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CHARACTERISTICS OF HOUSEHOLDS OF INFANTS WHO LIVE OR DIE IN A NEONATAL INTENSIVE CARE UNIT: AN ECOLOGICAL ANALYSIS

presented by

Ann Stirling Mullen Johnson

has been accepted towards fulfillment of the requirements for

Ph.D. degree in Family and Child Ecology

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OR DIE IN A NEONATAL INTENSIVE CARE UNIT: AN ECOLOGICAL ANALYSIS

Ву

Ann Stirling Mullen Johnson

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Department of Family and Child Ecology

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ABSTRACT

CHARACTERISTICS OF HOUSEHOLDS OF INFANTS WHO LIVE OR DIE IN A NEONATAL INTENSIVE CARE UNIT: AN ECOLOGICAL ANALYSIS

Bv

Ann Stirling Mullen Johnson

This research concentrated on the development and testing of household variables in a study of factors related to infant mortality. Twenty-seven mothers of infants who died in a neonatal intensive care unit and 30 mothers whose infants survived were surveyed through use of a mail questionnaire in the spring of 1985. The factors that characterize the households of infants who die in the general population did not characterize the infants who died in a neonatal intensive care unit. Furthermore, the households of infants who survived in a neonatal intensive care unit did not appear to be particularly "at risk" before their birth. A path analysis was conducted on a population of infants who died and a matched sample of infants who survived. The results of the path analysis accounted for 57% of the variance in birth status. Survival was enhanced by a pattern of low household number and high income or high household number and mother working more. These combinations yielded a high number of sources of tangible assistance and support to the household during pregnancy. High levels of support

yielded high levels of information about pregnancy which, in spite of anxieties over being laid off from work, resulted in the survival of a vulnerable infant. A separate path, seemingly unaffected by the present variables, indicated that high birthweight also resulted in the survival of a vulnerable infant. Smoking and adequacy of prenatal medical care had no effect on outcome. The data supported the critical importance of support and information on outcome and the value of the household as a source of data.

To my mother, Alberta Blanche Thom Mullen, born a two-pound, full-term baby in the Canadian Northwest; to my grandmother, Kathryn Blanche Stirling Thom, who died in childbirth, longing for her native Michigan; and to my great-grandmother, Ann Collins Stirling, whose passion for knowledge has transcended four generations.

ACKNOWLEDGMENTS

Many people have contributed to the completion of this study. I would like to mention a few of them, though all are appreciated.

I am deeply grateful to my advisors: Dr. Margaret Bubolz for her continued guidance and support; Dr. Linda Nelson for her expertise in helping me edit the manuscript and for her abundant encouragement; Dr. David J. Kallen and Dr. Robert Griffore, with whom I worked in the development of the project; Dr. Beatrice Paolucci, who, before her death, was a source of inspiration and encouragement; and Dr. Andrea Doughty, who assisted with the questionnaire development. I particularly want to thank Dr. Kallen and Dr. Sue Kallen for their expertise, guidance, and hospitality during my visit to California to plan the data analysis.

I want to express my appreciation to the United States Department of Health and Social Services for the Biomedical Research Support Grant #RR 05656-16, and to the College of Human Ecology for a Dissertation Award and the Alice J. Thorpe Award. Dr. Eugene Dolanski, M.D., Medical Director of the E. W. Sparrow Neonatal Intensive Care Unit, and his staff were most helpful and supportive. Thanks are also due to the women who responded to the questionnaire. Without their help, the project could not have been completed.

A number of others contributed valued services. Paul Nelson did an excellent job of printing the questionnaire. Sue Cooley, my typist, provided fine technical assistance on the manuscript. Alice Kalush, Ginny Powell, and Beverly Fico-Brown were helpful to me in setting up and maintaining the computer program. The staffs of several departments were also helpful in a variety of ways: The Departments of Family and Child Ecology, Pediatrics and Human Development, the Instructional Media Center, as well as the Michigan and Ingham County Departments of Public Health.

I am grateful to my family and friends. I want to thank my mother and father, Alberta Blanche and Donald M. Mullen, for their love and nurturance through the years; and all my family for their tangible assistance and loving support. I am especially grateful to my daughter, Stirling Johnson, who made it all possible. Her understanding and companionship are deeply remembered and treasured.

Many friends also contributed to the completion of this study and my enjoyment of it. Several deserve particular mention: Norman Frisch; Martha Napior; Bunee Kayne; Fred Fico; Lawain Willett; Barb, Dave, and Renee Cummings; and Marah and Wayne Grist. They, and others, contributed in important ways to a rich learning experience.

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CHAPTER T

INTRODUCTION

Infant mortality in the United States has declined from 162.4 per thousand in 1900 to 10.5 per thousand in 1984 (U.S. Dept. of Commerce, 1976). In the past 5 years alone, the rate has dropped by 3 per thousand (Advance Report, 1984b). It is generally agreed that the decline is a result of improved health and sanitation and general economic conditions in the country, the availability of family planning services and abortion, and advances in medical care (Fuchs, 1983).

These factors are very much interdependent. Economic conditions made possible improved general hygiene and sanitation. Economic prosperity has been credited with the decline of the number of children per household. When families no longer needed children to help them make a living, they began to choose to have fewer children. The reductions in infant death assured families that they would not have to have more children than they desired to reach their expected family size. Family planning services and abortion made it possible for families to control if and when they had children and to terminate pregnancies that were unwanted. Medical advances helped create safe methods for abortion and for the treatment of newborn infants who were having difficulties as a result of being born prematurely or with congenital

anomalies. In addition, medical technology helped to reduce the infections associated with postneonatal death.

In spite of the decline nationally, there remain high rates of infant mortality for black infants that compare to U.S. rates for 1970 (Advance Report, 1984b). Some cities presently have infant mortality rates that rival third-world nations (Children's Defense Fund, 1984). The gap between blacks and whites persists, and there is some indication that it is increasing (Advanced Report, 1984b; Kessel, Rooks, & Cushner, 1976; Michigan Health Statistics, 1981; Moriyama, 1960; Shin, 1975a).

It is this continued disparity that has prompted investigators to search for the causes of infant mortality. An abundance of documentation over the last century has produced much data on demographic and social factors and a small number of behavioral and psychological factors. Using this information to intervene, program specialists have created risk scales for geographic areas and for mothers by rating them on the basis of the findings from research. These risk factors include mother's age; parity; prior fetal and infant losses; race; socioeconomic, nutritional, and marital status; smoking; drug consumption; and prenatal care.

The problem with the risk approach is that even where these factors are compounded, most of the babies of these mothers survive. For example, very young women with little education had an infant mortality rate in 1968 in New York City of 33.5 per thousand. Women 25 to 29 who had 4 or more years of college had a rate of 8.4 infant deaths per

thousand births (Kessner, Singer, Kalk, & Schlesinger, 1973). While this meant a difference in 25.1 infants per thousand, there were 966.5 surviving babies per thousand born of women 15 to 19 with an elementary education or less. What factors impinge on those 25.1 per thousand that make the difference between an acceptable rate of mortality and an unacceptable one? On the other hand, we might well be concerned about those 8.4 who should be experiencing optimum conditions.

In spite of the decline, the rate of infant mortality in the United States remains an embarrassment. The U.S. has ranked between 14th and 18th in the rate of infant mortality among nations and in 1984 was tied with West Germany for 14th place. Taiwan, Spain, Luxembourg and Iceland, Japan, Sweden, and Finland have lower infant mortality rates than the U.S. (Population Reference Bureau, 1984).

The United States is frequently compared with Sweden, whose rate of infant mortality is considerably lower than that of the U.S. This has frequently been explained by the fact that Sweden has a small, homogeneous population, with a high level of education, a high standard of housing, a more even distribution of wealth, national health insurance, and free medical care. The fundamental difference in the mortality rates is the higher proportion of low birth weight infants in the United States. Geijerstam (1969) has shown that the differences in neonatal mortality between the two countries decreased from 42 to 12% when the U.S. incidence of low birth weight infants and the Swedish weight-specific mortality were used in the equation.

Low birth weight is a major predictor of neonatal mortality (infant death within the first 28 days of life). Six percent of the births in the U.S. are low birth weight. This group, however, comprises 75% of all the neonatal mortality. Among babies of less than 1,000 grams (2 pounds 3 ounces), three of four died during the neonatal period. Babies over 4,500 grams (9 pounds 15 ounces) also died at increased rates. Due to increased surgical skill and technology, there has been a reduction in the rates of neonatal mortality, but no significant reduction in the population of low birth weight infants (Brooten, 1983; Lee, Paneth, Gartner, Pearlman, & Gruss, 1980).

The impact of low birth weight goes beyond the neonatal period. Birth weight is said to affect postneonatal mortality and results in significant increases in congenital anomalies, developmental delay, and rehospitalization. Low birth weight babies are said to be twice as likely to be rehospitalized; very low birth weight babies are 4.5 times as likely to be rehospitalized. McCormick, Shapiro, and Starfield (1984) claimed that this increased vulnerability is not entirely explained by the increased prevalence of congenital anomalies and developmental delay in low birth weight infants or interaction with the adverse sociodemographic correlates of low birth weight. Even low birth weight infants in advantaged families are more likely to be rehospitalized.

Estimates of handicap indicate that among babies of 751 to 1,000 grams (1 pound 10 ounces to 2 pounds 3 ounces) one of four will have a major handicap. The prevalence of handicap for very low birth weight

infants has remained at 6 to 8%, even though the chances of survival of these tiny infants have increased from the early 1960s (Stewart, Reynolds, & Lipscomb, 1981).

According to Cohen, Sigman, Parmalee, & Beckwith (1982) studies analyzing both biological and social factors have concluded that the major impact on developmental outcomes is made by the environmental factors, not by medical complications. "The results indicated that early illness cannot be ignored, although it does not predict outcome" (p. 337). Thus it appears that the factors that affect low birth weight also have an impact on the child's survival of the first year as well as health during the first years of childhood, whether this is a function of the medical problems at birth or the continued effects of precipitating factors of low birth weight.

Recent data show that low birth weight is the major cause of death for black infants, while congenital anomalies are the major cause of death for white infants (Advanced Report, 1984b). While low birth weight and congenital anomalies are frequently associated, it is likely that because black infants have a better chance of survival at very low birth weights (Yerushalmy, vandenBerg, Erhardt, & Jacobziner, 1965), white surviving babies with congenital anomalies are more likely to be larger. Thus the causes of death of white babies are not listed as low birth weight, but congenital anomalies.

Statement of the Problem

The problem of infant mortality continues to mystify researchers. One reason may be that researchers continue to use similar

variables and similar operational measures and similar methodologies. In some instances it appears that the heavy emphasis on assessing the relationship between prenatal medical care and outcome of pregnancy is self-serving; that is, it mobilizes social efforts to pay physicians for medical care. The focus of prenatal care may also be explained by the relative ability to intervene. Involving women in prenatal care may appear easier than redistributing income or assuring adequate employment or nutrition to all households, factors that may ultimately affect outcome of pregnancy more than prenatal care.

It appears that some new approaches are needed. For that reason, this study concentrated on the development and testing of household characteristics and family relationships. Furthermore, it focused on the most vulnerable infants: those who were in a neonatal intensive care unit at or shortly after birth. The question thus became whether household characteristics and family relationships are associated with a vulnerable infant's death or survival before leaving the neonatal intensive care unit.

Research Questions

The research questions in this study involved comparisons of the two groups of infants who were treated in a neonatal intensive care unit: the households of the infants who died prior to leaving the NICU and the households of the infants who lived following treatment in a NICU. To what extent did the two groups differ on traditional measures such as conditions prior to pregnancy, prenatal care, health conditions

during pregnancy, and economic resources? To what extent did the two groups differ on household characteristics and family relationships? The study attempted to assess the relative importance of household characteristics and family relationships in comparison to the traditional factors that distinguish the households of the infants who die from the households of the infants who live in the general population.

Importance of the Study

An understanding of the household characteristics and relation—
ships relating to the death or survival of a vulnerable infant could
greatly enhance the development of a social policy that adequately
intervenes to protect the health of babies. Since medical advances
have enabled many vulnerable infants to survive, the focus now needs to
be on preventing low birthweight and debilitating birth condition.

Present social policy, although acknowledging the contributions of income, education, and other factors, has focused on the providing of prenatal care. This has been promulgated in spite of evidence that the correlations between prenatal care and outcome do not infer causation. In fact, in many instances, there is no correlation between prenatal care and outcome when gestational age, income, and other factors are controlled.

Changes in social policy would affect the nature of professional intervention. Should household crowding, social support, and job anxieties prove to be critical in the survival of a vulnerable infant, two approaches might be more beneficial: societal efforts toward redistributing income in a more equitable manner, such that the

amount of poverty in this country is reduced and helping individual households generate needed resources. It would also indicate the importance of a family specialist in assessing household problems, generating resources, alleviating stress and crowding, and helping to restore household relationships. Thus, family advocates both at program and household levels of intervention would play more important roles in reducing infant mortality.

Indications that household characteristics and relationships are important would prompt reanalysis of present studies and development of new studies focusing on further uncovering the role of the household in the outcome of pregnancy.

Conceptual Framework: A Family Ecosystems Perspective on Infant Mortality

This project recasts the literature available into a family ecosystems framework and, in doing so, conceptualizes the household as the unit of analysis. The fetus is seen as the "active growing human being" (Bronfenbrenner, 1979, p. 21) involved in a microsystem—a pattern of activities, roles, and interpersonal relationships. The only microsystem that the fetus is involved with is the household. The exosystems—parent's work, kin and friendship networks, prenatal care (all those systems that impinge on the fetus but which have no direct involvement with it)—are investigated to discover the links between them and the household. Some consideration will be given to the macrosystem—the "consistencies, in the form and content of lower—order systems (micro— and exo—)—that exist, or could exist, at the level of

the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies" (Bronfenbrenner, 1979, p. 26). Since the fetus is not involved with any other microsystems, there are no links between microsystems (mesosystem).

To further elaborate a model of the relationship between fetushousehold and the environment, the schema developed by Paolucci, Bubolz, and Rainey (1976) is used (Figure 1.1). These authors saw the family as individuals with personal attributes organized as a corporate unit: the family. It is conceived as the site of human resource formation and transformation. It interacts with three other systems: the physical environment (composed of land, raw materials, climate, water, air, fuel, plants, and animals), the human-built physical environment, and the socio-institutional environment. The family is conceptualized as interacting and interdependent with these systems. In the process of interaction, the family becomes involved in market-economy activities generating income for the family and nonmarket activities consisting of household production, management of resources, farming and fishing for home use, individual maintenance, human resource development, community participation, and voluntary assistance. The family likewise provides an integrative function between the market and nonmarket activities culminating in four social and economic development functions: increased well-being (health, competence, skills, literacy), fertility management, increased income production, and increased social equity. Each of these factors is fed back into the family directly and into each of the defined environments, thus creating both change and

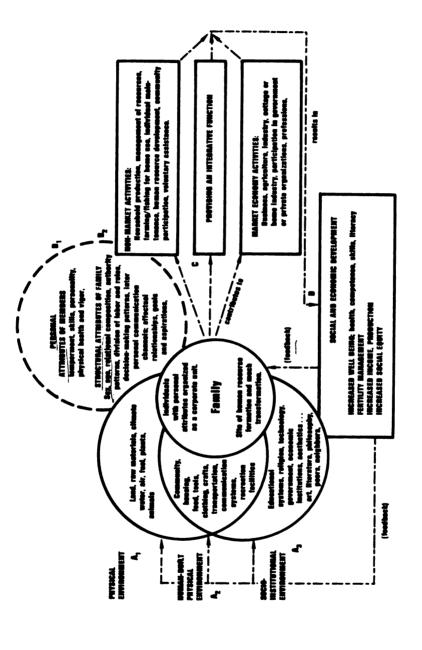


Figure 1.1.--Diagram of family ecological framework. (From B. Paolucci, M. M. Bubolz, & M. Rainey, 1976, December, Women, families, and non-formal learning programs. East Lansing: Michigan State University.)

stability that affect the institution's behavior and culture and the physical environment and, through them, the family.

Definitions

The terms used in this study are presented here in their conventional usage.

<u>Infant mortality</u>: Death of a child before his or her first birthday.

Neonatal mortality: Death of an infant before 28 days of life.

<u>Fetal mortality</u>: Stillbirth of an infant of 20 weeks or more of gestation.

Perinatal mortality: Still birth or death of an infant or fetus stillbirth or death of an infant from 20 weeks of gestation until 1 week following birth.

<u>Postneonatal mortality</u>: Death of an infant from 28 days until the first birthday.

Prenatal care: A term that generally refers to medical monitoring of a child before birth. In some studies, it has included care during labor and delivery. More recently, the term has come to include services of a nutritionist, social worker, and other personnel associated with a medical clinic.

Household: The term "household" refers to the term "family" in the sense of persons related by blood or adoption, or a "bonded unit of interacting and interdependent persons" (Andrews, Bubolz, & Paolucci, 1980, p. 32). The intention is to limit the unit to persons occupying the same living space.

Income: A term that refers to all sources of revenue for a household. Sometimes it refers only to father's income; sometimes to household income. This study includes per capita income: the amount of income from all sources in the household divided by the number of people in the household.

Neonatal intensive care unit (NICU): A unit of a hospital that specializes in care of neonates. This includes special staff as well as highly technical equipment. These units are found throughout the United States on a regional basis. Transportation is sometimes provided to the NICU from outlying areas.

Summary and Overview

In response to the continued need to understand the factors behind why some babies live and some die, this study investigates the characteristics and relationships of households of vulnerable infants who live or die. The ultimate purpose of this study is to provide information to enhance survival of infants. A more immediate purpose is to identify variables that are worthy of study on a larger scale. It should be emphasized that this study is an exploration of many variables, in the hope of identifying the role of the household in infant mortality.

Chapter II reviews the literature on infant mortality. It includes studies as early as 1949 and as late as 1985. It also covers a broad range of factors including characteristics of the mother before pregnancy, prenatal care, health factors, and economic resources.

Chapter III outlines in more detail the purposes of the study and provides a rationale for the development of several new variables and outcome measures.

Chapter IV provides the data from the study and the data analysis.

The significance and implications of the study are assessed in Chapter V_{\bullet}

CHAPTER II

REVIEW OF THE LITERATURE ON INFANT MORTALITY

This literature review attempts to cover a broad range of factors that influence infant mortality. The focus here is on prenatal factors and does not cover the intrapartum period, delivery, or type of care. Some references are made to morbidity to infants as it appears in the literature on mortality. A few references are made to studies done outside the United States where the U.S. literature is lacking. This review will define, briefly, both outcome and independent variables and summarize the literature pertaining to them.

Dependent Variables

Several outcome measures are found in the literature on infant mortality. They are neonatal mortality (death under 28 days) and postneonatal mortality (death from 28 days through 11 months). The term "infant mortality" combines these two measures. Fetal death is the death of an infant more than 20 weeks of gestation and stillborn. Perinatal combines fetal death and death occurring within 1 week of birth. Rates are calculated by dividing infant deaths by the number of births (plus fetal deaths in the case of stillborns) and multiplying by 100.

Prematurity refers to weight and gestation. Low birthweight (less than 5 pounds 8 ounces) and very low birthweight (3 pounds 5 ounces) technically refer only to weight. Since most infants who are low birthweight are also low gestation (less than 37 weeks), the terms have become synonymous. However, there are a few babies who are small for dates; that is, they have experienced intrauterine growth retardation (IUGR), and although they are fully mature, they are smaller than normal. Some authors separate the two (Yerushalmy et al., 1965).

Less frequently, outcome measures used are Apgar scores (a rating of the infant's vital signs), pregnancy complications, obstetric complications, congenital anomalies, and developmental delay.

Independent Variables

The factors that affect outcome for the infant, based on the categories in this study, are:

- 1. Mother's pregnancy history. This includes factors that affect the mother prior to her pregnancy: age, parity, prior fetal and infant loss, marital status, and race.
- 2. Prenatal care. This has been defined in the literature almost exclusively in terms of the number of visits to a physician, the trimester of the start of care, "adequacy" of care, a combination of the two types of delivery service, and "adequacy" of care which combines these measures. Some efforts have been made to assess the quality of care.
- 3. Mother's health during pregnancy. This includes some of the major factors said to affect a woman's health during pregnancy:

weight, cigarette smoking, drug consumption, disease, and psychological factors.

4. Economic resources. This includes resources available to the household that affect the health and development of the fetus: education of the mother, occupation of father and mother, work status of father and mother, income, and crowding. Other factors such as housing conditions and receipt of public assistance have been used to create indices of socioeconomic status.

Mother's Pregnancy History

Age has consistently been shown to affect the outcome of pregnancy (McCormick et al., 1984; Perinatal Association, 1983; Tokuhata, Digon, & Mann, 1973). Both Heady, Daly, and Morris (1955) and Robinson (1967) have found more stillbirths among older women. On the other hand, as age increases, the tendency to have a low weight baby diminishes (Crump, Horton, Masuoka, & Ryan, 1957). Others have found no association with age, when other factors are controlled (Shah & Abbey, 1971). Sellig (1984) found that black women between the ages of 20 and 24 had a higher rate of infant mortality than younger or older women.

Multiparity increases the risk of stillbirth (Heady et al., 1955), neonatal mortality (Wallace, 1970), and perinatal mortality (Chamberlain, 1979; Ross, 1964). Parity dramatically increases postneonatal mortality (Heady et al., 1955). Crump et al. (1957), however, found that the greater the parity, the heavier the infant at birth. But the lower the socioeconomic status (SES), the lower the birthweight. Thus,

grand multiparas (who tend to be lower SES) remain at higher risk for lower birthweight.

Prior fetal and infant loss has frequently been found to be associated with adverse outcome. Boone (1982) found both types of losses associated with low birthweight and very low birthweight infants when compared with control infants of normal weight. In addition, low birthweight was associated with previous therapeutic abortion. Shapiro, McCormick, Starfield, Krischer, & Bross (1980) found that prior fetal loss was associated with significantly higher neonatal loss, congenital anomalies, and developmental delay. However, among those survivors, there was a decreased risk for postneonatal death. Other studies have also found a relationship of fetal loss and the increased presence of congenital anomalies and developmental delay (Myrianthopaulos & Chung, 1974; Shapiro, Schlesinger, & Nesbitt, 1978).

There is some question as to the interpretation of the association of fetal loss and mortality. Gray (1984) suggested that the loss may lead to a short interval until the next pregnancy (also considered a risk factor in itself) because mothers tend to replace a lost child and go on to further pregnancies. He suggested that this may introduce a bias in longitudinal or cross-sectional studies when observation is truncated before family formation is complete since the progression to higher-order births may selectively occur among women with prior adverse outcomes.

Illegitimacy is frequently found to be related to adverse outcome.

Brooks (1980), using hierarchical multiple regression analysis to a

proposed causal ordering of variables, found that family income and racial composition almost perfectly predicted legitimacy. Legitimacy and racial composition predicted low birthweight ratios. Neonatal and postneonatal mortality were strongly determined by low birthweight levels. Chase and Nelson (1973) and Kessner et al. (1973) found rates of mortality higher for illegitimate children. Stickle and Ma (1977) found that unmarried women over 20 had relatively low rates of mortality and low birthweight, but in the category of under age 20, unmarried women had rates about six times as high as the other two age categories. Boone (1982) found no differences among very low birthweight, low birthweight, and control groups because of marital status. This was, however, a population of black women in a Washington, D.C., hospital, where there was a likelihood of a very high rate of illegitimacy.

Race, likewise, has consistently been considered an important factor in infant mortality. Brooks (1980) found that racial composition of the population strongly predicted low birthweight ratios, which in turn were found to directly affect the neonatal and postneonatal mortality rates. Low birthweight accounts for large differences in the death rates for black and white infants (Erhardt & Chase, 1973; Shah & Abbey, 1971; Shapiro et al., 1980; Yankauer, 1950). Shah and Abbey further elaborated that white babies had a lower risk of dying than did nonwhite babies, but when adjusted for birthweight, white babies had only a slightly better chance than did nonwhites. The adjustment of economic status, maternal age, and birth order did not

significantly affect the percentage deviations of either white or nonwhite babies. That is, these factors did not influence the effect of race on neonatal mortality.

On the other hand, Yerushalmy et al. (1965) found that when birth-weight was adjusted for gestational age, blacks had lower rates of neonatal mortality than whites in the low birthweight categories.

However, among mature infants of normal birthweight, whites had lower rates than blacks.

Naeye (1979a), in a large prospective study, found that he could account for racial differences in perinatal death by prepregnancy body weight and medical care. He concluded that race, per se, is not responsible for the differences.

Both neonatal and infant mortality are higher for males than for females in the U.S. This pattern holds for both blacks and whites. However, Scrimshaw (1978) has noted the opposite trend for some countries. Little effort has been made in U.S. research undertakings to understand this phenomenon.

Prenatal Care

Three major issues relate to prenatal care. First is the question of its value. To what extent does the provision of prenatal care make a difference in the outcome of pregnancy? The second question relates to barriers to that care. Why do women not seek or continue with prenatal care? Third, how is the research on prenatal care being used? Several public documents are examined from both state (Michigan) and

national levels to see how research is being used to justify proposed programs.

The term "prenatal care" has come to be synonymous with medical care during pregnancy. Since childbirth has come to be seen as a medical event (MacIntyre, 1977; Rothman, 1982; Stewart & Erickson, 1977), care during pregnancy has also come to be defined as the domain of physicians. The American College of Obstetricians and Gynecologists (Standards, 1974) defined prenatal care as "a planned program of medical evaluation and management, observation and education of the pregnant woman directed toward making pregnancy, labor, delivery and the postpartum recovery a safe and satisfying experience" (p. 35).

The standards for care espoused by ACOG include at least one visit in the first trimester of pregnancy, one visit per month until the seventh month of pregnancy, two visits per month until the ninth month, and four visits per month thereafter until delivery.

Most measures which have been used for research derive from this standard. Operational definitions of prenatal care have consisted of trimester of start of care, number of visits, type of delivery service, or measures of "adequacy" of care based on a combination of these measures.

Many women do not have care that matches the standard. Gortmaker (1979) noted that only 45.8% of native white women in his sample (New York City) got "adequate" care. Chase and Nelson (1973) found that only 20% of their sample (also New York City) got "adequate" care.

If one considers only the proportion of women starting care in the first trimester, the number is somewhat higher. According to the U.S. natality statistics (Advance Report, 1984a), the proportion of mothers who received prenatal care in the first trimester increased steadily from 68% in 1969 to 76% in 1979. Since that time the proportion of women getting first-trimester care has remained the same. While the proportion of white mothers remained the same, the proportion of black women getting first-trimester care dropped slightly. There were increases in the proportions of white and black mothers receiving delayed or no care in 1982. Between 1981 and 1982, more women 25-29 and fewer women 30 and older received early care. With regard to socioeconomic status, the only group that showed an increase in the receipt of early care was mothers who had completed college. There were increased levels of delayed or no care for women with 9-11 and 12 years of schooling.

The number of prenatal visits remained largely the same, 11.4 visits, in 1982. The median number of visits for whites was up slightly; for blacks it remained the same. There was a slight decline in the median number of visits for women beginning care in their third trimester.

In terms of age, women between 25 and 34 were more likely to receive care in the first trimester than were younger women (82% compared to 53%). Women pregnant with their first child were less likely than women pregnant with their second child to get first-trimester care. The proportion of women getting first-trimester care

declined after the second birth. Women who were unmarried, women who had not completed high school, and rural women got less care than their counterparts (Advance Report, 1984a).

In order to assess the relationship between prenatal care and the outcome of pregnancy, a variety of operational measures have been used. Several studies have utilized the timing of care as a measure of prenatal care (Elster, 1984; Harris, 1982; Lewit, 1983; Shah & Abbey, 1971). Others have used prenatal visits (Dott & Fort, 1975; Ryan, Sweeney, & Solola, 1980). Most, however, have used combinations of these measures to create an index of care. Schwartz and Vinyard (1965) assessed the timing of care in relation to gestational age. Terris and Gold (1969) used time of first care and the ratio of observed to expected number of visits. Kessner et al. (1973) created an index of adequacy based on the ACOG standards for care, which included the type of delivery service. To be adequate, a woman must have had care in the first trimester and a number of visits based on length of gestation and private delivery service. Chase and Nelson (1973) also used that index. Gortmaker (1979) modified the index, eliminating the type of delivery service. While many authors have made a distinction between care and no care, Boone (1982) used that as her sole measure of care. While most researchers have used only quantitative measures, Hall, Chng, and MacGillivray (1980) compared diagnosed versus actual outcome of pregnancy in a sample of mothers.

Many of the studies on prenatal care have suffered from methodological problems.

- 1. The quantitative measures cannot assess the quality of care.

 Physicians are assumed to be equally competent in the care they provide and provide comparable care.
- 2. The number of visits is the least reliable measure. A given number of visits may be scattered throughout the period of pregnancy, may occur at the beginning or at the end of care. They are considered as equivalent. Too few visits has been associated with poor outcome. The assumption is that it is the lack of care that results in poor outcome. However, an excessive number of visits has also been associated with poor outcome (Perinatal Association, 1983). No one, however, has suggested that too much prenatal care is responsible for that outcome.
- 3. The timing of the start of care may be problematic, too. It has been assumed that once care is started, it is continued. This may not always be the case. Birth records, the source of most of these data, may be inaccurate. Anecdotal evidence (Institute of Medicine, 1985) suggests that when birth records are completed, the trimester start of care may be dated from the beginning of the care received by the physician who was treating the woman just before delivery. Previous care at another facility may not be counted. Watkins (1968) found that among black, married, low-income women, 46% of those she would have categorized as starting in their third trimester actually sought care in the first trimester but did not continue. Furthermore, a woman may be seen by a physician early in pregnancy to verify pregnancy and assess the expected date of delivery, thus qualifying a woman

for program benefits, such as Aid to Dependent Children or Women,
Infants and Children (WIC) food supplements. She may or may not continue, but might be counted as first-trimester start of care.

4. There has been an implicit redefinition of prenatal care from medical observation (the basis for epidemiological studies) to multi-service delivery (the basis for programs and program evaluation). The meaning has changed, but the actual interventions that are said to be responsible for the improved outcome remain unclear. The emphasis in these programs appears to be counseling and education. With the exception of health problems such as diabetes and heart disease, most medical interventions are diagnostic. There is little evidence that physicians can prolong gestation or increase birthweight. Even where ocytocin is used to forestall delivery when it is considered premature, there is no assurance that contractions were not from false labor and thus would have stopped anyway.

There seem to be two basic questions: Did the counseling actually take place? And if so, did it have any effect? For example, only 35% of cigarette smokers in one study reported getting any advice from physicians about smoking (Harris, 1982). A second example concerns food. To what extent, if one is counseled on proper diet, is the mother willing and able to follow instructions? Diets prescribed by physicians (and nutritional counselors) are frequently culturally biased (Institute of Medicine, 1985). Even where appropriate to the mother's life style, the counseling does not mean she is able to purchase and prepare the foods accordingly. Where food supplements are

part of the program, are they actually consumed by the mother? There is evidence that food supplements are actually distributed to the remaining family members (Jacobson, 1980). These questions, however, have not been systematically addressed.

5. The generalizability of the result of program evaluations is questionable. Programs usually service high-risk women who may be at risk for a variety of reasons: age, parity, socioeconomic status, or medical problems. While epidemiologic studies are correlational but more generalizable, program evaluations would seem to indicate causative or ameliorative effects but are not generalizable. What is needed are random clinical trials to avoid the problem of self-selection into care. This has been considered unacceptable and unethical precisely because medical care has been considered to be of value in affecting outcome.

In spite of acknowledged methodological difficulties, Gray (1984) referred to the literature as a methodological mine field. Research studies continue to infer that prenatal care makes a difference in both prematurity and mortality.

The value of care: epidemiological studies. Prematurity is an important outcome measure because birthweight and length of gestation are factors that strongly influence whether or not a child survives. Its relation to prenatal care has been the subject of many studies.

Kessner et al. (1973) found a strong association between prenatal care and birthweight. Gortmaker (1979) likewise found an association between care and outcome when he reviewed Kessner's data, modifying

Kessner's measure by eliminating the type of delivery service and using only a measure of "adequacy" based on trimester of start of care and number of visits. However, prenatal care made little difference among white women who delivered on a private service. Prenatal care did make a difference for white women who delivered on a general service and all black women. He suggested that socioeconomic conditions may account for this difference. Elster (1984) found that poor care had more effect on primiparas, whereas age had a greater effect on multiparas. Very young primiparas with early prenatal care were not at greater risk than adult primiparas in the same category. Multipara teenagers were at increased risk regardless of whether they had prenatal care.

Terris and Gold (1969) and Ryan et al. (1980) investigated the relationship of prenatal care to birthweight in low-income populations. They came to different conclusions. Terris and Gold found that when mothers of premature and mature babies were matched for sex of infant, birth order, age, and marital status, there was no difference in the amount of prenatal care. Ryan et al. found that among women in a hospital who had zero to three or four or more prenatal visits and where they were similar in terms of education, medical complications, age, parity, and other sociodemographic factors, there was a significant difference in the amount of low birthweight, as well as fetal death, neonatal and perinatal death. Terris and Gold measured prematurity as being birth before 37 weeks gestation; Ryan et al. measured prematurity in terms of birthweight. Whether their respective definitions made a difference is not known. One likely influential factor is

that Terris and Gold measured prenatal care by the timing of the first visit and the ratio of observed to expected number of prenatal visits. Ryan et al. measured only the number of visits. The differential between the mean number of visits of the zero to three visits group was 1.43; the mean number of visits of the four or more visits group was 12.78. It is likely that in the Ryan et al. study, termination of pregnancy (resulting from early delivery) interrupted prenatal care, thus creating a spurious association between the two variables.

Moreover, although Ryan et al. claimed that there was little difference in socioeconomic status, they found that the group with zero to three prenatal visits contained half again as many women with less than eighth-grade education as the four or more visits group. Thus, in the first group, there could be considerably more women with less than high school education and in the second group many more women with college degrees. Since this measure was their only measure of SES, their claim of no difference in SES should be questioned.

Schwartz and Vinyard (1965) found that the influence of the timing of prenatal care was limited to uncomplicated pregnancies over 36 weeks gestation. In this interval, the prematurity rate (small for gestational age) is significantly higher in babies of women with very late or no care than in those with earlier care. This association is independent of maternal age, parity, race, and income level. Unknown components of prenatal care unrelated to the medical aspects of care may be responsible, they claimed. The authors suggested that for babies born at less than 36 weeks, care is interrupted by termination

of pregnancy rather than prematurity being affected by the lack of care.

The trimester start of care is responsible for birthweight and obstetric abnormalities except pregnancy complications, according to Tokuhata et al. (1973). This was true regardless of mother's race, off-spring's sex, mother's age, the number of previous pregnancies, and the legitimacy of birth and month of delivery. They did not, however, control for socioeconomic status. Eisner, Brazie, Pratt, and Hexter (1979) controlled for education, age, parity, and race and attributed differences to lack of prenatal care. Differences, however, were between those with care and no care. There were no appreciable differences between those with care, regardless of the timing of the visit and the number of visits. When the population was all black, low-income women, having at least one prenatal care visit did distinguish the women having a mature baby and women having a very low birthweight baby (Boone, 1982).

Several authors attempted to calculate the relative importance of the effect of prenatal care. Harris (1982) claimed that the effect of prenatal care on birthweight was through increasing gestation. He could account for 2 to 4 ounces increase due to prenatal care. Greenberg (1983) found prenatal care to be important even when education and race were controlled. Five percent of low birthweight among blacks and 1% of low birthweight among whites could be attributed to care.

Lewit (1983) found prenatal care to be associated with a 140 gram (5 ounce) increase in birthweight. He noted the possibility that

prenatal care may serve as a proxy measure for other behaviors that may be more causally related to birth outcome. He suggested that it is important to begin to separate out the effects of maternal diet, smoking, and alcohol consumption, factors he was unable to control because this information is not included in birth records. The extent to which prenatal care contributes to favorable outcomes by promoting healthful behavior needs to be investigated. However, Rosenzweig and Schultz (1982), controlling for smoking, found that delay in seeking care accounted for only 1.5 ounces, where smoking a pack of cigarettes per day accounted for a reduction in weight of 10 ounces.

Other studies have shown an inverse relationship between the amount and timing of prenatal care to mortality. Infant mortality was related to the adequacy of prenatal care for infants over 36 weeks gestation (Chase & Nelson, 1973). Those with "inadequate" care had a rate of mortality three times as high. In spite of marked differences between ethnic groups, the relationship with care remained.

In another study (Dott & Fort, 1975), the rate of infant mortality was eight times greater for infants whose mothers received no care compared to women who had nine or more visits. The association remained when birthweight-specific mortality was considered. Fetal death was not considered. Thus, those at any given birthweight who were stillborn were not considered in the calculations. Infant mortality was inversely related to prenatal visits in both charity (low-income) and major urban hospitals. However, the rate of mortality to infants born in major urban hospitals with one to four visits was

higher than the rate for infants born in charity hospitals with no visits. This phenomenon is probably due to the lower rates of death at very low birthweight for black infants than for white infants (North & MacDonald, 1977), suggesting that a substantial number of women with few visits deliver prematurely. Stickle and Ma (1977) showed that the death rate for infants was higher where mothers had late or no prenatal care.

McCormick, Shapiro, and Horn's (1979) study of infant mortality in Chile concluded:

Infant mortality rates were negatively associated with antenatal services personnel and utilization, medical services personnel and utilization and indicators of increasing socioeconomic status. The hypotheses not supported were those pertaining to immunization and nutritional status. (p. 151)

However, in the multiple regression, number of university-trained midwives per 100,000 population was dropped from the equation because it had no predictive value. The only variable that had predictive value was professional attention at birth. Other variables (ambulatory visits, pediatric visits, illiteracy, and urbanization) added very little to the variance explained. Professional attention at birth explained between 70 and 90% of the variance, indicating that high percentages of births with professional attention were strongly associated with low values of infant mortality rates for the years studied. It may be that those who had a physician-attended delivery also had prenatal care, but that was not explicit.

Because of the clear evidence of influence of obstetric care at birth and the recent emphasis on intervention during the interuterine period, professional attention at birth should not be equated with prenatal care. Both Dott and Fort (1975) and Shah and Abbey (1971) found that postneonatal mortality was influenced by prenatal care. This suggests that prenatal care is acting as a proxy for other variables, perhaps including postnatal care.

The most valid conclusions with regard to prenatal care would seem to come from mortality more closely associated with the interuterine period: fetal and neonatal mortality. Fetal death, according to Robinson (1967), is more likely to be found among whites. Black babies have a higher survival rate at very low weights, but at higher weights (above 2,500 grams) black babies are more likely to die. For the women with the most economic and social problems, those with no prenatal care had a fetal death rate half again as much as in the best cared for and most affluent group. When multiparity was controlled (higher in the poor-care group), there was less evidence of the influence of prenatal care on the fetus. Furthermore, there was no difference in mean fetal weight in the care groups.

Infants whose mothers had no prenatal care had much higher than average rates of neonatal mortality than those who had care, even when controlling for socioeconomic status, race, birthweight, maternal age, and live birth order (Shah & Abbey, 1971). When comparison was made between prenatal care groups, those who started prenatal care in the first trimester did not fare as well as those who started in the second and third trimesters. This may be accounted for by the premature births interrupting the care of some of those who started in the first

trimester, whereas all of those who started in the third trimester were still pregnant. In Shah and Abbey's study, those in the no-care group continued to have the highest risk for neonatal mortality, while those starting in the third trimester had the lowest risk, when controlling only for birthweight. However, when other factors are controlled, the negative impact on the no-care group is reduced by 50%.

Kessner et al. (1973), widely quoted as supporting the relation—ship between prenatal care and infant death, noted that the addition of a medical care "adequacy" and six other independent variables had no explanatory power beyond birthweight alone.

Most studies that have shown a correlation between prenatal care and outcome also included a reminder that the association does not signify causation (Gortmaker, 1979; Kessner et al., 1973; Shah & Abbey, 1971). Tokuhata et al. (1973), having claimed that "no conclusions can be drawn as to 'cause and effect' relationship of the statistical associations" (p. 183), suggested that the provision of care is ameliorative: "Our study . . . has shown some interesting and significant results which support the importance of early prenatal care to reduce the risk of obstetric abnormalities" (p. 163).

In spite of the cautions about confusing correlation with causality and the frequent findings of relationships between prenatal care and socioeconomic status and other factors such as age and parity, there has been a great deal of effort to develop and evaluate programs of care for high-risk women. The assumption is that the relationship

between prenatal care and outcome is causative and ameliorative. This assumption should be questioned in light of the evidence.

The value of care: program evaluations. Several program evaluations are reviewed here, dating from the 1960s to the present time.

One of the studies compared the high-risk population served with previous pregnancies in that group (Aubry & Nesbitt, 1969). Some compared a population served with a population unserved (Korenbrot, 1984; Levi, Wilkinson, & Marine, 1971; Peoples & Siegel, 1983; Sokol, Woolf, Rosen, & Weingarden, 1980). Others attempted to show the improvement in the rate of adverse outcome in the general population that a program serves (Peoples, Grimson, & Daughtry, 1984; Wallace, 1978).

Aubry and Nesbitt screened 1,000 ward prenatal care recipients for low income, psychological adjustment, age, marital status, medical conditions, and past problems. A team composed of social workers, psychologists, nutritionists, and medical consultants were provided to the women as needed. The outcome was assessed in comparison to the women's previous pregnancies. Outcomes included: a lower abortion rate, lower rate of low birthweight, and lower rates of neonatal mortality. The fact that there was a higher rate of low birthweight among infants born after 36 weeks gestation was accounted for as the program's effect of extending the gestational age of the infants. The authors concluded that the special program for high-risk mothers was effective.

The comparison between present pregnancies with a known risk level and previous pregnancies (an average of four) with no assessment of risk level may be inappropriate.

Levy et al. (1971) studied the effect of a nurse-midwife program on infant deaths. Nurse-midwives were assigned the care of low-risk mothers, while physicians were assigned the high-risk mothers in a county hospital. In the 2 years of the program, the rate of prematurity (defined as low birthweight) dropped, as did the fetal and neonatal deaths. When the project ended, the rates of low birthweight and fetal and neonatal deaths increased dramatically. In contrast, in the rest of the county, the rate of low birthweight increased slightly in the program period, the rate of fetal mortality remained about the same, and the rate of neonatal mortality increased.

While the authors attributed the changes to the special care received, they acknowledged that there were changes in the populations of the county hospital group during the two time periods that would better account for the changes in outcome. There were also indications that during the program period, the social worker was actively involved with mothers in determining eligibility for public-income programs. The effect of these interventions was not identified.

The program evaluation also identified a dramatic increase in the postneonatal mortality rate. The rate was 6.0 before the program, increased to 16.5 during the program, and decreased to 8.0 after the program. Although this might be accounted for by a change in population served by the hospital, it is likely that the reduction in the

neonatal mortality rate did not represent as dramatic a reduction in death rate as is apparent. Rather, the effect of the specialized medical care may have been to prolong the lives of vulnerable infants past the 28-day cut-off for neonatal mortality. Adding the rates of neonatal and postneonatal deaths, there was a reduction of 3.1 from the baseline time period to the program period and an increase of 13.4 from the program period to the postprogram period. Given that there was a 10.3 increase in postneonatal deaths from the baseline period to the postprogram period, it is likely that there was a significant change in the population served.

Wallace (1978) evaluated the effect of the U.S. Public Health
Department's Maternal and Infant Programs (MIC). MIC programs include
care to women during pregnancy, labor, delivery, and postpartum.

Services include medical, dental, social, nutritional, educational,
family planning, nursing, transportation, and child care. The studies
attributed the decline in mortality and low birthweight to the presence of MIC projects. Although there were rather continuous declines
in adverse outcome during the study periods, it appears that the project was not clearly responsible for the changes. Wallace acknowledged
the conclusions of Gendell and Hellegers (1973), Morris, Udry, and
Chase (1975), Pakter and Nelson (1974), and Westoff (1972), who indicated that the decline in infant mortality was due to the shifting ageparity distribution of births, contraceptive use, and abortion.

Sokol et al. (1980) also evaluated MICs, comparing women from MIC neighborhoods and non-MIC neighborhoods who used the same prenatal

medical monitoring and delivery services. MIC participants had a lower incidence of preterm deliveries and of infants weighing under 2,500 grams than women in the control group. Since the women came from neighborhoods with similar socioeconomic characteristics, he attributed the differences to the ancillary services of the MIC project: education, home visitation, nutrition assessment and counseling, social service assessment and intervention, and dental care.

Peoples and Siegel (1983) assessed an MIC project in North Carolina. They found a reduction in low birthweight infants for the high-risk but not the low-risk population. They suggested that the reasons for the differences in effect on the two subgroups may be that high-risk clients are more responsive to MIC services or that MIC services are provided differentially to the two groups.

OB Access, a special program funded and administered by the California Medi-Cal and the Maternal and Child Health programs, was found to reduce the incidence of low birthweight (Korenbrot, 1984).

OB Access participants who received medical, educational, and psychosocial services and vitamin supplements were compared to Medi-Cal participants who received only medical visits. Groups were matched by race/ethnicity, maternal age, parity, plurality of births, gender of infant, and county of residence. The incidence of low birthweight was 4.7% for OB Access and 7.1% for the Medi-Cal births. The rate of very low birthweight (under 1,500 grams) was 61% lower in the OB Access group. The implication is that outcome is substantially influenced by nonmedical services.

It may also be that there were differences in the populations.

The OB Access project, although designed to serve the Medi-Cal eligible population, was set up to serve women who did not have access to medical care. It may be that even though they were all "medically indigent," there may have been unidentified differences in the population that affected the differential rates.

Another project in North Carolina, the Improved Pregnancy Outcome Projects studied by Peoples et al. (1984), found an increase in the number of black women, especially teenagers, receiving prenatal care, but did not find a difference in outcome. They attributed the lack of differences to the possibility of unidentified differences in control groups, lack of protocols for dealing with high-risk women, or lack of information about the etiology of the problem of poor pregnancy outcome.

Several scholars have challenged the pervasive belief that prenatal medical care makes a difference in outcome. A review of the literature (Abramowicz & Kass, 1966) revealed no compelling evidence to support the direct influence of prenatal care in the outcome of pregnancy. The authors concluded:

It is uncontested that certain factors in pregnancy, such as toxemia, placenta previa, incompetent cervix and Rh incompatibility, may be factors in prematurity, and are to some degree made less operative as causes of prematurity if effective preventive obstetrics is practiced. However, these are numerically small causes of prematurity, and it is therefore not yet clear how prenatal care can be expected to play a major part in preventing the majority of premature deliveries. The fact that rates of prematurity have not changed significantly in major obstetric institutions during the past thirty years also suggests that at present prenatal care may have only a small role in preventing prematurity. (p. 1003)

Hall et al. (1980) have shown that physicians overdiagnose and underdiagnose, leaving only a small portion who are appropriately treated. Furthermore, there are only a small number of conditions that are treatable, so screening procedures such as prenatal medical care may not be as useful as it has been considered. A substantial proportion of the conditions that resulted in emergency procedures during pregnancy were not identified during routine office visits. Some of the screening may be helpful for obstetric care, in which case monitoring could be reduced to two or three visits during the course of a pregnancy (Hall et al., 1980; Holland, 1974).

Barriers to prenatal medical care. The questions "Why don't some women get prenatal medical care?" and "Why don't some women get adequate prenatal care?" presume that a pregnant woman should get medical care. Although the data on the value of prenatal care are inconclusive, these questions continue to be posed by those searching for reduction of infant mortality and low birthweight.

While much is written on why women do not get prenatal care, little has been said about why women do get prenatal care. One study that focused on the latter question (Perinatal Association, 1983) found that women are prompted by concern for the baby's and own health and are responding to social pressures and social norms to get care. Many women who do get what has been labeled "inadequate" care also are responding to those same concerns. Refusal to spend money to get to a clinic—even when the care is free—may represent decisions to use

transportation money for rent and food, which would also indicate concerns for self and baby.

Much of the literature on the reasons why women do not seek or continue care attributed the problems to characteristics of the women themselves. Women may lack information about the importance of prenatal care (Perinatal Association, 1983) or the facilities that are available to them. They may be unwilling to be examined by a male physician or have fears about physician examinations (Institute of Medicine, 1985). Some women have expressed the belief that no care is needed because they were part of a large family and observed their mothers pregnant many times. Others believe that prenatal care is for wealthy women (Wright, 1985). Poverty, lack of transportation, and lack of child care are further barriers to care (Fox. Goldman, & Brumfield, 1968: Institute of Medicine, 1985; O'Brien & Smith, 1981). Monahan and Spencer (1962) characterized women who did not get prenatal care as largely uneducated, older, users of public transportation, and women who lacked prenatal care in a previous pregnancy. The fact that a woman worried about the impending birth or had medical problems did not always motivate her to seek care. Attendance at the clinic was adversely affected by language problems, employment of mothers, and problems in caring for other children.

O'Brien and Smith compared prenatal care in hospital clinics and with general practitioners of 100 mothers of legitimate children.

Those who had attended a hospital clinic were more likely to feel they had waited longer than a reasonable time and spent more time undressed

waiting for the examination than those who had a general practitioner. These women spent more time traveling because they had to use public transportation. They found clinic hours inconvenient. Women who received care from a general practitioner experienced fewer different physicians: 92% versus 38% of the clinic population had only one or two physicians. Women who had a general practitioner were more likely to express satisfaction with care.

Watkins (1968), interviewing black, low-income married women who had at least one child living at the time the study was conducted, found that early initiators of prenatal care were younger, had carried fewer pregnancies to term, had fewer living children, and were less likely to have a child less than 1 year old. She rated each in terms of kinds and number of stresses and found no differences among the early and late initiators of care. She did, however, find differences in the timing of care, depending on their attitude toward pregnancy. A significantly higher proportion of women who sought care in their first trimester were rated as positive or ambivalent about being pregnant.

Early initiators in the Watkins study were significantly more likely to believe they were susceptible to illness or disability. Among the early initiators were the women who had experienced a fetal or infant loss, which might have prompted them to suspect that they were vulnerable and could be helped by a physician. There was, however, no difference in the proportion of early and late initiators who sought care because they felt sick.

In the literature on help seeking, but not specifically with reference to prenatal care, the nature of a person's social support was identified as influencing the seeking of professional services. Women with denser social networks (where network members know each other) attended fewer parent groups (Birkel & Reppucci, 1983) than did those whose networks were less dense. The more contact a woman had with her kin, the fewer parent-group sessions she attended. Birkel also found that self-described low-competence women in dense networks were least likely to participate in food programs. Low-competence women in low-density networks were most likely to participate, with high-competence women in between.

Liberman and Mullan (1978) claimed that there was no evidence that those who seek professional help are better off than nonseekers or those who seek help from informal sources.

If these assessments are correct in relation to help seeking in pregnancy, some women may be brought into care at the cost of disturbing some of the protective relationships without obvious benefit. However, because these groups were self-selected, and because the studies were not done in relation to outcome of pregnancy, caution should be exercised in applying these conclusions.

Other literature has identified subgroups in the population that do not share common (or scientifically supported) views of how the human body functions (Johnson & Snow, 1982; Snow, 1983) and different beliefs about healing (Chrisman & Kleinman, 1980; Snow, 1983). Chrisman and Kleinman claimed that members of groups who

come into contact with orthodox medicine that differs significantly from their traditional practices will often react by ignoring the treatment prescribed, or misusing it, or complaining about the quality of care they are getting. (p. 452)

There appears to be a growing number of women, principally middle—and upper-class educated women, who are getting prenatal care from midwives, through attending pregnancy and childbirth classes and by reading books on the subject. Since "prenatal" care on birth registrations has been presumed to be medical care but is still vaguely defined, it may be that women who receive midwife care are indicating that they received prenatal care by trimester start of care and number of visits. Some of these women are also giving birth at home with husband or midwife as attendant at birth. The fact that the definition of prenatal care is ambiguous may account for the fact that there has been no decline in prenatal care, whereas there has been a significant decline in the number of hospital, physician-attended, births (Advance Report, 1984a).

Structural barriers to care have been identified as time delay in certifying a woman for Medicaid (Perinatal Association, 1983; Institute for Medicine, 1985), lack of providers, ineligibility of some women where loss of employment leaves them without health insurance coverage yet amount of resources leaves them ineligible for Medicaid (Prenatal Care, 1984), high malpractice insurance costs for some providers, lack of legal authority for midwives to practice and collect third-party payments, and lack of resources and facilities by health departments. Another major barrier is the lack of cultural sensitivity of medical personnel. Some women do not seek or continue in care because

of lack of understanding of their needs and customs (Institute for Medicine, 1985). Another barrier is the lack of legitimacy for alternative forms of prenatal care outside the medical system: classes, midwife care, family care, and television and radio counseling.

Access to care has been enhanced by assertive outreach: radio and television advertising in several languages, free hot-line for women with problems, and policies of requiring prenatal care to receive WIC food supplements, layettes and other tangible benefits, free transportation and child care, and support groups.

It seems clear that the target group is low income. Research is needed to verify if getting women into care will make a difference in outcome, or if substantial enhancement of living conditions will be required.

The use of research findings. Program documents assessing the need for programs of prenatal care are included in this review to show how the literature on infant mortality and low birthweight is being used. Documents serving as a basis for policy for the State of Michigan include "Barriers to Early Prenatal Care in Michigan," published by the Perinatal Association of Michigan; "Meeting the Problem of Infant Mortality: A Plan of Action for Michigan" and "Prenatal Care: A Healthy Beginning for Michigan's Children," both published by the Michigan Department of Public Health; and "Estimating the Need for Prenatal Care," prepared by University Associates, Lansing, Michigan. The last includes an extensive literature review, "Current Perspectives on Prenatal Care" (Bergquist, 1984).

"Barriers to Early Prenatal Care in Michigan" is a 1983 study compiling vital statistics about prenatal care in the state. The study showed that:

- --The rate of low birthweight is slightly higher for mothers under 18 than mothers 20-29 with no prenatal visits (9.8% compared to 8.5%). For 13-14 visits, the percentages are 3.6 and 1.9, respectively.
- --Unmarried women have a higher percentage of low birthweight babies at every level of prenatal care.
- -- There are more black and unmarried women whose mothers had fewer than five prenatal visits.
- -- The mode for prenatal visits was 12, with 59.6% of all women having between 10 and 14 visits.
- --Fetal death rate and low birthweight varied inversely with the amount of prenatal care.
- --A higher percentage of women with an eighth-grade education or less received no prenatal care or began care after the first trimester.
- --Fifty percent of the women under 15 did not receive prenatal care or got no prenatal care in the first trimester.
- -- The amount of care generally decreased with increasing birth order.

The study cited the March of Dimes report, which concluded:

Women at greatest risk of having low-weight babies are non-white, age 17 or younger, have less than eight years of schooling and are unmarried. Yet these groups characteristically have the fewest prenatal visits.

The only major research study cited to show a correlation between prenatal care and outcomes was that of Tokuhata et al., (1973).

Tokuhata et al., as mentioned above, did not control for income or socioeconomic status, a major factor that is frequently associated with both poor outcome and the receipt of prenatal care.

"Meeting the Problem of Infant Mortality: A Plan of Action for Michigan" (1983) described the situation with regard to unemployment in Michigan and the association of unemployment with infant mortality. The document suggested that prenatal care was a mediating factor between unemployment and mortality because unemployment results in a large number of people lacking medical insurance. The unemployed, it explained, frequently have too many resources to qualify for Medicaid. During the early 1980s, many unemployed did not seek care or were turned away from hospitals for lack of ability to pay. The number of women arriving at hospitals as "walk-ins" for delivery having had no prenatal care increased. Funds to some centers were cut and services to some hospitals were jeopardized because so many were unable to pay. The document assumed the usefulness of prenatal care, then proceeded to provide evidence that there are many women lacking the service and that it would be cost effective for the state to provide it.

"Prenatal Care: A Healthy Beginning for Michigan's Children" asserted the importance of prenatal care:

There really is no mystery concerning what is needed to increase birth weights and reduce infant mortality. Since the 1920s, the medical literature has been replete with references to the fact that early comprehensive prenatal care increases birth weight and decreases infant morality. (p. 18)

Thus what has appeared in the literature as correlation becomes causation.

"Estimating the Need for Prenatal Care" (1984) is an assessment of the number of women in Michigan who are without prenatal care because of lack of insurance, low income, and inaccessibility of services. The author estimated that there are 9,500 women in Michigan who do not get care and are in need economically and medically. The only source of evidence of a relationship between care and outcome is Ryan et al. (1980), whose research supported a correlation between low birthweight, still birth, neonatal mortality, and the number of visits to a physician.

The literature review that accompanied the University Associates' report, like "Barriers to Prenatal Care," showed that Michigan women at greater risk of poor outcome are less likely to start prenatal care early and have fewer visits to a physician. In addition, two studies were cited by the author as evidence of the relationship between prenatal care and outcome (Greenberg, 1983; Ryan et al., 1980).

The author of the review included the cautionary notes from Ryan et al. and Greenberg, who reminded the reader that those who do not receive prenatal care are those already at risk for poor outcome. Greenberg's study controlled for race and education. However, he acknowledged that he did not control for age, smoking, parity, prior low birthweight, or other possibly confounding factors.

Two documents that are likely to have an impact on the direction of programs at the federal level are reviewed here. They are

"Preventing Low Birth Weight," the report of a study of the Institute of Medicine (1985), and the report on Community Health Centers (Schwartz & Poppen, 1982).

Nine of the 12 major studies on low birthweight reviewed here (see Figure 2.1) are cited as evidence of the strong relationship between prenatal care and birthweight. Except for Rosenzweig (1982), none of the studies controlled for two important variables, alcohol and smoking. Five of the studies did not control for parity. Each of these studies was qualified in this review to show that, at best, there is a correlation, but not causation, implied in these studies. At worst, prenatal care is a proxy for something else. It is, perhaps, a more sensitive indicator of socioeconomic status.

Program evaluations would seem to be better evidence of a causative or ameliorative relationship between prenatal care and outcome. The studies by Korenbrot (1984), Levy et al. (1971), Peoples and Siegel (1983), and Sokol et al. (1980) identified in the Institute study as supporting the ameliorative effect of prenatal care were discussed above.

Although the document clearly stated the problems with the methodology of prenatal care and outcome studies, and although the document cited literature identifying qualifying factors in the correlations between prenatal care and outcome, the authors concluded:

The overwhelming weight of the evidence is that prenatal care reduces low birthweight. This finding is strong enough to support a broad, national commitment to ensuring that all pregnant women, especially those at medical or socioeconomic risk, receive high-quality care. (p. 146)

	Outcome	PNCVisits	PNCStart	PNCAdequacy	Education	Age	Parity	Smoking	Alcohol	Race	0ther	
E1sner (1979)	BW	×			×	×	×			×	×	
E1ster (1984)	GA		×			×	×			×	×	
Gortmaker (1979)	BW			×	×	×						
Greenberg (1983)	BW			ת	×					×		
Harris (1982)	BW		×			×				×		
Kessner (1973)	ALL			×	×	×	×			×	×	
Lewit (1983)	BW GA		×		×	×				×	×	
Rosenzweig (1982)	BW				×	×	×	×			×	
Showstack (1984)	BW			×	×	×				×		

Key: BW = birthweight; GA = gestational age; ALL = birthweight, neonatal, postneonatal, and infant mortaltiy.

Figure 2.1. Schematic representation of factors tested in major birthweight studies cited by Institute of Medicine (1985).

^aGreenberg measured prenatal care by some/no prenatal care.

The authors added:

Because content of prenatal care is not defined carefully in many of the studies reviewed, it is not possible to trace the benefits of care to specific aspects of the total care package. (p. 146)

The authors acknowledge promising interventions in other fields. Income-maintenance programs have been shown to reduce the incidence of low birthweight (Kehrer & Wolin, 1979); early childhood education programs (Weikart, 1983) have been shown to reduce teenage pregnancy, which has been shown to be a factor in the reduction of mortality. These kinds of solutions, they maintained, lie outside the purview of the investigation committee (11 of the 12 members were either physicians or associated with university hospitals or medical institutions). "The inquiry has been limited to interventions in the general domain of health services—an appropriate focus given the composition of the committee and its charge" (p. 115).

The committee equated health with medical services, rather than considering any programs that enhance outcome of pregnancy as a health outcome.

Reducing poverty and improving education could do much to decrease low birthweight, given the strong associations among birthweight, socioeconomic status and education. . . , but such perspectives are not explored in this report. (p. 115)

The authors of the report on Community Health Centers (Schwartz & Poppen, 1982) were more cautious:

. . . it is commonly asserted that prenatal care has an impact on pregnancy outcome, the literature shows that it has been difficult to demonstrate a strong relationship between care and outcome. This is the case for a number of reasons: there are many variables which affect outcome; studies have had problems adequately controlling for these variables; data have not been routinely

available on variables such as alcohol abuse, smoking, and nutrition; and, finally, multi-variate analysis has only recently come into widespread use. (p. B-34)

Russell (1982) in her examination of the "Short Report" (Second Report, 1980) noted some parallels. The Short Report, a British study, claimed it became involved "because of mounting public concern that babies were unnecessarily dying or suffering permanent damage during the latter part of pregnancy and the earliest part of infancy" (p. 1). Russell responded that there is a concern, but that it is not about death or handicap. She said:

Dissatisfaction with existing patterns of reproductive health-care has been widely expressed, not only amongst the articulate middle class, but, given chance of expression, amongst working-class women too. The development of the current debate on perinatal mortality at the same time as these movements toward social change is not, I would argue, a coincidence, nor are apparent contractions inexplicable. They are the result of a deliberate policy, not about babies, but rather the role of women. (p. 315)

She claimed that the data presented to support the claims that babies are "unnecessarily dying or suffering . . . may be unhelpful, and at worst, misleading" (p. 304). If the issue were babies' health, the interventions could be different, she claimed. The commission that wrote the report acknowledged that the interventions might be directed elsewhere:

Perinatal and neonatal mortality are twice as high in the lowest socioeconomic classes as in the highest. . . . We recognize that in the long term raising the standard of living is the best remedy for overcoming the problems of babies of socially disadvantaged mothers . . . but suggest that much of the death and handicap suffered by these babies . . . can be overcome by well applied medical intervention. (pp. 158-159)

If there were a causal relationship between prenatal care and outcome, or if prenatal care, particularly with nutritional and parent

education and social services, could overcome the handicap of socioeconomic conditions, age parity, nutritional deficits, and whether the programs are implemented, then babies and families would benefit in terms of better health. If the relationship is correlational, with prenatal care acting as a proxy, perhaps as a more sensitive indicator than education or income, then the medical facilities and public health departments will benefit. Unemployed people may be employed to transport women to public facilities, to dispense WIC coupons, and to provide child care. Social work services may become better established within health programs.

Mother's Health During Pregnancy

Other factors said to influence the health of the fetus and infant are mother's weight and weight gain, maternal smoking, consumption of alcohol and drugs, health conditions, attitude toward pregnancy, and stress. They are briefly reviewed here.

Weight. Prematurity was lowest among women whose pregravid weight showed them to be overweight, highest among women whose pregravid weight showed them to be underweight (Terris & Gold, 1969). Naeye (1979b) and Eastman and Jackson (1968) claimed that weight gain in the second and third trimesters is critical.

Naeye (1979b) investigated the relationship of nutritional status to perinatal mortality with a formula of optimal weight gain. He found that women who were at lower than desirable pregravid weight had the lowest rate of infant mortality if their pregnancy weights were 80 to

120% of optimal values and the highest infant mortality when they were less than 25% of optimum. Overweight women had the lowest infant mortality when they were at 24 to 54% of optimal values. While outcome was less affected by variations in weight gain, overweight mothers had higher infant mortality rates in every category of weight gain.

Smoking. Maternal smoking of cigarettes has been found to to be associated with increased risk of perinatal mortality, spontaneous abortions, congenital anomalies, birthweight, and a number of pregnancy complications (abruptio placentae, placenta previa, bleeding, and ruptured membranes) (Davies, Gray, Ellwood, & Abernethy, 1976; Deibel, 1980; Meyer & Tonascia, 1977). Infants of smokers are not only lighter but have smaller head circumference and are shorter, and have lower Apgar and Bayley scores. Rosenzweig and Schultz (1982) estimated that smoking a pack of cigarettes a day during pregnancy lowers birthweight by 10 ounces. Since the infants of smokers have a normal layer of subcutaneous fat, smoking is thought to affect the infant through hypoxia (deficiency of oxygen reaching the fetus) and not through nutritional deficiencies (DiSouza & Richards, 1978).

<u>Drugs.</u> Unfortunately, studies on smoking have not controlled for alcohol consumption, which may account for some of the adverse effects. Alcohol, according to Harlap and Shiono (1980), may harm the fetus not only when alcohol is abused, but when taken in moderation. Two drinks per week raise the likelihood of spontaneous abortion by 25%.

Drugs have been implicated in congenital anomalies and mortality.

Prescription drugs, nonprescription drugs, and illegal drugs have all

been found to have teratogenic effects on the fetus (Hill & Stern, 1979; Moore, 1981). Drugs affect the fetus through the placenta. A number of factors affect the way in which a specific drug affects the fetus. Molecular weight, fat solubility, and the degree to which ionization occurs and the degree to which the drug binds to albumin in maternal blood affect the transfer of drugs through the placenta.

Maternal acid-base balance and placental blood flow also may influence transfer. If the mother hyperventilates and blood pH rises, the fetus becomes acidotic. Drugs crossing the placenta may become trapped inside the fetus. Genetic factors may also affect the transfer of drugs (Moore, 1983).

<u>Disease</u>. Two maternal conditions of particular concern are heart disease and diabetes. Hypertension is present in 7% of pregnancies in the United States (Wilson & Matzke, 1981). It is one of the leading causes of maternal death, fetal morbidity, and mortality. Friedman and Neff (1978), in a study of 38,636 cases, found that a maternal diastolic pressure of 84 mm Hg at any time during pregnancy increased the risk of fetal mortality. Hypertension and protenuria combined increased the risk further (Naeye & Friedman, 1979).

Diabetes is a systemic disease characterized by abnormal glucose metabolism. Like hypertension, it is a chronic condition, but may also develop as a result of pregnancy. At one time, a majority of infants of diabetic mothers died (Weingold, 1981). Mortality has been reduced to 15% due to insulin diabetes management. Unrecognized gestational

diabetes, about 3% of the pregnant population, is a major problem (Barden & Knowles, 1981).

While most of the literature on health and adverse outcome of pregnancy deals with physical health, a smaller number of studies investigate the relationship of mental health and outcome. They are categorized here as attitude and stress.

Psychological factors. Several studies have attempted to measure the attitude toward pregnancy and to assess its influence on outcome. Laucaran (1980) found that mother's attitude toward pregnancy was associated with perinatal death, congenital anomalies, postpartum hemorrhage or infection, injuries, and psychosocial conditions of the mother. Birthweight and prematurity seemed to be unaffected by attitude. Frenzen and Hogan (1982), investigating families and mortality in Thailand, found that parents' attitude toward pregnancy was significant even after controlling for social class. Where parents wanted the child, there was less risk of mortality regardless of the ability of the family to provide.

Life change events have been shown to relate to illness (Holmes & Rahe, 1967; Lipowski, 1973; Masuda & Holmes, 1967) and to pregnancy outcome (Nuckolls, Cassel, & Kaplan, 1972; Schwartz, 1979).

Nuckolls found that neither life change nor psychosocial assets were significantly related to pregnancy complications. However, when life change score was high both before and during pregnancy, women with high psychosocial asset scores had only one—third of the complications as the women with low psychosocial asset scores. Women who had a low

birthweight baby were found to have experienced considerably more minor and major life changes compared to a control group of infants of normal birthweight (Schwartz, 1979).

Much of the information gathered about the conditions of women during pregnancy is not based on birth registrations because information on weight, smoking, drug consumption, and disease is not recorded. Much of the information, therefore, comes either from mother's report or from medical charts. Unfortunately, most studies, perhaps because these data require much work to obtain information, do not control for some major factors. Thus, answers to questions of whether the effect of drugs causes reduction in mother's weight, or whether alcohol acts in combination or acts as proxy for smoking, are unknown. Even if a random clinical trial could be implemented, these major factors would have to be considered.

Economic Resources

With a few exceptions, the literature has identified a strong relationship between socioeconomic status and outcome of pregnancy in spite of a wide variety of operational measures and a lack of clarity in the conceptual definitions. Education, occupation, employment status, and income have been consistently identified as affecting mortality and birthweight.

Education is the most used measure. It is relatively stable and available. Not only is maternal and paternal education noted on birth certificates, but it is available in public records. Maternal education has been found to be associated with outcome by Adelman (1963),

Chase and Nelson (1973), Ekanem (1972), Kessner et al. (1973), and Stickle and Ma (1977). Erhardt and Chase (1973) noted that there is a sharp drop in the proportion of low birthweight babies of women who have between 1 and 3 years and those who have 4 or more years of high school. Foreign-born white women have a lower rate of low birthweight than native-born white women at each level of educational attainment except for 4 or more years of college, where the rate is similar. Brooks (1975) found, in a comparison of factors related to infant mortality in 1938 and 1968, that the importance of the number of school years completed had not changed.

Education may not be an accurate measure for very young women. Since most young adolescents have not completed their education, this measure may not represent their family (parental) income or socioeconomic level. Thus some not-at-risk women may be miscategorized as at-risk.

Occupation has been measured by percentage of white-collar workers in a given population (Brooks, 1975) or percentage of technical workers (McCormick et al., 1979). In Frenzen and Hogan's (1982) study on mortality in rural Thailand, social class was divided into three groups by whether the father was in a nonagricultural occupation (highest class) or whether he was a farm owner (middle class) or a farm laborer (lowest class). Willie and Rothney (1962), studying mortality in Syracuse, used occupation, as well as education and housing information, to create an index of socioeconomic status by census tract.

Donabedian, Rosenfelt, and Southern (1965) included income, education, and occupation.

Occupation alone and occupation as a contributing factor in social class are considered to be associated with adverse outcome (Frenzen & Hogan, 1982; Hemminki, Niemi, Saloniemi, Vainio, & Hemminki, 1980).

Willie and Rothney (1962) found that neonatal mortality is more associated with family income characteristics, but postneonatal mortality rates with socioeconomic status. The correlation of coefficients was low, however, and accounted for less than 15% of the variance in the distribution of mortality rates. McCormick et al. (1979) found that the percentage of technical workers in the population accounted for very little of the variance in mortality. Willie and Rothney (1962) and Donabedian et al. (1965) found little association of SES and infant mortality.

The employment of women, although at one time considered to be an important factor in outcome (Dyhouse, 1982), is found now to be more a function of social class rather than employment per se. Gofin (1979) found a higher rate of women in heavy employment activities experienced abnormal conditions, but he considered this more a function of heavy physical strain than employment per se. It may also be the added stress of coping with larger families on smaller incomes.

Unemployment, however, has been found to be associated with infant mortality. Brenner (1973) found that there are differential lags in fetal and infant mortality. Increases in fetal mortality rates generally occur within the same year in which the national economic

indicator declines. Increase in infant mortality under 1 day tends to lag 1 year behind any given year of an economic downturn. Postneonatal mortality, however, tends to lag from 3 to 5 years behind any given year of an economic downturn. Shin (1975b) had similar findings in a study of 63 countries.

Stockwell (1962) divided the census tracts of Providence, Rhode Island, into socioeconomic areas based on occupation, education, and income. He found that although income and crowding do correlate modestly with infant mortality, based on his measures, the highest SES area had the highest infant mortality. However, although Stockwell did not note this, the two highest areas, I and II, combined had lower rates than Areas II, IV, and V. He claimed that changes are occurring in the established inverse relationships because of medical care.

Willie and Rothney (1962) also found no association between neonatal mortality and SES (based on occupation, median school years completed in adult population, average monthly rental, average market value of own homes, and percentage of single-family dwelling units). However, within the lowest socioeconomic area, they found that income distinguishes survival and mortality. In the very lowest income levels, they found high rates of mortality. These lowest levels were all white, but of different ethnic backgrounds. The Polish and Italians had higher incomes and lower rates of mortality. The native-white area not associated with any ethnic group had lower incomes and higher rates of mortality. This would appear to be related to income, but they also found that among census tracts of the same income level, native blacks

did not have a higher rate of neonatal mortality than native whites. Willie and Rothney conjectured that there is a critical level of income, below which an infant is at considerably higher risk. It is possible, however, that the critical factor among whites was the tight community bonds among Polish and Italians compared to native whites.

The only epidemiological study located that used per capita income was that of Altenderfer and Crowther (1949). They found that in cities of 100,000 or more, infant mortality varies inversely with per capita income and with the percentage of white persons in the population. They suggested, however, that this association is a consequence of the association of mortality with the percentage of births hospitalized for labor and delivery. They concluded that hospitalization at delivery appears to be important in preventing infant deaths.

Negative income transfers have been shown to be associated with birthweight (Kehrer & Wolin, 1979). While most studies do not consider family income in relation to family size, this program guaranteed each family a certain income above the poverty line, based on number of family members. Mothers who were at high risk for experiencing adverse outcome of pregnancy had infants who were higher in weight than a control baby. The weight gain was 0.3 to 1.2 pounds. Because there did not appear to be a significant increase in prenatal care, the impact was attributed to improved nutrition of the mother. The exact mechanism cannot be ascertained. The guaranteed income may have, in fact, acted to reduce stress.

Crowding may be a factor that relates closely to economic resources. Some studies in animals have indicated that crowding causes physical harm, self-destruction, or failure to reproduce. Studies in humans have had mixed findings. Both Cassel (1970, 1971) and Dubos (1965, 1968) suggested that crowding is a factor in the interplay of human social and physical factors and the way that stress affects the organism, making a person more susceptible to disease. Other studies have shown that humans adapt to crowded conditions. Immediate reactions to overcrowdedness may differ from later reactions. Thus, studies that measure only the former may conclude a negative effect of crowding, while longitudinal studies may show coping mechanisms.

Overcrowding (measured by ratio of persons to rooms in social planning units in New York City) was shown to be a factor in both low birthweight and infant mortality (Streuning, Rabkin, Cohen, Raabe, Muhline, & Cohen, 1973). Galle, Gove, and McPherson (1972) found crowding to be directly associated with infant mortality in Chicago. Streuning et al. asserted that the association with poverty and overcrowdedness is greater in white neighborhoods than in heterogeneous neighborhoods, suggesting that other factors may be important in non-white areas. The degree to which crowdedness is independent of poverty needs to be clarified.

The measures of SES and education tell us little about the actual familial and social processes that affect the child (Kitchen et al., 1982). Osofsky and Kendall (1973) summarized the literature on economic security in the following way:

Low income individuals, who are more likely to have early, frequent, and more numerous pregnancies extending into later life, are more likely to have premature deliveries with the increased risk of perinatal mortality, and are more likely to have the medical complications of pregnancy which predispose either to perinatal mortality directly or to premature and small-for-dates infants with their increased risk of mortality. (p. 108)

Summary of the Literature

The literature on infant mortality tends to find that women whose infants die are at the extremes of the childbearing ages, have had more pregnancies, and are more likely to be unmarried. They, likewise, have had less prenatal care--if only because the gestational ages of the infants are shorter. These women start prenatal care later and have fewer than the recommended number of prenatal visits. It also appears that mothers who have the most prenatal care visits are more likely to lose a child, perhaps because the infant is already in danger and the woman is under close medical supervision. Women who lose their babies are said to be more likely to be underweight or overweight prior to pregnancy, and are more likely to smoke, take drugs, or have major health conditions such as diabetes or hypertension. Finally, hoseholds of infants who die are more likely to be economically deprived. Parents are likely to have less education than parents of infants who live. They are more likely to be lower socioeconomic status, are more likely to have lower status jobs, and have less income.

In spite of numerous challenges to the findings, this remains the profile of the households of the infants who die. Challenges to these findings include reassessments of the critical factors when factors such as maternal age, parity, and prenatal care are controlled for

socioeconomic status, suggesting that it is economic deprivation that remains the critical factor in infant mortality. Other researchers have suggested that the importance of socioeconomic status is declining due to general health and well being of the general population. Birthweight remains one of the most critical factors that differentiate the infants who die from the infants who live. At very low birthweights, infants die at about the same rate, regardless of their socioeconomic status.

CHAPTER III

CONCEPTUAL FRAMEWORK AND METHODOLOGY

This chapter provides a rationale for the development of a new conceptual framework for the study of infant mortality. This framework is based on the household and consists of variables representing characteristics of and relationships within the household. The conceptual frameworks of Bronfenbrenner (1979) and Paolucci et al. (1976) described in Chapter I provide the basis for the reconceptualization. In addition, this chapter identifies the methodology of the study designed to test the household variables.

The Rationale

There are two general types of studies on infant mortality, based on the source of the data: geographic entities and individuals.

Geographic entities. These studies consider the attributes of blocks (Lewis, Charles, & Patwary, 1973), census tracts (Donabedian et al., 1965; Shah & Abbey, 1971; Stockwell, 1962; Willie & Rothney, 1962), cities (Altenderfer & Crowther, 1949), states (Brenner, 1973; Brooks, 1975, 1980; Moriyama, 1960), and countries (Shin, 1975a). Census data and vital and health statistics are frequently used. The advantage of this type of study is that broad geographic areas of risk can be identified. Individuals, however, cannot be identified.

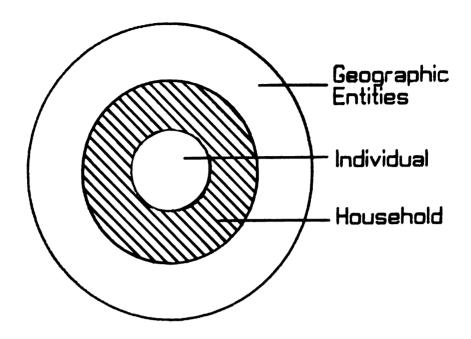


Figure 3.1.—Schematic representation of the literature on infant mortality.

Individuals. These studies consider the attributes of individuals, usually the mother who has given birth. To some extent the attributes of the fathers and infants are described. The most usual source of the information about individuals is birth registrations and birth-death records. Frequently these studies include thousands or hundreds of thousands of births (Amante & Brandt, 1978; Chase & Nelson, 1973; Eisner et al., 1979; Erhardt & Chase, 1973; Kessner et al., 1973; McCormick et al., 1984; Rosenwaike, 1972; Stickle & Ma, 1977; Yerushalmy et al., 1965). Naeye's (1979a, 1979b) work on weight gain came from the Collaborative Perinatal Project, a prospective study of 33,318 pregnancies in 12 U.S. hospitals between 1959 and 1966. The

Rosenzweig and Schultz (1982) study came from the National Natality Followback Survey in the years 1967-1969. Other studies have combined birth certificate data and interviews (Shapiro et al., 1980). Knodel and Hermalin (1984) used birth records from 18th and 19th century German villages.

Data from these studies have been used to create profiles of individuals at high risk for pregnancy outcome (Hobel, 1978; Sokol, Rosen, Stojkov, & Chik, 1977). Unfortunately, birth records are not always complete. While some data (such as birth weight) are usually in the records and accurate, other data are not. Information about the father is frequently missing. Gestational age, if given, may be inaccurate due to the difficulty of assessing the weeks of gestation through observation and the inaccuracies associated with the reporting of the last menstrual period. Missing data are sometimes counted with no prenatal care or low socioeconomic status (Gortmaker, 1979; Harris, 1982). In other cases they are counted separately or excluded (Chase & Nelson, 1973; Shapiro et al., 1980). Inaccuracies in the reporting of prenatal care have been mentioned previously.

While there is abundant information on the characteristics of geographic entities and individuals, there are no studies known that have used the household as the source of information and as the basis of variables in studies on infant mortality (Figure 3.1). Two studies are described here to illustrate how household information might be conceptualized and used as variables in such studies. Osterweis, Bush, and Zuckerman (1979) found that the family unit is a key determinant of

individual health and illness behaviors. In a study of 2,700 individuals living in 800 families, using hierarchical and stepwise multivariate regression, they found that the set of family context variables—size of family, income, percentage females, percentage children in family, average family morbidity, and average other's nonprescribed and prescribed medicine use—is a better predictor of individual medicine use than the set of individual variables—age, sex, race, and morbidity. Some variables, such as family size, that have been shown previously to be significantly related to medicine use are not important in the presence of other variables in multivariate analysis.

A second study concerns the illnesses of school children. Using components of the construct of competence developed by Foote and Cottrell (1955), Boardman, Zyzanski, and Cottrell (1975) found a strong negative association between school absences (proxy for illness) and the selected measures of family competence: mother's assessment of family participation, creativity, self-confidence, commitment, judgment, pride in family, and communication. These factors remained important even when social position, chronic illness, father in the home, family size, age of mother, belief in education, and race were considered.

Whereas most of the literature deals with attributes or statuses of geographic entities or individuals, there is little reference to processes, or, in Bronfenbrenner's terms, role and relationships.

Boardman et al. used family processes (described above) as variables to predict illness. Several other studies are presented here to

illustrate the kinds of processes that might be relevant in the investigation of infant mortality.

Zuckerman, Winsmore, and Alpert (1979) compared primiparous adolescents and older mothers on their attitudes, maternal self-image, and social support systems at 2 weeks and 3 months postpartum. They noted their receptivity to advice or help from social workers, nurses, television, radio, and books. They found that, in comparing primiparous adolescents, primiparous women over 21, and multiparous women over 21, there were no differences in their attitudes toward their baby, discipline, attachment, or investment in their babies. At Time 1, adolescent mothers expressed insecurity about their maternal role and selfimage, but at Time 2, no differences were noted. The adolescent mothers typically lived in an extended family, used family members as support, and were more likely to seek help from their mothers rather than professional help. At Time 2, adolescent mothers were more likely to have someone to share infant care. There was no difference in the willingness to receive advice or help from social workers, nurses, television, radio, or books, or their plans on how they were going to raise their children. Unfortunately, only women with good outcome of pregnancy were included.

Podell (1972) surveyed mothers on welfare in New York City. He found that, regardless of ethnic group, women with more education, organizational participation, and media exposure were more likely to use preventive care services for young children. Although Puerto Ricans and Blacks were less likely to receive prenatal care during the

initial trimester, they were more likely to make use of preventive care services than Caucasians.

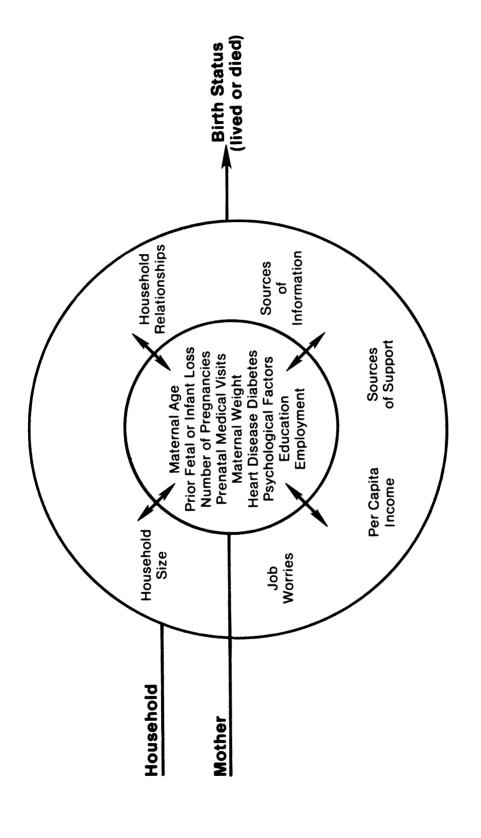
Warnecke, Graham, Mosher, Montgomery, and Schotz (1975) found that, among blacks in Buffalo, New York, those who discussed health with close relatives were more likely to use available health services than those who did not discuss health with others. Besides discussion, need was also important. Those with children were more likely to use health services. Attendance at public meetings appeared to be limited to those with specific needs and concerns. The authors cautioned that it may also be that those most concerned about health were those most likely to have discussed health matters with health guides.

A Reconceptualization of Some Traditional Variables

In this section, some traditional variables are reconceptualized in terms of the household unit of analysis and in keeping with a family ecological approach. (See Figure 3.2.) Conceptual changes in the variables related to pregnancy history, prenatal care, and economic resources are made. Traditional variables as well as household variables in all four areas are tested in the study. (See Table 3.1.)

Pregnancy History

Some of the variables relating to pregnancy history are transformed into household characteristics. While all of the traditional variables—age, parity, marital status, prior fetal and infant losses, race, and sex—are retained in this study, parity and marital status



Schematic representation of the relationship of factors concerning the household and the mother. Figure 3.2:

Table 3.1: Traditional and household variables used in NICU project study.

Traditional

Household

Pregnancy History

Age
Number of pregnancies
Prior fetal & infant
losses

Marital status
Race (controlled)

Number of persons in household Number of preschool children Number of school-age children Presence of husband/partner

Planning of pregnancy Change of residence Crowdedness of household

Presence of pets

Prenatal Care

Number of medical visits Trimester of start of medical care Mother got instruction on diet, exercise Mother got instruction on drugs, smoking Mother followed physician instructions

Number of different physicians Helpfulness of physicians Barriers to prenatal care Number of sources of support Number of sources of information

Mother's Health During Pregnancy

Weight
Cigarette smoking
Drug consumption
Disease

Psychological factors

Support from husband/partner Separation from husband/partner Arguing with husband/partner Arguing with others Life satisfaction

Economic Resources

Education
Job status
Income

Lay-off from work Receipt of benefits

Childhood economic deprivation Per capita household income are transformed into household composition. Not only are the concepts changed, but the operational measures as well.

The basis for the change in the concept of parity from the number of live births a woman has had to the concept of children in the household is research by Knodel and Hermalin (1984). Their finding that it is not birth order (parity) but completed family size that best predicted survival or mortality in 18th and 19th century German families suggests that the amount of resources available per child may be more important in predicting outcome than the biological wear and tear on the mother, which is implied by the parity concept.

It is anticipated that, even though completed family size cannot be controlled in a cross-sectional study such as this, present household size may be a better predictor of outcome than parity. Divorce, remarriage, and out-of-wedlock births often mean that household size is not synonymous with parity. A nulliparous woman can live in a family of six because she is unmarried and living with her family of origin. A woman who has had six children may be divorced and have custody of three children, or she may be remarried and have eight children in the household.

Marital status, highly predictive of infant outcome, may represent more than a legal document. Millard (1985) reasoned that marital status represents economic status. Single status at first pregnancy probably reflects the inability of a Mexican family to provide the requisite wedding ceremonies. Single status at the time she interviewed the mother (post-reproductive age) may represent the loss of a

wage earner. It may also reflect the presence or absence of a loving and supportive partner. Since economic status is already controlled, the variable is conceptualized in terms of presence of a husband/partner and the degree of separation from him. In the absence of a husband/partner, extended family is included in this concept. Legal status is expected to be relatively unimportant compared to the absence of a significant household other, or economic variables.

Several new variables emerge from the concept of household: planning the pregnancy, pets in the household, the degree of crowdedness of the living space, whether or not the household has moved, and the quality of relationship with the husband/partner.

The planning of pregnancy is seen as the desire to add to the household. It is assumed that a household would not plan a child unless resources were expected to be available to nourish the fetus as well as the entire household. Thus the households that did not plan the pregnancy are expected to have the less desirable outcome.

Pets are frequently part of the household. Although they, too, use household resources, they may serve as social support, helping to reduce stress. Thus it is expected that the presence of a pet will enhance outcome.

The degree of crowdedness indicates a lack of resources for household members. The operational measure for crowdedness is the number of bedrooms and bathrooms divided by the number of persons in the home. Although it may be a proxy for deprivation or lack of income, the lack of space itself may negatively affect outcome. Moving

from one residence to another, even where conditions are better, is expected to be stressful and adversely affect outcome.

This study views the household composition not only in terms of who is there and how much physical space they have, but in the quality of the relationships. This study asks how much members argued about money and other things and asks the mother to rate her relationship with her husband/partner.

Prenatal Care

In this set of variables, it is the concept of prenatal care and health that is being changed, rather than individual variables within the set. Most of the literature on prenatal care is concerned with quantitative aspects of care: trimester of start of care and the number of visits to a physician. This study expands the notion of prenatal care to include the qualitative aspects of medical care. The woman is asked if she got instruction on diet, smoking and drug consumption, and the degree to which she adhered to her doctor's instructions. She is also asked how many different doctors in how many settings provided care as a way of measuring continuity of care. Several doctors in different settings would likely not have access to each other's records. It may be that even the examinations by different doctors within the same settings may not provide the same quality of care as having the same physician. Her rating of the usefulness of her physician is likewise a measure of quality of care.

Another ramification of the quality of care is the difficulty or ease with which she was able to secure prenatal medical care. Thus the search for factors that impeded this care may be useful.

This project explores the concept of prenatal care as the care and nurturance of the mother and fetus by household and community. The noninstitutional sources of care—husband/partner, kin, friends, and other support persons—are investigated. In addition, sources of information regarding pregnancy—radio, television, magazines, classes, friends, neighbors, and medical and nonmedical professionals—may likewise be important.

Mother's Health During Pregnancy

The concept of health, traditionally measured by weight, smoking, drugs, disease, and psychological factors, is reconceptualized in terms of household factors. Rather than focusing on the mother's physical and emotional health, the focus is on the emotional climate in the household. Thus, the extent of separation of the woman from her husband/partner, the amount of help and support she received from him, her assessment of her relationship with him, the amount of arguing about money and other things with her husband/partner and others, and her assessment of her satisfaction with life are assessed to determine the emotional health of the household. A low degree of separation and arguing, a high degree of support and life satisfaction, and a good relationship with husband/partner are expected to be associated with survival of the infant.

Economic Resources

In this set of variables, the concept of "socioeconomic status" frequently found in the literature is limited to economic resources in the household. Income is conceptualized as household income per capita. The traditional variables—father's and household income—place households of any number of members into the same risk category just because they have the same income. Father's income is also inade—quate because the household may have other sources of income. Using this measure, households would be placed in the same risk category whether the mother did not work or whether she had substantial earn—ings. It is apparent that, in attempting to measure economic resources, studies using father's or household income may have grossly miscategorized respondents.

The literature on unemployment does not tell us if it is the unemployed households that are at risk or if unemployment in the community leaves some employed more destitute, while many of the unemployed have the cushion of unemployment insurance to shield them from adverse outcome of pregnancy. This study seeks to know if it is the unemployed who are at risk of adverse pregnancy outcome—if it is the absolute loss of income or a relative loss of income that creates the risk. In addition, we inquire if the mother feared a lay-off, or if she worried or argued about money with her husband/partner, predicting that stress relating to finances would contribute to the risk of mortality.

In addition to the lack or loss of income, a household may be at risk for low birth weight or mortality because of a lack of medical insurance. It is suspected that, in Michigan, unemployment during the early 1980s and the consequent loss of medical coverage affected the household's ability to get prenatal medical care and obstetric care during labor and delivery ("Meeting the Problem," 1983).

Another new variable in this study is parents' school attendance. It is anticipated that this would indicate both low income (especially if both are in school) and stress, which are expected to affect outcome.

A final new variable is mother's childhood economic situation. While most of the literature on infant mortality assumes that the conditions or interventions would result in an outcome during the same calendar year, Brenner (1973) and Shin (1975b) have indicated that there is a lag effect, such that the effects are not felt until some time later. Some English studies have suggested that childhood nutritional status is associated with pregnancy outcome (Terris & Gold, 1969). Mother's childhood economic situation is measured by her own assessment of adequacy of household resources when she was under 12 years old. As an adjunct to this hypothesis, an estimate of the amount of time the mother has experienced poverty may help to establish the relevance of lifetime deprivation to pregnancy outcome.

Summary

The intention of reconceptualizing the variables from the traditional literature on infant mortality into a household unit of analysis with a family ecosystems perspective is to be able to compare and contrast the predictability of these variables, both traditional and new, to neonatal mortality among high-risk babies. The new variables are expected to add predictive value and assert the validity of the household unit of analysis and a family ecosystems approach to the study of infant mortality. Kaplan (1975) posed the question aptly:

The need to develop better methods of assessing family functioning and its relationship to family and/or individual well-being is still a central problem in the sociology of the family and health (p. 89)

The Study

This study explored the differences between the households of the infants who died in the Neonatal Intensive Care Unit of E. W. Sparrow Hospital in Lansing, Michigan, between July 1982 and June 1984, and the infants who lived. The project was partially funded by the Biomedical Research Support Grant #RR 05656-16. Human subjects approval was granted by the E. W. Sparrow Hospital Institutional Review Committee and by the Michigan State University Committee on Research Involving Human Subjects (Appendix A).

This study compared the households of the entire population of infants who died in the neonatal intensive care unit (index group) during a 2-year period with a sample of the surviving NICU infants. The procedure involved matching the household of each infant who died with the household of the next surviving infant of the same race and sex as listed in the NICU log bok, a chronological account of the infants as they are admitted to the unit. Of the 916 infants who were

listed in the NICU log book for that time period, 69 died during their hospitalization. The households of 13 multiple births and 5 whose records were incomplete were removed from the index group, leaving a total of 51. An equal number of households of surviving infants brought the study group to 102.

Medical records elicited the following information for each child:

Birth day, month, year, and hour Admission day, month, and year Discharge day, month, and year Expiration day, month, year, and hour Birth weight in grams Gestational age in weeks (where range was given, lower limit was recorded) Age on admission to NICU Birth size (small, normal, or large for gestational age) Apgar scores Presence of congenital anomalies City of birth Hospital of birth Maternal age in years Grav 1d1ty Anaesthetic used in delivery Type of delivery Address of household

Questionnaire

The questionnaire (Appendix B) was a 17-page instrument designed to elicit direct information from the mothers in the households relevant to the hypotheses developed and presented here. It covered the three categories identified in the literature: pregnancy history, prenatal care and health, and economic resources. The questionnaire was coded to insure anonymity of the respondents.

The final page of the questionnaire provided a consent form so that those who were willing to be interviewed could be identified. In

addition, a space was left for those who wished to have a written summary of the results to indicate their interest.

The Total Design Method (TDM) developed by Dillman (1978) was used to maximize the return of the completed instrument. A cover letter (Appendix C) to the respondent embodied three principles of eliciting the cooperation of the respondent: (a) minimize the costs for responding, (b) maximize the rewards for responding, and (3) establish trust that those rewards will be delivered.

Specifically, the respondent was involved as a consultant in an important undertaking. The instrument was simplified so that she could complete it in a short time with little effort. A postage-free envelope was provided, as well as a complimentary pen that she retained as a token of appreciation for her efforts. Trust was established through the affiliation with the NICU and its medical director, whom some of the respondents knew personally.

The mailing procedure entailed mailing the questionnaire with a letter personally addressed to her and signed in ball-point pen (so as to confirm its importance and personal interest). After I week a postcard was sent to all respondents thanking them if they had mailed their questionnaire and reminding them if they had not done so. A second letter (Appendix C) was sent at 3 weeks to those who had not responded, including a second copy of the questionnaire. Respondents were assured of complete confidentiality and were given a telephone number to call if they had questions.

Statistical Measures

The households of the infants who died and the households of the infants who survived were compared on the basis of pregnancy history, household characteristics, prenatal care, and health and economic resources. The dependent variable of interest was mortality prior to leaving the NICU. Chi-square goodness-of-fit tests and student t-tests were performed to determine if there were differences between the characteristics and relationships of households of the infants who lived and those who died. Factor analysis was conducted on the 300 variables to assess the factors that clustered together. The scales that emerged from the factor analysis as well as those emerging directly from the instrument were correlated with each other to determine which scales in the same domain were correlated with each other. Scales that appeared to represent the same factors as other scales were removed. Fourteen scales remained and were subjected to path analysis to test a hypothetical causal order of factors relating to mortality or survival of a newborn.

Limitations

1. The study compared the households of the most vulnerable infants, those who were cared for in the Neonatal Intensive Care Unit of E. W. Sparrow Hospital between July 1, 1982, and June 30, 1984. While the care given there was the most skilled available and the facilities the best in the area, some infants were born in other hospitals. There was, then, some variation in care at birth. It may be that the infants who were transported were hardier than those who were

born at E. W. Sparrow Hospital. It may also be that the process of transporting the infants adversely affected them. Nevertheless, this study considered that the infants had comparable treatment at birth.

- 2. The comparisons being made were between those babies who lived or died in the NICU. It may be that the babies who lived or died in the NICU are more similar than different and that a non-NICU control group would have been preferable. Such a group was not available for study at that time.
- 3. A control group consisting of infants of the same birth weight might have been desirable. This could have been done sacrificing age and sex, but combining the three in this small study was virtually impossible because of the small number of nonwhite infants.
- 4. Because of the time span, recall of information about pregnancy may be less for those who delivered 2 years previously. Thus we compared women whose recall may have varied considerably.
- 5. This study does not include fetal deaths. Since all the infants were born outside the NICU, those who were dead at delivery were never admitted to the NICU.

Assumptions

- 1. It was assumed that women can with reasonable accuracy recall the events prior to and during their pregnancy.
- 2. It was assumed that women can distinguish with reasonable accuracy what happened prior to and during their pregnancy.

- 3. It was assumed that, in comparing information between groups, the actual duration of pregnancy was not important, but rather the period just prior to and during pregnancy. Women in both groups have ranges of duration of pregnancy from 6 to 9 months.
- 4. It was assumed that the differences between an infant living or dying are not due to any differences in obstetrical care during or following delivery.

CHAPTER IV

RESULTS AND ANALYSIS

Chapter IV is the analysis of the data from the NICU Research
Project. The first part is a comparison of respondents and nonrespondents in terms of the data available for every case found in the medical records. The data from the respondents are then analyzed through the use of chi-square goodness-of-fit tests and student <u>t</u>-tests. The groups are compared on each variable in the study. Finally, the path analysis is discussed. This includes a description of the scales constructed to represent the major factors of the hypothesis, a statement of the hypothetical path model, and a testing of the hypothesis with the data from the study. The hypothetical model, the path analytic model, and examples of the paths to survival and mortality are illustrated in Figures 4.1 to 4.4.

Response Rate

One hundred two questionnaires were mailed to the mothers of the infants in the study: 51 to mothers of babies who died before leaving the NICU and 51 to mothers of the control infants who survived.

Dillman's Total Design Method (TDM) was used to enhance the return of the questionnaire. By the end of the first week, 21 questionnaires had been returned. Of those, 13 were from mothers of infants who died and 8 from mothers of infants who survived. A postcard was mailed in the

second week to all participants (except those whose questionnaires had been returned undeliverable), thanking them if they had already responded and reminding them if they had not responded. During the second week, 12 more questionnaires were received, five from mothers of infants who died and seven from mothers of surviving infants.

At the end of 3 weeks, a second letter was sent to women who had not previously responded (Appendix B). Enclosed with this letter was a duplicate questionnaire. Probably as a direct response to this effort, 24 more questionnaires were received, for a total of 57. Unlike the first week, when many more mothers of nonsurviving babies responded, the final weeks included responses from more mothers of surviving babies.

Three women refused to participate. Two of them explained that the questionnaire seemed too long; a third objected to the purpose of the study. A fourth woman telephoned to say she was having difficulty completing the questionnaire because she was still feeling grief over the loss of her child 2 years ago. Her permission was obtained to make a referral to the hospital social worker. Eleven questionnaires were undeliverable because of lack of forwarding address.

The total return by mothers of dead infants was 27 or 53%; by mothers of surviving infants, 30 or 59%. Adjusted for questionnaires delivered, the rate of return was 61% and 64%, respectively.

It appeared that the first wave of responses represented a good deal of emotion, both gratitude and anger. A number of women, particularly among those who responded immediately, took advantage of the

invitation to comment on their experiences. Most of the comments related not to the pregnancy, but to their experiences in the NICU. Several indicated that they wished they and their husbands could have had some time alone with a baby who had died. One woman wrote her baby's name, birth date, and death date on the front of the questionnaire, making it appear to be an epitaph. It appeared, in any case, that there was a residue of feelings about the birth, even among the women who had given birth more than 2 years ago.

More mothers of dead babies (77% compared to 66%) indicated they were interested in receiving a copy of the project report. Considerably more mothers of dead babies consented to be interviewed (52% compared to 36%).

Of the households that responded, 48 were white, 9 nonwhite; 21 had female infants, 36 had male infants. For 21 households, this was a first child; 29 women had had two to four pregnancies; five had had more than four pregnancies. While about 40% of the women were having their first babies, only one of the respondents was less than 16 when she had the child. Fifty-two of the respondents were between 16 and 35, and only one was over 35. 1

An analysis was performed to determine if there were significant differences among those who responded to the questionnaire and those who did not respond. The comparison included the information derived from the medical records. This information included:

¹Data are missing for some of the cases.

Birth status Birth year (1982, 1983, or 1984) Gestational age Maternal age Gravidity Prior prematurity Prior multiple birth Prior abortion History of diabetes History of hypertension Other family history of disease Anesthetic used in delivery Type of delivery Sex of the infant Race of the infant Age on admission to the NICU Size of the child (small, normal, or large for gestational age) APGAR score at 1 minute APGAR score at 5 minutes Presence of congenital anomalies Place of birth Hospital of birth

A chi-square analysis was performed on these variables. None of these factors was significant at the .05 level. Whites were more likely than non-whites to respond, but the difference was not significant.

Results of Chi-Square and Student t-Tests

A first task in analyzing the data was to determine if the infants who died could be distinguished from the infants who survived in terms of the factors that are considered to be major predictors in epidemiological studies. Chi-square goodness-of-fit tests were used on the nominal variables, and student <u>t</u>-tests on variables where interval data were available.

There were no differences between the two groups in terms of marital status, maternal age, number of pregnancies, the trimester

start of care, the number of physician visits, major health conditions, father's or mother's education, or father's or household income.

Existing studies have suggested that marital status is a major factor in determining outcome of pregnancy. Illegitimate children are more likely to die in infancy than legitimate ones. Among the most vulnerable babies, marital status of the mother made no difference in outcome. In fact, there were slightly more mothers of surviving babies who were either divorced or single (seven compared to four). While some of the women who were single at 6 months before pregnancy got married during pregnancy, status at 6 months before pregnancy did not distinguish the groups either.

Mothers in both groups tended to be between 16 and 35 and to have had from two to four pregnancies. Curiously, there were twice as many mothers of surviving babies who were having their first baby (14 as compared to 7). Four mothers of dead babies compared to one mother of a surviving baby had had more than four pregnancies. The differences were not significant. Thus, with regard to age and gravidity, mothers of vulnerable infants did not fit the pattern of infant mortality and survival in the larger population.

There were likewise no significant differences in the two groups with regard to prior loss. According to the hospital records, no woman in either group had had a prior infant who was premature.

There were no differences between the two groups with regard to the traditional measures of prenatal medical care. Most of the mothers in the two groups started care in the first trimester. Of the four

women who started care in the second trimester, three had infants who survived. There were no differences with regard to the number of physician visits, in spite of the fact that the babies who died tended to be of lower birthweight and lower gestational age, and delivery would, in that case, have preempted prenatal care and resulted in fewer visits. The two groups could not be distinguished on the basis of the source of prenatal care: private physician, clinic, or health maintenance organization.

Women who are overweight, underweight, have diabetes or heart disease, and smoke and take drugs have been considered in the literature as at risk for infant loss. The findings here were that these characteristics did not distinguish the groups with and without infant loss. Not unexpectedly, with this small number of respondents, there were no women at all in some of the categories: those with a family history of heart disease and diabetes, other diseases, women with prior prematurity, and those with prior multiple births.

There were no differences between the two groups in the amount of weight gained during pregnancy. Pounds gained by the index-group mothers ranged from 3 to 40, and in the matched group from 6 to 50. The index group had a mean weight gain of 26 pounds; the matched group had a mean weight gain of 28 pounds, but the difference was not significant.

Mother's pregnancy weight in the two groups was similar: 156 for index mothers and 153 for matched-group mothers. Again, the difference was not significant.

Quetlet's index (weight divided by height squared) was used to compute weight adjusted for height to determine if there was a difference in the two groups (Khosla & Lowe, 1967). The mean adjusted weight resulting from this equation was .0380 for mothers of dead babies and .0389 for mothers of surviving babies. The student <u>t</u>-test indicated there was no difference in the adjusted weight.

Smoking, considered to be a risk factor in pregnancy, made no difference in the outcome of the pregnancy, nor did the consumption of drugs. One might expect that birthweight of babies of smokers would be less than that of infants of nonsmokers. In fact, the mean birthweight of the babies of nonsmokers was less than the birthweight of babies of smokers (1,959 grams compared to 2,440 grams—a difference of more than a pound). The difference was not significant.

In the epidemiological studies, there is frequently a difference found between the groups in terms of mother's education, father's income, and household income. This was not so among these vulnerable babies. Educational level of mothers of surviving babies (13.6) was almost identical to that of mothers of dead babies (13.4). For fathers, educational levels were 13.0 and 14.1, respectively.

The number of mothers and "other person" working full time both before and during pregnancy was similar. The mothers of dead babies did not worry more or less about someone in the household being laid off than mothers of surviving babies, nor were there differences in the number of persons unemployed. The groups were similar in the receipt of public assistance, food stamps, unemployment benefits, and in having

health and pregnancy insurance coverage. On the whole, parents of NICU babies, whether they lived or died, were not recipients of public assistance, food stamps, or unemployment benefits. About a third of the households in both groups did not have pregnancy insurance.

Income was similar in the two groups. While studies using income as a measure have found households of dead babies more deprived, neither household income nor father's income differentiated between the groups.

Most studies have found birthweight to be a major predictor of outcome of pregnancy. In this comparison of the most vulnerable infants, birthweight did distinguish the groups of babies who lived and those who died. The mean birthweight of the infants who lived was 2,622 grams; of the infants who died, the mean birthweight was 1,704 (p = .001), a difference of about 2 pounds (Table 4.1).

As might be expected, gestational age also was significantly different in the two groups ($X^2 = 17.95$, df = 4, p = .001). As can be seen in Table 4.2, many more babies of less than 28 weeks gestation died, and more survivors can be found in the upper-birthweight categories.

According to census records, boys are more vulnerable than girls, and nonwhites are more vulnerable than whites. But chi-square analysis indicated that in this study there were no differences between females and males or between racial groups in terms of outcome of pregnancy. The mean birthweight for girls was less than for boys (2,039 grams compared to 2,274 grams, a difference of about 8 ounces). Nonwhite

Table 4.1: Birth status by birthweight.

				Birth	Birthweight (in Grams)	n Grams)				
	<500	<500 501- 1,000	1,001-	1,501-2,000	2,001-2,500	2,501-3,000	3,001-	3,501- 4,000	>4,000	Total
Dead	3 9 100\$ 100\$	9 100%	1 50%	5 41.78	1 12.5%	3 33.3%	2 33.3%	3	0	27 47.48
Alive	0	0	1 50%	7 58.3%	7 87.5%	66.7%	4 66.7%	2 40%	3 100%	30 52.6%
Total	3 5.3%	3 9 5.3% 15.8%	2 3.5%	12 21.18	8 14.0%	9 15.8%	6 10.5%	8.8%	3 5.3%	57 100.0%

 $\frac{6}{6} = .52$

P = .006

df = 1

infants had a slightly lower birthweight than whites: 1,680 grams compared to 2,282 grams, a difference of 1 pound, 5 ounces. Student <u>t</u>-tests indicated there were no significant differences.

Table 4.2: Birth status by gestational age.

		Gestatio	nal Age (1	n Weeks)		
	<28	28-32	33 - 37	38-41	>41	Total
Dead	13 92 .9%	2 33.3%	3 25.0%	8 38.0%	0	26 46 .4%
Alive	1 7.1%	4 66.7%	9 75 . 0%	13 61.9%	3 100%	30 53.6%
Total	14 25.0%	6 10 .7%	12 21 .4%	21 37 . 5%	3 5.4%	56 100 . 0%

While the traditional measures failed to predict substantial differences between the two groups, household measures did not fare any better. Only two of the household variables differentiated between the two groups: household size during pregnancy (but not before pregnancy) and the planning of pregnancy. Student <u>t</u>-test on household size indi-

cated that the difference in the mean number of persons in the household for each group was significant ($\underline{p} < .05$). The mean number of persons was 2.7 for households of dead infants and 3.0 for households of surviving infants. The small number in the households is probably

accounted for by the large proportion of babies in both groups born to women who were pregnant for the first time.

Although household number distinguished the two groups, number of children (both preschool and school age) did not. Nor did the presence of the father or other person in the household or the amount of separation the mother had from him during pregnancy. Presence of another adult in the household did not differentiate the two groups.

The literature has suggested that attitude toward pregnancy and the planning of pregnancy make contributions to the outcome of pregnancy. As shown in Table 4.3, chi-square analysis showed significant differences between the two groups ($X^2 = 4.88$, df = 1, p = .03). It appears that the households of the babies who died were more likely to plan the pregnancy than those of the babies who survived, the opposite of what might be expected.

Table 4.3: Birth status by planning for pregnancy.

	Planning 1	Planning for Pregnancy	
	Planned	Not Planned	Total
Dead	22	5	27
	59 .5%	25.0%	47 . 4%
Alive	15	15	30
	40 . 5%	75 . 0%	52.6%
Total	37	20	57
	64.9%	35 .1%	100.0 %

 $x^2 = 4.88$ df = 1 p = .03

The measures of prenatal care incorporated the notion of quality of care and, departing from the idea that "prenatal care" is the province of physicians, developed measures of household and community support for the pregnant woman and measures of sources of information about pregnancy.

In terms of the variables that reflected quality of care, there were no group differences in the number of women who were refused prenatal care, in the number who were worried about paying for prenatal care, or in the number of different physicians examining the mothers during pregnancy. The number of sources of assistance and support was similar in both groups $(\overline{X} = 2.63)$ for households of dead infants; $\overline{X} = 2.27$ for the mothers of surviving infants). Number of sources of information was similar for the two groups $(\overline{X} = 3.96)$ and 4.00, respectively).

The household measure, per capita income, like household and father's income, showed no differences between the two groups. Asked about the amount of poverty in their lives, members of both groups responded that they had experienced no poverty in their lives, and that when they were children, their families could afford almost everything they needed.

Thus, only two traditional variables—birthweight and gestational age—were different in the two groups. Likewise, only two of the household variables showed significant differences. This is somewhat surprising because, of 300 variables, 15 could be expected to be

significantly different by chance. Household variables, therefore, failed to be better predictors of outcome of pregnancy.

It appears from these data that the households of the infants who lived or died in a neonatal intensive care unit did not fit the pattern of the infants described in epidemiological studies. The literature, however, dealt with the general population of infants, most of whom experience no difficulties in the first few weeks of life. It appears that, on the basis of these variables, both traditional and household NICU infants may have more in common than babies who live or die in the larger population. Furthermore, household variables were not better predictors of mortality and survival, as had been hypothesized.

Deficiencies in the High-Risk Approach

Neither traditional nor household variables appear to be important in predicting NICU mortality. But, in fact, the high-risk approach which derives from studies of infants in the general population who lived or died has not been shown to be effective in reducing infant mortality. Studies identifying higher rates of mortality among younger and older mothers, women at the extremes of child-bearing ages, high parity, low education, and low income have revealed that most of the babies survive, even when the risks are compounded. The high-risk approach requires that a great many women who are technically at risk by these standards must be served at great expense to salvage a few babies who might otherwise have died. Even so, this assumes that prenatal medical care (the major approach to intervention in this

problem) has ameliorative effects on a high-risk pregnancy. This assertion has been questioned, as indicated in the literature review.

The linear approach, from which the "high-risk" model evolved, has failed to demonstrate how infants come to die within the first weeks of life. The discovery that the difference between survivors and nonsurvivors in the general population does not hold for survivors and nonsurvivors in the NICU population further indicates that there are some deficiencies in our understanding of the etiology of infant mortality. If the "risk" model were adequate, the households of the NICU survivors would have been classifiable as at risk, whereas the households of the NICU fatalities should have been classifiable as at high risk. But in the NICU population, there were a substantial number who were not at risk in the sense of such factors as extremes of child-bearing age, high parity, low education, and low income. Most women in both groups were between 16 and 34 and had had between two and four pregnancies. The mean educational level for women and men in both groups was between 13 and 14. Four households in each group had incomes in excess of \$40,000 per year.

The deficiencies in the usefulness of the "risk" model may derive from the fact that the right variables have not been identified or that the linear model is inadequate to describe the process by which a fetus develops into a vulnerable, nonsurviving infant. It is clear that another approach is needed that describes the interrelationships among the factors that affect the well-being of the fetus and newborn infant.

While it is possible that other variables might be identified that offered more power in terms of predicting mortality, it is more likely that this single-variable approach will remain inadequate to describe complex processes. It is even more likely that there are a variety of paths to infant mortality, rather than a single path.

The Ecological Model

What happens in the macrosystem (government, culture, and belief systems) and the exosystem (in this case, parents' jobs, friendship, and informational networks) is linked to the fetus through the household microsystem (Bronfenbrenner, 1979). More specifically, what happens in the physical environment, the human built physical environment, and the socio-institutional environments affects the characteristics and relationships in the household. The household, through its income-producing capacities (market and nonmarket) and through its market and nonmarket activities, affects its own well-being, fertility management, income production, and social equity (Paolucci et al., 1976).

This study is not a test of these models, but rather a use of parts of the ecological model to test some hypotheses about the interrelationships of the various factors involved in the death or survival of an NICU infant. Specifically, the health and well-being of an individual (in this case, the fetus) are affected by the events, activities, and relationships within the household. To the extent that the stresses occurring within a household affect the mother physiologically and emotionally, the fetus is likely to be affected. To the extent that stresses are mitigated by adequate income, support,

information about pregnancy, and prenatal care, the fetus is likely to be affected. Smoking and prior losses, thought to represent biological processes, may also be prompted by events, activities, and relationships within the household. Until the interrelationships between these factors can be understood, efforts to intervene will remain thwarted.

Rationale for Path Analysis

The literature on infant mortality has tended to infer causality without using an appropriate statistical model. Particularly with regard to prenatal care, the literature has frequently suggested that prenatal care makes a difference. Furthermore, policy makers and program developers have relied on correlations of outcome with prenatal care to justify massive outlay of public funds to pay for medical care on the grounds that it will save money now being spent in paying for neonatal intensive care facilities and services.

One problem with inferring causation from correlation is that there are a number of factors that correlate with infant mortality. Moreover, there is little evidence that the provision of prenatal care is ameliorative; that is, given problems of poverty, poor nutrition, and very early childbearing, that prenatal care can exert an ameliorative effect.

Chamberlain (1984) pointed out the consequences of using this "risk" model, that a great many women have to have special prenatal care in order to identify a few who are in need. The author suggested

that an "ecological" model would shift the focus from physicianintensive programs to communitywide programs that reach all families and children, just as sanitation and disease programs have done.

Regardless of the type of program, a basic understanding is needed about the relationship of the factors that interact and influence the well-being and survival of neonates. To that end, a model is proposed here that provides a hypothesis about the relationship between the factors that influence outcome of pregnancy.

Requirements for a Causal Model

There are three criteria for inferring a causal relationship between variables (Lazarsfeld, 1959). The first criterion is that cause precede the effect in time. The second criterion is that the two variables be empirically correlated with one another. The third criterion is that the two variables cannot be explained by a third variable that influences both of them.

Path analysis, a method developed by Sewall Wright (1934, 1960) and Duncan (1966), is a means of decomposing and interpreting linear relationships among a set of variables. It has two basic assumptions. It assumes, first, a causal order. One variable may affect a second, but the second cannot affect the first. This implies that the two are correlated, and that there is a time sequence. The second assumption is that the relationships among the variables are causally closed; that is, the variables in the analysis are not affected by other factors outside the analysis (Kim & Kohout, 1975).

Path analysis represents a linear relationship between variables and is uncharacteristic of the relationships found in an ecosystems analysis, in which it is assumed that components of the system mutually influence each other. However, causal relationships do exist within an ecosystem. Path analysis is used here, in spite of its limitations, as a means to advance the present knowledge about infant mortality by showing the interrelationships among the variables that are said to affect, or exert a causal effect on, the outcome of pregnancy. From a theoretical viewpoint, the relationships represent correlation; that is, a change in one variable is said to correspond to a change in another variable. The development of risk scales and the creation of prenatal care programs infer that these factors are causative in that the manipulation of the independent variables is said to result in improved outcome of pregnancy. In spite of its limitations, the path model advances the understanding of the etiology of infant mortality by showing the relationships between variables in a hypothetical model.

Scales Used in Path Analysis

Fourteen scales were used in this study to represent the factors in the hypothetical path model. They include the following variables:

BIRTH STATUS. The condition of the infant prior to leaving the NICU. (1) Death of infant, (2) Survival.

BIRTHWEIGHT. This variable represents the actual birthweight in grams of the infant.

WORRY1. This scale represents worry resulting from mother being unemployed and looking for work. The information derives from the question:

Did you (the mother) have a job? (Check)
Yes, a full-time jobYes, a part-time jobNo, but I was looking for workNo, and I was not looking for work.
Those who indicated they were either working full time, part time,
or not looking for work were assigned a l; those who were looking for
work were assigned a 2.
WORRY2. This scale represents worry resulting from an actual job
loss of the mother. It derives from the question about job changes.
Yes, I was laid off or lost a job.
If the mother did not check this statement, she was assigned a 1;
if she checked this statement, she was assigned a 2.
WORRY3. This scale represents worry from a potential job loss.
Was there a time when you were worried that you might be laid off whether or not you actually were laid off? (Check)
Yes No
Those who checked "No" were assigned a 1; those who checked "Yes" were
assigned a 2.
WORRY4. This scale represents the mother's feelings about her
job.
Good Neither good nor bad Bad
If she checked "Good" or "Neither good nor bad," she was assigned a l.
If she checked "Bad," she was assigned a 2.

INFO. INFO is the actual number of sources of information the mother had during pregnancy. The question was:

How did you learn about what you should and should not do during pregnancy? Please check all that apply.
Already knew from previous experience
Members of your household
Family outside your household
Friends
Net ghbors
Physicians
Other medical people (nurses, nutrition counselor, health educators)
Social workers
Radio and television
Preparation for childbirth class
Other classes
Books, magazines or newspapers
0ther
The score on INFO was the total number of checks. WORK. WORK is represented by the proportion of the period in which the mother was working:
Were you working for the full six-month period? (Check)
Yes No, only part of the six-month period
If the mother had indicated she was not working, she was assigned a 1;
if she was working part of the 6 months, she was assigned a 2; if she
was working full time, she was assigned a 3.
ADECARE. ADECARE indicates whether or not the mother received
adequate prenatal medical care. Prenatal medical care was considered

adequate if the mother started prenatal care in the first trimester and

had the appropriate number of visits, as judged by gestational age.

Specifically, the number of visits was adequate if it met the following criteria:

gestational age < 28 weeks and number of visits = 1-4 or more gestational age 28-32 weeks and number of visits = 3-8 or more gestational age 33-37 weeks and number of visits = 9-12 or more gestational age 38-41 weeks and number of visits = 9-12 or more gestational age > 41 weeks and number of visits = 12-16 or more

Lack of adequate care was assigned 1, adequate care, 2.

LOSS. LOSS represents an actual fetal or infant loss through miscarriage, stillbirth, or death. No loss was represented by 1, a loss by 2.

HOUSEHOLD. This variable represents the actual number of persons in the household. This may include husband/partner, children, other family, or unrelated persons if they participated in the household activities and shared income and food preparation.

SUPPORT. SUPPORT is the actual number of sources of tangible assistance and support during pregnancy.

Put one check by all the people who assisted you in any way during this pregnancy (meals, food, money, health care, transportation, child care, someone to talk with, advice, etc.) Do not count labor and delivery. Put two checks by all the people whom you found very helpful and supportive.

 Husband or partner
 Members of your household
Family outside your household
 Friends
Neighbors
Physicians
 Other medical people (nurses, nutrition counselor, health educators)
 Social workers
Counselor or psychologist
 Support group
Other

Respondents were given a 0 for no checks, 1 for 1 check, 2 points for 2 checks. The number for each respondent was the actual total of checks.

PER CAPITA INCOME. This variable represents per capita income 6 months prior to pregnancy. Per capita income equals household income prior to pregnancy divided by the number of persons in the household prior to pregnancy.

SMOKE. This variable represents the effect of smoke on the fetus. If mother did not smoke and was not around other persons who smoked a lot during pregnancy, she was assigned a 1; if she smoked or was around people who smoked a lot, she was assigned a 2.

Procedure

The procedure for conducting a path analysis involves the statement of the hypothetical model (Figure 4.1). This model is guided by both the literature on infant mortality and the zero-order correlations between the variables considered important in this study. The zero-order correlations are particularly important because of the fact that the population under study—the households of the infants who died following treatment in a neonatal intensive care unit and a matched sample of infants who survived—may differ from the households of infants who died or lived in the general population from which most of the literature derives.

An assessment of the zero-order correlations (Table 4.4) suggested that birthweight was the key factor to outcome of pregnancy. A relationship of .42 (p = .001) suggested that low birthweight strongly

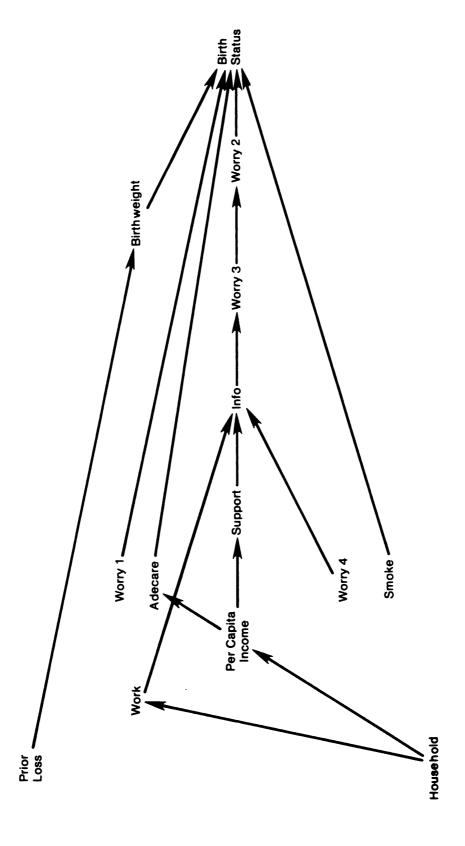


Figure 4.1: The proposed path model.

Table 4.4: Zero-order correlations among 14 scales used in the path analytic model.

ZWOKE		.22											.30	
INCOME	25		30				.32	33			52	.34		
TAOAAUS							.50				22			
нолгеногр						.34	94	.32						
SSOT		22					.22							
ADECARE							.23							
МОВК						33								
INEO					.26									
МОВВУ					.32									
МОККҮЗ				98.										
MORRY2	.22													
МОККУІ														
ВІВТНИЕІСНТ	.42													
SUTATS HTAI8														
	BIRTH STATUS	BIRTHWEIGHT	WORRYI	WORRY2	WORRY3	WORRY4	INFO	WORK	ADECARE	LOSS	HOUSEHOLD	SUPPORT	INCOME	SMOKE

Note: Only correlations significant at < .05 are reported.

predicted infant death. Associations were also shown with WORRY2, representing being laid off or fired from a job (\underline{r} = .22, \underline{p} < .05; being fired was associated with survival) and with per capita income (\underline{r} = -.25, \underline{p} < .05; survival here was associated with lower per capita income).

Per capita income was related to WORRY1, job status ($\underline{r} = -.30$, $\underline{p} < .05$), but not with the other "job worry" categories, WORRY2 and WORRY3 were correlated with each other ($\underline{r} = .86$, $\underline{p} = .001$). WORRY3 was also associated with INFO (number of sources of information about pregnancy; $\underline{r} = .26$, $\underline{p} < .05$) and WORRY4 (mother's feelings about her job; $\underline{r} = .32$, $\underline{p} < .01$). Thus feeling bad about one's job was related to worry about being laid off and appeared to be related to the number of sources of information about pregnancy. Put another way, the worse a mother felt about her job, the more likely she was to lose her job and the more sources of information she was likely to have.

The number of sources of information was associated with the number of persons in the household. That is, the more persons in the household, the fewer the sources of information (r = -.46, p = .001). Whether this was actually an effect of a negative relationship of number of persons in the family with per capita income (r = -.52, p = .001) or whether it suggested that a larger family (with presumably

more children) has a limiting effect on a mother's contacts with other people and her access to books, classes, and media is not clear.

In addition to being associated with HOUSEHOLD, INFO was associated with SUPPORT and PER CAPITA INCOME. The more support, the more sources of information ($\underline{r} = .50$, $\underline{p} = .001$), and the more per capita income, the more sources of information ($\underline{r} = .32$, $\underline{p} < .01$).

The amount of work (whether mother was not working, working part of the time, or working full time) had a negative relationship with per capita income and a positive relationship with number in the household. That is, the lower the per capita household income, the greater proportion of the time she was working (r = -.33, p < .01); the more persons there were in the household, the greater proportion of the time she was working (r = .32, p < .01).

Number of persons in the household and per capita income were associated with the number of sources of assistance and support (\underline{r} = -.22, \underline{p} < .05; \underline{r} = .34, \underline{p} < .01, respectively). The smaller the household and the larger the income, the greater number of sources of support.

Adequacy of prenatal care was associated with INFO (\underline{r} = .23, \underline{p} < .05) but not with birthweight or birth status. However, the literature would suggest that there is a strong association with outcome, either

birthweight or survival (Boone, 1982; Kessner et al., 1973; Ryan et al., 1980).

Prior fetal or infant loss is said to be associated with outcome (Boone, 1982; Shapiro et al., 1980). Loss, in the zero-order correlations, was associated with birthweight ($\mathbf{r} = -.22$, $\mathbf{p} < .05$). Some literature (Rosenzweig & Schultz, 1982) has shown a strong association of smoking cigarettes with birthweight and outcome of pregnancy. Smoking was also seen in the zero-order correlations to be associated with birthweight ($\mathbf{r} = .22$, $\mathbf{p} < .05$), but the positive correlation suggests smoking is associated with higher birthweight. The inclusion of another person smoking frequently in the mother's presence in the SMOKE scale may have confounded the association.

The Michigan documents (Meeting, 1983; Prenatal Care, 1984) have inferred that unemployment directly and through its effects on prenatal care has affected the rate of infant mortality. It is hypothesized here that mother's being unemployed and looking for work directly affects the outcome of pregnancy (BIRTH STATUS). Low PER CAPITA INCOME tends to reduce prenatal care (ADECARE) and this, in turn, tends to increase the likelihood of infant death.

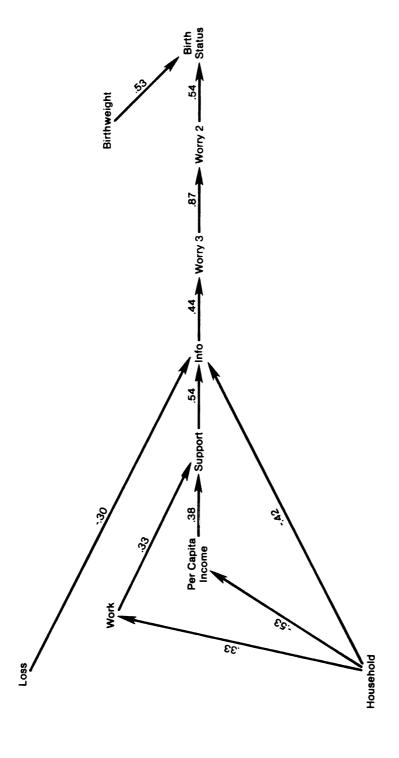
LOSS, representing prior fetal or infant loss, is hypothesized to increase the likelihood of low birthweight and this, in turn, increases the likelihood of infant death. Smoking (and being closely associated with a smoker) is predicted to increase the likelihood of an infant dying. Per capita income, through its effects on support, and amount mother worked and her feelings about her work are expected to affect

expected to result in high number of sources of support during pregnancy, and this is expected to contribute to a large number of sources of information. The more the mother worked, the more sources of information she is expected to have; the worse she felt about her job, the fewer sources of information she is expected to have; the worse she felt about her hold number is predicted to affect per capita income and amount of mother's work. Few persons in the household is expected to increase the per capita income and to decrease the amount a mother works.

The procedure for implementing the path model is a series of multiple regressions whereby a dependent variable is regressed against the remaining variables in the hypothetical model. The variables which are shown to be significantly correlated with the dependent variable become the dependent variables for the remaining variables in the equation. They are, in turn, regressed against the remaining variables in the hypothetical model. This process is continued until no variables in the model are significantly correlated with the dependent variable. The multiple regressions provide more useful information than the zero-order correlations because each variable in the regression is controlled for the other variables in the equation. A schematic representation of the relationships between variables, although not essential (Duncan, 1966), is usually a part of the path analysis.

Results

The actual path analytic model (Figure 4.2) suggests a need for revision of the hypothetical model. Two paths to survival or mortality



Final path analytic model showing the influence of prior fetal or infant loss, number of persons in household, amount of time mother worked, per capita income, number of sources of tangible assistance and support, number of sources of information about pregnancy, fear of layoff, and actual layoff, birthweight, and birth status. Figure 4.2:

4

are indicated by the first regression of BIRTH STATUS on the remaining variables (Table 4.5). The first path is through BIRTHWEIGHT, with a path coefficient of .53 indicating that infants with higher birthweight are more likely to survive. This path accounts for 28% of the variance in BIRTH STATUS. When the remaining variables in the path were regressed on BIRTHWEIGHT, none was significantly related. The second path was through WORRY2, mother's being fired or laid off from work. The relationship between BIRTH STATUS and WORRY2 was a positive one with a path coefficient of .54, thus accounting for 29% of the variance in BIRTH STATUS. Together the two paths account for 57% of the variance in BIRTH STATUS.

Table 4.5: Regressions performed for path analysis.

Independent Variable	Beta Weight	Significance		
Depender	nt Variable: BIRTH STATUS			
BIRTHWEIGHT*	.53	.000		
INFO	.26	.145		
WORK	23	.099		
SMOKE	02	.895		
WORRY2*	.54	.035		
ADECARE	16	.190		
WORRY1	.03	.804		
LOSS	.22	.128		
WORRY4	19	.166		
PER CAPITA INCOME	16	.342		
HOUSEHOLD	.18	.286		
SUPPORT	09	.612		
WORRY3	42	.112		

Table 4.5: Continued.

Independent Variable	Beta Weight	Significance					
Dependent Variable: BIRTHWEIGHT							
INFO	 06	.788					
WORK	.00	.987					
SMOKE	.25	.109					
ADECARE	.09	.565					
WORRY1	02	.896					
LOSS	 30	.065					
VORRY4	.08	.630					
PER CAPITA INCOME	.05	.811					
HOUSEHOLD	.07	.713					
SUPPORT	08	.705					
Depe	ndent Variable: WORRY2						
INFO	.00	.974					
NORK	.05	.544					
SMOKE	.07	.361					
ADECARE	 06	.455					
VORRY1	03	.692					
_OSS	07	.424					
ORRY4	 12	.149					
PER CAPITA INCOME	 05	.657					
HOUSEHOLD	10	.353					
SUPPORT	08	.448					
VORRY3*	.87	.000					
Depe	ndent Variable: WORRY3						
	.44	.028					
NORK	01	.973					
SMOKE	.04	.798					
MDECARE	15	.291					
VORRY1	07	.650					
.oss	.16	.281					
VORRY4	.25	.102					
PER CAPITA INCOME	18	.362					
HOUSEHOLD	 07	.698					
SUPPORT	21	.269					

Table 4.5: Continued.

Independent Variable	Beta Weight	Significance
Depe	ndent Variable: INFO	
WORK	.02	.869
SMOKE	01	.920
ADECARE	.10	.322
WORRY1	18	.127
LOSS*	 30	.007
WORRY4	.02	.840
PER CAPITA INCOME	14	.359
HOUSEHOLD* SUPPORT*	42 .54	.002 .000
Depe	ondent Variable: SUPPOR	T
PER CAPITA INCOME*	.38	.001
LOSS	.09	.483
WORK*	.33	.015
HOUSEHOLD	12	.432
Depende	ent Variable: WORK	
LOSS	05	.697
HOUSEHOLD*	.33	.014
Dependent \	/ariable: PER CAPITA IN	COME
LOSS	.01	.912
HOUSEHOLD*	52	.000

^{*}Significant at < .05.

The path to BIRTH STATUS through WORRY2 suggests that the actuality of mother's losing her job precedes the survival of the infant. It is preceded in time by WORRY3, anxiety over the prospects of mother's losing her job. The path coefficient is .87, accounting for three-fourths of the variance in WORRY2. WORRY3 is linked to INFO with a path coefficient of .44.

The number of sources of information about pregnancy played a key role in the second path to BIRTH STATUS. Prior loss affected the number of sources of information, with a path coefficient of -30, suggesting that having no prior fetal or infant losses was associated with an increase in the number of sources of information. Household number tended to decrease the number of sources of information (path coefficient of -.42), and there was a path coefficient of .54 between SUPPORT and INFO.

Household number has a path coefficient of -52 with PER CAPITA INCOME and a coefficient of 33 with WORK, suggesting that few in the household leads to a higher per capita income, and many in the household leads to mother working more. Both high income and high work situations induce high levels of support, with no relationship between mother's work and household income. WORK has a path coefficient of 33 with SUPPORT, and PER CAPITA INCOME has a path coefficient with SUPPORT of 38.

Summary

There appear to be two key elements in the path to survival: number of persons in the household and number of sources of information about pregnancy. The number in the household directly affects the number of sources of information. The fewer in the household, the more sources of information about pregnancy. Not experiencing a prior loss also results in a greater likelihood of having more sources of information. In addition to having a direct influence on the number of sources of information, the number of persons in the household has an indirect influence on sources of information. Not unexpectedly, having few persons in the household increases the amount of per capita income available to the household. Having a higher per capita income generates more support, which increases the number of sources of information. Mother's working more is another pathway to increased support, increasing the assurance of survival. While having a large number of persons in the household depresses per capita income, it also increases the likelihood of mother's working full time, which in turn generates support for the household during the pregnancy. The number of sources of information results in worries about being fired and an actual layoff. This path results in the survival of an NICU infant.

The second path, which accounts for 28% of the variance in BIRTH STATUS, is birthweight. The higher birthweight babies tend to survive. None of the factors tested in the present study influenced birthweight.

Discussion

It appears that in looking at the "job loss" path to outcome of pregnancy, the NICU infants who die fit the profile of the infants who die in the general population; the NICU infants who live fit the profile of the infants who survive in the general population. It also appears that were it not for the job anxieties, the NICU survivors might have been born under normal circumstances. It also appears that, because of the importance of the SUPPORT-INFO link, were it not for working more, large households (with presumably less income) might have been unable to generate the critical support and information needed for survival following treatment in the NICU.

A surprising finding is that smoking and adequacy of prenatal medical care, as defined in this study, play no part either in survival or death of a vulnerable infant. It may be, however, that these two factors are influenced by a different set of factors not appearing in this equation. Forty-three percent of the variance is unexplained in this path analysis.

CHAPTER V

SUMMARY AND RECOMMENDATIONS

This research project sought to develop and test household variables related to infant mortality. Fifty-seven women whose infants were treated in a neonatal intensive care unit responded to a mail questionnaire in the spring of 1985. More than 300 variables were tested to see whether any of them related significantly to death or survival of an infant treated at birth in a neonatal intensive care unit.

Birthweight and gestational age were significantly related to outcome. That is, infants who died before leaving the NICU were significantly more likely to be of low birthweight and low gestational age. In addition, two of the household variables were significantly related to outcome for the infant: the planning of pregnancy and the number of persons in the household during pregnancy. The differences were not in the expected direction: Households of the infants who died were more likely to have planned the pregnancy and tended to be smaller. The variables that have frequently been found to distinguish the two groups—maternal age, number of pregnancies, prior fetal or infant loss, prenatal medical care, maternal health conditions, income,

and education--did not differ among the households of the infants who lived or died following treatment in a neonatal intensive care unit.

A path analysis was conducted to identify the relationships between selected traditional and household variables and birth status. The path analysis tests a hypothetical model of the causal relationship between selected variables. The actual path analytic model showed that prior fetal and infant losses, the number of persons in the household, and the number of sources of social support during pregnancy affect the number of sources of information about pregnancy. The number of sources of information is significantly related to fears about job loss, which, in turn, is significantly related to an actual job loss. A large number of sources of information about pregnancy appears to relate to anxiety about job loss. Mother's fears about job loss preceding actual job loss tend to predict survival in a child receiving treatment in a neonatal intensive care unit.

While these findings seem inconsistent with the association of deprivation and infant loss in the general population, they are consistent if one looks closely at the relationship between income, work, and sources of social support during pregnancy. Households with either few persons in the household and higher per capita income, or households with more persons and where mother is working more tend to have more sources of social support during pregnancy. The number of sources of social support during pregnancy is directly related to the number of sources of information about pregnancy. Thus it is the households with more economic and social resources that tend to have

infants who survive, in spite of maternal job losses. The households of infants who die following treatment in a neonatal intensive care unit tend to be those that have more persons in the household and fewer economic and social resources. These mothers have not experienced job losses, but may be employed in low-paying occupations, or may be unemployed by choice and have husbands or partners who have low incomes.

Significance

There are five findings of significance in the path analysis.

- 1. Although it is apparent that there are several paths to survival or mortality, two were identified in this study. One path, accounting for 28% of the variance, was through birthweight. None of the variables in this study appeared to influence birthweight. The second path was through job loss. Together they accounted for 57% of the variance in outcome. Forty-three percent of the variance was not accounted for by these variables.
- 2. The paths through birthweight and job loss appeared to be uninfluenced by smoking or the adequacy of medical care. If these factors affected the outcome for the infants in a neonatal intensive care unit, it was through their association with variables not tested in this study.
- 3. The number of sources of information appeared to play a key role in one path to survival or mortality. The "job loss" path showed that the number of sources of information was significantly associated with prior loss, number of persons in the household, and the number of

sources of support. Not experiencing a prior fetal or infant loss, having few persons in the household, and having a larger number of sources of support all appeared to contribute to an increase in the number of sources of information. This is particularly important in light of the fact that prenatal care programs have stressed the informational components of the care. Since doctor and other medical resources comprised two of the possible sources of information, this component appears to be included in this variable. Women who had only a physician and medical staff as sources of information could be more vulnerable to infant loss because of the critical importance of this variable.

- 4. Work and per capita income provided alternative paths for sources of social support. The more per capita income the household has, and the more the mother is working during her pregnancy, the more sources of support she has. Both work and per capita income appeared to be influenced by the number of persons in the household. The more persons in the household, the lower the per capita income and the more a mother tends to work. So while a larger household would tend to have fewer sources of information (a direct relationship between the two variables), a larger household would tend to prompt a mother to work more during her pregnancy. This would appear to help generate more sources of support, and through the sources of support would appear to increase the number of sources of information.
- 5. Household number, like number of sources of information, appeared to play a major role in determining survival or mortality

along this particular path. This supported the contention of authors cited in the literature review (Gendell & Hellegers, 1973; Morris, Udry, & Chase, 1975; Pakter & Nelson, 1974; Westoff, 1972) of the importance of family planning and abortion in the reduction of infant mortality.

Limitations

Several limitations exist in the data that suggest that caution be exercised in the interpretation of the data.

- 1. The two paths to outcome for the infant accounted for 57% of the variance. Forty-three percent of the variance was not accounted for by the variables that were used in the hypothetical path model. The apparent lack of importance of two variables recognized in the literature—smoking and prenatal medical care—may be explained by their relative position when the variables in the hypothetical model were considered. There may be a number of paths in which these two variables play a part.
- 2. Some important data on the mothers were available by categories only. For instance, the available records provided maternal age in categories of under 16, 16-35, and over 35. Had the actual ages been used, some difference might have been found in the maternal ages for the infants who lived or died. The questionnaire sought information as to whether a woman had ever had a stillborn child, an abortion, a miscarriage, or an infant loss. Had the actual number been available, there might have been differences between the groups.

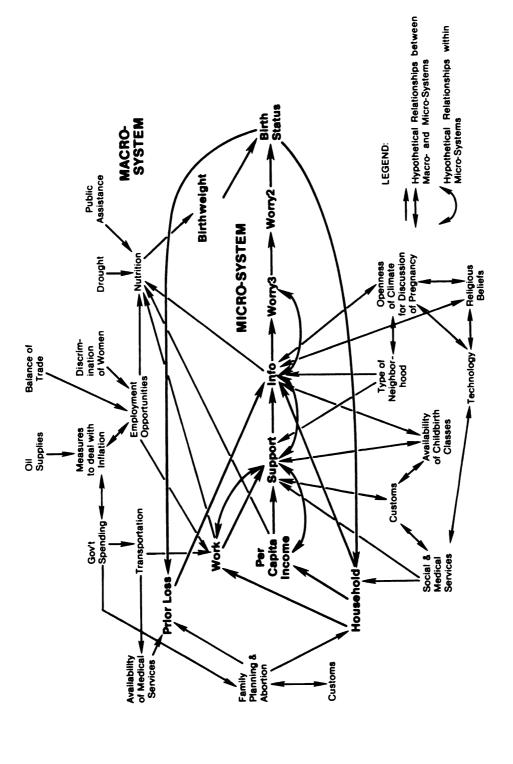
- 3. The support and information variables measured only the number of sources of support and information recalled by the mother. The number of sources of information cannot be equated with accuracy of information (and, in fact, sources could conflict in the information provided, causing conflict and worry). The number of sources of support may reflect quality better than number of sources of information in that the question asks the mother for support that was considered useful to her.
- 4. The relationship of smoking with outcome may have been confounded by the inclusion of the presence of other persons smoking around the mother. It may also have been confounded by the inclusion of any amount of smoking. Had the smoking variable been limited to a certain amount of smoking, for example, more than a pack of cigarettes per day, this might have revealed differences between groups or influenced its appearance in the path model.
- 5. Father's job worries were not included in the analysis.

 Mother's job anxieties were related to survival of an NICU infant. Had father's job worries been included in the analysis, a different pattern might have emerged. In addition, the fact that mothers whose infants died did not have job anxieties did not mean that they did not have worries over money. Had the items regarding worries about money been included, a different pattern might have emerged.
- 6. Since this study was retrospective, the accuracy of information provided by the mothers may have been influenced by the passage of time and the outcome for the infant.

The Path Model in Ecosystem Perspective

Although the path analytic model adds considerably to the existing literature, the linear relationships are not characteristic of an ecosystem approach. An ecosystem model would take into consideration that there may be reciprocal as well as linear relationships between variables (see Figure 5.1). Within the path model, for example, the number of sources of support and the number of sources of information are likely to influence each other, rather than being a one-way effect. As a household receives tangible assistance and support, it is also likely to receive information from those same sources in the process of receiving support. Likewise, as a household finds information about pregnancy, it may identify sources of support. The relationships between per capita income and sources of support are likely to be reciprocal. The more per capita income a household has, the more social support it is likely to have during a pregnancy. But, likewise, these same sources of support may have helped household members identify sources of income either through employment opportunities or through sources of public support. These relationships cannot be shown in a path analysis even though they might exist because the path analysis is based on a hypothetical, linear, model. It can only show relationships as they are hypothesized to occur. Furthermore, it can only show relationships in one direction.

The outcome of pregnancy, whether a child survives or dies, may also be related to the survival or death of a subsequent child. To the extent that the literature on infant mortality is appropriate to this



Final path analytic model in ecosystems perspective: Some hypothetical relationships between the macro- and micro-systems, and within micro-systems. Figure 5.1:

population, it appears that survival of the infant may contribute to the survival of a subsequent infant (lack of infant loss) or the death of a subsequent infant (through the increase in the number of persons in the household). Other factors are likely to be more closely related to outcome.

By placing the entire path analytic model in an ecosystem perspective, the effect of the macro-system (physical, human constructed, and human behavioral environments) on the micro-system (household, including mother and baby) can be hypothesized. Figure 5.1 identifies selected hypothetical reciprocal relationships among the factors in the macro- and micro-systems. Although the relationships indicated in Figure 5.1 are far from complete, they illustrate the complexity of effects on the household, which then affects the mother and fetus. One example shown in the figure is the potential effect of such macrosystem variables as governmental measures to control inflation and the balance of trade on employment opportunities. Coupled with customs of discrimination against women and lower pay in female-dominated occupations, household per capita income and mother's work are affected. Mother's working and per capita income are shown in the path analysis to affect the outcome of pregnancy through their effects on the number of sources of support, the number of sources of information, and job worries. A second example is the effects of governmental spending on the availability of family planning services and abortion. Family planning services and abortion may be related to infant mortality rates through influencing the number of persons in the household and through

the number of sources of information. The number of sources of information is also likely to be related to the openness of the climate for discussion of pregnancy, religious beliefs, and the neighborhood, e.g., proximity to friends and relatives or whether there are close or distant relationships between people. Level of technology, e.g., television and radio, and religious beliefs influence the openness of climate about discussing pregnancy. These examples serve to indicate the interrelationship between factors in the macro-system and micro-systems that ultimately may affect the outcome of pregnancy.

Implications

The potential for generalizing to a more general population or to other populations of NICU babies is limited. This suggests that more studies are needed to validate the path analytic model that was developed here and to test further the usefulness of household variables. Should further studies support the conclusions, different approaches to assisting households during pregnancy may be needed.

Support for the model suggests that social policy should be redirected toward redistribution of income and income maintenance, job security, and Employee Assistance Programs. This may, in itself, help households develop wider sources of support and information. It also suggests that family specialists need to assist communities to develop social support and information systems. This may mean extension of childbirth classes, support groups, and peer counseling systems. The concept of labor coach could be extended to include the development and training of pregnancy coaches to provide both support and information.

In addition to creating an environment that is conducive to healthy growth and development of infants, prenatal care should be reconceptualized. The importance of household number and sources of information and support suggests that rather than having only individualized medical care and a standardized educational program, intervention should be made throughout the household. A family specialist could determine if there are household factors present that might lead to an infant's needing special care or being vulnerable to death in the first few days or weeks of life. Counseling to reduce stress, advocacy to provide assistance with job finding, or the provision of social support may be just as critical as nutritional counseling or medical monitoring.

Regardless of the specific implications, it appears that if the results of this study are validated through the further testing of infants in neonatal intensive care units and the further testing of the household variables, the exclusive reliance on prenatal medical care may be replaced by broader, community supports for households expecting a baby.

Recommendations

1. In light of the apparent importance of the sources of support and information, clarification is needed on the importance of these factors in the functioning of a household expecting a baby. The development of a theory regarding the relationship between these and other variables that appear to affect the outcome of pregnancy is

needed. It is recommended that the mothers and fathers of the infants in the study be interviewed to assess their observations concerning some of these important variables, as a basis for theory development from a grounded perspective.

- 2. The relationship of household variables in the general population to the outcome of pregnancy needs to be assessed. This is a more difficult task than the usual epidemiological studies because the latter have been able to rely on public records such as birth registrations. Assessing household factors requires either a mail questionnaire or interviewing members of the household. It is recommended that studies of this nature be done through sampling households and making contact with mothers in hospitals shortly after a baby is born. An understanding of the relationship of household variables to outcome in the general population would lend support for a household intervention rather than relying exclusively on intervention through the mother.
- 3. The present study should be replicated with households of infants who have died in other neonatal intensive care units and matched samples of households of surviving infants. It is recommended that studies be done in low-income as well as heterogeneous populations to assess differences in the path analysis by income level.
- 4. Should support be found for the results of the present study, new approaches should be developed to reduce infant mortality and to prevent the need for intensive care of neonates.

APPENDICES

APPENDIX A

HUMAN SUBJECTS APPROVAL

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS (UCRIHS) 238 ADMINISTRATION BUILDING 55(7) 355-2186 EAST LANSING - MICHIGAN - 48824

April 5, 1983

Dr. David J. Kallen
Pediatrics & Human Development

Dear Dr. Kallen:

Subject: Proposal Entitled, "Infant Mortality: High Risk Infants Who Live or Die"

UCRIHS review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on April 4, 1983

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to the anniversary date noted above.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck Chairman, UCRIHS

HEB/jms

FRANCIS A. BREEN, JR., M.D.

PROFESSIONAL CORPORATION

P.D. 80X 30480 • 1215 E. MICHIGAN AVENUE • LANSING, MICHIGAN 48909 (ACROSS FROM SPARROW)

FRANCIS A. BREEN, JR., M.D., F.A.C.P. PRACTICE LIMITED TO MEDICAL DINCOLDBY AND HEMATOLOGY

TELEPHONE (517)

PETER G. GULICK, D.D. PRACTICE LIMITED TO MEDICAL DISCULDBY AND INFECTIOUS DISCASES

September 5, 1984

Ann Stirling Johnson, A.C.S.W. Dept. of Pediatrics/Human Development B-240 Life Sciences Building Michigan State University East Lansing, MI 48824-1317

Dear Ms. Johnson,

The Edward W. Sparrow Hospital Institutional Research Review Committee at its regular monthly meeting on September 4, 1984, approved continuation of your study "Infant Mortality: High Risk Infants Who Live or Die". The Committee had some reservation that the length and complexity of your questionnaire might discourage response.

Sincerely,

Francis A. Breen, Jr., M.D., Chairman Institutional Research Review Committee

mms

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS (UCRIHS) 238 ADMINISTRATION BUILDING (517) 355-2186 EAST LANSING . MICHIGAN . 48824

November 6, 1984

Dr. David J. Kallen
Pediatrics & Human Development

Dear Dr. Kallen:

Subject: Proposal Entitled, "Children Who Live and Die"

UCRIHS review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on November 5, 1984.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to November 5, 1985.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck Chairman, UCRIHS

HEB/jms

cc: Ain Johnson

APPENDIX B

NICU PROJECT INSTRUMENT

CODE	NUMBER

NEONATAL INTENSIVE CARE UNIT STUDY

QUESTIONNAIRE

A cooperative effort between E. W. Sparrow Hospital, Michigan State University and the families of NICU babies.

May, 1985

THERE ARE A FEW IMPORTANT THINGS YOU NEED TO KNOW BEFORE BEGINNING THIS QUESTIONNAIRE. PLEASE TAKE A MOMENT TO READ THIS:

- 1. This questionnaire should be filled out by the woman whose infant was in the Neonatal Intensive Care Unit at Sparrow Hospital.
- 2. When we refer to pregnancy, we are asking about your pregnancy for the child who was in the Neonatal Intensive Care Unit at Sparrow Hospital.
- 3. When we talk about household, we are asking about the people with whom you lived. This might include someone who was not part of your family.
- 4. Some questions refer to "the baby's father." Some questions refer to "your husband or partner." For some people this will be the same person. For some people this will be a different person.
- 5. Some questions may appear to be the same. In one place we ask about the number of living children you have had. In another place we ask for the number of children in the household. These may be the same, but they may be different. Where there have been remarriages or divorces, children also get separated. Try to answer the question just as it is written.
- 6. Answer every question unless you are directed otherwise. Put one answer for each question unless you are directed otherwise.
- 7. If you have any questions about the study, please call Ms. Johnson, (517) 355-6092 or (517) 353-5042. You may call collect to the first number if you live outside the Lansing area.
- 8. Your help is very much appreciated.

PLEASE TELL US ABOUT THE PEOPLE IN YOUR HOUSEHOLD. WE WOULD LIKE TO KNOW ABOUT THE PEOPLE WITH WHOM YOU LIVED SIX MONTHS BEFORE YOUR PREGNANCY AND DURING THE PREGNANCY FOR THIS CHILD.

Household Information:	Six Months Before Pregnancy	During Pregnancy
What was the total number of people who lived in the household. Do not count renters unless they ate meals and were part of your household activities. (Fill in number).		
How many pre-school children lived in your household? (Fill in number).	<u></u>	
How many school-age children lived in your household? (Fill in number).		

Household Information:	Six Months Before Pregnance	During Pregnancy
Your marital status:	1. Married 2. Divorced 3. Single 4. Widowed 5. Separated	1. Married 2. Divorced 3. Single 4. Widowed 5. Separated
Was the father of the baby living in the household? (Check).	1. Yes 2. No	1. Yes 2. No
What other adult was living in your household with you? (Check)	1. No one 2. Parent 3. Other	1. No one 2. Parent 3. Other
What pets did you have in the household? (Check).	1. None 2. Cat 3. Dog 4. Bird 5. Fish 6. Other	1. None 2. Cat 3. Dog 4. Bird 5. Fish 6. Other
Did you change your residence? (Check).	1. Yes 2. No	1. Yes 2. No
How many bedrooms did you have in your apartment or house? (Fill in number).		
How many bathrooms did you have in your apartment or house? (Fill in number).		
Were you going to school during these time periods? (Check).	1. Yes 2. No	1. Yes 2. No
Was the baby's father going to school during these time periods? (Check).	1. Yes 2. No	1. Yes 2. No
At the time this child was born, what was had completed? (Circle number). School 1 2 3 4 5 6 7 8 9 10 11 12	College/Techn	Craduate/Prof.
At the time this child was born, what was baby's father had completed? (Circle numb	the highest leve er). College/Techn	

WE WOULD LIKE TO KNOW ABOUT YOU.
How much did you weigh before this pregnancy?pounds.
How much weight did you gain during this pregnancy?pounds.
How tall are you?feetinches
Before this pregnancy, had you ever had (check): 1. A stillborn child 2. An abortion 3. A miscarriage 4. An infant who died 5. A handicapped child who lived 6. A child who died
Before this pregnancy, how many living children had you had? (Number).
Was this pregnancy a planned pregnancy? 1. Yes2. No
How many months pregnant were you when you first noticed the pregnancy? (Check). 1. Less than 1 month2. 1-3 months3. 4-6 months4. 7-9 months
When did you first go to a doctor for this pregnancy? 1. Less than 1 month2. 1-3 months3. 4-6 months4. 7-9 months5. During labor
Please check all the places you went for medical care while you were pregnant.
How many visits did you make to a physician during this pregnancy? (Check). 1. None 2. 1-4 3. 5-8 4. 9-12 5. 13-16 6. More than 16

Were you worried about being able to pay for prenatal care? (Check). 1. Yes2. No	
Did anyone refuse to give you prenatal care? (Check). 1. Yes2. No	
Was anyone else in your household pregnant when you were pregnant with this chi (Check).	.1d?
Here are some reasons why people seek medical care during their pregnancy. Which were true for you? Check all the reasons that apply to you. 1. Felt sick 2. Wanted to see if you were pregnant 3. Think every woman should have prenatal medical care 4. Needed some information on pregnancy 5. Wanted to make sure baby was healthy 6. Husband or other adult wanted me to get care 7. Other reason	
Here are some reasons why people put off going for prenatal medical care. Pleatheack all the reasons that were true for you. 1. Didn't know where to go for prenatal medical care 2. Did not want prenatal medical care 3. Did not have enough money 4. Did not have medical insurance 5. Did not need medical care 6. Did not have anyone to stay with other children 7. Couldn't get time off from work 8. Husband or other adult didn't want you to go 9. Didn't like long wait in doctor's office 10. Other reason	se
Put one check by all the people who assisted you in any way during this pregnam (meals, food, money, health care, transportation, child care, someone to talk with, advise, etc). Do not count labor and delivery. Put two checks by all the people who you found very helpful and supportive. 1. Husband or partner 2. Members of your household 3. Family outside your household 4. Friends 5. Neighbors 6. Physicians 7. Other medical people (nurses, nutrition counselor, health educators) 8. Social Workers 9. Counselor or Psychologist 10. Support group 11. Other	

1. No 2. On 3. Tw	ne ly one o	ns examined you duri	ing this pre	gnancy, not counting
Did you have pregnancy)?1. Ye2. No	(Check). S	g a place to get med	lical prenat	al care (<u>care during</u>
Please check	all that apply eady knew from band or partne bers of your h mily outside you ends ghbors sicians her medical pec ial Workers dio and televi reparation for her classes oks, magazines her TIONS ASK YOU THERE ARE TI	n previous experiencer household our household ople (nurses, nutritation childbirth class or newspapers	e ion counseld OW OFTEN SOR RIBE POSSIBI	or, health educators) METHING HAPPENED LE ANSWERS.
YOUR ANSWER.	FOR EXAMPLE:	Numbers. Please cir		BER THAT MATCHES
How helpful wa Not at all 1	as your mother 2	during this pregnan Some 3	cy? _. 4	Very helpful 5
HELPFUL TO "SO	ME" EXTENT, C	ALL" HELPFUL, YOU WO IRCLE 3. IF SHE WAS E THREE POINTS.	ULD CIRCLE 1 "VERY HELP!	l. IF SHE WAS FUL" CIRCLE 5.
We had enoug Never 1	ch money to ge 2	t along on. Some of the time 3	4	Always 5
We had enoug Never 1	gh food. 2	Some of the time	4	Always 5

We had transports	ition.	Come of the time		43	
Never 1	2	Some of the time 3	4	Always 5	
We had a telephor	ne.				
Never 1	2	Some of the time	4	Always 5	
We had enough hea	t in the h	ouse.	·	_	
Never	_	Some of the time		Always	
1	2	3	4	5	
We had a televisi Never	.on	Some of the time		Always	
1	2	3	4	5	
We had enough clo	thing.				
Never 1	2	Some of the time	4	Always 5	
_	th members	of our family outside	de the househo	าเส	
Never		Some of the time	se the local	Always	
1	2	3	4	5	
We had trouble wi Never	th people	in our neighborhood. Some of the time		Always	
1	2	3	4	5	
hu helnful were ti	ne N hveicia	ans who examined you	during your n	respancy?	
Do not include la	or and de	livery).	•	•	
ot helpful	2	Moderately helpful	4	Very helpful	
		doctor or other med	ical people g	ive you on wha	t
ou should eat?		Some		A lot	
1	2	3	4	5	
	ollow their	r instructions on wha	t you should		
iot at all	2	Some 3	4	Completely 5	
	on did you	doctor or other med	ical people g	ive you on	
moking and drugs? Hone		Some		A lot	
1	2	3	4	5	
	ollow their	instruction on smok	ing a nd drugs		
ot at all	2	Some	4	Completely	

To what extent were	e you separate	ed from your hu	sband or par	tner during your
pregnancy? Never separated		Some		Frequently
1	2	3	4	5
How much help and	support did yo	<u> </u>	r husband or	
None	•	Some	4	A lot 5
1	2	3	4 .	3
How much did you we No worries at all		ey during your Some worries	pregnancy?	Worried a lot
1	2	3	4	5
How much did you as during this pregnat	ncy?	husband/partne	er about mon	
Did not argue at a	11 2	Some arguments 3	4	Argued a lot 5
How much did you as this pregnancy?		er people about	money or oth	
Did not argue at a	11 2	Some arguments 3	4	Argued a lot 5
How difficult was : No difficulties	it for you to	get medical car Some difficult		is pregnancy? lot of difficulty
1	2	3	4	5
How satisfied were your pregnancy?	you with your	relationship	with your hus	sband/partner before
Very dissatisfied	2	OK 3	4	Very sa tisfied 5
How satisfied were this pregnancy?	you with your	relationship	with your hu	sband/partner during
Very dissatisfied		OK		Very satisfied
1	2	3	4	´ 5
Overall, how satisf Very dissatisfied	ied were you w		before this	pregnancy?
1	2	OK 3	4	Very satisfied 5
Overall, how satisf Very dissatisfied	ied were you w	with your life o	during this	oregnancy? Very satisfied
1	2	3	4	5

THE NEXT QUESTIONS CONCERN THE EMPLOYMENT SITUATION IN YOUR HOUSEHOLD. LET'S START WITH YOU AND YOUR WORK EXPERIENCE IN THE SIX MONTHS BEFORE YOU GOT PREGNANT WITH THIS CHILD.

Did you have a j	ob? (Check).
	full-time job.
2. Yes, a	part-time job.
3. No, bu	t I was looking for work.
4. No, an	d I was not looking for work. \downarrow
	If yes, were you working for the full six month period? (Check).
	1. Yes
	2. No, only part of the six months.
	During the six months prior to this pregnancy, did you get
	laid off, lose a job, quit a job, or get a new job or get
	a promotion? (Check).
	1. No, my employment status did not change.
	2. Yes, I was laid off or lost a job.
	3. Yes, I quit a job.
	4. ies, i got a new job.
İ	5. Yes, I got a promotion.
	If you were working at all before you got pregnant, what was
į	your job title and what did you do?
1	Was there a time when you were worried that you might be
	laid off whether or not you actually were laid off? (Check).
	1. Yes
	2. No
	How did you feel about your work situation just before you
1	got pregnant with this child? (Check).
	1. Good
\	2. Neither good nor bad
	3. Bad
YOUR WORK EXPERI	ENCE DURING YOUR PREGNANCY:
Did you have a j	ob? (Check).
	full-time job.
	part-time job.
3. No, bu	it I was looking for work.
4. No, an	d I was not looking for work.
	If yes, were you working all during this pregnancy? (Check).
	1. Yes 2. No
	During this pregnancy, did you get laid off, lose a job, quit
	a job, get a new job or get a promotion? (Check).
	1. No, my employment status did not change.
	2. Yes, I was laid off or lost a job.
	3. Yes, I quit a job.
	4. Yes, I got a new job. 5. Yes, I got a promotion.
~	To rest r Bor a bromorton.

If you were working at all during this pregnancy, what was your job title and what did you do?
Was there a time when you were worried that you might be laid off whether or not you actually were laid off?
How did you feel about your work situation during this pregnancy? (Check)1. Good
2. Neither good nor bad 3. Bad
NOW WE WOULD LIKE TO KNOW ABOUT OTHER PEOPLE IN YOUR HOUSEHOLD WHO WERE IN THE LABOR FORCE IN THE SIX MONTHS BEFORE YOU GOT PREGNANT WITH THIS CHILD.
who usually contributed the most money to the household income? (Check). 1. I did 2. My husband/partner 3. Parent 4. Other person in the household
Not counting yourself, how many other people in your household were working? (Fill in number)
Not counting yourself, how many other people in your household were unemployed and looking for work? (Fill in number).
PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT THE ONE <u>OTHER</u> PERSON WHO USUALLY CONTRIBUTED THE MOST TO THE HOUSEHOLD INCOME. IF NO <u>ONE</u> ELSE BESIDES YOURSELF CONTRIBUTED TO THE HOUSEHOLD INCOME, SKIP TO THE SECTION CALLED "DURING YOUR PREGNANCY."
Was this person working before this pregnancy? (Check). 1. Yes, a full time job 2. Yes, a part-time job 3. No, but he/she was looking for work. 4. No, and he/she was not looking for work.
If yes, was he/she working for the full six month period?(Check).
Before this pregnancy, did he/she get laid off or lose a job, quit a job, get a new job or get a promotion? (Check). 1. No, his/her employment status did not change. 2. Yes, he/she was laid off or lost a job. 3. Yes, he/she quit a job. 4. Yes, he/she got a new job. 5. Yes, he/she got a promotion.
If he/she was working at all before the pregnancy, what was his/her job title and what did he/she do?

WE WOULD LIKE TO KNOW IF YOU RECEIVED ANY OTHER FORMS OF INCOME OR SUPPORT BEFORE AND DURING YOUR PREGNANCY FOR THIS CHILD. (CIRCLE YES OR NO).

Benefits:	Six M Befor	onths e Pregnancy	Durin	
Unemployment benefits	Yes	No	Yes	No
Food stamps	Yes	No	Yes	No
Public Assistance	Yes	No	Yes	No
Health insurance (any kind)	Yes	No	Yes	No
Did insurance cover pregnancy?	Yes	No	Yes	No

WE WOULD LIKE TO KNOW APPROXIMATELY HOW MUCH INCOME YOUR HOUSEHOLD RECEIVED DURING THE TWO TIME PERIODS. PLEASE INCLUDE INCOME FROM ALL ADULTS, GOVERNMENT PAYMENTS, PAYMENTS FROM OTHER INDIVIDUALS SUCH AS CHILD SUPPORT AND REGULAR GIFTS. INCLUDE INTEREST FROM SAVINGS. INCLUDE RENT FROM RENTERS AND BOARDERS, BUT NOT THEIR ENTIRE INCOME UNLESS IT IS AVAILABLE FOR YOUR USE. INCLUDE STUDENT LOANS AND SCHOLARSHIPS FOR LIVING EXPENSES.

Please add up all the amounts and check which best describes your income. If it is easiest to figure monthly, please use the "Income Per Month" chart. If it is easiest to figure yearly, please use the "Income Per Year" chart. Do not use both.

Income Per Month:	Six Months Before Pregnancy	During Pregnancy
Less than \$400 per month		
Between \$400 and \$699 per month		
Between \$700 and \$999 per month		
Between \$1,000 and \$1,299 per month		
Between \$1,300 and \$1,599 per month		
Between \$1,600 and \$1,899 per month		
Between \$1,900 and \$2,199 per month		
Between \$2,200 and \$2,499 per month		
Between \$2,500 and \$2,799 per month		
Between \$2,800 and \$3,099 per month		
Between \$3,100 and \$3,399 per month		
More than \$3,400 per month		

Income Per Year:	Six Months Before Pregnancy	During Pregnancy
Less than \$4,800 per year		
Between \$4,800 and \$8,399 per year		
Between \$8,400 and \$11,999 per year		
Between \$12,000 and \$15,599 per year		
Between \$15,600 and \$19,199 per year		
Between \$19,200 and \$22,799 per year		
Between \$22,800 and \$26,399 per year		
Between \$26,400 and \$29,999 per year		
Between \$30,000 and \$33,599 per year		
Between \$33,600 and \$37,199 per year		
Between \$37,200 and \$40,799 per year		
More than \$40,800 per year		

WE WOULD LIKE TO KNOW APPROXIMATELY HOW MUCH INCOME THE MALE HEAD OF HOUSEHOLD CONTRIBUTED TO THE HOUSEHOLD INCOME DURING THOSE TWO TIME PERIODS. THE MALE HEAD OF HOUSEHOLD IS NOT NECESSARILY THE SAME PERSON YOU IDENTIFIED IN THE EMPLOYMENT QUESTIONS, BUT IT MIGHT BE. INCLUDE STUDENT LOANS FOR LIVING EXPENSES IF THE MALE HEAD OF HOUSEHOLD IS THE STUDENT RECEIVING IT. DO NOT INCLUDE INCOME FROM OTHER SOURCES.

The following are the same charts used for household income. Put a check in each of the two time periods next to the income level. If it is easiest to figure monthly, use "Income Per Month" chart. If it is easiest to figure yearly, use "Income Per Year" chart. Do not use both.

Whose :	income	are you	listing h	ere?	(Check).		Husband Partner		Husband Partner	_
							Your		Your	•
						4.	father No male	4.	father No male	.
							head		head	
							(If no m	are ue	ed or ux	zusenota
							go to pe	ıge 14)	•	

Income Per Month:	Six Months Before Pregnancy	During Pregnancy
Less than \$400 per month		
Between \$400 and \$699 per month		
Between \$700 and \$999 per month		
Between \$1,000 and \$1,299 per month		
Between \$1,300 and \$1,599 per month		
Between \$1,600 and \$1,899 per month		
Between \$1,900 and \$2,199 per month		
Between \$2,200 and \$2,499 per month		
Between \$2,500 and \$2,799 per month		
Between \$2,800 and \$3,099 per month		
Between \$3,100 and \$3,399 per month		
More than \$3,400 per month		
Income Per Year:	Six Months Before Pregnancy	<u>During</u> <u>Pregnancy</u>
Less than \$4,800 per year	Before	
	Before	
Less than \$4,800 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year Between \$15,600 and \$19,199 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year Between \$15,600 and \$19,199 per year Between \$19,200 and \$22,799 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year Between \$15,600 and \$19,199 per year Between \$19,200 and \$22,799 per year Between \$22,800 and \$26,399 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year Between \$15,600 and \$19,199 per year Between \$19,200 and \$22,799 per year Between \$22,800 and \$26,399 per year Between \$26,400 and \$29,999 per year	Before	
Less than \$4,800 per year Between \$4,800 and \$8,399 per year Between \$8,400 and \$11,999 per year Between \$12,000 and \$15,599 per year Between \$15,600 and \$19,199 per year Between \$19,200 and \$22,799 per year Between \$22,800 and \$26,399 per year Between \$26,400 and \$29,999 per year Between \$30,000 and \$33,599 per year	Before	

WE WOULD LIKE TO KNOW ABOUT YOUR OWN FAMILY'S INCOME.	
How much of your life have you been poor (not had enough food, clothing, shelter). (Check). 1. Not at all	
2. A quarter of my life 3. Half of my life 4. Most of my life 5. Only for brief periods	
What was your family's financial situation when you were less than 12 years old? (Check). 1. We couldn't buy some things that were necessary. 2. We could buy necessities only. 3. We could afford some of the things we wanted, but not everything. 4. We could afford about everything we wanted. 5. We could afford about everything we wanted and had some left over	•

PLEASE TELL US ABOUT YOURSELF DURING THE TWO TIME PERIODS: SIX MONTHS BEFORE YOU GOT PREGNANT WITH THIS CHILD AND DURING YOUR PREGNANCY

	Six Months Before Pregnancy	During Pregnancy
Did you smoke cigarettes (at least one, but less than a pack a day). (Check).	1. Yes 2. No	1. Yes 2. No
Did you smoke more than a pack of cigarettes a day? (Check).	1. Yes 2. No	1. Yes 2. No
Did anybody around you smoke frequently? (Check).	1. Yes 2. No	1. Yes 2. No
Did you live or work in an area of air pollution? (Check).	1. Yes 2. No	1. Yes 2. No
Did you take dilantin or any other medication prescribed for seizure disorders? (Check)	1. Yes 2. No	1. Yes 2. No
Did you take insulin? (Check).	1. Yes 2. No	1. Yes 2. No
Did you drink caffeinated coffee or soda pop? (Check).	1. Yes 2. No	1. Yes 2. No
Did you have high blood pressure? (Check).	1. Yes 2. No	1. Yes 2. No

WE ARE INTERESTED IN WHETHER CERTAIN EVENTS HAPPENED IN YOUR HOUSEHOLD. IF THEY DID HAPPEN, WE WOULD LIKE TO KNOW HOW YOU FELT ABOUT EACH OF THEM. HERE ARE FOUR STATEMENTS NUMBERED FROM 1 TO 4. AFTER EACH EVENT BELOW, CIRCLE 1 OF THE FOUR NUMBERS IN EACH SPACE, DEPENDING ON WHICH STATEMENT IS TRUE.

1. It did not happen

2. It happened but it did not worry me.

3. It happened and it worried me somewhat

4. It happened and it worried me a lot.

FOR EXAMPLE, IF SOMEONE GOT REALLY SICK IN YOUR HOUSEHOLD SIX MONTHS BEFORE YOUR PREGNANCY AND IT WORRIED YOU A LOT, PUT 4. IF NO ONE WAS SICK DURING YOUR PREGNANCY, PUT 1. INCLUDE YOURSELF AND EVERYONE IN YOUR HOUSEHOLD.

In our household:	Before Pregnancy	During Pregnancy
someone got married	1234	1234
someone was born (do not count NICU baby)	1234	1 2 3 4
someone got really sick	1234	1 2 3 4
someone smoked cigarettes a lot	1 2 3 4	1234
someone had their marriage break up	1234	1234
someone stopped smoking cigarettes	1234	1234
someone got drunk often	1234	1234
someone died	1 2 3 4	1234
someone got pregnant (do not include pregnancy for child who was in NICU)	1 2 3 4	1 2 3 4
someone had trouble with the law	1 2 3 4	1234
someone was using over-the-counter drugs such as aspirin	1 2 3 4	1234
someone was using prescription drugs	1234	1234
someone was using home remedies	1 2 3 4	1234
someone was turned down for unemployment benefits	1 2 3 4	1 2 3 4
someone's employment benefits ran out	1 2 3 4	1 2 3 4
someone was turned down for food stamps	1 2 3 4	1 2 3 4
someone was turned down for ADC	1 2 3 4	1 2 3 4
someone lost health insurance (any kind)	1 2 3 4	1234

WE WOULD LIKE TO KNOW WHAT HAPPENED AFTER YOUR BABY WAS BORN
What was the outcome for the child born in the NICU? (Check)
1. It was born sick, and died2. It was born sick, but survived and it healthy3. It was born sick, but survived with some handicaps
How long was your baby in the Sparrow Hospital Neonatal Intensive Care Unit? (Write in numbers).
months
weeks
days
hours
How often did you see your baby in the NICU? (Check).
1. Not at all 2. Once a week 3. A few times per week 4. Once a day 5. More than once a day 6. Other: describe
Did you participate in the HOPING group meetings? (Check).
1. Yes 2. No
Was your family helpful and supportive during the time your baby was in the NICU?
Were the families of other NICU babies helpful and supportive during this time?
4. I had no contact with other families

HERE ARE A NUMBER OF WAYS THAT PEOPLE SOMETIMES FEEL ABOUT HOSPITALS. FOR EACH ONE. PLEASE SAY WHETHER OR NOT YOU FELT THIS WAY WHEN YOUR CHILD WAS IN THE NICU. CHECK YES OR NO. I was treated with dignity. 1.Yes 2.No I was made to feel I was not respected as a person. 1.Yes: 2.No I was made to feel I was behaving responsibly. 1.Yes 2.No I was made to feel the doctors were really interested in me as a person. 1.Yes: 2.No I was made to feel the nurses were really interested in me as a person. 2.No 1.Yes I was made to feel I was just another number in the system. 1.Yes 2.No I had a good chance to have my questions about treatment answered. 1.Yes 2.No I had a good chance to talk to people about how I felt about what was happening in the hospital. 1.Yes 2.No I really felt alone and isolated during the hospitalization. 2.No 1.Yes 2.No I felt upset and frightened a lot. 1.Yes

IS THERE ANYTHING ELSE YOU'D LIKE TO TELL US? PLEASE FEEL FREE TO USE THE EXTRA SPACE ON THIS SHEET.

1.Yes

2.No

THANKS FOR HELPING!

Most of the time I felt I could cope.

YOU ARE ENTITLED TO RECEIVE A WRITTEN REPORT OF THIS STUDY. IF YOU WOULD LIKE A COPY, PLEASE FILL IN YOUR NAME AND ADDRESS ON THE LAST PAGE.

IF YOU WOULD LIKE TO BE INTERVIEWED, PLEASE SIGN THE CONSENT FORM ON THE LAST PAGE.

WHEN YOU ARE DONE, PLEASE PUT THE QUESTIONNAIRE IN THE ENCLOSED ENVELOPE AND MAIL IT. THE ENVELOPE DOES NOT NEED ANY POSTAGE.

YES, I WOULD LIKE TO RECEIVE A WRITTEN REPORT ON THE STUDY.
NAME:
STREET AND NUMBER:
CITY:
STATE:
ZIP CODE:
YES, I WOULD BE WILLING TO BE INTERVIEWED ABOUT MY EXPERIENCES.
SIGNATURE:
NAME:
STREET AND NUMBER:
STATE:
CITY:
ZIP CODE:
TELEPHONE NUMBER:

APPENDIX C

COVER LETTERS

DEPARTMENT OF PEDIATRICS/HUMAN DEVELOPMENT BOAR LINE OCTUBER

EAST LANSING . MICHIGAN . 48824-1317

May 6, 1985

We are seeking information about the situations of families whose babies were in the Neonatal Intensive Care Unit of E. W. Sperrow Hospital within the last three years.

Sometimes it is unknown what events, if any, leading up to the birth of a child, make it necessary for an infant to need the special care of a Neonatal Intensive Care Unit. So we are asking a number of women whose babies were in the NICU many questions in the hopes that we can begin to find out what problems women and families have during pregnancy that may make this care necessary. Records show that you had a child in the NICU during that time.

We hope you will help us understand the conditions that may result in a new-born baby's needing this special help. We realize the hours, days or weeks when your baby was in the NICU were probably very difficult for you. We ask that you spend a few minutes now so that we can help other mothers, families and bebies.

Of course, your participation in this study is voluntary and confidential. Your answers will be combined with those of other women so that no one except the researchers will ever know what your answers are or if you returned the questionnaire. The envelope provided for returning the questionnaire does not need postage.

We realise that you may have some information for us that is not on the questionnaire, or you may have some questions about the study. If so, please call Ms. Johnson at (517) 355-6092 or (517) 353-5042. You may call collect to the first number if you live outside the Lansing area.

At the end of the questionnaire is a place for you to indicate if you are willing to be interviewed. You are entitled to receive a copy of a written report of the study. If you would like one, please put your name and address on the last page. We welcome your participation.

Sincerely,

Eugene A. Dolanski, M.D. Medical Director, NICU

Eugene a Dolanding

E. W. Sparrow Hospital

Ann Johnson

Project Manager, NICU Study For David J. Kallen, Ph.D.

Professor

Department of Pediatrics and

Human Development

And Robert J. Griffore, Ph.D. Associate Professor and Chair

Department of Family and Child Ecology

enclosure

DEPARTMENT OF PEDIATRICS/HUMAN DEVELOPMENT

EAST LANSING . MICHIGAN . 48824-1317

May 30, 1985

About three weeks ago, I wrote you asking about your experiences during your pregnancy for a baby who was in the Neonatal Intensive Care Unit at E. W. Sparrow Hospital.

The researchers involved have undertaken this study because we believe it is important to understand the circumstances of mothers and families during this time.

I am writing to you again because of the importance of each response. The information about your household will remain confidential. It will be combined with information about other households where an infant has been in the NICU.

In case the questionnaire has been misplaced, a replacement has been enclosed with an envelope that does not need postage.

Thank you so much for your help.

Sincerely,

Ann Johnson

MICU Project Manager

enclosure

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REFERENCES

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