perinatal death. Crisis intervention is one technique through which health professionals can help families recover after the death of their child. Research has shown that the care of this family is a fundamental and very demanding responsibility of all health professionals and has identified the nurse as having the most unique opportunity to work with families in the resolution of their crisis (Arney, Nagy & Little, 1978; Hiley & King, 1978; Morris and Beard, 1978; Perrault et al., 1979; Shosenberg, 1980). While there is no easy way for parents to move through the grieving process there are some documented ways of making their journey more meaningful and hopefully less destructive to the total structure of the family.

Statement of the Problem

The main purpose of this study was to investigate the importance parents place on their needs and concerns while experiencing the death of their newborn. It was also intended to compare and contrast parents' responses to those of the NICC nursing staff regarding these same issues and needs. Finally, it was the hope of the investigator to determine whether parents' needs were met and by whom.

On the basis of the review of the literature the following propositions were formulated:

Proposition 1. Parents and nurses agree regarding the relative importance of the needs of parents with a dying newborn.

1A. Fathers and nurses agree regarding the relative importance of the needs of parents with a dying newborn.

1B. Mothers and nurses agree regarding the relative importance of the needs of parents with a dying newborn.

Proposition 2. A difference exists between mothers' and fathers' perceptions of the relative importance of their needs at the time of their newborn's death. There is no direct evidence from the literature to support this proposition. However, if fathers have more difficulty than mothers in expressing their grief, as suggested by Benefield et al. (1976); Mandell et al. (1980); and Smialek (1978), they may also experience different needs during the death of their newborn.

Proposition 3. The needs of parents determined to be very important by nurses and parents may not be met in the NICC. In

most NICC's, the pressure of immediate life-saving tasks may require postponement, and therefore eventual nonperformance, of many secondary activities viewed as altering distress in family members. Insofar as the majority of nurses in the unit studied were employed on a part-time basis, it was also reasoned that such arrangements would strongly affect continuity of care and the consistency with which parents' needs would be met.

Proposition 4. The nurse is the staff member who most frequently meets the needs of parents with dying newborns in the NICC setting. There is a large volume of literature supporting this proposition.

CHAPTER II

METHODS

Setting

The Neonatal Intensive Care Center (NICC) of the Oregon Health Sciences University (OHSU), was the setting for this study. Total capacity of the unit is 24 beds with a daily occupied census of 20 beds. The admission rate for the year July 1980 to July 1981 was 568 newborns. Of those 568 admitted, 131 or 23% expired while in the unit.

The OHSU is a teaching institute with medical, nursing and paramedical students rotating through the NICC. The medical staff consists of a chief physician, 2 chief assistants, 2 neonatal fellows and 1 rotating resident. Total care nursing is practiced by the 71 Registered Nurses (R.N.'s) and Licensed Practical Nurse (LPN) employed through nursing service. One nurse on each shift is assigned to give total care to one or more infants and their families. The same nurse cares for the family unit from the date of admission until date of discharge. Total family care is viewed as primarily the role of the nurse. Physicians perform a consultant and supporter role in family care and are most involved with medical management and maintaining the newborn's life.

A full-time respiratory therapist and 2 laboratory technicians are available 24 hours a day. Chaplain and social services are also provided on request by the University South Hospital. Staff may seek guidance and support for themselves or for parents from therapists in the OHSU Departments of Medical Psychology and of Psychiatry.

There are no formal visiting hours on the unit. Parents may visit

their baby 24 hours a day or telephone the unit on its toll free WATS line at any time day or night to talk with their baby's nurse.

When a newborn is admitted to the NICC a formal conference is arranged with the parents and the chief physician or one of his assistants, the resident and the baby's primary nurse. The infant's diagnosis, prognosis and medical care plan are explained, in addition to the layout and mechanics of the unit. If the infant's mother is recuperating from the delivery in another hospital, the primary nurse keeps daily contact with her, letting her know how the baby is progressing.

These conferences continue periodically, according to the parents' needs. If the newborn is doing poorly and has no chance of survival, parents again meet with the staff to discuss taking the baby off the respirator. The final decision is the parents'. Privacy is provided as much as possible with the nurse nearby continuing to support the parents in their difficult choice. If they do opt to discontinue the respirator, parents are encouraged to hold the infant until death occurs. If the parents do not want to hold their infant or cannot be there at the time of death, the nurse will sit and hold the baby so that parents will not fear that their baby died alone.

The NICC has a three-fold system of follow-up and support. At the time of discharge from the unit, referrals are made to the Public Health Department for a home visit with all families regardless of whether their newborn died or survived. The Public Health Nurse helps clarify any unanswered questions and assesses the family's level of coping and areas that may need additional nursing or medical interven-

tion. In addition, parents whose infant has died receive a telephone call from a member of the Compassionate Friend Organization and are encouraged to participate in their self-help program for bereaved parents. The infant's primary nurse may also maintain contact with the family providing an important link between the family and the NICC.

Subjects

Nurses

All nursing personnel who have been employed and working in the NICC of the OHSU for at least 6 months were asked to participate in this study. Full and part-time staff were included as well as the Head Nurse and her assistant and the LPN and aides. About 65 out of the total of 72 nursing staff met this criterion.

Sample of Parents

For parents to participate in this study, their newborn infant must have died in the NICC of the OHSU Hospital, 3 to 6 months previously. Infants must have lived a minimum of 2 days to insure parent-staff interaction. Only newborns with diagnoses of Respiratory Distress Syndrome or Congenital Anomalies were included since these were the diseases from which the majority of newborn deaths occurred and thus provided the largest sample population. Twins and multiple birth infants were not included.

All mother-father pairs, who met the above criteria comprised the sample. Names of parents were obtained from the list of "expired" infants filed in the NICC. The sample size initially contemplated was 20 pairs.

Design and Procedure

This ex post-facto study was both descriptive and explanatory in nature. All information was gathered through the use of a 53-item structured questionnaire (Appendices A and B). The Parent questionnaire was submitted to a panel of 7 faculty members and 8 graduate nursing students of the Family-Centered Child Nursing Department for review and criticism. Revisions were made in accord with suggestions.

The procedure was as follows. The list of "expired" infants was reviewed just prior to data collection. The names of parents whose newborns had died within the previous 3 to 6 months were consecutively compiled. A cover letter identifying the researcher, describing the study with its risks and benefits, and notifying parents of a follow-up telephone call was mailed to these parents (Appendix C). One week after the letter was mailed, parents were contacted by telephone to clarify any misconceptions about the study and to arrange for an appointment if they wished to participate.

Parent questionnaires were distributed at the beginning of the third month following their baby's death in an effort to control for variations in parents' stages of grief and the effects different stages may have on how parents respond to the statements in the questionnaire. Engel (1964) has stated that the stage of restitution follows shock and disbelief, and may occur months after a loss. It is a time when family members are working through their feelings of loss and are most able to share their experience with others.

Parent questionnaires were completed in their homes at a convenient time when both mother and father were present. Each parent completed

a separate questionnaire while the researcher was present and available to answer any of their questions.

Cover letters similar to those mailed to parents were attached to nurse questionnaires and labeled with the staff member's name (Appendix D). Questionnaires were distributed on the NICC over a 5 week period to nurses working on all 3 shifts. Code numbers were used to insure confidentiality but permit identification of staff that did not respond. Staff were given a 1 week deadline to complete questionnaires at their own convenience. They were asked to drop completed questionnaires into a large envelope accessibly located on the office door of the chief physician adjacent to the nursing unit. Additional cover letters and questionnaires were posted on 2 bulletin boards in the NICC for non-respondents who had forgotten about or lost their original questionnaires. The researcher visited the NICC to check with nursing staff on the completion of their questionnaires and posted several reminders over the 5 week period.

Data

Data for this study were gathered by a questionnaire, modified from Molter's (1976) structured interview guide (See Appendix E). In her original study, Molter interviewed 40 relatives of critically ill adults who were in an Intensive Care Unit (ICU). Four variables were covered by her 45-item tool and included: (1) the perceived needs of relatives of critically ill patients who are in an ICU; (2) perceptions of the relative importance of each need; (3) whether or not that need was met and (4) if the need was met, by whom. Relatives were given an answer sheet and asked to respond to each of the 45 "need" statements

by: (1) rating the need using a 4-point Likert-type scale, from 1 (not important) to 4 (very important); (2) checking "yes" or "no" to indicate if the need had or had not been met, and (3) indicating by whom the need was met (A = doctor, B = nurse, C = chaplain, D = other relative, E = Friend, F = other visitor, G = other).

No information concerning the reliability of Molter's list of needs has been provided in her study. Content validity was established by the use of professional nurses in compiling the list of need statements and its approval by two Intensive Care Nurse Specialists.

Molter's interview was modified and converted to a questionnaire for use in this study. Changes in wording were made to alter the focus from the care of ill adults and their relatives in the ICU setting, to neonatal care and the parents of dying newborns in the NICC setting. In all the statements the word "baby" was substituted for "relative". Additionally, questionnaires distributed to nurses began with the phrase "parents need---" instead of "I needed---".

Five of the need statements from Molter's original interview were deleted because of irrelevancy and redundancy. They are as follows:

7. Because there were visiting hours I needed to have them start on time.(not applicable to setting)
10. I needed to have visiting hours changed because of special conditions.(not applicable to setting)
14. I needed to be alone. (Same as question #4)
31. I needed to have the pastor visit me. (Same as question #17)
43. I needed to be told about someone who could help me with my family problems. (Too vague)

Two questions were reworded to highlight the NICC setting and include statements 4 and 6 of Molter's original interview schedule. They subsequently read:

4. I needed to have a place available near the Neonatal Intensive Care Center to be alone while in the hospital.
6. I needed to have a specific person to call at the Neonatal Intensive Care Center when I could not be there.

Furthermore, 12 questions were added after review of the literature because of their relevance to the care of families after the death of a newborn. They include statements 26, and 42 through 53 of the questionnaire. Statement 54 is open-ended and requests respondents to list any important needs not mentioned in the questionnaire.

The validity of this instrument is unknown. Content validity is claimed in that a thorough review of the literature was conducted to validate each of the 53 need statements in the questionnaire (Appendix F). In addition, the questionnaire was reviewed, critiqued and approved by 7 faculty members and 8 graduate nursing students in the Family Centered Child Nursing Department.

Parents' perceptions of the importance of specified needs were measured along with the extent to which these needs were met. All needs categorized as "very important" received a score of 4, on the same Likert-type scale which Molter (1976) used. Each parent was asked to reply "yes" or "no" as to whether each need was met in the NICC. The proportion of "yes" responses to the total number of "very important" items was taken as a measure of the extent to which important needs were met. The means of these proportions for the group of mothers was

calculated, to arrive at the average percentage of very important needs met. The same procedure was used to calculate the extent to which fathers felt their needs were met.

Nurses' perceptions of the relative importance of parents' needs, and whether the needs were met 50% of the time or more, were similarly examined. The method of scoring and analyzing data for the nurses was similar to that used for parent responses.

Additional Data

Information regarding the gestational age of the deceased infant, cause of death, and days of life were obtained from the NICC's "expired" file. In order to describe the parent sample adequately, background information was requested during a preliminary interview of parents before they were given the questionnaires to complete. The usual demographic data were elicited, regarding age, last grade completed in school, and occupation. In addition, information was obtained regarding number of pregnancies, number of living children, and the occurrence of any other infant deaths within the immediate family. (See Table 2).

Additional information regarding background characteristics of nurses included age, sex, employment status (full or part-time), primary shift worked, number of months and years worked in this NICC and occurrence of any neonatal deaths within their immediate families. This information was used only to describe the sample of nurses.

CHAPTER III

RESULTS

Subjects

A total of 63 questionnaires was distributed over a 5 week period to nurses in the NICC. After several follow-up requests, 35 were returned, of which one was incompletely answered and discarded. The 34 usable questionnaires represented a response rate of 54%. Table 1 provides a description of nurse respondents by shift worked. Most nurses worked the day shift. All but one were female, and most were young adults (mean age of 31.9 years). Many had worked in the NICC 2 to 4 years, and only a few reported the personal experience of a newborn death in the immediate family.

Fourteen parent-pairs qualified for inclusion in this study. Four of these parent-pairs refused to participate, five could not be reached by telephone and five agreed to participate. Response rate was 35%. In the five families, fathers were major wage earners, and were employed as a production supervisor, Air Force engineer, building inspector, auto parts manager and attorney. Two mothers were employed outside the home in clerical positions. Table 2 provides a description of each parent pair, and lists the gestational age and length of life of their deceased newborn. Two of the newborns died of prematurity and Respiratory Distress Syndrome. One newborn was born in acute renal failure and had meconium aspirate. Another had bilateral pneumonia, renal agenesis/dysplasia and questionable Potter's syndrome. The fifth newborn also had meconium staining, a pneumothorax and dextrocardia.

All parents were young adults with a mean age of 28 years for mothers and 30.6 years for fathers. All but one mother had completed

TABLE 1

CHARACTERISTICS OF NURSE RESPONDENTS BY SHIFT

Characteristics	Day Shift (N = 18)	Evening Shift (N = 10)	Night Shift (N = 6)	Total (N = 34)
Sex				
Male	-	1	-	1
Female	18	9	6	33
Age (Years)				
25 and under	1	1	3	5
26 to 30	6	6	1	13
31 to 35	7	2	2	11
36 to 40	1	1	-	2
41 & over	3	-	-	3
Employment Status				
Full time	7	3	5	15
Part time	11	7	1	19
Time employed in NICC				
Under 12 months	-	1	2	3
12 to 24 months	-	2	-	2
25 to 48 months	6	6	4	16
49 to 72 months	4	1	-	5
more than 72 months	8	-	-	8
Personal Experience with Neonatal Death	4	-	1	5

TABLE 2

CHARACTERISTICS OF PARENT RESPONDENTS

Characteristics	Parent Pairs 1	2	3	4	5	Mean Value
Age (Years)						
Mother	33	28	31	26	22	28.0
Father	33	27	37	31	25	30.6
Education (Years completed)						
Mother	13	12	17	10	12	12.8
Father	19	14	12	16	14	15.0
Gestational Age of Infant at Birth						
(Weeks)	40	27	28	42	40	35.4
Duration of Infant's Life						
(Days)	2	8	3	3	2	3.6
Total Number of Pregnancies	3	4	1	5	3	3.2
Number of Other Living Children	2	2	0	4	0	2.0

high school. All fathers completed high school and held high managerial and professional positions. Two of the parent-pairs had lost more than one infant through previous miscarriages. This was the first pregnancy for only one couple. One father had a previous experience with a neonatal death through the death of the child of his sister and brother-in-law.

Relative Importance of Parents' Needs

The first proposition posed for examination concerned the importance of parents' needs.

Proposition 1. Parents and nurses agree on the relative importance of the needs of parents with a dying newborn.

Proposition 1A. Fathers and nurses agree on the relative importance of the needs of parents with a dying newborn.

Proposition 1B. Mothers and nurses agree on the relative importance of the needs of parents with a dying newborn.

To examine this first proposition, nurses were asked to rate the importance of each of 53 stipulated parent needs on a 4-point scale, ranging from "not important" (scored 1) to "very important" (scored 4). Means of the scores were calculated. The 53 mean scores ranged from 2.44 to 3.97, indicating a marked negative skewness in distribution. In short, nurses tended to rate all the specified needs as important to some degree. The 10 needs receiving the highest scores are listed in Table 3. The 10 needs receiving the lowest scores (all under 3.0) are listed in Table 4.

TABLE 3

MOST IMPORTANT NEEDS AS IDENTIFIED BY NICC REGISTERED NURSES

Item #	MOST IMPORTANT NEEDS	Mean Importance Score
2.	Parents need to have their questions answered honestly.	3.97
26.	Parents need to touch and hold their baby.	3.97
3.	Parents need to be able to visit whenever they want.	3.94
10.	Parents need to feel that hospital personnel care about their baby.	3.94
31.	Parents need to have explanations given in terms they can understand.	3.82
39.	Parents need to know that it is all right to cry.	3.79
49.	Parents need a snapshot, bracelet, bootie or something to remember their baby by.	3.79
27.	Parents need to have family and friends nearby for support.	3.79
16.	Parents need to know why things are being done for their baby.	3.79
12.	Parents need to know exactly what is being done for their baby.	3.77

TABLE 4

LEAST IMPORTANT NEEDS AS IDENTIFIED BY NICC REGISTERED NURSES

Item #	LEAST IMPORTANT NEEDS	Mean Importance Score
29.	Parents need to have a bathroom near the waiting room.	2.44
47.	Parents need to meet with their baby's doctor 2-3 months after their baby's death.	2.63
28.	Parents need to talk to the doctor at least once a day.	2.68
9.	Parents need to have good food easily available in the hospital.	2.68
41.	Parents need to have another person with them when visiting their baby.	2.71
46.	Parents need someone to talk to their other children about the baby's death.	2.76
53.	Parents need to have a Public Health Nurse visit their home after the death of their baby.	2.82
33.	Parents need to know what types of staff members can give what type of information.	2.85
34.	Parents need to have comfortable furniture in the waiting room.	2.94
14.	Parents need to be told about Chaplain services.	2.94

Parents were asked to rate the importance of these same 53 needs along the same 4-point scale. The 53 mean scores computed from fathers' responses were much more widely distributed than those of the nurses and ranged from 1.00 to 4.00. Eleven needs received mean ratings of 4.0, being considered "most important" by fathers. They are listed in Table 5. Twelve needs received mean ratings less than 2.0 and are identified in Table 6. In general, fathers tended to rate more of the specified needs, 29 of the 53 needs, as "not important" or only "slightly important" than did the nurses. Fathers also rated fewer needs (24 of the 53) as "important" (scored 3) or "very important" (scored 4).

Mothers, just as did fathers, made more distinctions regarding the importance of needs than did the nurses. Their 53 mean scores also ranged from 1.00 to 4.00. Scores were evenly distributed with 25 of the 53 needs receiving ratings of "not important" or "slightly important" and 28 rated "important" and "very important". Twelve needs received mean importance scores of 4.00 by the mothers. They are listed in Table 7. Table 8 lists the needs that they rated as least important.

To what extent did fathers and nurses agree on the importance of the 53 needs? The mean importance scores of fathers and nurses were found to be significantly correlated ($r = .58$, $p < .001$). Six of the 11 needs rated "very important" by fathers were also rated "very important" by nurses. They include Items #2, 3, 10, 12, 16 and 26. Four needs rated "very important" by fathers with mean importance scores of 4.0 were not among the 10 most important needs identified by

TABLE 5

MOST IMPORTANT NEEDS AS IDENTIFIED BY FATHERS

Item #	MOST IMPORTANT NEEDS	Mean Importance Score
2.	I needed to have my questions answered honestly.	4.00
3.	I needed to be able to visit whenever I wanted.	4.00
10.	I needed to feel that hospital personnel cared about my baby.	4.00
12.	I needed to know exactly what was being done for my baby.	4.00
13.	I needed to know how my baby was going to be treated medically.	4.00
16.	I needed to know why things were being done for my baby.	4.00
26.	I needed to touch and hold my baby.	4.00
28.	I needed to talk to the doctor at least once a day.	4.00
36.	I needed to know my baby's chances for becoming well.	4.00
37.	I needed to know that I would be called at home if there were any changes in my baby's condition, good or bad.	4.00
40.	I needed to receive information about my baby's condition at least once a day.	4.00

TABLE 6

LEAST IMPORTANT NEEDS AS IDENTIFIED BY FATHERS

Item #	LEAST IMPORTANT NEEDS	Mean Importance Score
9.	I needed to have good food easily available to me while in the hospital.	1.00
50.	I needed to be encouraged to name my baby.	1.00
53.	I needed to have the Public Health Nurse visit my home after my baby's death.	1.00
47.	I needed to meet with my baby's doctor 2-3 months after my baby's death.	1.40
51.	I needed to talk with other parents who had also experienced the death of a newborn.	1.40
52.	I needed to be informed of community resources available that provide support for families after the death of their baby.	1.40
5.	I needed to be told about other people in the hospital that could help me.	1.50
39.	I needed to know that it was all right to cry.	1.60
34.	I needed to have comfortable furniture in the waiting room.	1.80
35.	I needed to have someone be concerned for my health.	1.80
46.	I needed someone to talk to my other children about our baby's death.	1.80
48.	I needed someone to encourage me to touch and hold my baby after he/she died.	1.80

TABLE 7

MOST IMPORTANT NEEDS AS IDENTIFIED BY MOTHERS

Item #	MOST IMPORTANT NEEDS	Mean Importance Score
2.	I needed to have my questions answered honestly.	4.00
3.	I needed to be able to visit whenever I wanted.	4.00
10.	I needed to feel that hospital personnel cared about my baby.	4.00
12.	I needed to know exactly what was being done for my baby.	4.00
13.	I needed to know how my baby was going to be treated medically.	4.00
20.	I needed to talk to someone about my feelings such as anger and guilt.	4.00
26.	I needed to touch and hold my baby.	4.00
31.	I needed to have explanations given in terms I could understand.	4.00
32.	I needed reassurance that the best possible care was being given to my baby.	4.00
40.	I needed to receive information about my baby's condition at least once a day.	4.00
42.	I needed to be present at the time of my baby's death.	4.00
49.	I needed a snapshot, bracelet, bootie or something to remember my baby by.	4.00

TABLE 8

LEAST IMPORTANT NEEDS AS IDENTIFIED BY MOTHERS

Item #	LEAST IMPORTANT NEEDS	Mean Importance Score
29.	I needed to have a bathroom near the waiting room.	1.00
46.	I needed to have someone talk to my other children about our baby's death.	1.00
47.	I needed to meet with my baby's doctor 2-3 months after my baby's death.	1.00
52.	I needed to be informed of community resources available that provide support for families after the death of their baby.	1.00
53.	I needed to have the Public Health Nurse visit my home after my baby's death.	1.00
9.	I needed to have good food easily available to me while in the hospital.	1.50
44.	I needed to meet with my baby's doctor immediately after my baby's death.	1.60
5.	I needed to be told about other people in the hospital that could help me.	1.75
38.	I needed to talk to the same nurse each day about my baby's condition.	1.75
50.	I needed to be encouraged to name my baby.	1.75

nurses. One statement, Item #28, "I needed to talk to the doctor at least once a day", was given a mean importance score of 2.67 by the nurses in comparison to the fathers' rating of 4.0.

To what extent did mothers and nurses agree? When mothers' and nurses' mean importance scores were correlated for the 53 items, a Pearsonian coefficient of .67 was obtained ($p < .001$). This coefficient signifies a higher level of agreement on the importance of the needs between mothers and nurses than between fathers and nurses. Seven of the 12 needs rated "very important" by mothers were also rated "very important" by nurses. They include Items #2, 3, 10, 12, 26, 31 and 49. Mothers rated 5 additional needs as "very important" with mean importance scores of 4.0. Although these 5 needs were rated "important" by the nurses with mean importance scores ranging from 3.79 to 3.32, they were not included among the 10 most important needs identified by nurses.

In summary, support was found for the first proposition, and it may be concluded that parents and nurses do agree regarding the relative importance of the needs of parents with a dying newborn.

Proposition 2. A difference exists between mothers' and fathers' perceptions of the relative importance of their needs at the time of their newborn's death.

Pearson's r was computed between the 53 mean importance scores of fathers and mothers and yielded a value of .82 ($p < .001$). This correlation coefficient indicates a very high level of agreement on the importance of the 53 need statements by mothers as a group and fathers as a group, but not as individual pairs. Seven of the 11 most important needs identified by fathers were also identified by mothers.

Table 9 compares each of the 5 parent groups as individual pairs in regard to the agreement between each father and each mother as to the importance of the needs. Three parent-pairs were in agreement in their ratings 50.9% of the time. One pair had a greater percentage of agreement and one pair had less than 50% agreement.

Needs Being Met

Proposition 3. The needs of parents determined to be very important by nurses and parents may not be met in the NICC.

Nurses were asked to verify which of the 53 needs were being met in the NICC at least 50% of the time. Table 10 lists the 10 most important needs identified by nurses and the percentage of nurses who stated the need was being met. Of these 10 needs, 5 were believed to be met by 100% of the nurses. Overall, those parents' needs judged to be "very important" by nurses, were also believed to be met by nurses.

Parents were also asked to verify which of the 53 needs were met through their experience in the NICC. Table 11 lists the most important needs as identified by fathers, and shows the percentage of fathers responding that each need was met. Of the 11 needs identified, 6 were met according to 100% of the fathers. Two needs were considered met by only 60% of the fathers.

A similar list of needs perceived by mothers to be most important is provided in Table 12. Twelve needs were identified as being very important, but only 5 of them were believed met by 100% of the mothers. Four needs were felt to be met by only 60% of the mothers. A fifth need "to talk to someone about my feelings such as anger and guilt", given a mean importance score of 4.0, was felt to be met by only 2 of the 5 mothers.

TABLE 9

FATHER'S AND MOTHER'S AGREEMENT ON PERCEIVED IMPORTANCE OF NEED STATEMENTS

Parent Pair	Number of Needs on the Importance of Which Both Parents Agreed	Father Rated More Important	Mother Rated More Important	Percent Agreement of Parents
1	27	19	7	50.9%
2	35	8	10	66.0
3	24	17	11	45.3
4	27	14	12	50.9
5	27	11	15	50.9

TABLE 10

MOST IMPORTANT NEEDS OF PARENTS AS IDENTIFIED BY NURSES;

WITH THE PERCENT OF NURSES STATING NEED IS BEING MET IN NICC, AND BY WHOM

Item #	MOST IMPORTANT NEEDS	Percent of Nurses Responding Need is Met	Need Met By Doctor	Need Met By Nurse
2.	Parents need to have their questions answered honestly.	100%	23	31
26.	Parents need to touch and hold their baby.	100	4	34
3.	Parents need to be able to visit whenever they want.	100	3	21
10.	Parents need to feel that hospital personnel care about their baby.	97	17	34
31.	Parents need to have explanations given in terms they can understand.	94	15	32
39.	Parents need to know that it is alright to cry.	85	6	28
49.	Parents need a snapshot, bracelet, bootie or something to remember their baby by.	100	2	34
[a]27.	Parents need to have family and friends nearby for support.	67	1	5
16.	Parents need to know why things are being done for their baby.	100	18	33
12.	Parents need to know exactly what is being done for their baby.	97	12	31
	TOTAL		113	283

[a] 27. Spouse and friend was the most frequent nurse response to who meets this parent need.

TABLE 11

MOST IMPORTANT NEEDS OF PARENTS AS IDENTIFIED BY FATHERS; WITH THE PERCENT OF FATHERS STATING NEED WAS MET IN NICC, AND BY WHOM

Item #	MOST IMPORTANT NEEDS	Percent of Fathers Responding Need was Met	Need Met By Doctor	Need Met By Nurse
2.	I needed to have my questions answered honestly.	100%	4	2
3.	I needed to be able to visit whenever I wanted.	100	2	1
10.	I needed to feel that hospital personnel cared about my baby.	100	3	3
12.	I needed to know exactly what was being done for my baby.	100	3	2
13.	I needed to know how my baby was going to be treated medically.	100	3	2
16.	I needed to know why things were being done for my baby.	80	1	3
26.	I needed to touch and hold my baby.	100	2	2
28.	I needed to talk to the doctor at least once a day.	80	3	-
36.	I needed to know my baby's chances for becoming well.	60	3	1
37.	I needed to know that I would be called at home if there were any changes in my baby's condition, good or bad.	80	4	3
40.	I needed to receive information about my baby's condition at least once a day.	60	2	1
	TOTAL		30	20

TABLE 12

MOST IMPORTANT NEEDS OF PARENTS AS IDENTIFIED BY MOTHERS; WITH THE PERCENT OF MOTHERS STATING NEED WAS MET IN NICC, AND BY WHOM

Item #	MOST IMPORTANT NEEDS	Percent of Mothers Responding Need was Met	Need Met By Doctor	Need Met By Nurse
2.	I needed to have my questions answered honestly.	60%	3	2
3.	I needed to be able to visit whenever I wanted.	60	3	3
10.	I needed to feel that hospital personnel cared about my baby.	100	3	4
12.	I needed to know exactly what was being done for my baby.	80	3	3
13.	I needed to know how my baby was going to be treated medically.	100	4	2
[a]20.	I needed to talk to someone about my feelings such as anger and guilt.	40	0	1
26.	I needed to touch and hold my baby.	60	1	3
31.	I needed to have explanations given in terms I could understand.	100	4	3
32.	I needed reassurance that the best possible care was being given to my baby.	100	4	3
40.	I needed to receive information about my baby's condition at least once a day.	100	2	4
42.	I needed to be present at the time of my baby's death.	60	3	2
49.	I needed a snapshot, bracelet, bootie or something to remember my baby by.	80	2	3
	TOTAL		32	33

[a]20. Relatives and spouses most often met this need for mothers.

Who Meets Needs

Proposition 4. The nurse is the staff member who most frequently meets the needs of parents with dying newborns in the NICC setting.

Nurses were asked to identify the person who most often meets each of the 53 needs of parents. Response choices included: no one, doctor, nurse, chaplain, spouse, other relative, friend, other visitor, other or all the above. Very rarely did the nurses identify any persons other than the doctor or nurse as meeting parents' needs. Table 10 summarizes the responses of nurses as to whether the doctor or nurse most frequently meets the most important needs of parents. Because multiple responses were possible, such as doctor and nurse or nurse and spouse, some items will have more than 34 responses. From Table 10 it is apparent that nurses stated that nurses, more than twice as frequently as doctors, met the needs of parents.

Parents were also asked to identify the person from the above list who most often met their needs. Doctor and nurse were most frequently identified, with an occasional reference to the spouse. Tables 11 and 12 tally the responses of the fathers and mothers to this question. Fathers responded that doctors, rather than nurses, were the staff members who most frequently met their needs. Mothers responded that doctors and nurses met their needs with almost the same frequency.

Additional Findings

Item #54 of the questionnaire was open-ended and asked the respondent if parents had any concerns or needs that were not mentioned in the

body of the questionnaire. Four nurses stated the following additional needs of parents experiencing the death of a newborn in a Neonatal Intensive Care Center:

"Parents need a follow-up visit by the primary nurse 2-3 months after the death of an infant."

"Parents need the nurse taking care of the baby to call 1-2 weeks after the baby's death to see how the family is doing."

"Siblings need to have contact with the infant whether well or critically ill."

"Parents need to be informed that it is alright not to be present when their baby dies and alright not to want to hold their baby after he/she has died and that someone in the NICC will do it for them."

"Parents need a list of telephone numbers of people who might help."

"Parents need information to read at a later time about grief work and perhaps something personal written by other parents who have lost a newborn."

As an interesting note, five nurses had experienced a neonatal loss themselves but none of them stated additional concerns or needs.

All five parent-pairs had additional concerns which they expressed in Item #54. They are presented below but as expressions of their innermost concerns and feelings:

"Hospital's location is inconvenient and the Neonatal Unit seems to be in an out of the way place inside the hospital."

"My wife was in a hospital 30 miles away which made it very difficult to give the support needed to her and the baby. It would have been much better if arrangements could have been made to get momma closer to baby and possibly spend more time with baby. My wife was only able to see (baby) for a couple of hours."

"We're thankful because we could bring her home to die."

"Encourage parents to talk to their baby even if they can't hold her."

"It would have been nice if I could have been moved to the University's Hospital."

"They wouldn't allow me my rights and used my baby as a guinea pig after they knew there was no chance --- and kept making me pay and suffer. False hope... I had to force them (doctors) to let baby die. I told them not to let anyone keep the baby alive artificially. They said it was not my choice. Why didn't we have the right to let baby die or even allowed to make decision on death after on the machines?"

"Very important that mother can hold and touch her baby even if she herself is in a different hospital. Also very important that father is taken care of and his concerns met."

"Help is needed in how to relate to others that the child was born and included in the family. Booklets are very good: Neonatal Intensive Care Booklet, Hello Means Good-Bye and the Rose Booklet."

In summary, support was found for the first proposition, and it may be concluded that parents and nurses do agree regarding the relative importance of the needs of parents with a dying newborn. Proposition 2 was not supported since the level of agreement was high on the perceived importance of the 53 needs by mothers as a group and fathers as a group. The third proposition was not supported by the responses of fathers and nurses. The majority of nurses believed that the most important needs of parents were being met in the NICC. Fathers also believed that their most important needs were met in the NICC. Mothers, however, believed that their needs were met less often than fathers. Regarding who meets the needs of parents in the NICC, nurses believed that they met the needs of parents more than twice as frequently as doctors. Mothers responded that doctors and nurses met their needs with almost the same frequency. Fathers responded that doctors, rather than nurses, were the staff members who most frequently met their needs.

CHAPTER IV

DISCUSSION

Subjects

The number of nurses participating in this study represented less than half of the nursing staff employed in the NICC. This relatively poor response rate may be attributed to a number of factors, such as the busyness of the NICC, the length of the questionnaire, lack of sufficient encouragement from nursing superiors to participate in the study, failure of the nurses to see a direct benefit from participation, and lack of identification with the researcher. The health team of the NICC appears to be a very tightly knit group, closed to outsiders. Perhaps the response rate would have been higher if the researcher had been an active and recognized member of the team, or had secured stronger sponsorship from leaders of the team. Perhaps the rate would have been higher if the researcher had been able to provide a structured and formal orientation to the study for the nurses. The researcher had secured permission to contact the group through the head nurse and chief physician. Many efforts had been made to meet with the nursing staff to explain the study and solicit cooperation, but no convenient and accessible time was ever established.

The response rate for parents was poor because 5 of the 14 eligible parent-pairs had moved since their newborn's death leaving no forwarding address or telephone number. Of the parents who refused to participate, one stated that there was no convenient time to talk with both her and her husband. Another 17-year old mother cried on the phone saying;

"Where were you 2 days after my baby died? That's when I wanted someone to talk to. I don't want to talk 3 months later. I'm trying to forget what happened."

The third set of parents who refused to participate was in the process of suing the University and NICC for negligence in the death of their day old daughter and thought it best not to discuss the events with anyone connected with the University. The fourth parent refused without stating a reason.

Note that parents were of upper middle-class status. Very different results might have been obtained from parents of lower economic status. The results of this study may be biased and therefore, are not truly generalizable to parents outside of the study population.

Relative Importance of Parents' Needs

When discussing the relative importance placed on the 53 needs by nurses and parents it is important to refer back to Appendix F, and review the list of references from the literature which validate the 53 need statements. It may be noted that all of the 10 need statements identified as most important by nurses (see Table 3) were also cited in the literature as very important. Similarly, 5 of the 10 needs rated least important by nurses were poorly validated in the literature. Item #46, however, "parents need someone to talk to their other children about the baby's death", was highly stressed in the literature as an important need of parents, but only received a mean importance score of 2.76 by nurses. In general, the nursing staff of the NICC appears to be adequately identifying the important and less important

needs of parents experiencing the death of a newborn, when compared to the writings of noted authors in this field.

All but one of the 11 most important needs identified by fathers were rated as very important in the literature as well. The fathers' need to "know their baby's chances for becoming well" was not well documented in the literature as being a very important need. Two of the 12 needs identified as least important by fathers were heavily documented in the literature as very important needs of parents experiencing a newborn death. Experts stressed that "parents need someone to talk to their other children about their baby's death" and that "parents need someone to encourage them to touch and hold their baby after he/she had died". Fathers in this study gave each of these needs a mean importance score of 1.80. They stated that no one needed to encourage them to touch their baby since they had overwhelming internal desires to do so. All fathers believed that they were better able, than any unfamiliar staff member, to share the facts of the baby's death with their other children.

All 12 needs identified by mothers to be most important were noted to be very important in the literature also. Mothers, as did fathers, felt better prepared to talk to their other children about the baby's death. Mothers gave this need a mean importance score of 1.00 although 5 authors noted it to be very important. Overall, parents are in agreement with authors on the importance of parents' needs when experiencing a newborn death. It is interesting to note that nurses and parents both differed from noted authors on the need for someone to talk to siblings about the newborn's death.

Propositions 1A and 1B of this study stated that fathers and nurses and mothers and nurses would agree regarding the relative importance of the needs of parents with dying newborns. The mean importance scores given to the 53 needs by fathers and nurses were significantly correlated ($r = .58$, $p < .001$) as were the mean importance scores of mothers and nurses ($r = .67$, $p < .001$).

Parents, however, demonstrated an even higher level of agreement on the importance of the 53 need statements ($r = .82$, $p < .001$). These results do not support the second proposition of this study which stated that a difference exists between mothers and fathers perceptions of the importance of their needs at the time of their newborn's death. The literature suggests that fathers have increased burdens placed on them because of the traditional expectations of masculine behavior and because many men have difficulty expressing their grief and concerns (Benefield, 1978; Mandel, 1980). This led the researcher to believe that fathers would have different and more subtle needs than mothers. These expectations of masculine behavior may be important factors in many situations and with many men, but they did not appear to be important factors affecting the fathers in this study.

Needs Being Met

Proposition 3 stated that the needs of parents determined to be most important by nurses and parents may not be met in the NICC. Crisis intervention, as outlined by August-Miller (1973), requires that the intervening person: 1) assess the newborn's illness, family background and family's attitude toward death; 2) intervene by providing adequate situational supports, coping mechanisms and a realistic

perception of events leading to the death; and 3) give anticipatory guidance in preparing the family for the newborn's death. The researcher believed that many of these interventions could not be adequately and consistently carried out by a predominately part-time nursing staff and on a unit without a social worker, psychologist or chaplain immediately available.

Half the needs of parents determined to be most important by nurses were believed to be met by 100% of the nurses. Only 1 of the 10 most important needs nurses identified was believed to be met by only 67% of the nurses indicating that the majority of nurses felt that the most important needs of parents were being met in the NICC.

Half the needs determined to be most important by fathers were believed to be met by 100% of the fathers. Only 2 of the 11 most important needs fathers identified were believed to be met by 60% or less of the fathers. Overall, the majority of fathers felt that their most important needs were met in the NICC.

Five of the 12 needs determined to be most important by mothers were believed to be met by 100% of the mothers. Of the remaining 7 needs 2 were felt to be met by 80% of the mothers and 4 were felt to be met by only 60% of the mothers. The one remaining need, "to talk to someone about my feelings such as anger and guilt", was believed to be met by only 40% of the mothers. Mothers believed that their needs were met less often than fathers because, as maternity patients in other hospitals, the NICC and their newborns were inaccessible to them. Only 1 of the 5 mothers in this study was in the maternity unit of the Oregon Health Sciences University Hospital. She was brought over to

the NICC to see her newborn in a wheelchair by her husband. It was much more difficult for the other mothers to see their newborns. One mother came by ambulance from a Portland hospital to hold her son before he died. Another mother was brought from a second Portland hospital in the back of her husband's van to hold her son after he was taken off the respirator. A third mother discharged herself from the hospital against medical advice after a cesarean section so that she could be with her baby in the NICC. She was readmitted that evening because of hemorrhage and was returned to bedrest.

All parents responded that it would be best to transport both mother and newborn at the time of delivery when the newborns was found to need admission to the NICC. Mothers could then be admitted to the University's post-partum unit. This would help to keep the family system intact and enable more frequent opportunities for mother and newborn to be together. It would also decrease the stress placed on the father who otherwise finds himself traveling between two different hospitals and often times making important decisions alone. All parents believed that the expense of the ambulance transfer would be far outweighed by the benefits of having both mother and father closer and more accessible to the newborn. Crisis intervention could also be more realistically implemented by the NICC staff by having contact with both parents.

Who Meets Needs

Proposition 4 stated that the nurse is the staff member who most often meets the needs of parents with dying newborns in the NICC setting. Nurse responses supported this proposition as did leading authors noted

in the review of the literature. The nurses in the OHSU NICC hold a philosophy of total care for the infant and the family and feel adequately prepared to meet their needs.

Mothers responded that doctors and nurses met their needs with almost the same frequency giving some support to Proposition 4. Interestingly, fathers responded that doctors were the staff members who most frequently met their needs and not nurses. Doctors in the NICC are responsible for making major life and death decisions. Fathers spent more time in the NICC than mothers who were themselves patients in other hospitals. Frequent parent-doctor conferences were held before any of the newborns in this study were removed from the respirator. The doctor may be the staff member who most often meets the needs of parents with dying newborns in the NICC setting because of the intensity of the medical emergency.

Fathers' responses may also, in part, be due to sex identification. Most of the physicians in the NICC are male. It is possible that fathers identified more with male staff members than female staff members because they felt more comfortable with them. If true, this has important nursing implications.

Present Findings and Molter's Findings Compared

The questionnaire used to gather data for this study was developed by modifying and converting a structured interview guide developed by Nancy C. Molter (1976) to study the needs of 40 relatives of critically ill adults in an Intensive Care Unit (ICU). Molter's study posed three questions: 1) what personal needs do relatives of critically ill patients identify?; 2) what is the importance of these needs to relatives?;

3) what are the needs being met, and, if so, by whom?

Seven of the 10 most important needs identified in Molter's study by relatives of critically ill patients in an ICU were also identified in the present study by nurses and parents to be most important to parents experiencing a newborn death in a NICC. They include the following needs:

1) To feel that hospital personnel care about the patient (baby).
2) To be called at home about changes in the condition of the patient (baby).
3) To know the prognosis (baby's chances for becoming well).
4) To have questions answered honestly.
5) To receive information about the patient (baby) at least once a day.
6) To have explanations given in terms that are understandable.
7) To see the patient frequently (to be able to visit whenever parents wanted).

Mothers in this study identified the need to "talk to someone about their feelings such as anger and guilt" to be very important (mean importance score of 4.0), but only 1 of the 40 relatives in Molter's study rated it as very important.

Molter's study also sought to determine whether relatives' needs were met. Only 4 needs were met less than 50% of the time when perceived as important or very important. Similarly, nurses and fathers in this study reported that the most important needs of parents in the NICC were being met at least 50% of the time. About half the needs of mothers identified as most important were believed to be met by 100% of the mothers.

The last objective of Molter's study was to determine who met the needs of relatives. Molter expected that needs would be met by persons other than hospital personnel. Using the same categories of responses as in this study, the majority of relatives responded that their needs were met by nurses.

Comparisons can be made between this study and the one conducted by Molter in 1976. Parents of dying newborns have many special needs in the NICC but they share many common needs with relatives of critically ill patients in an ICU. The Intensive Care setting is a stressful environment but it appears that the nurse and doctor are adequately meeting the needs of families and relatives.

In Molter's study, 30 of the 40 respondents were men. Unlike the fathers in this study, male relatives identified the nurse as most often meeting their needs. Their responses did not appear to be influenced by sex identification with the doctor.

Additional Related Findings

Parents reacted strongly to many of the statements in the questionnaire. Some of their concerns and opinions need to be conveyed to NICC health care workers.

The literature suggests that parents need help making funeral arrangements (Smialek, 1978), but parents unanimously stated that staff was unprepared to offer them this help. One father had experienced a recent death in the family and felt better prepared to make the arrangements for his newborn than did other parents. It was noted that staff did not offer information on the care of the body after death or usual protocol on how to arrange for cremation or funeral services. Parents

suggested that the NICC put together a booklet providing this information or contact a local funeral director who would be interested in providing this service to parents.

Many noted authors stressed the importance of giving parents something to remember their newborn baby (Perrault et al., 1979; Schneider & Daniel, 1979; Dillard et al., 1980; Parrish, 1980). Parents overwhelmingly agreed that, at first, they felt uncomfortable with the snapshots and booties but were thankful for them 3 to 4 months later. Many said it helped to confirm in their minds that they really had had a baby even if he/she only lived a few days.

Routine care of the family after the death of an infant in the NICC includes a referral to the Public Health Department for a home visit by a Public Health Nurse (PHN). All the families in this study talked with the PHN on the telephone but refused to allow a home visit. Parents questioned the appropriateness of the PHN's home visit and suggested that the primary nurse, who cared for their newborn in the NICC, call or visit. This would reduce the workload of the PHN and protect the parents from unnecessary involvement with health professionals who are unfamiliar with them and the circumstances of their newborn's death.

George Engel (1964) is noted in the review of the literature to have identified four stages of bereavement as they apply to the sudden death situation where initial management is brief and concentrated on the loss. Four of the five parent-pairs in this study were in the stage of Restitution at the time of their questionnaire completion. They were verbally working through their feelings of loss and eager to

share the circumstances surrounding their newborn's death with the researcher. This is a time for family members to acknowledge their need for support and lasts for months before the final stage of Resolution occurs.

One family in this study appeared to be in Engel's stage of Developing Awareness. Their newborn had died 4 1/2 months prior to the time the researcher met with them but still they had many strong feelings of anger and guilt that had not been resolved. The father shouted and pounded his fist on the table while discussing the events leading up to his wife's labor and delivery and his son's admission to the NICC. The wife sat very quietly looking at her lap and crying. Their baby had been born at 27 weeks gestation and weighed less than 2 pounds. With serious respiratory difficulties and prematurity working against the baby, the father asked that the baby not be transferred to the NICC and put on a respirator, but instead be allowed to die. He was told that it was not his decision to make but a matter of medical opinion and the baby was transferred. Eight days later the baby died leaving behind a $25,000.00 hospital bill.

This case presentation brings up many ethical and moral dilemmas which every health care professional must address. Does a father have a right to make life and death decisions for his child? What are the limits of neonatal intensive care medicine? Unfortunately, the answers to these questions have not yet been found.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

The death of a newborn is an overwhelming disappointment which brings grief and distress not only to the parents and family of the infant, but also to the doctors and nurses involved in the care of the infant. There has been, however, little research into the needs of parents of dying newborns or into the extent that those needs are being met in Neonatal Intensive Care Units. The present descriptive study was undertaken to expand knowledge in this area. More specifically, the purpose of the research was to ascertain the congruence of nurses' and parents' perceptions of the needs of parents whose infants succumb in the Neonatal Intensive Care Unit of the Oregon Health Sciences University Hospital. The following propositions were examined.

Proposition 1: Parents and nurses agree regarding the relative importance of the needs of parents of dying newborns.

Proposition 2: A difference exists between mothers' and fathers' perceptions of the relative importance of their needs at the time of their newborn's death.

Proposition 3: The needs of parents determined to be very important by nurses and parents may not be met in the NICC.

Proposition 4: The nurse is the staff member who most often meets the needs of parents with dying newborns in the NICC setting.

The study subjects included 34 registered nurses and five parent-pairs. Data were obtained via questionnaires administered to the nurses in the NICC. Parent questionnaires were completed in their homes in

the presence of the researcher. A modified version of an instrument developed by Molter (1976) was used to measure the relative importance of 53 specified parents' needs and to determine which of these needs were being met and by whom. The data analysis consisted mainly in correlating the responses of nurses and parents, and of mothers and fathers.

A high level of agreement between nurses and parents regarding the importance of the 53 needs was found, lending support to the first proposition. The second proposition was not upheld, however, in that the level of agreement between mothers and fathers was even higher than that between nurses and parents. The third proposition was also overturned. The majority of nurses believed that the most important needs of parents were being met in the NICC, as did the majority of fathers. Mothers believed their needs were met to a lesser extent because, as postpartum patients in other hospitals, the NICC where their newborns were being treated was inaccessible to them.

With regard to the fourth proposition, nurses responded that they were the staff members who usually met parents' needs. Mothers responded that doctors and nurses both met their needs to the same extent. Fathers, however, designated doctors rather than nurses as the staff members most frequently meeting their needs.

These findings must be regarded as suggestive, and not generalized broadly to other settings and to other groups of nurses and parents. In view of the small and nonrepresentative sample, these findings at most apply only to middle class parents, living in the Portland/Vancouver metropolitan area, whose newborn infants died in the NICC of the OHSU.

The results cannot be generalized to parents of low socioeconomic status, or to parents whose infants died in other neonatal intensive care units.

Recommendations for Further Study

The findings and problems encountered during this investigation suggest a number of possible modifications and extensions for further research. First, it is obvious that more than one NICC must be studied, and that more representative samples of parents and nurses should be obtained. Second, higher response rates are essential. In the present instance, the relatively poor response rates of nurses, despite extensive follow-up efforts, may be attributed in part to the fact that health teams of neonatal intensive care units appear to be tight groups, closed to outsiders. It is difficult for a researcher to penetrate this group and to engage its full cooperation. Ideally, in future research, the investigator might be a recognized member of the team. Otherwise, the researcher needs to lay a careful groundwork, securing the support of the head nurse and chief physician, meeting several times with professionals and nurses of all shifts and explaining the nature of the project, together with emphasis on possible benefits for participants. The response rate of parents might also be increased by employing one of the infants' caregivers as interviewer. The primary nurse would be in an excellent position to meet with parents, three months after the infant's death, to interview or administer a questionnaire.

Third, research is needed to further refine the instrument for measuring needs, and to establish its reliability and validity. Fourth,

the relative advantages of home visits versus self-administered questionnaires should be carefully weighed. It is true that home visits are costly and time consuming, considerations which may limit sample size. In this study, visits lasted from three to four hours. One hour sufficed for data collection, but parents seized on the opportunity to ventilate feelings. (This behavior in itself speaks to the existence of an unmet need.) Perhaps the therapeutic benefit to be derived from talking with an interviewer about one's problems is an inducement to some parents to participate in a study, which is lacking when asked to respond to an impersonal questionnaire.

Several extensions of the present research are also recommended. As one instance, a longitudinal study might be undertaken, with periodic interviews of parents during the first year of bereavement. Such a study might illuminate the nature of the grief process, and identify continuing, unresolved concerns of parents. Knowledge of these long term effects should serve to guide the NICC staff in planning interventions to help the family.

As another extension, this investigation might be replicated with different populations, as, for example, with parents of lower socioeconomic status, single mothers, and teenage parents. Replications might also be conducted with parents whose infants died following prolonged hospitalization in the NICC. Comparison of the needs of such groups with those of older parents, in intact marriages, experiencing the death of newborns might provide many insights for interventions. Such research might also shed light on bonding and family attachments as they are affected by an infant's illness and death.

Still another possibility for study are the needs of parents with newborns who are critically ill but who survive and are discharged home. Such parents might reveal a much greater reliance on nurses than did the parents of the present investigation, in that doctor-patient interactions might be expected to diminish gradually over the period of recovery, once the initial life-threatening crisis is over.

Finally, the investigator strongly recommends that a feasibility study be undertaken regarding changing the health care system itself so that when a newborn is admitted to a neonatal intensive care unit, the mother simultaneously be transferred to the same hospital. The needs and satisfactions of mothers who are transferred with their infants might be compared to the needs and satisfactions of mothers who are not transferred to determine the effects of separation from her dying newborn on the grieving process of the mother.

In conclusion, whatever the cause for admission of a newborn to a Neonatal Intensive Care Center and whatever the eventual outcome, it is apparent that parents have special needs which must be met by all staff involved in their care. This research project has been one small step toward discovering what health professionals can do to lessen the trauma and crisis parents experience when faced with a newborn's death. It is only a beginning.

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APPENDIX A

NURSE QUESTIONNAIRE

Code #_____

NURSE QUESTIONNAIRE

The following information is needed from you so that I may adequately describe the sample of nurses completing this questionnaire. It will be used for no other purpose.

Date of Birth:_____

Sex: M___ F___

Number of years worked in this NICC_____years_____months

Shift worked_____days_____evenings_____nights

Employment status_____full time_____part time

Have you or anyone in your immediate family experienced the death of a newborn?_____

Instructions:

Please read each of the following "need" statements and determine how important you think the need is for parents whose infant dies in your unit. Mark an "X" under the column which pertains to the level of importance you perceive that need to have: (1) if you feel the need is not at all important to parents; (2) if you feel the need is slightly important to parents; (3) if you think the need is important to parents; and (4) if you feel the need is very important to parents.

After rating the statement and determining its level of importance to parents, determine if this need is being met on your unit greater than 50% of the time. Mark an "X" under the "Yes" column if that particular parent need is in fact being met 50% of the time or more frequently. Mark an "X" under the "No" column if that need is not being met on the unit at least 50% of the time.

In the last column, write in the letter that corresponds to the person who most often helps parents meet that need according to the code at the top of each page of the questionnaire. If you answered "no", that this parent need is not being met on your unit, this column will be left blank.

The following example will help to clarify these instructions. Statement #1 reads as follows:

By Whom (BW):

A - Doctor	E - Other Relative
B - Nurse	F - Friend
C - Chaplain	G - Other Visitor
D - Spouse	H - Other

1. Parents need to feel accepted by hospital personnel.

1 Not Important	2 Slightly Important	3 Important	4 Very Important	Is the need being met 50% of the time. Yes	No	If "Yes", then by whom (BW)
		X		X		B

In this example, if you feel the need is "important" to parents you would mark an "X" under column #3 labeled "important". If you feel that 50% of the time, parents with dying infants feel accepted by hospital personnel you would mark an "X" under the "Yes" column. In the last column, you would mark "B" if you feel that the Nurse is most often the person on the Unit who helps make parents feel accepted by the hospital personnel.

Please, take your time in responding to each of the following statements. Your input is vital to the completion of my study.

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Is the need being met 50% of the time? Yes	No	If "yes", then by whom? BW
1. Parents need to feel accepted by hospital personnel.							
2. Parents need to have their questions answered honestly.							
3. Parents need to be able to visit whenever they want.							
4. Parents need to have a place available near the Neonatal Intensive Care Center to be alone while in the hospital.							
5. Parents need to be told about other people in the hospital that could help them.							
6. Parents need to have a specific person to call at the Neonatal Intensive Care Center when they cannot be there.							
7. Parents need to have a telephone nearby where they are waiting.							
8. Parents need to have someone help with financial problems.							
9. Parents need to have good food easily available while in the hospital.							
10. Parents need to feel that hospital personnel care about their baby.							
11. Parents need to have a waiting room near their baby.							
12. Parents need to know exactly what is being done for their baby.							
13. Parents need to be told how their baby is going to be treated medically.							

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Is the need being met 50% of the time? Yes	No	If "Yes", then by whom? BW
14. Parents need to be told about Chaplain services.							
15. Parents need to feel that there is hope.							
16. Parents need to know why things are being done for their baby.							
17. Parents need to be told about transfer plans when they are being made.							
18. Parents need to have someone explain to them about the sounds and equipment of the Intensive Care Center before going in for the first time.							
19. Parents need to talk to someone about the possibility that their baby might die.							
20. Parents need to talk to someone about their feelings such as anger or guilt.							
21. Parents need direction from staff as to what is expected of them while at their baby's bedside.							
22. Parents need to know about the various types of staff taking care of their baby.							
23. Parents need to see their baby frequently.							
24. Parents need to have specific facts concerning their baby's progress.							
25. Parents need to do some of the physical care of their baby.							
26. Parents need to touch and hold their baby.							
27. Parents need to have family and friends nearby for support.							

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	Not Important 1	Slightly Important 2	Important 3	Very Important 4	Is the need being met 50% of the time? Yes	No	If "yes", then by whom? BW
28. Parents need to talk to the doctor at least once a day.							
29. Parents need to have a bathroom near the waiting room.							
30. Parents need to be reassured that it is alright to leave the hospital for a while.							
31. Parents need to have explanations given in terms they can understand.							
32. Parents need reassurance that the best possible care is being given to their baby.							
33. Parents need to know what type of staff members can give what type of information.							
34. Parents need to have comfortable furniture in the waiting room.							
35. Parents need to have someone concerned for their health.							
36. Parents need to know their baby's chances for becoming well.							
37. Parents need to know that they will be called at home if there is any change in their baby's condition, good or bad.							
38. Parents need to talk to the same nurse each day about their baby's condition.							
39. Parents need to know that it is alright to cry.							
40. Parents need to receive information about their baby's condition at least once a day.							
41. Parents need to have another person with them when visiting their baby.							

By Whom (BW):

A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Is the need being met 50% of the time? Yes	No	If "yes", then by whom? BW
42. Parents need to be present at the time of their baby's death.							
43. Parents need to have someone help them with funeral arrangements.							
44. Parents need to meet with their baby's doctor immediately after their baby's death.							
45. Parents need to be advised concerning future children.							
46. Parents need someone to talk to their other children about the baby's death.							
47. Parents need to meet with their baby's doctor 2-3 months after their baby's death.							
48. Parents need to be encouraged to touch and hold their baby after their baby's death.							
49. Parents need a snapshot, bracelet, bootie or something to remember their baby by.							
50. Parents need to be encouraged to name their baby.							
51. Parents need to talk with other parents who have also experienced the death of a newborn.							
52. Parents need to be informed of community resources available that provide support for families after the death of their baby.							
53. Parents need to have a Public Health Nurse visit their home after the death of their baby.							

54. Is there any concern or need that you feel parents have that was not mentioned in the previous statements?

_____

_____

APPENDIX B

PARENT QUESTIONNAIRE

PARENT QUESTIONNAIRE CODE#_____

Purpose of this questionnaire:

Through this research I hope to find out the types of needs you had and how important the needs were to you while your baby was in the Oregon Health Sciences University's Neonatal Intensive Care Center. I also want to find out if the needs of mothers and fathers differ and so I am asking each of you to answer a separate questionnaire. This study will also help in determining which of your needs were met and by whom.

The following information is needed from both of you so that I may adequately describe the sample of parents completing this questionnaire. It will be used for no other purpose.

Name of Mother_____

Name of Father_____

Mother's Date of Birth_____ Educational Level_____

Father's Date of Birth_____ Educational Level_____

(number of last grade completed)

Mother's Occupation_____

Father's Occupation_____

Number of Pregnancies_____

Number of Living Children_____

Occurrence of any other infant deaths in the immediate family

Self_____

Relative_____

CODE# _____

By Whom (BW):
A - Doctor E - Other Relative
B - Nurse F - Friend
C - Chaplain G - Other Visitor
D - Spouse H - Other

Statements:	Not Important 1	Slightly Important 2	Important 3	Very Important 4	Was your need met? Yes	Was your need met? No	If "yes", then by whom? BW
1. I needed to feel accepted by hospital personnel.							
2. I needed to have my questions answered honestly.							
3. I needed to be able to visit whenever I wanted.							
4. I needed to have a place available near the Neonatal Intensive Care Center to be alone while in the hospital.							
5. I needed to be told about other people in the hospital that could help me.							
6. I needed to have a specific person to call at the Neonatal Intensive Care Center when I could not be there.							
7. I needed to have a telephone nearby where I was waiting.							
8. I needed to have someone help me with my financial problems.							
9. I needed to have good food easily available to me while in the hospital.							
10. I needed to feel that hospital personnel cared about my baby.							
11. I needed to have a waiting room near my baby.							
12. I needed to know exactly what was being done for my baby.							
13. I needed to be told how my baby was going to be treated medically.							

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Was your need met? Yes	No	If "yes", then by whom? BW
14. I needed to be told about chaplain services.							
15. I needed to feel that there was hope.							
16. I needed to know why things were being done for my baby.							
17. I needed to be told about transfer plans when they were being made.							
18. I needed to have someone explain to me about the sounds and equipment of the Intensive Care Center before I went in for the first time.							
19. I needed to talk to someone about the possibility that my baby might die.							
20. I needed to talk to someone about my feelings such as anger and guilt.							
21. I needed direction from the staff as to what was expected of me while I was at my baby's bedside.							
22. I needed to know about the various types of staff taking care of my baby.							
23. I needed to see my baby frequently.							
24. I needed to have specific facts concerning my baby's progress.							
25. I needed to be able to do some of the physical care of my baby.							
26. I needed to touch and hold my baby.							
27. I needed to have family and friends nearby for support.							
28. I needed to talk to the doctor at least once a day.							
29. I needed to have a bathroom near the waiting room.							

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Was your Need met? Yes	Was your Need met? No	If "yes", then by whom? BW
30. I needed to be reassured that it was alright to leave the hospital for a while.							
31. I needed to have explanations given in terms I could understand.							
32. I needed reassurance that the best possible care was being given to my baby.							
33. I needed to know what type of staff members could give me what type of information.							
34. I needed to have comfortable furniture in the waiting room.							
35. I needed to have someone be concerned for my health.							
36. I needed to know my baby's chances for becoming well.							
37. I needed to know that I would be called at home if there were any changes in my baby's condition, good or bad.							
38. I needed to talk to the same nurse each day about my baby's condition.							
39. I needed to know that it was alright to cry.							
40. I needed to receive information about my baby's condition at least once a day.							
41. I needed to have another person with me when I visited my baby.							
42. I needed to be present at the time of my baby's death.							
43. I needed to have someone help me with funeral arrangements.							
44. I needed to meet with my baby's doctor immediately after my baby's death.							

By Whom (BW):
A - Doctor
B - Nurse
C - Chaplain
D - Spouse
E - Other Relative
F - Friend
G - Other Visitor
H - Other

Statements:	1 Not Important	2 Slightly Important	3 Important	4 Very Important	Was your need met? Yes	No	If "yes", then by whom? BW
45. I needed to have someone advise me concerning future children.							
46. I needed someone to talk to my other children about our baby's death.							
47. I needed to meet with my baby's doctor 2-3 months after my baby's death.							
48. I needed someone to encourage me to touch and hold my baby after my baby died.							
49. I needed a snapshot, bracelet, bootie or something to remember my baby by.							
50. I needed to be encouraged to name my baby.							
51. I needed to talk with other parents who had also experienced the death of a newborn.							
52. I needed to be informed of community resources available that provide support for families after the death of their baby.							
53. I needed to have the Public Health Nurse visit my home after my baby's death.							

54. Is there any concern or need that you had that was not mentioned in the previous statements?_____

_____

_____

APPENDIX C

PARENTS' QUESTIONNAIRE COVER LETTER

THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing
Department of
Family Nursing

3181 S.W. Sam Jackson Park Road Portland, Oregon 97201 (503) 225-8382

Dear_____:

I am a registered nurse and a graduate student in family-centered child nursing at the Oregon Health Sciences University in Portland. I am conducting a study of parents who have experienced the death of their newborn infant while the baby was in the Neonatal Intensive Care Center (NICC) of the Oregon Health Sciences University hospital. I am interested in determining how parents rate their needs and concerns while their infant is dying and if we at the University are meeting these needs adequately. Nurses working in the NICC will rate how important they perceive these same parent needs to be. In addition, I want to see if there is a difference between the needs of mothers and fathers. I hope that by learning what needs are most important to parents with dying newborns and what issues, if any, are more significant to fathers, insights and advances can be made which will enable health professionals to give optimal care, support and assistance to parents who experience a newborn death in the future.

Dr. Reynolds, the chief physician in the NICC, has given his consent for me to request your participation in this study. I will ask you both to complete a 53 item questionnaire at a time that is convenient for you when I may visit you in your home. It will take about 1 hour to complete it.

There are no direct risks to you if you decide to participate in this study. You may benefit by having the opportunity to express your satisfaction and dissatisfaction with the care you and your baby received in the NICC.

Your participation in this study is voluntary and you may feel free to withdraw from the study at any time without affecting you or your family's care or treatment at the Oregon Health Sciences University. To preserve your anonymity and maintain confidentiality you will receive a code number for the purpose of data analysis. Your individual responses will not be shared with anyone.

I will contact you by telephone in 1 week to see if you both would like to participate in this study. If you have any questions about this study or your participation in it we can talk about it then. Thank you for taking the time to read this letter.

Sincerely,

Patti Turecki, R.N.

APPENDIX D

NURSES' QUESTIONNAIRE COVER LETTER

THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing
Department of
Family Nursing

3181 S.W. Sam Jackson Park Road Portland Oregon 97201 (503) 225-8382

Dear_____:

I am a registered nurse and a graduate student in family-centered child nursing at the Oregon Health Sciences University. I am conducting a study of the needs of parents who have experienced the death of their newborn while the baby was in this University's NICC. I am interested in determining how parents rate their needs and concerns while the infant is dying and if these needs are being adequately met on the unit. I also want to determine how important the nursing staff perceives these same parent needs to be. In addition I want to see if there is a difference between the needs of mothers and fathers. I hope that by learning what needs are most important to parents with dying newborns and what issues, if any, are more significant to fathers, insights and advances can be made which will enable health professionals to give optimal care, support and assistance to parents who experience a newborn death in the future.

Participation in this study will take about 45 minutes of your time. I ask that you return completed questionnaires within one week of receiving them by dropping them into the envelope tacked on Jackie Staven's door.

There are no direct risks to you if you decide to participate in this study. You may benefit by having the opportunity to rate and validate the care you give now and would like to give in the future.

Your participation is voluntary and you may feel free to withdraw from the study at any time without affecting your care or treatment at the Oregon Health Sciences University. To preserve your anonymity and maintain confidentiality you will receive a code number for the purpose of data analysis. Your individual responses will not be shared with anyone.

Thank you for taking the time to read this letter.

Sincerely,

Patti Turecki, R.N.

APPENDIX E

MOLTER'S QUESTIONNAIRE

Molter, Nancy C.

NEEDS OF RELATIVES OF CRITICALLY ILL PATIENTS

Explanation of Purpose of Interview:

Through this interview I hope to find out the types of needs you had and how important the needs were to you while your relative was in the intensive care unit. I also want to find out if your needs were met and, if so, by whom. Information concerning your age, education, occupation, and sex will help me categorize my findings.

Instructions

I will read to you a statement and then ask you to tell me if it was (1) not important at all to you, (2) slightly important to you, (3) important to you, or (4) very important to you. The card I have given to you will help you choose your answer each time. (A 5 x 8 card is given to the subject that contains the responses that they may choose from). I will then ask you if the need was met and, if so, by whom?

Statements:

1. I needed to feel accepted by hospital personnel.
2. I needed to have my questions answered honestly.
3. I needed to be able to visit whenever I wanted.
4. I needed to have a place to be alone while in the hospital.
5. I needed to be told about the other people in the hospital that could help me.

6. I needed to have a specific person to call at the hospital when I couldn't be there.
7. Because there were visiting hours, I needed to have them start on time.
8. I needed to have a telephone nearby where I was waiting.
9. I needed to have someone help me with my financial problems.
10. I needed to have visiting hours changed because of special conditions.
11. I needed to have good food easily available to me while in the hospital.
12. I needed to feel that hospital personnel cared about my relative.
13. I needed to have the waiting room near my relative.
14. I needed to be alone.
15. I needed to know exactly what was being done for my relative.
16. I needed to be told about how my relative was going to be treated medically.
17. I needed to be told about the chaplain services.
18. I needed to feel that there was hope.
19. I needed to know why things were being done for my relative.
20. I needed to be told about transfer plans when they were being made.
21. I needed to have someone explain to me about the sounds and equipment in the intensive care unit before I went in for the first time.
22. I needed someone to talk to about the possibility that my relative might die.
23. I needed to talk to someone about my negative feelings such as guilt or anger.

24. I needed direction from the staff as to what was expected of me while I was at my relative's bedside.
25. I needed to know about the various types of staff taking care of my relative.
26. I needed to see my relative frequently.
27. I needed to have specific facts concerning my relative's progress.
28. I needed to be able to do some of the physical care of my relative.
29. I needed to have friends nearby for support.
30. I needed to talk to the doctor at least once a day.
31. I needed to have the pastor visit me.
32. I needed to have a bathroom near the waiting room.
33. I needed to be reassured that it was all right to leave the hospital for a while.
34. I needed to have explanations given in terms I could understand.
35. I needed reassurance that the best care possible was being given to my relative.
36. I needed to know what type of staff members could give me what type of information.
37. I needed to have comfortable furniture in the waiting room.
38. I needed to have someone be concerned for my health.
39. I needed to know my relative's chances for becoming well.
40. I needed to know that I would be called at home if there was any changes in my relative's condition, good or bad.
41. I needed to talk to the same nurse each day about my relative's condition.

42. I needed someone to encourage me to cry.
43. I needed to be told about someone who could help me with my family problems.
44. I needed to receive information about my relative's condition at least once a day.
45. I needed to have another person with me when I visited my relative at the bedside.

APPENDIX F

VALIDATION OF NEED STATEMENTS FROM REVIEW OF THE LITERATURE

REFERENCES

Validation of need statements from review of the literature:

1. Hampe (1975)
2. Portman (1970); Irwin & Meier (1973)
3. Portman (1970);Hampe (1975); Benfield (1978); Perrault (1979)
4. Miller (1978); Hymovich (1979)
5. Perrault (1979)
6. Arney (1978); Perrault (1979)
7. Hymovich (1979)
8.
9.
10. Rowe (1978)
11. Hymovich (1979)
12. Portman (1970); Irwin & Meier (1973); Rowe (1978)
13. Portman (1970); Irwin & Meier (1973)
14. Hymovich (1979)
15.
16. Irwin & Meier (1973); Hampe (1975); Freihofer (1976); Rowe (1978)
17. Benfield (1976)
18. Wallace (1970); Hiley (1978); Perrault (1979)
19. Hampe (1975); Freihofer (1976); August-Miller (1978)
20. Hampe (1975); Freihofer (1976); August-Miller (1978); Smialek (1978)
21.
22. Fox (1972); Hampe (1975)
23. Portman (1970)
24. Hampe (1975)
25. Portman (1970); Hampe (1975); Hymovich (1979)
26. Smialek (1978)
27. Hampe (1975), August-Miller (1978); Perrault (1979); Schneider (1979)
28. Hampe (1975); Arney (1978); Perrault (1979)
29. August-Miller (1978); Hymovich (1979)
30. Hymovich (1979)
31. Irwin & Meier (1973); Rowe (1978)
32. Hampe (1975)
33. Fox (1972)
34. August-Miller (1978); Hymovich (1979)
35. Hymovich (1979)
36.
37. Irwin & Meier (1973); Freihofer (1976)
38. Irwin & Meier (1973); Arney (1978)
39. Freihofer (1976); August-Miller (1973)
40. Engel (1964); Portman (1970); Irwin & Meier (1973); Hampe (1975); Freihofer (1976); Arney (1978)
41. Perrault (1979)
42. Wooten (1981)
43. Benfield (1978); Furnan (1978); Morris (1978); Hymovich (1979); Smialek (1978); Parrish (1980)
44. Kennell (1970); Benfield (1978); Smialek (1978)
45. Benfield (1978); Morris (1978); Rowe (1978); Schneider (1979); Dillard (1980)

46. Furnan (1978); Morris (1978); Smialek (1978); Hymovich (1979); Schneider (1979)
47. Kennell (1970); Benfield (1978); Rowe (1978); Hymovich (1979)
48. August-Miller (1978); Morris (1978); Smialek (1978); Schneider (1979); Dillard (1980); Parrish (1980)
49. Perrault (1979); Schneider (1979); Dillard (1980); Parrish (1980)
50. Schneider (1979)
51. Morris (1978)
52. Smialek (1978); Perrault (1979)
53.

APPENDIX G

PARENT'S CONSENT FORM

THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing
Department of
Family Nursing

3181 S.W. Sam Jackson Park Road Portland, Oregon 97201 (503) 225-8382

Parent's Informed Consent Form

I,_____
(First Name) (Middle Name) (Last Name)

agree to serve as a subject in the investigation named, The Needs and Concerns of Parents with Dying Neonates: Comparison of the Viewpoints of Nurses and Parents, by Patricia J. Turecki, R.N. under the supervision of Julia Brown, Ph.D. The purpose of this investigation is to determine whether nurses and parents have similar or different ideas concerning the needs of parents experiencing the death of their newborn.

I understand that I will be visited by Patricia Turecki, R.N. in my home and that I will be required to complete a 53 item questionnaire which will take approximately one hour. I understand that all information that I give will be considered confidential and that a code number system will be established to maintain my anonymity.

I may benefit from this investigation by having an opportunity to discuss my satisfactions and dissatisfactions with the care my family and I received at the Oregon Health Sciences University hospital's Neonatal Intensive Care Center. In addition, the nursing and medical staff of the Neonatal Intensive Care Center will gain valuable information on the importance of the care they give and the frequency with which they are not meeting the needs of parents with dying newborns.

Patricia Turecki, R.N. has offered to answer any questions I might have about my participation in this study. I can contact her at (206) 834-3996.

I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with, or treatment at, the Oregon Health Sciences University hospital.

"It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the Center, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014."

I have read the above explanation and agree to participate in the study as described.

DATE:_____ SIGNATURE_____

WITNESS _____

APPENDIX H

NURSES' CONSENT FORM

THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing
Department of
Family Nursing

3181 S.W. Sam Jackson Park Road Portland, Oregon 97201 (503) 225-8382

Nurses Informed Consent Form

I, _____
(First Name) (Middle Name) (Last Name)

agree to serve as a subject in the investigation named, The Needs and Concerns of Parents with Dying Neonates: Comparison of the Viewpoints of Nurses and Parents, by Patricia J. Turecki, R.N. under the supervision of Julia Brown, Ph.D. The purpose of this investigation is to determine whether nurses and parents have similar or different ideas concerning the needs of parents experiencing the death of their newborn.

I understand that I will be required to complete a 53 item questionnaire which will take about 45 minutes. I understand that all information given will be considered confidential and that a code number system will be established to maintain anonymity.

I may benefit from this investigation by having an opportunity to validate the care I give and perhaps improve my effectiveness when dealing with parents experiencing a neonatal loss.

Patricia J. Turecki, R.N. has offered to answer any questions I might have about my participation in this study. I can contact her at (206) 834-3996.

I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with, or treatment at, the Oregon Health Sciences University hospital.

> "It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the Center, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014."

I have read the above explanations and agree to participate in the study as described.

DATE:_____ SIGNATURE_____

WITNESS_____

ABSTRACT

AN ABSTRACT OF THE THESIS OF

PATRICIA JOAN TURECKI

For the MASTER OF NURSING

Date of Receiving this Degree: June 11, 1982

Title: THE NEEDS AND CONCERNS OF PARENTS WITH DYING NEONATES: COMPARISON OF THE VIEWPOINTS OF NURSES AND PARENTS.

APPROVED: [redacted]
Professor

The death of a newborn is an overwhelming disappointment which brings grief and distress not only to the parents of the newborn but also to the doctors and nurses involved with that family. There has been little research on the needs of parents with dying newborns and how well we are meeting these needs in our busy Neonatal Intensive Care Centers (NICC). The present study was undertaken to ascertain the importance of 53 specified needs to parents who have experienced the death of their newborn in the Oregon Health Sciences University Hospital's NICC. Parents' responses regarding the relative importance of these needs were compared to the responses of nurses working in the NICC. Parents and nurses were asked if these needs were being met in the NICC and, if so, by whom. This study also explored differences in mothers' and fathers' needs at the time of their newborn's death.

The study subjects included 34 registered nurses and 5 parent-pairs. Data were obtained via questionnaires administered to the nurses in the NICC. Parent questionnaires were completed in their homes in the presence

of the researcher. The instrument used was a modified version of a structured interview guide developed by Molter (1976).

Findings indicated a high level of agreement between nurses and parents on the relative importance of the 53 need statements. The level of agreement between mothers and fathers was even higher ($r = .82$, $p < .001$). The majority of nurses and fathers felt that the most important needs of parents were being met. Mothers believed that their needs were met less often than fathers.

Regarding who meets the needs of parents in the NICC, nurses responded that nurses are the staff members who meet parents' needs when their newborn is dying. Mothers responded that doctors and nurses met their needs with almost the same frequency. Fathers, however, responded that doctors most frequently met their needs, and not nurses.

These findings present important implications for nursing. Recommendations for further study were made.