# PROTECTIVE GOVERNING: STRATEGIES FOR MANAGING A PREGNANCY-ILLNESS

by

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ABSTRACT
of
PROTECTIVE GOVERNING: STRATEGIES
FOR MANAGING A PREGNANCY-ILLNESS

The purpose of this study is the discovery of a theoretical scheme to explain the events and actions that occur in the life of women as they attempt to manage the problems encountered in a pregnancy complicated by chronic illness, a high-risk pregnancy. While medical science is making a forward stride in the treatment of chronic illness and high-risk pregnancy, little attention has been given to the woman's role in the management of such a pregnancy or to the relationship of her management to a successful outcome. The problems of everyday living she confronts as she attempts to carry out the medical tasks of management are rarely considered. While there is a considerable amount of documented literature in the areas of the psychosocial aspects of a normal pregnancy and on adaptation to illness, a review of the literature has not yielded, to date, any published studies that examine the psychosocial aspects of managing a pregnancy complicated by chronic illness, despite the widespread interest in the area of high-risk pregnancies. What literature is available is based upon anecdotal and experiential data. This study is an initial contribution to this area of neglected inquiry. The specific questions this study addresses include: What strategies do women adopt for managing the medical components of a pregnancy-illness in order to produce a healthy infant and secure their own health while at the same time maintaining some balance in their emotional and social lives? What

antecedent conditions are necessary for management of a problematic situation so that the probability for achieving a positive outcome is increased? What is the character of the structural conditions in which the management tasks are performed?

The Interactionist perspective, in conjunction with the literature on psychosocial adaptation to pregnancy and illness, provided a matrix for guiding initial observations and interviews and for determining certain methodological approaches necessary for this study. The design chosen for analysis of this problem was the longitudinal field study, utilizing the constant comparative method of data analysis to evolve a substantive, grounded theory. The setting was two large teaching medical-centers, located on urban university campuses within the San Francisco Bay area. The total sample was comprised of twenty pregnant women with chronic illness. The data were collected by observation, interview, and from review of medical records.

The theoretical framework that emerged from the data in this study of the women's management of their problems associated with their pregnancy-illness was a process of "protective governing." Protective governing refers to the tasks that must be performed to guard the fetus and the woman against the threat of morbidity and mortality. Protective governing encompasses the psychosocial interactions occurring among the important participants involved in the management process as well as the social settings in which this form of management occurs. The implementing processes of protective governing are assessing, balancing, and controlling. Four required conditions facilitating management ability are possessing adequate information, possessing adequate support, stable internal and external conditions, and a perceived sense of control. Protective governing is accom-

plished within the structural condition of joint participation of the woman, her family and the medical team.

This management system of protective governing has implications for the care of all high-risk pregnant women, especially those whose pregnancies are complicated by chronic illness. The protective governing framework provides a model for: sensitizing nurses and other health professionals to the many problems a woman confronts as she attempts to carry out the medical components of management of a high-risk pregnancy; systematizing, and thereby improving, the care of high-risk pregnant women while at the same time increasing the satisfaction of health care providers; and, for assessing and intervening in the care of high-risk pregnant women which enables health professionals to assist each woman to reach her potential for a positive outcome within the limitations imposed by her complicating factor.

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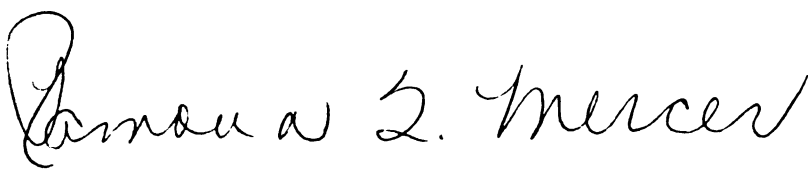

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J.C.C.

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# PART ONE

# THE INTRODUCTION

# Chapter 1.

# THE PROBLEM

## Section A: Introduction to the Problem

> I've had many mixed emotions about this pregnancy. My husband gets discouraged because I get discouraged. That is hard to deal with. I can't hide my emotions. He wants me to be happy. Everybody else he looks at is having a normal pregnancy and are real estatic about it. They have something to look forward to. He thought it was all joyous and everything was happy-go-lucky like you see on television where rosy-cheeked women are jumping around and doing their housework. Everytime I go to the clinic they tell me something else is wrong. How can I be happy and say I've had a great day. It has been hard, but I think we are managing. (Excerpt from fieldnotes, Heather and Edward.)

The expression of emotional reaction by both Heather and her husband, Edward, is not normally expected from a pregnant woman. Heather is apprehensive because her pregnancy is one complicated by chronic pyelonephritis.

In this culture, pregnancy is considered a very special and a normal biological period within a woman's life. Except in the case of an undesired pregnancy, a woman is usually excited by the confirmation of a conception and eagerly shares that joy with family and friends. Though she may experience nausea, fatigue, backache, or heartburn, these problems are usually perceived as minor discomforts and seldom detract from the joy of the pregnancy itself. These symptoms rarely prevent her from leading an active and normal life. Typically, she eagerly plans for the baby and may attend prenatal classes. She may opt for delivery in a family birth unit.

Little girls grow up with the expectation that they are capable of bearing children, if they so desire, without encountering risk or difficulty.

Yet, many of these girls, when women, discover that not to be the case. There are women whose pregnancies are complicated by medical and/or obstetrical problems such as diabetes, hypertensive disorders, and premature labor. These and other similar problems complicate the pregnancy by placing the expected infant and mother at high risk for morbidity and mortality. For example, diabetes, which complicates one to two percent of all pregnancies, increases the likelihood of intrauterine death, congenital anomalies, or respiratory distress syndrome in the infant. Although pregnancy is not as dangerous as it once was for diabetic women, maternal mortality and morbidity rates are still higher than those for uncomplicated pregnancies. Fatalities may result from associated complications such as hypertension and renal disease. In addition, diabetics often experience hypoglycemic episodes in early pregnancy and hyperglycemia in late pregnancy. These conditions, if not treated promptly and appropriately, can compromise the life of both the mother and fetus. The diabetic is also more likely than the nondiabetic to develop related obstetrical complications such as preeclampsia or polyhydramnios (an excess of amniotic fluid) which further increases the risks to both mother and infant (Gabbe, 1978). It is obvious that the diabetic pregnancy requires more competent and complex management to protect the mother and fetus against these complications than does the more typical and normal pregnancy for which the risk of complications is considerably lower.

A high-risk pregnancy creates a special set of circumstances for the woman to manage if she hopes to achieve a positive outcome. It is the process of managing a high-risk pregnancy and its effects on the women's lives that is the central problem examined in this study. The focus is upon one select population of high-risk pregnant women, namely, those with chronic illness.

## Section B: Background of the Problem

As a professional nurse, I have encountered many women whose pregnancies were complicated by medical and/or obstetrical conditions. I became increasingly aware of the many problems they faced as they attempted to cope with high-risk pregnancies. Years ago, while searching for a subject to pursue as part of a class project, I met a young mother-to-be, hospitalized during the last trimester of her pregnancy with a cardiac condition. I was intrigued and impressed by her heroic efforts to cope with her serious condition. Though she kept the bedside curtains drawn to shield herself from the on-going activities of mothers with their babies, she made active preparation for her own baby while hospitalized. She embroidered bibs and enjoyed displaying the baby gifts she was receiving. She literally escaped from the hospital so that she could go home to view the nursery rhyme characters her husband had painted on the nursery walls and to supplement her low-salt hospital diet with a MacDonald's hamburger. In spite of her high-risk pregnancy, she also planned to participate in her sister's wedding even though it was scheduled before her anticipated delivery. As the time of delivery approached, she became very resolute that she do nothing that would place either herself or baby in jeopardy.

The mother-to-be partially managed her high-risk pregnancy by cooperating and, at times, not cooperating with the medical regimen. She was even able to constructively tolerate the prolonged hospitalization. She, as Heather in the prefatory excerpt, reveal that living with and managing a high-risk pregnancy involves interaction with others, and is influenced by the various milieus in which management occurs. Obviously, the nature of the complicating illness is a major factor in the management process.

The excerpt also reveals the differences in perception regarding how pregnant women, and those around them, ought to behave which is derived from the belief systems that individuals hold regarding "proper" behavior during pregnancy.

The medical profession is intellectually aware of the complicated facets of managing a high-risk pregnancy; however, it is not sufficiently involved with the psychosocial aspects of coping. If management of a high-risk pregnancy is to be complete, it is important that the factors which affect a successful outcome be made available. While there is abundant literature addressing psychosocial adaptation to a normal pregnancy and, separately, to chronic illness, there is no reference to research studies which attempt to combine the two in order that the involved psychosocial aspects of adaptation may be examined.

## Section C: Significance of the Problem

Findings from a National Health Survey (1974) indicate that from a total population of nearly 42 million women between the ages of 14 and 44, about three and a half million or 8.6 percent of that population have a chronic disease which, to varying degrees, impairs their activity. These referenced chronic illnesses include diabetes, asthma, heart conditions, hypertension without heart involvement, and diseases of the kidney and ureters. The prevalence of chronic conditions in women of childbearing age, as evidenced by these statistics, is considerable. However, because of medical advances in the treatment of chronic illness such as insulin for the treatment of diabetes, steroids for lupus erythematosus, open-heart surgery to correct cardiac defects, and transplant to remove diseased

kidneys, the life span is lengthened and the reproductive capability of women with chronic disease is enhanced. Since the quality of life is an issue in today's society, it is expected that these women would want to lead as normal a life as possible, within the limitations of their illness, and that a considerable number of them now and in the future will bear children.

In conjunction with the improvement for the treatments of chronic illnesses, advances in medical knowledge and technology have lead to a general decline in fetal and neonatal mortality in the United States. The work of Gyves, Rodman, Little, Fanaroff, and Merkatz (1977), which is based upon recent knowledge of maternal-fetal carbohydrate homeostasis, demonstrated that assessment of fetal development and maternal-fetal well-being in conjunction with strict control of the mother's diabetes could improve pregnancy outcomes for diabetic pregnant women.

The neonatal death rate has declined from about 20 per 1000 live births, in 1950, to an estimated rate of 10.9 per 1000 live births in 1976 (Babson et al., 1980). Factors which may account for the descending trend include the identification of the mother and fetus as high risk during the prenatal, intrapartum, postpartum, and neonatal periods; the regionalization and team approach to perinatal care; and, improvement in perinatal care in community hospitals. Other factors which may have contributed to the descending trend include improvements in the standard of living, in nutrition, and in the health care delivery system.

Approximately eight million conceptions occur in the United States each year. Three to four million of these are lost because of early spontaneous and legal or illegal abortions. Of the remaining pregnancies which reach twenty or more weeks, approximately 80 thousand die either in utero

or within the first month of life. Approximately another 40 thousand infants are born with congenital defects and about 90 thousand are determined to be mentally retarded (Babson et al., 1980). While the exact cause of these occurrences are frequently difficult to isolate, it has been determined that morbidity and mortality rates increase in relation to complications of pregnancy, labor, and delivery.

Coopland et al. (1977) in a retrospective study of 5,450 cases, found that as the numerical risks on a high-risk antepartum scoring form increased there was a concomitant increase in the incidence of perinatal mortality. The rate of mortality increased from 4.0 per 1000 live births, that had a score of zero, to 112.0 per 1000 live births that had a risk score of seven or more. The number of infants requiring intensive care also increased with the rise in risk score. The percentage of infants requiring intensive care rose from 1.5 with a risk score of 0 to 27.0 with a risk score of seven or more.

Although the overall trend is descending, the occurrences of perinatal morbidity and mortality are perplexingly too frequent for an advanced and industrialized nation. It is urgent that efforts to identify those mothers and infants at risk due to medical, obstetrical or psychosocial factors be put forth. Once identified, it is also important to provide specialized care necessary to prevent damage or death to either or both the fetus and the mother. While medical science is making forward strides in this area through advances in perinatology and in the treatment of chronic illness, there is little attention given to the woman's role in the management of a high-risk pregnancy and its relationship to a successful outcome. The effect of her management on the outcome may be difficult to statistically document yet, ultimately, it is she that makes the decision to obtain or not to obtain prenatal care and it is with her that rests the ultimate responsibility for carrying out the medical regimen.

## Section D: Emergence of the Problem

There is a paucity of substantiated knowledge regarding the management of everyday living by women with high-risk pregnancies due to the presence of a chronic illness. The subject is an important one if these women are to be helped to increase their chances of delivering a healthy baby and to ensure their own health in spite of the risk circumstances. It became my primary concern. I was particularly curious about the type of problems they encountered in the management process and in the means taken to resolve them. Although I entered the field with this general focus in mind, the specific problem explored in this study emerged only after examination of my initial interviews and observations; hence, the problem evolved from the research process. The salient problem of the population under study was to discover the techniques for controlling a pregnancy-illness so as to protect the baby and self from harm and death while at the same time attempting to maintain a sense of normalcy in general life activities.

## Section E: Definitive Statement of the Problem

Considering the psychosocial consequences associated with managing the problems of a pregnancy complicated by chronic illness, how do women attempt to increase the probabilities for producing healthy infants and securing their own health. This problem is probed in analysis of a management system termed "protective governing." Protective governing encompasses the tasks which must be performed so as to guard the fetus and the woman against the threat of morbidity and mortality. Management

by protective governing also addresses the psychosocial interaction occurring between and among the important and involved participants as well as the social setting in which this form of management occurs. Protective governing is implemented by three interrelated processes. The first, assessing, is the process of identifying the risk factors in response to ongoing physical, interactional, temporal, and objective cues. The second, balancing, is the process of giving weight to alternatives for controlling the pregnancy and/or illness in terms of outcome and making a choice. The third, controlling, is the process of making continued adjustments and alignments of effort necessary for managing the tasks associated with a pregnancy-illness, by the principle interactants involved in the management process, for the purpose of maximizing chances of achieving a positive outcome.

## Summary

Chronic illness among women of childbearing age is prevalent, not withstanding the potential for these women to bear children is high. Although medical science has extended knowledge and developed sophisticated technology for treating and caring for women with high-risk pregnancies due to the presence of a chronic illness, only minimal attention has been given to the daily experiences of the women as they manage these pregnancies. This study is intended to fill this knowledge gap by carefully examining some of the important strategies that women, in this study, devised to resolve the problems they perceived as lessening their probabilities for producing healthy infants and securing their own health.

# Chapter 2.
# INTENT OF THE RESEARCH

## Section A: Research Focus

There is extensive literature (reviewed and analyzed in Chapter 3.) which gives account of adaptation to chronic illness. The basic adaptive tasks include coping with its threats, controlling its symptoms, and adjusting to the problematic realities imposed by it. There is also considerable information that deals with the psychosocial aspects of adaptation to an uncomplicated pregnancy and the preparation for the maternal role. Studies related to the medical management of high-risk pregnancies are also represented, but the literature dealing with psychosocial aspects of management of such a pregnancy is scant. This study focuses on the psychosocial problems that a select group of women encounter as they attend to the tasks of managing the medical components necessary for increasing their probabilities for achieving a positive outcome.

## Section B: Goals of the Research

The intent for this study is that it be both practically and theoretically relevant and applicable.

The Practical. The practical goals of this study are fourfold: 1) to identify the management strategies that women devise and utilize as they attempt to resolve the problems they encounter during the period of time that their pregnancy is complicated by chronic illness; 2) to develop

a nursing management approach for these women that will give consideration to the role assumed by the women themselves in the management of their pregnancies; 3) to show how their management style affects and is affected by the woman's milieu (home, clinic, hospital) in which the work of managing a high-risk pregnancy occurs; and, 4) to show how the quality and nature of the occurring interactional processes among the principal participants are influenced by the belief systems, past experiences, and cultural patterns that each brings into the social settings in which the pregnancy-illness is experienced.

The Theoretical. The theoretical goal of this study is the development of a grounded substantive theory that is capable of explaining the psychosocial dynamics associated with management of the problems associated with and created by a pregnancy complicated by a chronic illness.

## Section C: The Research Purpose and Questions

The purpose of this study is one of discovering a theoretical scheme that will explain the events and actions that occur in the life of a woman with high-risk pregnancies. Though the purpose is not one of data verification, the specific questions that are examined include: What strategies do women adopt for managing the medical components of a pregnancy-illness in order to produce a healthy infant and secure their own health while at the same time maintaining some balance in their emotional and social lives? What antecedent conditions are necessary for management of a problematic situation so that the probability for achieving a positive outcome is increased? What is the character of the structural conditions in which the management tasks are performed?

## Section D: Intended Impact

These findings can have a significant impact on the health care delivery system, particularly in nursing and medical intervention and health care programs for women with high-risk pregnancies. It is also hoped that important aspects of these findings will influence and bring about change in related areas of nursing education and practice. A multidisciplinary approach is vital if the social, psychological, ethical, and economic factors that affect management of these women are to be appreciated and understood.

## Section E: Research Design

An in-depth study of critical problems, important to health professionals and interested others, requires an organized presentation that is suited to the academic requirements of the author while, at the same time, lucid and interesting for the objective reader.

The presentation of the research components of method, findings, and conclusions is designed to faithfully reflect the psychosocial perspective of Glaser and Strauss (1967). Application of this point of view envisions the pregnant woman with a chronic disease as having a combination of social, psychological, organizational, and physiological problems that require investigation and detects what happens in the woman's life when a high-risk pregnancy is being managed.

Part One introduces the reader to the preliminary and academic dimensions of the study. Chapter 1. describes the parameters, the background, and the significance of the problem and defines its scope. Chapter 2. pre-

sents the purposes, goals, and focus of the total investigation. Chapter 3. reviews the approaches and findings of important studies which are significant for the management of a chronic illness and pregnancy. This chapter also sketches the Interactionist perspective which has implications for the emphasis given to this work. Chapter 4. details the essential task of this form of investigation; that is, developing a grounded substantive theory that evolves from the theoretical sampling process and explains how a woman manages her pregnancy when confronted with the many aforementioned problems that surround her. The method is detailed but in a manner which applies the process to the actual data content, its collection and analysis.

Part Two, The Findings, portrays the daily realities of women whose pregnancies are threatened by illness. Chapter 5. reveals real-life segments of the struggles associated with protection of a pregnancy through the "window" of two case histories. This chapter also looks at certain of the categories, coded from the data, and their relationship to management. Chapter 6. is an overview of the management task including analyses of the risk factors; the protective processes of assessing, balancing, and controlling by which governing of the events is carried forth; and some of the possible consequences of managing by protective governing. Chapter 7. vividly presents the action contexts of four different illness-pregnancy situations where protective governing is in operation under the structured conditions, characterized by joint participation.

Part Three, The Conclusion, summarizes and concludes the study by setting forth the study's implications, applications, and recommendations.

# Chapter 3.

# CONTRIBUTIONS FROM THE LITERATURE

This research is not directed by one particular framework; however, it does reflect and build upon earlier substantive studies, views, approaches, and established concepts derived by nurses, sociologists, psychologists, and other health professionals. These writings provide a general background and conceptual basis for explaining psychosocial adaptation to a pregnancy that is complicated by a chronic illness, particularly the personal and interactional components of management as they affect and are affected by the social settings.

This chapter reviews these earlier studies and records their relevant aspects to this research in terms of their relationship to design and methodology. My analysis includes the conceptual approach of the Interactionist school perspective as well as those studies that emphasize the psychosocial problems associated with chronic illness and pregnancy.

## Section A: The Interactionist Perspective

The Interactionist perspective was derived from the contributions of men such as W.I. Thomas, Robert E. Park, John Dewey, Horton Cooley, and George Herbert Mead. Their work was further articulated by the "Chicago Tradition" whose membership included Herbert Blumer, E. Faris, and Everett Hughes. Each of them, in turn, carried their respective insights into the tradition on to their students (Fisher and Strauss, 1978).

Theoretical Concepts. According to Fisher and Strauss (1978), the major strand of this tradition is the relationship of social process and freedom of action to social constraints. From this perspective, the individual is viewed as an active agent involved in an ongoing process of shaping his or her environment and dealing with the encountered problems within the limitations imposed by structurally determined conditions. Simultaneously, the structural conditions are in process, however minutely, and between them and the shaping process there is an interactive effect as well as singular consequences for each. As the social structure changes, it creates a different set of conditions which then lead to yet another and different situation requiring further coping by the individual. On the other hand, the manner in which an act is accomplished may likewise cause a change in the social structure (Strauss, 1978). The actions that an individual takes as he or she confronts encountered situations are based upon the meanings that the individual attributes to these situations which usually include persons and things. The assigned meanings derived from past social interactions are generally modified through an interpretive process (Blumer, 1969).

Implications for this Study. When applying these concepts to the problem under study, the woman is visualized as taking an active role in the management of the problems, created by her pregnancy-illness, within the limitations imposed by the structural conditions at any given time. These conditions are created largely by the nature and severity of her illness, the condition of her pregnancy, and the intra-systemic action of one upon the other. While the nature of the pregnancy in combination with the illness creates specific conditions that affect her management, how she decides to manage, or mismanage, these conditions will, in turn,

affect the nature of the illness and/or pregnancy and further create a new set of conditions. The settings in which risk-pregnancy management occurs are the woman's home, the clinic, and the hospital. The structural conditions, including the organization, of these environments impose a new set of conditions that will inevitably affect her management. Her style and management process will, in turn, affect the organization of these various environmental contexts.

The management behaviors the woman adopts, and ultimately the outcomes she achieves as a result of those behaviors, evolve from the meanings that she attributes to the factors in the situation and which are derived from past complex interactions. These include her continuous interactions with the health team, her partner, and important others, which are characterized by both concensus and conflict. Her new meanings, thus formed, are modified, examined, and transformed in the light of her unique life experiences which include her past and present experiences and her attitudes toward the illness, the pregnancy, the illness-pregnancy combination, the infant-to-be, personal commitments, desires, obligations, beliefs, and future plans. Thus, how the woman adapts to her pregnancy-illness, and the measure of her success, reflect this process of giving meaning to the situation in relationship to the prevailing conditions and chosen behavior patterns. Her sense of achievement, in this regard, affords her some control over the outcome she most desires.

There are many past, present, and future facets of a woman's biography that she brings with her to the pregnancy. It is the mingling of these facets of her life that creates the enormous forces with which she must cope as she progresses through the course of her high-risk pregnancy. On the one hand she must deal with the chronic illness with all its salient

physical, emotional, and social aspects. There is also the pregnancy which produces physiological, psychological, and social changes. For a period of time she must live with the combination of illness and pregnancy. She either desires or does not desire a baby.

Frame of Reference. The Interactionist perspective also provides a frame of reference for reviewing the literature. While there are no studies that respond directly to the subject under investigation, there is considerable literature referencing adaptation to illness and to normal pregnancy which provides insight into the current problem and initial conceptualizations and hypotheses. With these I began my field-work and later verified, modified, or discarded them as the data for this work were accumulated and analyzed.

## Section B: Chronic Illness

A woman with a chronic illness either adapts or fails to adapt to the requirements of her chronic illness. Most women develop strategies for managing the illness and preventing crises. The extent of adjustment, from woman to woman, varies and depends on her attitude toward the illness, the nature and severity of the symptoms, the duration of the illness, and the inconveniences it causes. From these combined factors is developed a meaning of illness and management style that is present when she becomes pregnant. The following studies provide an understanding of how individuals adapt to illness, the type of problems it creates, the strategies utilized, and the major factors that may influence adaptation.

Adaptation. According to Lazarus, Averill and Opton (1974), an individual evaluates the impact of events through a process of cognitive appraisal. That is, the individual makes an appraisal of the situation as a threat or as a challenge through a process which involves weighing the potential of an event to produce harm against the resources he or she has available to neutralize that harm. The key for understanding the coping efforts and the emotional reactions is an understanding of how the individual construes the event. Efforts at coping are designed to manage the internal and external demands that arise from the individual's appraisal of that event. Lazarus and his associates identify four modes of coping: information seeking, direct actions, intrapsychic processes, and turning to others for support.

Applying this process of adaptation to illness, Cohen and Lazarus (1970) noted that adaptation is the individual's effort to cope with the appraisal that illness can be a threatening situation. He or she senses that the illness can be a: 1) threat to life, the fear of dying; 2) threat to physical integrity and comfort in the form of bodily injury, permanent bodily change, pain, or incapacitation; 3) threat to self esteem and future goals that includes the necessity to alter one's body image, the possibility of losing one's autonomy and control, and the feeling of uncertainty; 4) threat to emotional equilibrium so that there is a need to deal with feelings of anger, anxiety, and other emotions; 5) threat to the capability of assuming one's customary social roles so that there is a necessity to depend on others; and, 6) threat that arises from the possible need to adjust to new physical and social environments such as a hospital or rest home settings.

Mechanic (1974) delineates adaptation within a social context and believes the components of successful adaptation to be: 1) the individual must have skills to deal with the demands to which he is exposed, which skills are derived from the social institutions and structures of which he or she is a part; 2) the individual must be motivated to meet these demands, which motivating incentives come from society; and, 3) the individual must be capable of maintaining a state of psychological equilibrium or defense, which psychological comfort maintenance depends not only on intrapsychic resources but also on the availability of social supports.

Mechanic (1977) states that the general principles for understanding adaptation and stress are applicable to the study of illness behavior. Illness behavior, the way in which individuals respond to their illness, is a process. The individual attempts to define the illness problem, struggle with and react to it, achieve a degree of mastery over it, or to accommodate him or herself to it. The individual's perception of and response to illness is dependent upon subjective experiences, social definitions, the severity and nature of the symptoms, and the extent of the physical incapacity. Important dimensions of the adaptive response that influence the manner in which individuals accommodate to serious or chronic illness include the search for meaning, social attribution, and social comparison. According to Mechanic, the coping strategies that an individual utilizes are based upon the meaning the illness situation has for that individual. While the social structure, in most instances, provides the necessary cues for arriving at comprehensible definitions of the situation, it may not provide those necessary cues in the case of illness which makes it difficult to arrive at definitions of the situation or its consequences.

Moos (1977) places adaptation to illness within a crisis framework. He suggests that the individual's cognitive appraisal of the significance of the crisis determines the basic adaptative tasks to which coping skills are applied. Cognitive appraisal, the perception of the adaptive tasks, and the selection of coping strategies are influenced by the individual's personal and background characteristics, illness related factors, and features of the socio-cultural environment.

Lawrence and Lawrence (1979) perceive illness as a stress producer, affecting individuals in different ways. They believe that for adaption to the continuing or recurring stress of chronic illness, the individual must pass through three states: shock and disbelief, developing awareness, and resolution of the loss of health.

In considering an individual's appraisal of an event, these studies consider an individual as responding to illness from a predetermined attitude toward threat, loss, or crisis. This idea of response to illness fails to take into account how meanings of events are selected, suspended, verified, formed, and revised in response to a particular situation so that meanings of the illness differ with changing conditions. For example, Lipowski (1970) suggests that illness may be perceived as a challenge, an enemy, a punishment, a weakness, a relief, a strategy, a value, an irreparable loss, a threat, or as bodily damage.

Properties of Chronic Illness. Chronic illness has its own set of properties which remain constant and independent of the meanings it generates for different individuals. The meaning an illness may have for an individual, it has been stated, varies according to one's past experience, the present set of life conditions, the severity of the illness, and the individuals with whom interaction occurs. However, while the individual

works out the meanings, the properties of the illness demand a specific set of tasks, work requiring the individual's attention regardless of attributed illness definition. A familiarity with the properties and the related adaptive tasks of chronic illness provides insight into some of the problems that women in this study with high-risk pregnancies must cope with and manage.

From a comparison study of chronic and acute illness by Gerson and Strauss (1975), the properties of chronic illness are outlined as follows: 1) chronic illness is long term; 2) the course of chronic illness is often uncertain; 3) chronic disease requires the extension of attention and the expenditure of effort as a palliative measure for controlling pain and other physical discomforts and for alleviating the patient's (and significant others') anxiety and grief; 4) chronic disease is frequently a combination of multiple diseases; 5) chronic disease is disproportionately intrusive into the life of an individual, limiting the activity imposed by symptoms and often requiring a reorganization of life style, commitments and activities; 6) chronic illness requires that the individual have a wide variety of ancillary services if he or she is to receive proper care; and, 7) chronic illness requires costly care, services, treatment, and medication.

Adaptive Tasks. The properties of chronic illness impose certain adaptive and necessary tasks which, according to Strauss and Glaser (1975), include: 1) taking steps to prevent medical crises; 2) controlling symptoms, 3) carrying out the prescribed regimen; 4) taking steps to prevent social isolation; 5) maintaining emotional equilibrium; and 6) continuing satisfying relationships with others.

Strategies for Managing. An individual devises a variety of strategies for coping with the physical, psychological, and social problems attendant to chronic illness. The findings from the following studies and personal accounts provide information about the wide assortment of strategies which may have been used in the past by the women in this study to manage their illness. It is likely that they will utilize these same or similar strategies for their illness during their pregnancy.

In a longitudinal study of fourteen families of children with polio, F. Davis (1963) found that the main problem confronting these families was the issue of identity. These families had difficulty interpreting and responding to the negative connotations imputed to the visibly handicapped in this society. Davis discovered that the families developed and used the two broad strategies of normalization and disassociation in their effort to adjust to this problem. Those families that used the normalization strategy denied the social significance of the handicap rather than denying the handicap itself. They explained it away, made light of it, and attempted to socially validate the claim that others ought to view the child as "normal" as they themselves did. Those families who tended toward disassociation attempted to insulate themselves from social situations, contacts, and involvements with others because it might force them to recognize that they and others viewed the child as somehow "different." Though no one family exclusively used one or the other strategy, some tended more toward one than toward the other.

M. Davis (1973), in the study of individuals living with multiple sclerosis, found that they used strategies for managing their illness similar to those used by the families in the F. Davis study (1963). The strategies she identified include passing, normalizing, and withdrawal.

Passing is described as an attempt to conceal some aspect of one's identity from others. Normalizing is referred to as an attempt to adjust to the perspective of others so as to appear more compatible with them. Withdrawal refers to the attempt by individuals with multiple sclerosis to protect their self concept by shielding themselves from experiences they consider as threatening.

Mages and Mendelsohn (1979), in their personological approach (the individual person is the basic unit of analysis), described three basic categories of coping strategies that are used by cancer patients. The first category of strategies was designed to minimize distress and include techniques of avoiding, controlling, forgetting, and detaching disturbing thoughts and feelings. The second category includes active attempts to deal with relevant issues such as seeking information about the illness, taking an active role in treatment decisions, attempting to compensate for or to replace body parts and functions, and volunteering to help others. The third includes techniques for turning to others such as seeking support and reassurance from family and friends, making demands upon others, and using the illness to manipulate and coerce others.

Katz et al. (1977), in interviews with thirty women awaiting breast tumor biopsy, found that they engaged in six major defense patterns: displacement, projection, denial with rationalization, hope and prayer, stoicism-fatalism, and a mixture of these defense mechanisms.

Bell (1977), in a comparative study of thirty psychiatric in-patients with a randomly selected matched control group, found that the experimental group utilized more short than long term coping methods as compared to the control group. The list of short term coping methods included the use of alcoholic beverages, daydreaming, eating food and food substitutes, cursing, drugs, and crying.

Cousins (1976), in a self-report, describes his approach to coping with illness as including the exercising of positive emotions such as love, hope, laughter, exerting faith, confidence, and the will to live, and coupling that with massive doses of vitamin C. He claims these as major factors bringing about his recovery from a rare disease.

Factors Affecting the Ability to Complete Adaptive Tasks of Illness. According to the literature, the ability to manage the problems produced by chronic illness is dependent upon many factors. While the potential range of these factors is almost limitless, they can be generally categorized under the following headings: personality factors, that which the individual brings with him or her to the situation, such as experience, coping techniques, knowledge, and beliefs; situational factors, that which is created by the situation such as the nature of the illness, the severity, duration, and the ease or difficulty with which it can be controlled; and, socio-structural factors, social support and environmental conditions. All of these factors tend, to some degree, to affect the ability to manage an illness. They influence how the illness is perceived, determine the illness associated problems, suggest the availability of managing strategies, and provide insight for future adaptive abilities when dealing with the illness-pregnancy situation.

Mages and Mendelsohn (1979), found that a meaningful analysis of coping with illness must begin with a careful delineation of the problems that need to be overcome. In cancer, the problems are generally based on the reality of the illness which determines, to a great extent, the possible modes of response. They view the nature of the illness as the single most important factor for determining adjustment to the cancer. In addition, they feel that coping efforts must be viewed in the context of

each individual's personal background and within the social contexts in which efforts to cope take place.

Andreasen et al. (1972), in a study of hospitalized burned patients, noted that prior physical problems and premorbid psychology was significantly more frequent for those who made a poor adjustment than for those who made a good adjustment to their condition. They found that those who adjusted poorly had a greater frequency of change or stress in their life situation prior to their injury which may have further contributed to their injury adjustment.

The influence of life changes on coping with illness was investigated by De Araujo et al. (1973) in a study in which they examined the association between psychosocial assets (using the Berle Index of Life Change Score and the Schedule of Recent Experience) and the severity of chronic asthma (determined by the amount of steroid required to control the asthma). They found that patients with chronic intrinsic asthma who had variable life changes but scored high in psychosocial assets required low dosages of steroids to control their disease. They also noted that patients who rated low in both psychosocial assets and Life Change Score required only low steriod dosages. However, those patients who scored low in psychosocial assets and high in Life Change Score required high steriod dosage to control their disease. The researchers concluded that an increased need for clinical attention and medication to control chronic asthma was directly related to the patient's ability to cope with life changes and the extent of change in the patient's life.

Nuckolls et al. (1972), in a study of the relationship of psychosocial assets and social stress to the prognosis of pregnancy, concluded that if the Life Change Score was high both before and during the pregnancy,

then women with favorable psychosocial assets had only one third the pregnancy complication rate as compared to women with low favorable psychosocial assets. In the absence of high cumulative life changes, there was no significant relationship between psychosocial assets and complications.

According to Mechanic (1976), the extent of adequate defense patterns (those that allow an individual to maintain his or her sense of equilibrium and esteem in the presence of stress so that ordinary demands can be met) is dependent upon the type and availability of social support from family, the kinship group, the work environment, and the community.

Other factors influencing the coping with illness include the ability to successfully resolve the ambiguity of a situation (Shalit, 1977); the personality type and one's sense of confidence, one's attitudes, beliefs, and personal resources (Cohen and Lazarus, 1979); and, the nature of the illness itself and its relationship to the individual's personality (Blacher, 1970).

Summary. There is a vast amount of literature in the area of chronic illness. For the most, it is descriptive and is derived from the static position that individuals respond to illness either as a threat, loss, or as a crisis. Except in a few instances, the studies neglect to identify the personal meaning of illness, the salient problems as perceived from the perspective of those who are ill, the structural conditions in which the illness-related problems occur, the coping strategies utilized in reaction to those problems, and the ultimate consequences of the choice of management strategies. Therefore, the literature and studies, to date, neglect to provide any grounded theoretical bases for understanding how illness affects the daily experiences of those afflicted and the inter-

action with those with whom they are closely associated. This study attempts to address this gap in knowledge and, thereby, provide a basis for assisting chronically ill individuals in dealing with their problems more effectively.

## Section C: The Pregnancy

Physiological Factors. Benedek describes pregnancy as a "psychobiological process," that is, it is a condition accompanied by psychological as well as biological changes. The dynamics of the pregnancy are best understood if each of these factors are considered and understood (Benedek, 1970). The biological changes that accompany pregnancy are usually only temporary and involve other body systems as well as the reproductive system. The uterus and breasts enlarge. The abdomen increases in size to accommodate the enlarging uterus. The metabolism rate increases. Total blood volume expands; cardiac stroke rate and output increase. Renal blood flow and the effective renal plasma flow are significantly elevated. The glomerular filtration rate increases thirty to fifty percent above normal. The ureters dilate. Pigmentary changes are visible, especially on the face and abdomen. The chemical action of digestion may be affected so that nausea, heartburn, and other problems are common. Estrogen and progesterone levels increase; first supplied by the sustained corpus luteum and by the seventh week of pregnancy, hormone production is gradually taken over by the placenta. The placenta produces pregnancy-related hormones, chorionic gonadotropin and human placental lactogen. These are but few of the many physiological changes that occur during the pregnancy (Greenhill and Friedman, 1974), and (Wilson et. al, 1975).

The chronically ill pregnant woman experiences the same physiologic changes that accompany a normal pregnancy. However, in that situation, the changes that occur within a woman's body as it accommodates to the pregnancy and growing fetus can seriously affect the course of the illness. It is then imperative that the woman evaluate this new situation and readjust to the altered status of her illness. Likewise, the illness can adversely affect the pregnancy as a risk factor and increase the risks of morbidity and mortality to the mother and/or fetus (Burrow, 1965).

The complications associated with a pregnancy-illness may have an impact upon the pregnancy itself, upon labor and delivery, or upon the postpartum period. Frequently, there is an acute interim related to all three phases. The patient with cardiac disease, for example, is closely monitored during pregnancy because the pregnancy increases the work load of the heart and the heart disease decreases the ability of the heart to accommodate to that load. In fact, the stress of pregnancy may lead to cardiac failure under certain conditions. During labor and delivery, the heart must be monitored constantly and the work load of the heart caused by physical and emotional stress, during this time, must be reduced by taking the appropriate measures. Close monitoring of the heart must continue into the postpartum period when stress on the heart again increases and the body returns to its normal hemodynamic state (Ueland, 1978).

Psychological Factors. The psychological changes which accompany pregnancy are concomitant with the physiological changes. Pregnancy has been described as a maturational crisis characterized by intrapsychic disorganization that results from the interaction of physiological and psychological factors (Deutsch, 1945), (Bibring, 1961), (Caplan, 1961), (Benedek, 1970), (Rubin, 1975), and (Colman and Colman, 1977). These researchers

refer to the hormonal and bodily changes which accompany pregnancy as the physiological factors; to the resurfacing of old and the emergence of new conflicts as the psychological factors. These conflicts include the ambivalent feelings towards the fetus, anxiety and fears related to the mothering role, or unresolved feelings of childhood guilt related to problems of dependency-independency with the woman's mother. It was found that successful resolution of these conflicts leads to a higher maturational level of functioning. These researchers also identified the psychological properties of the pregnancy experience as emotional lability, fears for self and fetus, a turning inward as characterized by introversion, dependency needs, a sensitivity to the self and surrounding environment, fantasies and dreams about the infant-to-be, and changes in her body image.

Studies within the last decade approach the psychological aspects of pregnancy from various frames of reference. However, more recent findings tend to supplement the studies reported by the aforementioned authors. Deutscher (1971) assumes a family developmental approach in his study of pregnancy. He reports that the physiological and psychological changes which accompany the first trimester of pregnancy match the sex-linked differences between the man and the woman. They examine their past histories and present needs for potential working models of family organization and parent-child relationships. When quickening occurs during the second trimester, the couple begins to perceive the family unit as a triad and differentiate themselves from the infant-to-be as a separate generation. They begin "tuning-in" to the unborn infant by deciding on a name and practicing baby talk. During the last trimester, they more actively prepare for the infant's arrival. The process of family formalization continues even though the anticipation of labor, delivery, and

parenthood are accompanied by anxiety, fear, and uncertainty. The post-partum period is a time for integrating and testing the process of family formalization.

Shereshefsky and Yarrow (1973) approach the study of adaptation to pregnancy from a multidisciplinary point of view. The results of their study indicate that there are a variety of personality characteristics which, if taken as a set, tend to predict the degree of adaptation to a first pregnancy. These characteristics include a high degree of nurturing ability, ego strength, and the ability to visualize the self in the role of a mother. The study also revealed a correlation between a positive adaptation to pregnancy and motherhood and the absence of physiological disturbances during pregnancy. Their findings also indicated that most pregnant women experience heightened emotional sensitivity and lability with anxiety at a high level during the first trimester, low in the second, and at a high level again toward the end of pregnancy when labor and delivery are imminent.

The referenced literature does not record the psychological changes during a pregnancy that is complicated by chronic illness; however, it appears as reasonable to assume that these women would experience similar changes and that pregnancy could promote maturational growth. Likewise, she may experience the same changes in perception of body image, the same fears, an increase of vulnerability and emotional lability; however, the extent and contour of these changes may differ from those experienced by women with normal pregnancies because of her past and present attitudes and beliefs regarding the risks associated with her illness in conjunction with the pregnancy.

Maternal Tasks Related to the Infant-to-be. Different cultural backgrounds and different religious beliefs produce a variety of diverse attitudes and feelings in each of the partners as they contemplate the arrival of an infant into the family. An infant may be welcome or unwelcome by one or both partners for any number of value-based reasons. However, the woman with a chronic illness complicating her pregnancy has an additional set of choices which require her consideration. She must decide if she will allow or disallow herself to become pregnant; or, should she become pregnant, should she allow a pregnancy that may impose a threat to her emotional and physical well-being to continue. Once she decides to accept a pregnancy, she must also accomplish the tasks of a normal pregnancy, do what is necessary to secure a healthy infant, and begin the process of attachment to her infant within the limitations imposed by her illness.

Bibring (1966) notes three mental tasks required of the woman. First, a woman must believe that she is pregnant and incorporate the idea of the fetus into her body image. Second, she must gradually perceive the fetus as a separate being and not as a part of herself. Third, she must prepare for the physical separation of the infant from her body at delivery.

Rubin (1975) delineates four tasks of pregnancy. The first is the task of securing safe passage for herself and for the fetus during pregnancy by means of protective and avoidance behaviors. The mother-to-be seeks competent prenatal care and shuns physical, emotional, and social behaviors derived from folklore and other unreliable sources which she believes would be injurious to herself and to her unborn infant. The second task is the gaining of acceptance for the infant by significant

others, a "keystone" task of a successful pregnancy. Family bonds and alignments must be conceptually loosened and realigned as a measure for assuring acceptance of the new infant into the household. The third task involves "binding-in" to the infant, incorporating the fetus into the woman's entire self system which includes body image, self image, and ideal image. The rate and the extent to which the woman binds-in to the fetus is determined, for the most, by the nature of her fears, her motivation, and her wishes regarding herself and the fetus. During the first trimester, binding-in is minimal; however, after quickening, the pace increases. As her commitment to the infant-to-be grows, the woman corresondingly invests her time and effort in tasks that will increase the probabilities for a healthy infant and provide a safe and secure environment both in utero and after birth. The final task of the pregnancy interim, as stated by Rubin, is the act of giving of one's self to the unborn infant by means of two modalities, food and clothing. During the first trimester, she balances her value of the infant against the cost to herself. Throughout the second trimester she explores the meaning of giving and being given to. Finally, in the third trimester, she has a renewed awareness of the demands of pregnancy and her ability to adequately give.

Leifer (1977) found the most significant developmental task of pregnancy to be the acceptance and the emotional incorporation of the fetus. Her findings suggest that during pregnancy maternal feelings develop along a continuum. While there is little apparent attachment to the fetus during the first trimester, the woman develops a deep sense of closeness to her fetus with the advent of quickening. While she realizes that the fetus is a separate organism, she is also aware of the fetus as part of herself

and her husband. The results of her study lead Leifer to conclude that the extent of affective involvement of a woman with her fetus by the third trimester is an accurate predictor of maternal feelings for the infant after birth. Her conclusions support the work of Bibring (1966), Rubin (1975), and others who regard the successful attitudinal incorporation of the fetus as a maturational accomplishment.

## Section D: High-Risk Pregnancy

Technological advances in obstetrical care and in the treatment of chronic illness have improved the morbidity and mortality statistics for both mothers and their neonates. However, technology has also produced problems for both the providers and the recipients of the advances in health care. Health providers find that the complex medical management and technical care necessary for minimizing the risks of morbidity and mortality associated with a high-risk pregnancy sometimes work against the woman in terms of satisfying her physical, emotional, and social needs. The woman may find, for example, that the time required for learning or administering a complex regimen that will help control her risk-pregnancy requires time away from her family or it may interfere with her job responsibilities. Either may provoke a sense of guilt and affect her relationships with her family and/or colleagues. The literature further elucidates some of these problems.

Emotional Factors. Leeman's (1970) article on high-risk pregnancies reports his clinical observations of eighteen diabetic women who participated in group discussion sessions, examining the psychological problems associated with risk pregnancies. He noted that their complicated preg-

nancies produced a variety of emotional problems. They had a tendency to exaggerate the normal fears of pregnancy because of the increased risks and to exacerbate the problems already created by the diabetes. He found that the women coped with these problems by total psychological denial. It is important to note that these group sessions occurred prior to the recent advances in perinatology which increase the chances for fetal survival and, thereby, diminish some of the fears associated with the life and health of the fetus. There is no account given in this study of the physical and/or social factors that could affect either the woman's perception of the situation or the variety of strategies available for managing the attendant problems.

Stewart (1977), in an unpublished pilot study, interviewed ten women who had been hospitalized for premature labor. He found that coping with prolonged hospitalization because of premature labor was negatively affected by emotional problems such as ambivalence (about the infant), insecurities (concerning mothering), and guilt (having a child for reasons of expediency). Though the result of his pilot study provides some systematically collected and valuable information regarding high-risk pregnancies, his observations were confined to women who, upon entering the hospital, relinquished responsibility for management of their medical problems to the hospital personnel.

In a study based upon their personal experience, Merkatz et. al., (1978) found that in providing optimum care for the pregnant diabetic, psychological factors must be brought into consideration. These are identified as: 1) the influence of the illness itself upon personality stability and upon the individual modes of coping; 2) the concomitant stress of diabetes and hospitalization during pregnancy; 3) the develop-

mental tasks which are part of every pregnancy; and, 4) the perinatal factors as possibly affecting the ability to complete the normal tasks of pregnancy. These authors purport that chronic illness has psychological implications and sequelae, particularly, if the disease commences in childhood when close cooperation between the child and parent or health-care providers for effective management are required. Over the years the child will develop strategies for coping with the illness. Health professionals then learn how to respond to those mechanisms and consider them in further instruction, in anticipation of complying behaviors, and in therapeutic recommendations. When this individual becomes pregnant, the health team will impose upon her rigid diabetic controls to effect normal blood sugar. This sudden change in the medical regimen can be emotionally threatening to a woman whose treatment over the years by those in whom she trusted, differs in many respects. A newly diagnosed gestational diabetic, by contrast, needs to confront the reality of an unexpected illness and develop effective coping mechanisms for dealing with its threat before she can even begin to accept the therapuetic recommendations.

These researchers further noted that if a diabetic woman is hospitalized during pregnancy, she may feel a loss of autonomy. They found that many women developed anxiety concerning the outcome for the infant because hospitalization is generally not anticipated during a normal pregnancy. The stress of hospitalization is intensified if the woman is overly concerned for her spouse and dependent children at home. They also believe that a delay in accepting and bonding to the unborn infant can occur when a woman persistently and negatively fantasizes about that infant as a result of her exaggerated body image negativism, incurred by her chronic illness. There are other psychological factors that may interfere with

successful resolution of the developmental pregnancy tasks and subsequent maternal-infant interactions. These include separation of the mother and infant at birth, exaggerated fear of fetus well-being during pregnancy, or unresolved grief from a prior fetal loss.

Galloway (1976) emphasizes the stress factor for women who must confront and resolve the many problems associated with a high-risk pregnancy. The initial emotional impact, the generalized fears for self and infant, the insecurity regarding safe passage for the infant, and the uncertain waiting period until the infant's arrival all serve to produce intense psychological strain.

Cranley (1978) and Jasper (1976) both point out that diabetes can incur serious ramifications for the physical, social, and psychological well-being of the mother and the physical well-being of the fetus during the pregnancy interim.

R. Cohen (1979) states that if a woman has a condition that she perceives as becoming more serious because of the pregnancy, her capacity to accept the pregnancy and identify with the fetus may be reduced.

Klaus and Kennell (1977) and Mercer (1977) all suggest that any health threat to the woman may interfere with her ability to later attach to the infant. This may be the result of her time, effort, and energy being directed toward coping with the threat rather than toward the planning for and anticipating of the infant.

Snyder (1979) describes a woman with a high-risk pregnancy as one who is first of all experiencing childbearing and, secondly, as one for whom this experience has been classified as a high-risk pregnancy. She believes that health professionals have a tendency to place greater emphasis upon the later description almost to the exclusion of the former. She proposes a holistic model of the childbearing experience for meeting the needs of

these women more adequately. The model would serve as a guide for implementing nursing care for these women and would take into account all of the social, cultural, psychological, and physiological factors that are relevant to this experience.

Social Factors. A woman whose pregnancy is characterized as a high risk does not experience this pregnancy in isolation. Rather, she is an integral member of a broader social network which includes her family and home, her place of work, and her religious and cultural groups.

As Galloway (1976) points out, family life is frequently disrupted by the stress imposed by a high-risk pregnancy. The family may worry about the outcome and wonder if the risks to mother and infant are worth taking. Financial burdens may accrue because of the high cost of medical care associated with a high-risk pregnancy, for both during the pregnancy and for the infant following delivery. Pregnancy-illness management is intricately associated with the woman's cultural beliefs and the priorities she sets for meeting her own needs, her family's needs, and those of her infant-to-be. For example, a woman's reluctance to comply with medical recommendations for her high-risk pregnancy, Galloway attributes to the patient's giving priority to the aforementioned needs over that of following the medical regimen.

Snow et al. (1978), in a study of low income and a multi-ethnic clinic population with high-risk pregnancies, found a disparity in perception of the risks between those of the women and those of the clinic staff. They noted that a woman's explanation for her adverse symptoms and poor pregnancy outcome was seldom related to the causal factors attributed by the health team. Also, the identified risk factors and causal explanation given by the health team were not in agreement with those perceived by the patients. In some cases, the women identified elements of their preg-

nancy as risk factors which were not considered as such by those caring for them. These authors concluded that although both the patients and the health practitioners shared the common goal, that is, the birth of a healthy infant to a healthy mother, the management practices considered necessary for achieving these goals frequently differed. They attributed this discrepancy to differences in belief systems between the women and the clinic staff. What each believed had an influence on the prescription of and compliance with the necessary regimen as well as the regularity with which the facilities were used.

## Summary

A review of the literature pertaining to illness and pregnancy adaptation demonstrates the wide variety of problems and adaptative tasks confronted by women in this situation. They have tasks and problems related to the illness, the pregnancy, the infant-to-be, their emotions, and to their social milieu as they live through the pregnancy interim. There is little doubt that management of a pregnancy complicated by an illness has considerable impact on these women and their close associates. It is not the intent of this study to examine the many questions regarding a woman's adaptation to a pregnancy that is complicated by a medical illness. My purpose is the development of a beginning substantive theory that will explain how women with high-risk pregnancies manage the problems associated with their daily experiences. The problem is approached from the Interactionist perspective as derived from the "Chicago tradition." This perspective considers the individual an active agent who is capable of shaping his or her environment by means of resolving the encountered problems and deterring the restraints on his or her ability to act.

# Chapter 4.

# THE RESEARCH METHOD AND TASK

The means adopted for exploring the management of the medical problems and the psychosocial processes, encountered by the women in this study, is the investigatory approach of Glaser and Strauss (1967). This chapter describes their method and associated fieldwork techniques in detail.

## Section A: The Primary Task

A study of the management problems incurred by women whose pregnancies are in jeopardy because of concurrent chronic illness imposes an arduous but vital task for the researcher. Their encounters with medical and common nonmedical problems in management of their condition are evidenced in the literature. The issues that confront these women as they relate to the milieu in which their pregnancy-illness is experienced and the divergent interactional patterns that these settings can provoke are not, however, clearly defined. Also, rarely alluded to are the effects of the interactional processes that take place between the woman and the health team, and her partner, and her family upon her perception of the experience and management of it.

The primary task of this study is that of generating a theoretical explanation for the psychosocial processes that occur in the management of a high-risk pregnancy that both emerges from and is grounded in the data.

## Section B: The Method

A longitudinal field study in conjunction with the constant comparative method of data analysis propounded by Glaser and Strauss (1967) is well suited for exploring the problems associated with the process of managing a pregnancy complicated by chronic illness. Pregnancy itself is a condition that progresses with time and provokes psychological and systemic changes within the woman. These changes variously affect the woman's life, particularly her social interaction and the settings in which it occurs. When the pregnancy is complicated by chronic illness, the health risks to the mother and fetus compound her management problems.

Gathering information by means of interviews and observations, as events occurred, allowed me to "enter into" the world of the individuals I was studying and to form a picture of reality as it was perceived by the interactants within those settings. The reality that forged their definitions of the problems to be managed, shaped their subsequent behavior, was observed within the context in which the behavior took place. The constant comparative method allows for the examination of the interactions and the comparison of responses to these problems as they unfold. In this way, I was able to grasp the subtleties of the situation and obtain insight into behavior which is often undiscerned when data collection and analysis are obtained by a more static method (Schatzman and Strauss, 1973).

Grounded theory generates a theoretical scheme that will explain behavior by identifying the basic processes of interaction as problematic situations within the social settings under study are encountered. The theory evolves from the systematic formulation of major concepts, the conceptual theoretical properties, and the relationship between the

two. Rather than searching for the frequency and distribution of events, the purpose of this method is the delineation of the conditions under which certain events occur, the conditions under which they vary, and their corresponding consequences. Because the data are qualified and not quantified, the predictive power of the theory generates hypotheses rather than verifies data. Theory derived by this method, as with many other methods, is constantly developing by means of modification, extension, and revision of new and available data.

Central to the logic of this method is the Interactionist orientation to individual behavior. Behavior evolves in response to meanings derived from an ongoing process of interactions of self with others within the existing conditions and modified by a uniquely individual interpretive process which bears upon the individual's past and future. This conception differs sharply from other more common perspectives which also view behavior as a response to meanings, but which state that attitudes, drives, motives, or societal functions and structure predestine behavior rather than behavior as a process or evolution within situations. By entering the world of individuals under study and observing their behavior as it unfolds within the surrounding conditions, explanations for that behavior can be derived that enlighten one as to their specific responses to situations, the meanings attributed to them, how these meanings are formed, and the consequences of these meanings.

Models for this method can be found in the work of Glaser and Strauss (1965) on terminal care and in Fagerhaugh and Strauss (1977) on pain management. Briefly, Glaser and Strauss examine the experience of dying and the management of it by the patient, the family, and the health team. They offer a theoretical scheme to explain who knows what about the

probabilities and time of death for the dying patient that they term the "awareness context." Fagerhaugh and Strauss emphasize the theoretical problems, associated with pain management, that are involved in the interactions between the patient and important others within the setting in which management occurs.

## Section C: The Sample

Setting. Two, large, teaching medical centers located on urban university campuses within the San Francisco Bay area provide the settings for this research. Both facilities provide clinics that serve as regional referral centers for high-risk obstetrical and neonatal care in northern California. They each have a reputation for their up-to-date technology, their advanced medical management techniques, and their low-cost set fee for care. These advantages attract women from a wide geographic area.

High-risk pregnancy care accounts for about sixteen percent of the obstetrical services provided by these two institutions. Represented in these clinics is a considerable variation in the types and degrees of severity of medical and obstetrical conditions that range from premature labor to kidney transplantation. Second year residents, under the supervision of faculty physicians, provide obstetrical care in the high-risk pregnancy clinics. The frequency of the women's clinic visits is dependent upon the severity of the condition that is complicating the pregnancy. At one medical center, private patients are seen during clinic hours by the faculty physicians.

These medical centers were ideally suited for recruitment and follow-up

of research subjects because they attracted a large population of women who presented a variety of substantial problems and attended prenatal clinics on prearranged dates and at specified times.

Gaining Access. A vital step in a research investigation is negotiating access to one's potential sample group. I developed this bridge of contact by seeking out my network of nurse colleagues who were willing to attest to my credibility and who had some affiliation with the aforementioned medical centers. From them I sought the names of medical and nursing personnel in charge of the obstetric services and information regarding the organization and management of these services.

With this information obtained, I established formal contact with introductory telephone calls to the administrators in charge of medical and nursing services. Meetings were scheduled so that I could submit my credentials, my organizational affiliation, and a copy of my research proposal. I extended assurance that I would maintain subject confidentiality and respect. I bargained a finished copy of my research findings for permission to contact patients and gather data. Permission was requested and granted to contact possible subjects, review medical records, sit in on prenatal visits, attend prenatal high-risk pregnancy conferences, and to make hospital visits.

Selection Criteria. Before entering the field, I determined five initial criterion by which the sample would be selected. They included: 1) the pregnancy was complicated by a chronic illness; 2) the woman was currently living with the father of the baby; 3) the woman was able to speak and understand English; 4) the woman was between 18 and 40 years old; and, 5) the woman had no history of psychiatric illness. After a preliminary analysis, the women were later selected for their type of illness,

for the degree of severity, for the approximate onset of illness, and for parity.

Recruitment. Subjects were recruited after ascertaining their eligibility for the study. Before each prenatal clinic, I reviewed the records of patients, to be seen that day, for those who could match my earlier criteria. I contacted those women in the privacy of the examining rooms, introduced myself, presented my qualifications, and explained the purpose of my study. Those who consented to participate were presented with a consent form for their perusal and signature. (See Appendix A. for a copy of this and other consent forms.)

Of the subjects contacted, three refused to participate in the study. One stated that she was working and felt that it would be difficult to arrange an interview time that would be mutually convenient. After time for consideration, another woman replied that her partner did not want her to participate in the study. The third woman offered no excuse. Assurance of confidentiality and anonymity was given to all of the women.

The majority of the subjects were recruited during their second trimester; however, two were recruited during their first trimester and two during the early weeks of the third trimester because their situational profile could maximize the variables for theoretical sampling.

Description. The composite of the final sample of twenty women is summarized in Table 1. Twenty-two women were originally recruited, but two were dropped. One of the two had a multitude of home problems and it appeared to me that the interviews might possibly contribute to her anxiety. The other woman was unable to offer any insight into her behavior, she was later diagnosed as having phenylketonuria and perhaps mental re-

TABLE 1

CHARACTERISTICS OF SAMPLE

| Code | Age | Parity | Race | Type of Illness | Duration | Other |
|---|---|---|---|---|---|---|
| 01 | 21 | 1 | Mongolian | Thalassemia | Hereditary | |
| 02 | 23 | 0 | Caucasian | Diabetes | 12 years | Possible kidney damage |
| 03 | 25 | 0 | Caucasian | Epilepsy | 10 years | |
| 04 | 31 | 2 | Caucasian | Cardiac murmur | Pregnancy | Dysplasia |
| 05 | 23 | 1 | Caucasian | Lupus erythematosus | 3 years | Possible kidney involvement |
| 06 | 30 | 0 | Mongolian | Mitral stenosis | 18 years | Mitral commissurotomy, 1975 |
| 07 | 30 | 1 | Caucasian | Lupus erythematosus | 7 years | |
| 08 | 22 | 0 | Caucasian | Diabetes | 13 years | |
| 09 | D | R O | P P | E D | | |
| 10 | 33 | 2 | Caucasian | Diabetes | 30 years | Kidney transplant retinopathy |
| 11 | 26 | 0 | Caucasian | Diabetes | 2 years | |
| 12 | 28 | 1 | Caucasian | Chronic pyelonephritis | 9 years | |
| 13 | 24 | 2 | Caucasian | Chronic hypertension | 6 years | |
| 14 | 26 | 0 | Caucasian | Diabetes | 8 years | |
| 15 | 26 | 1 | Caucasian | Asthma | Pregnancy | |
| 16 | 30 | 2 | Negro | Chronic pyelonephritis | 8 years | |
| 17 | D | R O | P P | E D | | |
| 18 | 26 | 3 | Caucasian | Chronic hypertension | 6 years | |
| 19 | 37 | 1 | Caucasian | Hypothyroidism | 22 years | |
| 20 | 35 | 1 | Caucasian | Chronic pyelonephritis | 9 years | Colitis, migraines hx: premature labor |
| 21 | 38 | 7 | Negro | Diabetes | Pregnancy | Insulin Dependent |
| 22 | 25 | 0 | Negro | Lupus erythematosis | 4 years | Severe chronic hypertension |

tardation contributed to her inability to express abstract feelings. Eighteen of the subjects were clinic patients and two were private patients. The subjects represented a variety of social classes and educational backgrounds. (See Appendix B., Demographic Data Sheet, for the types of demographic data that were collected for each of the subjects.)

## Section D: Data Collection

Data were collected from the women under study, from their partners, and from the health professionals. In addition, clinic and hospital records were reviewed for demographic and medical data.

The method for collecting and analyzing data for this study is unlike the more conventional methods whereby the collecting process is one of many separate and distinct research tasks. This study is based upon the constant comparative method designed, by Glaser and Strauss (1967) and Glaser (1978), to generate a grounded substantive theory. This model requires that the data collection process be controlled by the emerging theory. For this to be accomplished, the work of collecting, coding, analyzing, and deciding what further data are required and where they can be found, must happen concurrently. Glaser and Strauss (1976) label this process theoretical sampling. However, for the sake of clarity, each step of the sampling will be presented and described separately.

Interviews. I conducted a total of ninety interviews, of one to two hours in length, with twenty women over a period of a year. I had two prenatal interviews, one during the second mid-trimester and one during the third mid-trimester, with all but the later recruited women. Those, recruited during the third trimester, I interviewed at the time of recruit-

ment and later in the trimester. All of the women were again interviewed both two to four days postpartum and six weeks postpartum. Additional interviews were scheduled for those who had a significant change in the status of either their illness or pregnancy.

Variations in individual actions and interactions occur because time, place, conditions, interactants, and other variables are in constant change. Interviews conducted at different times, in different places, under different conditions, and with sometimes different participants, afford "slices of data." Because I could better capture the idea of high-risk pregnancy management as a process, I also interviewed the women informally within different settings and among different interactants. I interviewed all of the women during most of their prenatal visits and observed their interactions with the health team. I attended clinic conferences at which time the patient's medical and obstetrical status and related plans for management were discussed with her by the residents and teaching staff. Periodic telephone calls were made to the women if they missed a prenatal visit or were approaching term. If a woman had a prenatal hospitalization, she was visited and informally interviewed. I also observed interaction between the women and health team when the latter performed amniocentesis or administered the oxytocin challenge tests for fetal well-being.

The interactional components were furthered when I interviewed eleven of the twenty partners to determine their perception of the high-risk pregnancy situation and their role in daily management routines. Their interactions were also observed whenever the two were present during an interview, a clinic appointment, or a hospital visit. I set up appointments with six health professions for the purpose of obtaining their verification

of my observations, their views of high-risk pregnancy management, and of determining their perception of the problems encountered in this management.

Data Recording. Ninety percent of the interviews were tape recorded. On five occasions, there was too much environmental noise for a clear recording of the interview; on four other occasions, I did not have my recorder. In both cases, I resorted to taking extensive notes which were typed later the same day. Since the women were aware that my data were to be used for research purposes, my taking of notes did not appear to distract them during the interviews. Taped interviews were transcribed verbatim either by myself or a professional typist.

Initially, the interviews were unstructured which allowed for the data to take focus. As categories began to emerge, the interviews became more structured in their format, permitting the expansion of theoretical properties of the categories and the verification of the hypotheses. However, at the same time, participants were given the opportunity to discuss subjects that were of importance to them, furthering the inclusion of possible pertinent and valuable data.

Validity. I determined the consistency of information given by the participants by paraphrasing their responses and reintroducing the same material for their further elaboration in the same and/or subsequent interviews. My persistent and frequent contacts with the women promoted, I believe, trusting relationships which enhanced openness and encouraged discussion. The frequency of contact also provided me the opportunity to verify earlier observations within the context of changed conditions.

Controlling for Researcher Bias. "Data collection does not take place in a vacuum. Perspective and perceptions of social reality are shaped by

social perceptions and interests of both the observed and the observer as they live through the present." This statement by Vidich (1969) implies that both the observer and the observed take a previous history with them to the research context. Both bring with them their unique life experiences that may include education and training, beliefs, attitudes, interests, values, and personality characteristics. These factors conjoin to form a frame of reference from which interpretation of interactions and events are made.

In field research, the various forms of observation and interview, necessary to the research, involve the process of interaction. Thus, a conscientious examination of one's own values and interactions is essential to the research. Subjective interpretations and responses are acknowledged, understood, controlled and utilized to the advantage of the researcher. While certain aspects of experience and training may, in some aspects, initially mislead the researcher, this background can provide insight into behavior, enable the ordering of observations and interviews, and provide ideas for initial hypotheses. Later on, however, as data accumulate and are analyzed, these initial interpretations and hypotheses may be modified and supplanted by concepts and relationships found to be more relevant to the substantive area under investigation (Schatzman and Strauss, 1973).

I found that my training as a professional nurse provided me with particular insight into and understanding of the medical context in which this study is centered. I am able to understand the purposes and the importance for particular medical measures involved in management. Over the years, as a nurse interacting with individuals under sometimes difficult and stressful conditions and as a woman experiencing childbearing, I learned

how to empathize. This learned empathy facilitated my "taking the role" of the women in this study. It has been a valuable and essential asset for viewing the problems of these women from their perspective and for understanding their behaviors (Schatzman and Strauss, 1963). But, as one trained in the objectivity of research methods, I was always able to move back from the situation and compare what I heard and observed in a situation with one woman with that which I had observed and heard from others in similar and different situations. This comparative knowledge became my base for a grounded theory.

## Section E: Data Analysis

The constant comparative method of data analysis is a systematic inductive method of theory building based upon data gathered in the field. This method, established by Glaser and Strauss (1967) and Glaser (1978), can be divided into four stages for explanatory purposes. The first stage is that of substantive coding, the development of categories and their properties from the empirical substance of the data. The second is that of theoretical coding, the establishment of relationships between categories, sometimes referred to as linkages. The third stage is that of delimitation of theory, reducing the bulkiness and establishing the boundaries of the theory. The final stage is that of writing the theory that evolves from the end products of the earlier stages.

Substantive Coding. The first stage in the process of data analysis consists of open coding. The data are read, line by line, and each event (action, expressed thought, experience, or happening) is coded as a concept and written in the margin. These concepts are then coded into cate-

gories or concept clusters that seem to fit together (Stern, 1980). Theory is grounded through this process of coding categories from the substance of the data rather than from coding data into preconceived categories that are derived from a theoretical framework or from the literature. One of the first categories to evolve from my data was "strategies for keeping the pregnancy-illness under control." It was inferred from statements such as "I've been staying in bed except to go to the bathroom" (resting-physical strategy); "Since I've been pregnant, I've worked harder at keeping my illness under control" (motivation); "I do a little bit and then I rest" (pacing-physical strategy); "If I weren't pregnant I would do more and push myself harder" (doing less-physical strategy); "Before the pregnancy I could walk like this, now I walk like this" (activity change-physical strategy);and, "I use positive thinking" (cognitive strategy).

As each incident is coded into a category, it is compared with concepts coded into the same or different categories. By making these comparisons, one begins to generate ideas about the theoretical properties of each category; that is, how is the cluster of concepts coded about a category linked together. The linkage could be the conditions under which it is either enhanced or minimized, the consequences, or the relationship to other categories. Referring to the example of "strategies for keeping the pregnancy-illness under control," I knew before entering the field that individuals with a chronic illness utilize a variety of strategies to keep their illness under control. What was not known was how the pregnancy made a difference in their control strategies. When comparing incident with incident coded under the same category, some sense of this difference begins to emerge. It was found that motivation to keep

the illness under control is higher (cause). The woman is motivated by her desire for a healthy baby (a consequence). In comparing this code along varying degrees of severity of the illness (intensity), it was noted that the number (range) of strategies needed to keep the illness under control increased with the severity of the illness. The pregnancy often made the illness more difficult to control or increased the severity of symptoms (an interactive effect). Similar to what was noted in the literature, two types of strategies were engaged for keeping the pregnancy and/or illness under control, physical strategies such as staying in bed and pacing and cognitive strategies such as positive thinking.

While coding, one needs to constantly ask a set of questions that will identify the major problems articulated by the participants of the study, the techniques they utilized to cope with these problems, and the effects of interactions and structural conditions upon the two. Some of the problem identifying questions included: "What is going on here?" "What seems to be the major problem?" "How is it being handled?" "What else is going on?" "Who else is involved?" "Where is it taking place and under what conditions?" "How does it affect what is being done?" "How does it affect outcome?"

At a particular point in the analysis process, two types of categories begin to emerge that differentiated the categories into levels of abstraction. One type of category is abstracted directly from the data while the other type is constructed by the researcher. Those taken from the data tend to describe behavior such as the category, "seeking information"; those constructed by the researcher tend to explain that behavior such as the category, "assessing the risks."

Open coding from the substance of the data serves several purposes. It fractures the data which allows for transcendence of its empirical

nature and renders it more abstract so that apparent unrelated concepts can be related. It directs the process of theoretical sampling. It allows for the verification, densification, expansion, and saturation of categories. Ideas, concepts, and attitudes originating from the researcher's training, reading, experience, and interests are in continual comparative interplay with the actual objective data, but are modified and incorporated into or discarded from the theory in accord with their relevance to the actual data. Categories that emerge by this process constitute the development of grounded theory.

Theoretical Coding. Theoretical coding is the establishment of hypothetical relationships, or linkages, between categories. Data that have been fractured by substantive coding are woven back together by theoretical coding into a conceptual scheme that can be used to explain patterns of behavior. As coding continues, the unit of comparison changes from comparing incident to incident, as in substantive coding, to comparing incident with properties of categories. As in the development of theoretical properties of categories, this process is aided by utilization of a set of concepts called theoretical codes (Glaser, 1978). They sensitize the researcher to possible relationships that may exist between the categories. While coding an incident against the properties of the categories, the data are further explored for questions such as: Does this incident indicate a degree, a range in a broader continuum? Does it indicate a phase, stage transition, or a process? Is it a tactic or a strategy of a broader process? Does it denote cause, condition, or consequence of behavior? Does it refer to a context in which behavior occurs?

In initial coding of incident with incident, the concept of "effort" evolved as a property of the category "controlling the pregnancy-illness."

In comparing incidents coded as "effort" it was noted that the amount of effort required to control the pregnancy-illness increased in ratio when compared to the extent of heightened severity and instability of the illness. After that awareness, each incident that was coded as "amount of effort needed to control" was compared with both the extent of the severity and the degree of stability of the illness. Through this type of comparison it was learned that one of the most important factors affecting the willingness to put forth effort was the woman's "perception of the risks" to self and fetus. Perception of the risks became more keen as the illness became more severe and unstable; in turn, her more serious condition influenced the amount of effort the woman felt necessary to control the pregnancy-illness if she wanted assurance of a positive outcome. In this way several categories denoting range, degree, cause, condition, and consequences were linked together.

As the process of building connections continues, the framework for a grounded theory begins to emerge. At first the categories appear hazy, but they become more integrated and the theory more pronounced as the analysis continues. For example, it was noted that the women's "perception of risks," as associated with their pregnancies, develop in the process of assessing. The women utilize a variety of strategies to determine the approximate degree to which they and their fetuses are at risk. These strategies include "tuning into cues" that originate from within the self, from the fetus, from the health team, and from others; and, "gathering information" from results of objective tests of maternal fetal well-being. As they interpret cues and ponder the information, they begin to perceive that the self and fetus are, to some degree, at risk. Furthermore, these women often express concern about the risks in terms of the options available

to them for controlling the pregnancy-illness with comments such as "I realize that the medication might have a negative effect on the baby, but if I don't take it I won't be able to breathe"; or, "it is difficult to stay in bed when there are other children to take care of, but if I don't I may lose the baby."

From repeated comments such as those, it becomes obvious that the women are balancing the increase of the risk probabilities with the taking of action to control the illness or pregnancy by assessing these in terms of self, fetus, and family against the benefits of the medication. In this manner, assessing, balancing, and controlling evolve as the major implementing processes of the central variable. Around this variable, all the categories can be organized into a theoretical scheme that is able to explain the means by which the women in this study attempt to resolve their basic problem of how to achieve a healthy infant while at the same time securing their own health. Commitment to this scheme followed after continued verification by means of techniques such as repeated theoretical sampling, more structured interviews, and making further comparisons with the literature.

Further Sampling. Further sampling is often required. Because the purpose of theoretical sampling is to generate as many properties of categories as possible, to note the degree to which these properties vary according to diverse conditions, and to verify relationships between categories, initial data are collected and coded into categories. The categories often prompt questions about possible relationships among them or or between a category and the problem under study, directing further sampling. For example, a hypothetical question of relationship is posed by this study was: the heightened severity of the illness versus the more willingness

to comply with the regimen. Women with varying degrees of severity of illness were sampled and the collected data compared. Cases in which the illness was severe but the prescribed regimen was not followed, the question "how come" was asked of the data. Relevant questions pondered were: What conditions exist so that the women are less willing to comply? What effects will their lack of compliance produce? Further sampling revealed that philosophical differences between the health team and the women in terms of how the illness should be managed were affecting compliance. That finding produced a still further question: How does a woman's past experience in managing her illness affect how she believes her illness should be managed during the pregnancy? This question directed sampling of women as to the onset of the illness. By means of this joint process of data collecting, coding, and making comparative analysis, categories were eventually saturated; that is, no new qualifying conditions or theoretical properties of a category emerged when making comparisons. Linkages were established between the categories and a theoretical framework evolved.

Comparison of apparent incomparable individuals or groups of individuals can be made because it is the specific variable (i.e., experience in managing an illness) that is compared, not the group of individuals. For instance, primiparas may be compared with multiparas; or, those who developed their illness during childhood versus those who developed it during the pregnancy. These comparisons can be made regardless of population characteristics such as race or social class; however, that is not to say that the process of analysis may reveal such a characteristic as relevant.

## Section F: Theory Development

Delimiting the Theory. Once there is commitment to a theoretical scheme, the task becomes one of delimiting the theory to that scheme so that the two major requirements of a theory, parsimony and scope, may be achieved. Delimitation occurs at both the theory and category levels and is comprised of three steps.

The first step is the reduction of the number of categories. As coding continues, underlying uniformities among the categories or their properties are noticed. The uniform characteristics help to consolidate several categories under one generalized heading. For example, while working with the data, I found that all the categories "seeking information" could be grouped together. Now as a group, it could be related to the theory's implementing processes of assessing, balancing, and controlling in a causal relationship; that is, "possessing adequate information" facilitated the woman's ability to assess, balance, and control the pregnancy-illness which resulted in advancing her chances for a positive outcome. The other categories could be organized around the three implementing processes in either a causal or consequence relationship in the same analytic manner.

Reduction delimits both the terminology and the text. It pushes the concepts to a higher level of abstraction so that the generalizability of the theory is increased. If the theory's implementing processes of managing by assessing, balancing, and controlling are derived from and apply to the management of a pregnancy complicated by chronic illness, then, by means of reduction, its level of generality is increased to where the theory could apply to the management of pregnancies that are at risk

due to other causes. It might also be applied to the problems created by the management of extended chronic illness or of stressful life events.

The second step is the establishment of the boundaries of the theory. Categories that neither fit nor extend the theory are deleted. Perhaps further sampling is pursued if there is any hint that the data will contribute to tightening of the theory.

The third step entails saturating the categories so as to give density to the theoretical concepts. After the theoretical scheme is established and the theory is trimmed to a workable size, it is outlined and studied so that categories which require further development become obvious. If further development appears necessary, the cycle of theoretical sampling is repeated. It is recalled that saturation occurs as new incidents are compared with incidents already coded and it is noted that no new qualifications are being added to the category. Coding into the category need not be done unless certain incidents will contribute to clarification of the theory. However, coding continues if there is discovery of an incident which adds a new dimension to a category. In this study, once it was established how experience had a positive effect on a woman's ability to manage her pregnancy-illness, incidents applicable to experience as they positively affect the ability to manage were no longer coded into the category of experience. However, if I came across a case in which experience tended to have a negative effect on her ability to manage, that was coded and I attempted to identify, by further comparison, the varying conditions that led to this event. If the newly defined situation relates to new conceptual dimensions rather than to mere description of events, the decision as to the feasability of further data collection is made. The decision does not preclude extension or revision of the theory if conditions change and new categories, and their properties, emerge.

Memos. Memos are the researcher's storehouse of recorded ideas. Writing memos is a technique which permits advancing beyond description of data to that of theory development. Memos are usually generated when comparing data. An idea may occur to the researcher when analyzing how an incident coded into a category may relate to other incidents coded into that category and thereby developing its theoretical properties; or later, how categories might relate to one another and integrate the theory. These ideas are written as either an extended or brief memo, contributing to the shaping of the formulated theory.

While there are no firm rules for writing memos, to be of value they must deal with abstractions that are embedded in the data rather than with objective data. They should be written at the time the ideas are generated so they are not lost to the mind while processing incoming data. The memos are developed in a manner that facilitates sorting them for subsequent theory organization and writing.

Writing the Theory. When the researcher is convinced that the theoretical framework is cohesively and systematically formulated and is characterized by parsimony, density, and scope, the theory can be articulated and put into written form. The organization of the sorted memos forms the basis for an outline to guide the final writing. However, throughout the writing, analysis continues to refine and integrate the theory.

Summary. How women manage the problems associated with a high-risk pregnancy is explored and formulated in a longitudinal field study based on the constant comparative method of data analysis, developed by Glaser and Strauss (1967) and Glaser (1978). The method, as detailed in this chapter, presents theory as process which evolves over time and gives

direction to both data collection and analysis. Its purpose is to explain what is happening in the social setting in which management occurs. Data from twenty women (their partners and attending health teams) were gathered by interview, observation, and from review of medical records.

# PART TWO

# THE FINDINGS

# Chapter 5.

## MANAGEMENT RELATED CATEGORIES COMPARED IN TWO CASE HISTORIES

Neither Diane nor Janet have ever known the nonthreatening reality of a typical pregnancy and the anticipatory joy of a near-certain positive outcome. Both women are diabetic. When each of them became pregnant they knew, or soon learned, that the precondition of diabetes can potentially preclude an outcome of a healthy self and infant. Worry, concern, and specialized problems are interjected into their daily lives. Their pregnancies are classified as at increased risk.

The case histories of Janet and Diane are presented to accent the elements essential to my perspective of management. They are evolving stories of interaction occurring within the specific settings of the home, clinic, and hospital. Each enacted drama makes visible the dimensions of management and the problems associated with the individual's attempt to manage the basic task of minimizing the risks enbedded within the pregnancy. While it is obvious that each woman worked hard at her managing task, the conditions under which Janet was managing were more favorable than were Diane's, facilitating her task and increasing her probabilities of achieving a positive outcome.

Both Janet and Diane are white, married women, who were twenty-six and twenty-two years old, respectively, at the onset of this study. Each had been diabetic since late childhood and neither had planned for the pregnancy.

Section A: Two High-Risk Interludes, Case Histories

Janet and Frank. Janet had an "easy diabetic life" and never considered her diabetes as a problem. As a child, she cared for herself well and abstained from sweets unless she required them to contain a hypoglycemic reaction. Except for an increase in her insulin dosage, transition into adolescence was medically uneventful. She did not require the constant supervision of a physician because her mother and sister were nurses and could assist her in maintaining control of the diabetes.

Approximately eighteen months before the pregnancy, Janet and her husband visited the center for high-risk pregnancy and consulted with a health team member regarding potential problems associated with a pregnancy complicated by diabetes. They were advised of the many problems common to diabetic pregnancies, however they were told that with proper management these problems can be minimized increasing the likelihood of a positive outcome. The couple felt sufficiently reassured that if she should become pregnant, "everything would turn out okay."

Once pregnant, she considered herself as "normal" and her diabetes very much under control. Although her insulin dosage was once again increased, she did not "feel helpless in managing the diabetes," but rather, she felt "very much at ease." She was methodical in her management tasks. She painstakingly recorded the results of her daily, self-administered urine tests and her dosages of insulin. These accounts she brought for the physician's perusal on each prenatal visit. Throughout the pregnancy, she had several hypoglycemic reactions which she attributed to insufficient food ingestion. Though she felt reassured that her blood sugars remained within the normal range, she did worry about the long-range consequences, for herself, of the interactive effects of her pregnancy in combination with the diabetes.

She placed considerable confidence in the health team and respected their ability. "It helps when you are going to someone who knows what they are doing." She realized that she would be "watched closely during the pregnancy" and that the status of her illness and pregnancy would be determined by frequent tests.

Janet was deeply commited to the well-being of her fetus. "I am thinking for two people now. I can take care of myself, but I also have someone inside who is dependent upon me." Generally, she was quite positive in her thoughts about her fetus. She frequently imagined its appearance and wondered about its sex. She enjoyed preparing the infant's nursery and shopping for furniture. Her fetus was quite active and it satisfied her to feel its movement.

At times her confidence waned and she would slip into a state of concern for her fetus. She wondered if after birth it would be hypoglycemic, possibly malformed, or retarded because of improper nutrients in her own diet. However, she did not believe the infant would be diabetic "because her husband was not diabetic."

During their married life, Frank (her husband) had become familiar with Janet's diabetes management and trusted her competence. However, he had a gnawing uncertainty about the possible effect on the fetus of her increased dosage of insulin. His fear was not altogether unfounded. He had just enough information to know that certain drugs, given to the woman to benefit her, may adversely affect the fetus. But, when he was informed that the fetus' supply of insulin is independent of that of the woman's, he was greatly relieved.

About four weeks before delivery, Janet began to retain fluid and complained of the "itchies." At her next prenatal visit, her blood pressure was found to be elevated. She attributed her symptoms to excessive activity and consumption of salt. She was briefly hospitalized for a mild case of preeclampsia. The noise level, associated with the organizational activities of the hospital, extended beyond her level of tolerance and she requested dismissal.

Janet's sense of confidence in her ability to manage her diabetes, and mild complication, was again evident when she related that she overheard the hospital physicians state that it was she they worried about, not her fetus. Even in view of that threatening statement and the preeclampsia, she believed she could take care of herself and believed with her "diabetes under control," that she could control the preeclampsia with bedrest. Even during that period of bedrest, she maintained a sense of independence in self care. "I felt I had myself under control and that I knew what I was doing."

When the fetus was 38 weeks' gestational age, induction of labor was indicated. She was given an epidural, but because the catheter was discovered not to be in place when she was transferred from her bed to the delivery table, she had, in fact, endured the labor without medication. On the second day of induction, she was delivered, vaginally, of a seven pound and eight ounce baby girl. She "was pretty proud" of herself because most diabetics do not have vaginal deliveries and it made "me feel good to go through something most people take for granted and still come out okay." There were no post-delivery complications for either Janet or her infant. The infant's apgar score was five, at one minute after birth, and eight at five minutes. The infant was allowed to room-in with Janet.

The attachment behaviors expressed to the infant were positive, "I already feel attached to her." She was tuned-in to the infant's feeding needs and breast fed her on demand. She held her infant closely. When noticing a forceps mark on its face, she concernedly told the infant that "everything will be okay."

At six weeks postpartum, Janet described her pregnancy, in retrospect, as an enjoyable experience, "a good nine months." "I've only had her for six weeks and, yet, there already is this love I can feel." Because it was important to her to perceive her diabetes not as an uncontrollable handicap, she enjoyed comparing her pregnancy and delivery experiences to those of "normal" women. She so implied when she stated, "I have a better feeling about myself that I have done the things normal women can do, like having a baby vaginally and a normal-sized baby that did not have lung problems." She had felt throughout the pregnancy that everything would work out because "back over my years as a diabetic, I knew that I had always taken good care of myself; and, it paid off." She had vascular changes in her eyes during pregnancy, but their self-correction after delivery she even attributed to the good care she had given herself during pregnancy and her early years.

A husband and wife relationship frequently undergoes change after the infant's arrival. Janet claimed that her major postpartum adjustment was that of relationship realignment. However, she had no doubt that she and her husband would have more children in the future.

Diane and Alex. As a child, Diane's diabetes was difficult to control and she was frequently hospitalized; as an adolescent, the control of the diabetes was less problematic. It was her understanding that the diabetes changed as the body changed. She had always faithfully followed her diabetic diet and tested her urine four times a day until, in recent years, she could determine the blood sugar elevation by the way she felt and discontinued the frequent testing. Overall, she had adjusted to her diabetes, but felt that "sometimes it is a pain in the neck, but I am use to it."

Because of her belief that the diabetes changes in relation to changes in the body, Diane began to again test her urine more frequently when she learned that she was pregnant. Also, "because of the baby" she was "extra strict" with her diet and very aware of how the changes in blood sugar could affect the fetus. She related several hypoglycemic reactions, during early pregnancy, to nausea and lack of appetite, again connecting the

reactions to regulation difficulties associated with the body changes of pregnancy. Whereas she continued with the prescribed insulin dosages, she did manipulate her diet according to how she felt and made certain that she included the nutrients necessary for fetal growth and well-being.

Diane did not basically understand the type and extent of problems that she could encounter during her pregnancy. She had earlier gained certain layman's knowledge of the diabetic and pregnancy from reading and minimal information about management from the prenatal clinic where they did not tell her "very much."

Diane's gynecologist referred her to the clinic center for high-risk pregnancy. His refusal to care for her pregnancy made her feel like a "freak" and she resented having "to chase around to find a place to go." However, when making contact with the center, the health team related to her how they had considerable experience with pregnant diabetics, with good results, and she felt reassured.

Various types of fears regarding the outcome for the fetus are common among most couples during the woman's pregnancy. Diane and Alex, her husband, were no exception. They had the normal fears as well as the fears associated with a pregnancy complicated by diabetes. They both feared fetus malformation. Diane associated malformation to her failure to provide the growing fetus with proper nutrients, including vitamins. Alex's fears originated from his reading that diabetic mothers have a high incidence of malformed infants. After an untrasonogram, both were much relieved to learn that the fetus, indeed, possessed all of its limbs. Diane also feared retardation, but not the possibility that her fetus might inherit the susceptibility for diabetes. "I wouldn't wish it on my child, but it could live with it. I live with it." She also projected the normal concern of a parent-to-be as she wondered about the responsibilities of properly raising a child.

Although Alex had continuing concern for the fetus, he had utmost confidence in Diane's ability to competently manage her diabetes. During the first trimester, she concurred with him when she knew that her "sugars are fairly well under control." However, at this time, she had an episode of vaginal bleeding and worried that it would cause her to lose her fetus. The results of an ultrasonogram reassured her that the fetus was in utero and very much alive. She remained in bed until the bleeding stopped. While at bedrest, Alex gave her support by assuming responsibility for the household chores. Diane returned to her job as parttime switchboard operator after the pregnancy was again stable.

Toward the end of the first trimester, Janet experienced mild inner turmoil. "So far, this has not been a good experience because of the worry about the baby, not feeling well, and having to stay in bed." Her anxiety was also reflected in her uncertainty about labor, about delivery which she viewed as "far off at this point," and about another pregnancy.

Alex's mother was hospitalized and died of cancer during Diane's second trimester. They had visited her daily and were distressed by her death. During this same period of time, they had purchased a home and intended to renovate it before the infant's arrival. Janet felt run down and seemed to contact every virus that came along. Her blood sugar was ranging from the high 200 mg/100 ml level to the low 300 mg/100 ml. The health team considered these levels too high for the safety of her fetus and hospitalized her.

The team attempted to regulate her blood sugar by decreasing her caloric intake and by increasing her insulin by amounts larger than the one to two units to which she was accustomed. Because of organizational structure that limits the time the team could spend with Diane, they had little patience for listening to her explain that her body had developed a tolerance for high sugar levels and if they were to suddenly lower it, she would experience hypoglycemia. They continued to manipulate her dietary intake and insulin dosage until she began having insulin reactions, which they chose to diagnose as "stress episodes."

When there are differences of opinions or perceptions about a matter, conflict generally ensues. The team accused Diane of not following her diet and neglecting to monitor her urine sugar while at home; she retorted with "how do you know what I do." Their continual manipulation incited her to feel "helpless and powerless." She could not comprehend why "nobody would listen" to her when she "knew what was going on." She attributed two reasons to the team's incorrigible behavior. Either they were "too proud to admit that I understand how my body works better than they do" or they were using her as a "guinea pig" for learning how to manage diabetes. Having had all she could take, she made the decision to leave the hospital and return home.

Fortunately, a third person called in an internist who verified that, due to drastic insulin and diet changes, she was indeed experiencing insulin reactions and not stress episodes. Divergent perceptions in a matter of strong beliefs can cause a person to doubt their mental capability and it was reassuring to Diane to realize that she was not going "crazy."

The conflict with the health team, while hospitalized, made it difficult for Diane to return to the clinic where she would have

to face her antagonists. However, she was well aware that she "needed them to care for the baby," if not for her diabetes. Nevertheless, she worked hard to cooperate with the health team and conceded that the high 100 mg/100 ml range was a good sugar level for her.

Because of these problems and the diabetes and bleeding problems of early pregnancy, Diane did "not feel real attached to the baby." She had, nevertheless, prepared the nursery and attended a baby shower given her by church friends. She even expressed interest in participating in a prenatal class which, in fact, she never realized.

As term approached, she continued to feel concern because of her inability to control her blood sugar and feared that her infant would not only be large, but possibly hypoglycemic. To allay her fears, she began to ask questions of the health team about tests for maternal well-being and how the diabetes might affect the fetus. She very much wanted a vaginal delivery rather than a cesarean section because she thought a cesarean delivery would not be "too good for me or the baby."

Near the 36th week, Janet experienced discomfort, "flu" symptoms of diarrhea and vomiting, "on and off" contractions, general malaise, and unusual abdominal largeness. Since she had a prenatal visit scheduled for that time, she decided to take a packed suitcase with her in the event that the health team would decide to hospitalize her. After discussing her case, the health team decided to hospitalize her because she was approaching term.

Approximately five days after admission, in her 37th week, four attempts to induce labor were made over a period of several days. Even though she was told that her blood pressure was elevated and her condition serious enough to warrant delivery, induction was continually delayed because, Diane was told, the staff was "too busy." She felt pushed around and alone; there was "no one here to help me." An attempt was finally made to remove some of the excess amniotic fluid. She found the procedure very uncomfortable.

After the fourth unsuccessful induction attempt, the decision was made to deliver her by cesarean section. The fetus was tolerating the stress of labor, but Diane had reached her level of tolerance and could take no more. She readily consented to a cesarean delivery in spite of her earlier objection to it. She felt afraid and "out of control." This was difficult for her to accept because she usually could maintain composure, no matter the circumstances.

She delivered a nine pound and two ounce baby boy. The infant's apgar score was six, at one minute after birth, and eight at five minutes. After Alex briefly saw and held his son, the infant

was placed in the intensive care unit because of hypoglycemia and a respiratory distress syndrome. Delivery notations in Diane's chart read "preeclampsia and polyhydramnios."

When Diane emerged from the recovery room, she was pleased to see that her husband, cousin, and some friends had remained at the hospital during her surgical delivery and early recovery. She felt a sense of support by their presence.

Soon after delivery, she developed a puerperal infection. She was treated with antibiotics, administered intravenously. Because of tissue infiltration, the catheter had to be inserted intraarterially. At this point she stated, "I've had it with being poked."

Diane had initial difficulty with attachment behaviors toward her infant because she could not see nor touch him for several days. These temporary feelings of detachment apparently were instilled during early pregnancy when she struggled with diabetes and bleeding problems and reinforced at the time of delivery. "I knew he was inside, I could feel him kicking. Then, I went to sleep. When I woke up, I knew that he wasn't there anymore, but that child over in that room was not my kid ... Maybe if it had been in the room where I could have seen it, it wouldn't have seemed that way. But, not seeing it, it is just like not having it at all."

Later, when feeding her infant in the nursery, she held the infant closely, called him by name, and directly gazed at him. Now involved with him, she felt him as really hers. "Since I've been able to touch him, hold him, and feed him, now I say, gee, it is our baby."

Again, during postpartum, she had problems with the health team's approach to her diabetes regulation. However, it seemed to Diane that they were now more willing to listen to her recommendations and to jointly work things out with her.

As the memories of her recent and unpleasant experiences faded, Diane remarked that "it was good to be alive." At the same time, however, she felt somewhat overwhelmed by the pending financial hospital charges that were not covered by the insurance "package." They would have to borrow money for their share of the costs because they only had minimal savings.

Though she had described her final experiences as "crummy," she perceived her son as very special. Neither Diane nor Alex had any desire for another child. She "had enough of being pregnant" and Alex, who had recently lost his mother, was fearful of losing Diane in another such pregnancy experience. She also doubted that she could go through it again, especially when she faced the fact that the infant might die, "it would not be worth it."

> While her experience also produced emotional strain, it appears that the close-call aspect of her experience further deepened her attachment to her son. She felt "especially attached to the baby after having undergone so much, although it was just too much emotionally and physically to go through it again."

These two case histories do not, of course, portray the total events of Janet's or Diane's nine month interlude with management of a high-risk pregnancy. They are presented to illustrate a sampling of the range of phenomena under study in terms of their relevance to the substantive theory of protective governing. The events occur in a variety of social settings and it is immediately apparent that the structure of these settings affect and are affected by the ideologies and the psychological interactions of the participants.

Each history dramatizes the problems of living that are incurred when a woman attempts to subdue her diabetes, to restrain it from adversely interfering with the pregnancy, and attempts to maintain the pregnancy on-course to avoid obstetric complications. Also to control the pregnancy-illness sufficiently to prevent physiologic changes that may have long term detrimental affects upon the self. The troublesome problems are usually those centered around symptom control, regimen manipulation, crisis management, maintenance of emotional equilibrium, and maintenance of social relationships.

## Section B: Comparison of Management-Related Categories

Prior to the more searching task of comparative analysis of all of the data, a casual perusal of these two histories revealed basic differ-

ences in the quality of the two high-risk pregnancy experiences. Janet's daily activities appear so casual and unhampered by even minor problems. On the other hand, one immediately senses that in spite of her most serious and expended effort, Diane's control of activities tends to elude her. There is no question that there are obvious attitude and personality differences between the two women. Diane, at times, readily mainifests a defensive attitude; at other times, indifference and resignation or underlying resentment. Janet tends to exercise an obvious relaxed attitude and a sense of confidence and commitment. These two case histories are, of course, only representative for there are several women in this study of the Janet type and several, typical of Diane.

When the data are coded, innumerable categories evolve which can be associated with the enabling of management. Obviously, not all of these categories coded can be annotated for this study nor do the histories of Janet and Diane contain all the "enabling" categories coded from the total data. However, the categories that evolved through comparison of all the cases gathered in this study are: illness career, knowledge, support, illness stability, pregnancy stability, emotional stability, stable social world, and a perceived sense of control. Further categories are then by reduction condensed (see Section C) to reveal the major factors that facilitate management ability.

Illness Career. Under this major category are found the subcategories of attitudes regarding the illness, compliance with the medical regimen before the pregnancy, strategies for self-management, ease of problems in management, and ability to interpret body cues. A comparison of Diane with Janet along these categories reveals major differences as well as

similarities. Both women were childhood diabetics. Janet described her diabetes as having been "easy" to manage all her life, Diane reported that she had been "in and out" of hospitals while growing up. Diane attributed her problems with diabetic management to the physical changes occurring within her body. Both women complied with their medical regimen and both felt they had made an adjustment to their illnesses. Janet relied upon the strategy of "normalizing" as a means of coping with her illness; this strategy was not evident in the data supplied by Diane. Both women had knowledge of the two basic problems associated with diabetes, hypoglycemia and hyperglycemia. Each knew how to interpret the symptoms of these problems and had strategies for managing them. However, Diane had less access to medical assistance than did Janet during the childhood and adolescence years. This can be explained partly by the presence of two supportive nursing "experts" in Janet's home, her mother and her sister. Both women expressed confidence in their ability to manage the problems associated with their illness.

Acquired Information. Assessing, having or lacking information, seeking knowledge, experience, and receiving conflicting information are the subcategories of acquired information. According to these categories, Janet was considerably more prepared to manage her at-risk pregnancy from the standpoint of being knowledgeable than was Diane. Janet entered the pregnancy with more basic information about diabetes which apparently enabled her to set realistic expectations of possible occurrences. She obtained this knowledge before the pregnancy by seeking out information regarding the effects of diabetes on pregnancy from the medical experts. She also received information about the various tests for determining fetal well-being and about cesarean sections from her sister who had been

through them and was therefore an expert in her own right. This knowledge enabled Janet to approach her pregnancy with an open mind, knowing that her delivery could be either vaginal or cesarean. She anticipated possible problems with the baby. This knowledge coupled with an ease in managing her illness in the past apparently gave her confidence that she could manage her high-risk pregnancy.

Diane, on the other hand, was less knowledgeable when entering the pregnancy. She had done some superficial reading in a book belonging to her aunt and had some idea of what to expect; but it was not enough to give her the confidence she required. She sought out and received minimal information during the pregnancy. Diane, unlike Janet, did not take prenatal classes though she had expressed a desire to do so. She was totally unprepared for her experience of a cesarean section. Though she sought out further information just prior to and during her amniocentesis, she nevertheless found it a very frightening experience. Both women utilized their knowledge in assessment of the risk factors. Diane viewed the bleeding in early pregnancy as an indication that she might lose the fetus, hence the risk to fetus was high. When Janet experienced preeclampsia, she overheard the doctors say that her fetus was "okay" and she, accordingly, assessed the risk to her fetus as low. The awareness of fetal movement was reassuring to both women, but significantly more so to Diane who felt the threatened loss of her fetus.

Diane received what she felt was conflicting information at the time of her first induction. She was told she was being induced because the risks to baby were high. Yet, on the following day she was not induced for what seemed to her an insignificant reason, "they were too busy." Both women continued to seek out information during the course of the

pregnancy. Janet gained pertinent information from the prenatal classes she attended; Diane by asking questions of the health team.

Support. The subcategories of support include joint management with the health team, trust in the health team, loss of trust, abandoment, and emotional and physical support from her partner and family members. Diane's husband accompanied her to all her prenatal appointments, remained with her during the inductions, and, though not allowed in the delivery room during the cesarean section, he and friends were waiting for her when she emerged from the recovery room. Diane's husband also took over the physical tasks of managing the home while she remained in bed during her bleeding episode. Janet's husband was also present during the labor and delivery and she had the emotional and physical support of her family, with whom she stayed, while on bedrest.

Janet had confidence in the health team throughout the pregnancy and perceived herself as managing with their support in order to achieve a positive outcome. Diane, on the other hand, did not have this continual trust relationship with the health team nor did they appear to trust her, indicated by their telling her that she was not following her diet and testing her urines. Though Diane felt that she was trying hard to work with the health team, there were occasions of management conflict. She also felt abandoned when she failed to "get through" to a trusted physician.

Stability of the Illness. Both women considered their illnesses to be under control at the onset of their pregnancies. Janet continued to perceive her illness as under control, or, manageable throughout the pregnancy. Diane was hospitalized for high blood glucose levels (considered by the health team to be problematic for the fetus) and she continued to have difficulty maintaining her glucose level at an acceptable level.

Stability of the Pregnancy. Stability of the pregnancy includes the subcategories of absence of obstetric and labor-delivery complications. Except for a mild case of preeclampsia that was treated by bedrest, Janet's pregnancy was stable. She delivered vaginally on the second day of induction. Diane's pregnancy was less stable. She had bleeding during early pregnancy and preeclampsia and polyhydramnios at the time of delivery. She was delivered by cesarean section after four unsuccessful inductions.

Stability of Emotional Elements. Stability of emotional factors does not refer to the women's mental stability but to a group of emotions and emotion-related categories such as fear, planning for the infant, or stress. Both women reported having fears that the infant-to-be would be retarded and malformed because of possible unintentional omission of nutrients in their diets. Both had specific fears related to the self and fetus as a result of complications of illness. Diane also had the fear that she might lose her fetus because of the bleeding.

Both women demonstrated "nesting" behaviors by making physical preparations for the infant. Because of her fears, however, Diane disallowed herself attachment to the infant until after it was born.

Stability of Social World. This major category includes the subcategories of death of a relative, financial worries, change of residence, and problems with other children. Though these problems may cause emotional stress, they are elements of the woman's social world and, thus, are classified under this category. Janet's social world was stable throughout the pregnancy. She was laid off from her job early in the pregnancy, but this did not appear to be a major problem for the couple. Diane's social environment was not as stable. During early pregnancy

her mother-in-law was hospitalized and died. The couple moved into a new home which required repairs. They also had financial concerns about the costs of Diane's prolonged hospitalization and were required to use up her small savings.

Perceived Sense of Control. This last category is includes the subcategories of helplessness, powerlessness, confidence in management capability, and the expressed ability to manage. Janet expressed her sense of control throughout the pregnancy. Diane perceived herself as capable of controlling her illness until near the end of term when she began having difficulty controlling her blood sugar levels at an acceptable level for the well-being of the fetus.

Twice during the pregnancy Diane described herself as feeling helpless. The first occurred during hospitalization for regulation of her blood glucose level. She experienced a deep sense of helplessness because she was unable to convince the health team that her hypoglycemic reactions were not "stress" episodes as they claimed. The second situation in which she felt helpless and powerless occurred just prior to her cesarean section when she was too frightened, too fatigued, and in too much pain to maintain control.

As previously stated, these two case histories are only representative and do not include all the possible variables which enable some women in this study to be more successful than others. However, the categories that did emerge do highlight very significant differences in the two women's ability to manage. By contrast, Janet more successfully managed and achieved a positive outcome because: 1) she had acquired more adequate knowledge, 2) she had maintained a supportive and working relationship with the health team throughout the pregnancy, 3) her illness remained

stable throughout the pregnancy because her blood sugar level remained within an acceptable range as regards its affect on the fetus, 4) her emotional factors remained stable, 5) her social world remained stable, and, 6) she continued to perceive her sense of control throughout the pregnancy.

Diane encountered many problems during her pregnancy. Her experience was not a positive one nor was her infant as healthy as Janet's. Yet, she did manage. In fact, she worked very hard at managing, perhaps harder than did Janet. What helped her to do as well as she did considering the many problems she had? First, she did have some knowledge about and experience with diabetes to draw from and she did continue to seek information throughout the pregnancy. Secondly, she had a strong support system. And last, she perceived that she could manage her illness in respect to herself, but not to the effects on the fetus. From analysis of these two case histories and other accumulated analyses, specific conditions, skills and information emerge as important for management of a high-risk pregnancy.

## Section C: Conditions That Influence Management Performance

The process of condensing the previous management related categories evolved four primary conditions that are fundamental and antecedent to the basic management functions of assessing, balancing, and of controlling. Data analysis indicates that these conditions significantly influence the woman's achievement of a positive outcome in a high-risk pregnancy. The first condition that contributes to a positive result is the acquisition of an adequate knowledge base. This condition is derived from the subcategories of illness career and acquired information. The second factor is acquisition of an

adequate support system; the third, stability of internal and external conditions, is condensed from the subcategories of stable illness and pregnancy and emotional and social elements; and, the last factor, a perceived sense of control.

Sufficient Knowledge Base. Before the woman can effectively assess and balance her options, she must have acquired sufficient and substantive information. This requirement compares favorably to the first of White's (1974) simultaneous management tasks for adaptation, "securing adequate information about the environment."[1] Having the proper amount of information, he believes, is a prerequisite for action and a necessary component for coping, particularly with problems of stress. One primary informational source is past experience. Susan's past successful experience with a high-risk pregnancy, complicated by controlled lupus erythematosus, provided her with a substantial data base for balancing her need for drugs that controlled her illness against their possible adverse effect on her fetus. As a result of balancing these options, she decided to again become pregnant.

> I knew I could push it. I had done it before. I knew I could push it nine months without drugs and get away with it. I would be able to bring the illness back under control, if need be. (Excerpt from fieldnotes, Susan and Bob.)

Other modes for deriving information include reading medical articles and books designed for the consumer, watching medically-oriented TV specials, assimilating instruction given by experts and lay informants, and observing other experienced women. It is important that the accumulated information not be conflicting, confusing, or inaccurate. Generally, more rather than less information is desirable because it provides a more expansive source from which choices can be made. The research data reveals that the amount of information a woman requires for management that will skillfully enhance her choices for a positive outcome is in ratio to the

severity-stability of the illness, to the extent that the pregnancy is on-course, and to the judged level of the risks.

It is crucial that a woman be informed about the illness and its complications, about the pregnancy and its complications, and the interactional effect of one upon the other. But, as important as knowledge content is, it serves no purpose if she lacks the skills for applying it. The data indicate that most women knew or learned how to differentiate symptoms, to interpret symptoms and medication prescriptions, to evaluate symptoms for severity or inconsequence, to monitor their own and fetus well-being, to devise a plan for daily activities and timing of her regimen, and how to make decisions. Carol had cardiac disease. At the onset of her pregnancy, she worried excessively over occasional chest pain and assessed it as serious, as "something wrong with me." However, having acquired expert information about the meaning of her pain, she had a new basis for pain assessment and the worry her stress incited gradually dissipated.

> ----before, when I had a pain or was a little uncomfortable, I worried a lot. Now, I don't worry as much because my cardiologist told me that my heart is perfect. (Excerpt from fieldnotes, Carol and Darrell.)

For Marsha, who was predisposed to asthmatic attacks, the situation was reversed. Apparently early in the pregnancy, her physician treated an asthmatic attack with an approximate 30 mg dosage of prednisone. When she was hospitalized during her pregnancy for a severe attack, the attending physician wanted to administer 60 mg of prednisone. Marsha assessed the dosage as excessive and particularly risky for her fetus. The assessment issue, based on her earlier informational input, no doubt also caused interactional problems with her attending physician.

> In my peak, in my worse condition, my doctor never gave me half that much. So, I immediately said that I would talk to my chest doctor. I wouldn't take it. She brought me down to 30 mg and 30 mg worked. 60 mg! What was that guy doing! (Excerpt from fieldnotes, Marsha and Gary.)

With sufficient knowledge and processing skills, the woman's task of maintaining control is facilitated because it enables her to more accurately assess the risk levels, to set realistic expectations regarding the outcome, to be aware of the available options for controlling the pregnancy-illness, and provides her with a repertoire of physical and cognitive management strategies.

Adequate Support System. A woman with a high-risk pregnancy realizes that she continually lives within the shadow of imminent crisis. The data reveal that her fears are eased and her management activities enabled when she has the presence of support from her partner, the health team, family, and/or friends. In his work on personal adaptation, Mechanic (1974) also points out that a basic component of successful psychological adjustment to environment demands is "the social supports available or absent in the environment."[2] Several women in this study required considerable physical support because the off-course state of their pregnancies and the severity of their illnesses rendered them partially or fully incapable for accomplishing the necessary management processes of assessing, balancing, and controlling. Others required more emotional than physical support, particularly if they were fearful and had pervasive feelings of uncertainty regarding their capability to carry out the management tasks.

The forms of support a woman receives to facilitate her achieving a positive outcome vary according to the individual/s extending the assistance. From the health team, she receives support in the form of information upon which to base assessment and balancing and verification of her own and fetal status from the results of tests and examinations. They give her praise when her management activities are positive and productive; they encourage her when her condition invokes fear. When hospitalized, most women sense the safety and security of the team's technical and expert watchfulness. This

was, no doubt, Louise's reaction as she received substantial support from the health team when hospitalized. There, and later in the clinic, they administered appropriate medications for her kidney infection and monitored her fetus' well-being, relieving her of unnecessary stress and giving her security.

> I had to go to the high-risk clinic every two weeks so they could keep up with my blood pressure, my infections, and watch for premature contractions so there wouldn't be any harm to the baby. I didn't mind as long as it kept me out of the hospital and the baby okay. (Excerpt from fieldnotes, Louise and Christian.)

A supportive partner who is as desirous of achieving a positive outcome as is the woman, works jointly with her to achieve that goal. He watches over her and encourages her to faithfully follow the medical regimen. He gives physical assistance in caring for the couple's other children and performs home chores, especially when she is hospitalized or at bedrest. He gives emotional support with his presence when she is provoked to fear and worry by frightening tests or stressful events. Marsha was well aware that Gary's comprehensive support furthered her task of controlling her illness-pregnancy.

> He takes good care of me. He sees that I take my medication. He goes out of his way so that I don't overdo. He does things he never did before. You know, the laundry, the vacuuming, things like that. That is an added plus. He just lets me alone; he lets me be myself. He doesn't pressure me to do more. He just lets me do what I want; he's very understanding. He's very patient and waits while I spend, maybe, two or three hours in the chest clinic. When I don't feel good, he doesn't get upset. (Excerpt from fieldnotes, Marsha and Gary.)

The data suggests that a woman's family and friends are also important providers of assistance in her management activities. Even though they express willingness to give physical assistance, emotional support, encouragement, and direction, Terrie indicates support from her partner to be even more important to control of her illness-pregnancy even though

his reluctance to assist imposes on her threatening and additional stress.

> This pregnancy is so stressful for me. It is the first time in my life that I have not been able to handle myself. I can't handle myself and it is very upsetting. I am angry with my husband. I am supposed to start my cesarean section classes after the holidays and he won't come with me. It is not outsiders that I should be getting support, it is from my own family [her husband - Ed.]. They [the health team -Ed.] want to put me in the hospital to regulate me, but I can't go because my husband yells at me and asks who will take care of our little boys. Then, when I come home he makes it very difficult for me for several days. It just isn't worth it. (Excerpt from fieldnotes, Terrie and Bernie.)

A system of support upon which the woman can depend for furthering the processes of assessing, balancing, and controlling is one which: 1) provides multiple informational sources necessary as a data base; 2) provides resource informants; 3) provides human resources that can verify incoming information so that the woman can establish the accuracy of her assessments; 4) facilitates the balancing process by extending the options for controlling; and, 5) provides sources that will assume the responsibility and make the effort, as necessary, to control problems created by serious conditions of the pregnancy-illness.

Some women require very little supportive assistance. It is necessary that the amount of support extended be appropriate to the woman's need for it. Too much has a tendency to smother and create in her a feeling of inadequacy; too little, as was the case with Terrie, provokes a sense of helplessness and a feeling of abandonment.

Stable Internal and External Conditions. When a woman is confronted with a pregnancy that is complicated by diabetes or another chronic illness, her most arduous task is maintaining, or regaining, consistent and rigorous control of the pregnancy and illness in order that she may achieve a positive outcome. A second and two-part task, only apparently less important, is the avoidance or minimization of the impact of external social

and emotional factors on her pregnancy-illness and restraining the pregnancy-illness from affecting her socially and emotionally. If all the conditions remain in equilibrium, i.e., the status of the illness stable and noncritical, the pregnancy on-course, the emotional status serene and unhampered by excessive fear and stress, and social concerns for children or finances minimal, the woman has greater facility for control. This major category, reduced from the data, also coincides with White's (1974) idea that if the individual is to adequately cope with the environment and prevent self harm, he or she must "maintain satisfactory internal conditions both for action and for processing information."[3] She is more effective in her ability to assess, balance, and control for maximizing her probabilities of achieving a healthy infant and an unimpaired self. The conditions are simply more controllable. There is ease in monitoring and interpreting symptomatic cues; and, the options for control tactics are increased when there is no necessity for making jeopardous decisions.

The woman's energy output is lessened if there is no imperative to restabilize an unstable condition; and, if unencumbered by anxiety and stress, energy can be directed toward other activities such as care for other children, maintenance of an organized home, engagement in social activities, and preparation for her infant. With these multiple stable conditions working for her, the scope of alternative balancing and controlling options are broadened. This also seemed to be the case for Carol who could now enjoy the positive aspects of the pregnancy.

> Before I didn't have time to think about the baby. Now that I feel better, I am thinking about the baby a lot. I think about what I will do. I am watching my friends with their babies very carefully. I don't have any experience caring for children. (Excerpt from fieldnotes, Carol and Darrell).

Finally and importantly, with all these conditions in stable status, the pregnancy can complete its entire course without impending hazard.

Perceived Sense of Control. Believing oneself to be in control of a situation generally provides the confidence and strength for accomplishment. If the woman with a high-risk pregnancy believes herself to be in control of the factors that ordinarily increase the risk probabilities, her chances for a positive outcome are significantly increased. Her sense of being in control presupposes that she has sufficient informational alternatives to guide her behaviors and decisions, a back-up support system, a stable illness and on-course pregnancy, a feeling of emotional equilibrium, and freedom from pressure of problematic social situations. This management-enabling category, a perceived sense of control, can also be matched with White's (1974) third adaptive task. He states that the individual must "maintain its autonomy or freedom of movement, freedom to use its repertoire in a flexible fashion."[4] When the women believed they were in control, they, too, were in a situation where they could freely choose from among alternatives and decide their course of action without constraint. A woman, such as Sarah, has her self sense of control inevitably expanded if, by means of instruction and new information, she can become more effective in managing a particular aspect of her pregnancy.

> We enjoyed going to Lamaze classes. They made us feel a lot more assured that we could handle anything that came up. We had read a lot before and all of that was confirmed in the classes, plus learning the breathing exercises. ---I was able to use my breathing after delivery also. (Excerpt from field-notes, Sarah and Donald.)

All of the management processes (assessing, balancing, and controlling) are more efficiently performed when the woman perceived herself in control. A perceived sense of control also instills confidence for selecting the information necessary to the accurate assessment of the risk level; for selecting appropriate resources that allow alternative options so that she is never forced into no-choice situations; and, confidence for deciding from among

the physical and cognitive strategies those most vital for maintaining, or recovering, control over the pregnancy-illness.

It is important to caution that if the woman is overconfident, she may overestimate her ability and restrain others from assuming necessary responsibility or she may endanger herself by setting unrealistic outcome expectations.

These four conditions evolving from the data as facilitators of successful management, were not all fully realized by the women in this study. Nor were there any women for whom none of these factors was operating. As presented, they form a composite of the total data that can be considered optimum requisites for facilitating successful management.

## Summary

The management process of protective governing explains what is occurring in the life of a woman when she is attempting to manage her life in such a way that her efforts will further her attainment of a positive outcome within the circumstances of a high-risk pregnancy. The case histories of Janet and Diane visualize the struggles, the hopes and disappointments, the successes, and the problems encountered as they learn how to cope with the uncertain physiological conditions within their bodies. Sometimes with ease, sometimes with difficulty, they work with greater or less confidence toward bettering their performances. They acquire pertinent information and develop a dependable support system so they can better manage both their internal and external conditions by means of the implementing, and sometimes controversial, processes of assessing, balancing, and controlling. With these management processes, backed up by the facilitating conditions, each woman hopes for a positive outcome arising out of her confrontation with the problems she encounters.

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3. White, loc. cit.

4. White, loc. cit.

# Chapter 6.

# OVERVIEW OF THE DYNAMICS OF THE MANAGEMENT TASK

In the study of a pregnancy that is complicated by chronic illness, one must take into consideration the probability of increased physical risk of morbidity and mortality to the woman and to the fetus or neonate. To maximize her chances of achieving a positive outcome from the pregnancy, the imposed risks must be minimized by means of careful management. A woman's ability to minimize the risks is, to a great extent, dependent upon her management skill in accurately perceiving the degree to which she and her expected infant are at risk at any given time during the course of the pregnancy and upon the nature of the settings in which the work of managing occurs. Chapter 6. describes the interplay between a woman's perception of the risk and the work of managing (successfully or unsuccessfully) within the settings of the home or of the clinic and hospital, where she aligns her efforts with those of the health team.

The purpose of this chapter is to introduce the theoretical framework, grounded in the data and verified with the literature, that evolved during the course of research sampling and analyses. This framework is used throughout the study as the organizing scheme for explaining how the women in this study managed to minimize the risks of their pregnancy-illness.

## Section A: Management Variables

While no pregnancy is entirely risk-free, a pregnancy in combination with an illness increases the probability of morbidity and mortality for

the mother and/or fetus. The chances of achieving a positive outcome in this risk situation are maximized if the conditions that increase the probabilities are properly managed. Management of these conditions involves work and, as for all work, effort and a sense of responsibility are required. The ramifications of risk for the mother and the fetus makes the work of minimizing the risks a task that a woman cannot accomplish alone.

Joint Management. If a woman enters the health care system, she is, in fact, enlisting the support of the health team and delegating certain responsibility for management to them. In so doing, the management effort is a joint activity involving interaction between the woman and the team. The extent of responsibility assumed and the amount of effort put forth by each managing participant depends upon the level of risk the illness situation produces and the particular organizational setting in which the event occurs.

To be more specific, in crisis situations where the risk probability is higher, more of the responsibility for managing the situation must be assumed by the health team. Furthermore, greater effort on their part is required than when the situation is less critical. Whenever the woman is in the clinic or hospital for assessment of her condition, for prescription of a management plan, for observation, or for treatment, it is more likely that the health team is assuming the major responsibility and is making the greater effort to manage.

On the other hand, because of the organization of either setting, it is often difficult for the woman to truly share in the managing efforts or maintain the degree of responsibility she may want to have. Attention to individual needs and desires is difficult to give in an institutional

setting because it is organized to provide services to large numbers of individuals, often designed as a teaching institution for providing experience and medical knowledge to the residents as well as provide high-risk obstetrical services to patients. The frequent rotation schedule of residents can also hinder the development of trust which is a necessary component of a shared working experience; yet, if a woman is to let another assume certain responsibility for her life and health, and that of her fetus, there must be a trusting relationship. Also, the large number of patients and the short amount of time alloted to each, in the clinic situation, is not conducive to individualized care. Because of limited time, the health personnel give more of their effort to managing the physical aspects of the illness and pregnancy. It is they who are accountable for the life and health of the mother and fetus; they are less accountable for the woman's psychological and social well-being. There is also the silent understanding that the clinic or doctor's office is the territory of the health team, and within that territory, they have the authority for most decision-making. The physical organization of the hospital, personnel shifts, patient schedules, and functional use of space and locations make it difficult for the woman to control even the most personal aspects of her life. However, in her own mind, she recognizes the health team as experts, possessing the knowledge and experience that she lacks.

In the home, the responsibility for managing remains principally with the woman. It is there that she has the responsibility for implementing the plan of management with her efforts and the freedom to decide the extent to which she desires to effectualize her plan. The home is her arena for monitoring herself and the fetus.

There are more than physical problems involved in a high-risk pregnancy; a woman's emotional and social being is also involved. A high-risk pregnancy is a paradox of sorts. On the one hand there is the abnormal element of risk; on the other, the normal expectations and experiences. A woman experiences the usual psychological need to accept and prepare for the infant. She must maintain an organized home, in some cases care for other children, and/or assume job responsibilities outside the home. Often the measures designed to manage the physical problems in the settings in which the work of managing occurs, interfere with her ability to carry out these tasks and restrains or intensifies the normal emotional processes of pregnancy.

That situation presents still other tasks in terms of finding a balance for her social life and emotional feelings. To manage and accomplish these tasks, she may well enlist the support and help of her partner, family members, and/or friends. In so doing, as with the joint management of the health team, the management effort becomes a joint endeavor; in fact, the quality and the amount of assistance she receives is an important variable that affects her ability to manage. When it is not possible for her to enlist the support of these others, her work becomes more difficult and the outcome of her pregnancy may be affected.

An important variable affecting the work of managing is the illness itself. Properties of the illness such as the extent of physiologic involvement, its duration, stability, and manageability are all important considerations. In most cases, the more severe the illness, the more difficult it is to keep under control during the pregnancy and the greater the possible risks to the woman and her fetus.

Another important variable that affects the work of managing is appointed time. Management effort and responsibility need to be coordinated along specified temporal lines by all involved helpers if the risks are to be minimized. Regimens prescribed by the health team have to be followed at fixed times; medications must be taken at regular and specificed time intervals; rest periods need to be incorporated into the daily schedule; and, home routines such as getting children off to school, making meals, and keeping social engagements are usually time set. Clinic or doctor appointments are scheduled at intervals regulated by the level of the risk at any given period of time. Tests for maternal and fetal well-being are appointed according to the progress of the pregnancy. When delivery is imminent, time is focused and the efforts of all who share in this event are intensified. The timing of delivery is very important for most women, but especially so for the diabetic. If the woman is hospitalized during a crisis, her timing for accomplishing her management tasks is surrendered to fit the organizational structure and demands.

The woman's personal history or career also affects her ability to manage. Each individual participating in the management of the problems associated with a pregnancy-illness has a set of past experiences that color his or her perceptions regarding the nature of tasks necessary for this process. In addition to their past experiences with management, or lack of it, their attitudes, recently acquired or past knowledge, belief systems, personal philosophies, expectations, and values are intricate components of personal history. How these characteristics of each participant intersect strongly influence how the risk pregnancy and its problems are managed. If, for example, a woman's beliefs regarding some aspect of illness management differ from those of the health team because

of different previous experiences, information sources, and personal philosophies, there may be conflict. Even this conflict, and its resolution, affect the management outcome. Or, the pregnancy may have meanings for the woman that are not shared by her partner because their respective past and present experiences and expectations differ. Coming to a meeting of the minds may be a stressful process and seriously affect the level of the risks for morbidity and mortality for the mother and the fetus or neonate. Conflict may certainly cause the partner to be less willing to assist with the managment task and thereby cause the woman to function less well, physically, emotionally, and socially.

The process of controlling, as used in this study, describes the continuing adjustments and alignments of responsible effort necessary for the management tasks associated with the pregnancy-illness. The various interactants in the settings of the home, the hospital, and the clinic accomplish (or, fail to accomplish) these tasks by different control modes, depending upon the nature of the setting and the particular task.

## Section B: The Course of a Pregnancy-Illness

Properties of a Pregnancy-Illness. Both a pregnancy complicated by a chronic illness and a normal pregnancy have a property of progression. They proceed along a course, a culturally and medically defined pathway. The pregnancy course may be divided into three stages: the 38-42 week gestational stage, the climactic labor and delivery stage, and the one to six week post-delivery stage of readjustment in which the neonate adapts to extrauterine from intrauterine life and the woman to the nonpregnant

from the pregnant state. Each of these stages is important in management for there are different problems, and hence, different tasks associated with each of them.

Another property of a pregnancy is an end product, an infant. In a normal pregnancy, the infant is expected to be alive and healthy; in a high-risk pregnancy, that expectation is not as certain. As a consequence, the baby becomes a central focus in the drama of controlling a pregnancy-illness. The pregnancy course and end product of an alive and healthy baby are very much interrelated. It is desirable that the infant remain in utero throughout the course of the pregnancy. It must mature so as to increase its chances for viability and more suitable physiologic development for adaptation to postnatal life. With that in mind, the gestational stage can be considered as divided into two phases. The phase of previability in which chances of life and health are nonexistent and the phase of viability in which the chances of life and health are dramatically increased but not certain (the infant may require assistance to sustain life and health on its own).

If the pregnancy is at risk, its course is characteristically uncertain because of the potential interactive effects of the pregnancy and illness. Physiologic changes which accompany pregnancy may have an adverse effect on the course of the illness; or, systemic problems due to the illness may threaten the viability of the fetus. At any point, the course of the pregnancy or illness may be interrupted or intervened by these and other causes. It is important to the health and life of the woman and fetus to keep the pregnancy and illness on course. Keeping on course is maintaining control over both the pregnancy and illness so that they remain in a stable state, free of complications. Should the illness

become unstable or the pregnancy incur obstetrical complications, the woman's objective is to get back on course by the process of control. The less time it requires to attain control, the greater is the possibility of minimizing the risks.

Emotional-Social Properties. Control of the pregnancy and illness not only increases the probabilities of life and health for the woman and fetus, it also helps her to maintain a sense of emotional and social equilibrium, facilitating normal planning and preparation for the infant. If she is not burdened with the critical physical tasks of stabilizing either the pregnancy or illness, she may decide to attend prenatal classes, consider a desirable method for the labor and delivery experience, carry out normal household routines, care for her children, and maintain a job.

Emotional stability and a stable social life are important factors contributing to the stability of the pregnancy and illness. Anxiety provoked by pre-delivery hospitalization or stress associated with the death of a close family member may result in illness associated complications, e.g., difficulty in blood sugar regulation by the diabetic. Or, excessive fear regarding the final outcome may intensify symptoms and interfere with her emotional and physical preparations for the infant. Maintaining stability in all of these areas is fundamental to the process of control.

## Section C: The Risk Factors

Definition. The term "risk," as used to qualify an imperiled pregnancy, refers to the possibility or chance of a hazardous event occurring or a dangerous condition developing. The risk "factor" references any one of many agents that cause a situation, event, action, or condition to

be dangerous or risky leading to morbidity or mortality in the woman and/or fetus. In this study, the element that contributes to produce the risky pregnancy condition is the presence of a chronic illness. The illness, if unstable and severe, can produce systemic complications that adversely affect the biological requirements of the pregnancy. The medication, required to treat the illness, can harm fetus well-being. Secondary dangers to the pregnancy, also putting it at risk, may be due to social, emotional, cultural, or economic factors (causes).

Levels of Risk. The degrees of risk range along a continuum from low to high, which degree depends upon the state of the causative factors at any given time. Within the low to high range, there are sub-ranges such that a high-risk pregnancy state can be at moderately low or extremely high risk at different times during the pregnancy. Because pregnancy involves two organisms, it is always important to specify who is at risk, the woman or the fetus. Sometimes the risk for the mother is higher than that for the fetus. If the mother has a cardiac disease, the effect on the fetus is secondary to the effect on the mother. If the woman is diabetic, the risk for the fetus (after the 37th week) is higher than that for the mother. There are occasions during the pregnancy of an asthmatic woman when the risks are very high for both mother and fetus. An acute asthma attack may deprive both the mother and fetus of oxygen and precipitate labor.

It is also important to note that during the course of a pregnancy-illness the level of risk may fluctuate along the ranges of the continuum. Depending on the circumstances, the level may vary from high to low or low to high on one or more occasions.

The Work of Assessing the Status of the Pregnancy-Illness. The primary risk factors associated with a pregnancy-illness are of a physiologic nature. The illness may produce a variety of systemic conditions which must be identified and managed so as to prevent the pregnancy moving from a lower to higher level of risk. This is a complex process comprised of different types of tasks and accomplished by either/or both the health team and the woman. The process of identifying the risk factors in response to ongoing physical, interactional, temporal, and objective cues is termed assessing.

Assessing is one of the most important tasks to be accomplished by the health team in the work of managing a risk pregnancy. It must be accurately performed if the pregnancy-illness is to remain on course or, if off course, restored to a stable state. Data for assessment are gathered by subjective and objective means such as physical examinations, listening to complaints, performing tests, and reviewing past history from the chart. It is important to note that not all health personnel are equally capable, experienced, or knowledgeable in gathering and interpreting data accurately.

The woman also makes assessments. Her data are derived from physical body cues, interactional signals, objective signals, and temporal elements. She interprets that data from her frame of reference to determine their importance and decide if such data are indicators of risk level. A woman who has had considerable experience with her illness is sensitive to her body signals and can interpret them to determine changes in the status of her illness. While a woman may not be aware of some of the more subtle cues that indicate potential problems with her pregnancy, she is usually alerted to possible problems by more overt signals such as bleeding, painful contractions, severe headaches, or edema. A woman who develops an illness during the pregnancy is somewhat at a disadvantage.

She not only has to learn to recognize symptomatic signals but how to manage the illness during the course of the pregnancy. She may also have entered the pregnancy not aware that it fell into a risk category. Whereas a woman who had developed the illness previous to the pregnancy may or may not have been aware of the risks to herself and fetus.

Interactional signals also come from other sources including the fetus, the partner, significant others, and the media. The fetus grows or fails to grow; it moves and kicks or fails to do either. (Women often report talking to their fetuses in response to the presence or absence of movement.) Growth and movement of the fetus and the stability of the pregnancy and illness are generally associated with life and health; however, there is always uncertainty regarding malformations or retardation.

From media sources, many women have gained general information to assist them in reducing uncertainty. They have learned to eat the proper diet, supplement their diets with vitamin pills, avoid substances such as coffee, drugs, and cigarettes, and to follow the medical regimen. The need for drugs or other stringent medical measures to control the illness or pregnancy is sometimes unavoidable. Possible dangerous side effects can usually be controlled by limiting the dosage or altering the timing of intake.

The health team provides both direct and indirect cues to signal the woman regarding the status of her pregnancy and illness. Certainly one of the most direct is the assignment of the woman to a "high-risk" clinic separated from the population with normal pregnancies. Equally direct is the reverse transfer from the "high-risk" clinic to the conventional clinic, indicating that the woman is no longer considered by them to have a risk pregnancy. The health team, in most cases, will

provide the woman with progress reports, allow her to listen to the fetus' heartbeat, and share the results of tests. If there are known side-effects of drugs or treatments for either the woman or fetus, the medical staff will generally describe them before these measures are undertaken. Non-verbal cues such as facial expressions, modulation of voice, and emergency responses are frequently conveyed by the health team and alert her to the probability of problems. The woman is constantly alert to that which the health team is <u>really</u> saying. She also learns a great deal unwittingly, while tuning-in to the medical staff, as they confer either in the doorway or just outside the examining room.

The woman's partner also provides significant interactional cues. She detects that he is aware of the risks associated with her pregnancy by the responsibility he assumes for helping to keep the pregnancy-illness on course and by the solicitious concern he demonstrates. He may also assist her in gathering assessment data when her condition (as in labor) prevents her from doing so. The couple may identify and discuss the risk factors even though their individual assessments may differ.

Helpful information is further gathered in the form of objective signals such as from test results. A diabetic is made aware of her illness status by knowing whether her urine is running negative or three to four plus, or if the results of her recent blood sugar were elevated or within the normal range. The status of a pregnancy is revealed to a woman through such measures as the result of an oxytocin challenge test, or a nonstress test.

Temporal elements are also important data. A woman frequently judges her status by how far along the course of the pregnancy she has progressed. She tends to relax after passing the point of viability because she senses

that the probabilities of a healthy infant have increased. For some women, approaching term may increase their anxiety and arouse their awareness of the involved risks, e.g., the cardiac patient who is apprehensive about the uncertainties of delivery. The apprehension tends to temporally shift according to the point of progress on the course of the pregnancy-illness.

If the woman is to do her share in managing the risk factors so as to keep her pregnancy and illness under control, her assessment must be accurate. This may be difficult if her information sources are inadequate. If cues are ambiguous or absent, if background information or experience is scant, if signals are denied or ignored because the reality of a situation is too difficult to handle, her data are insufficient and her interpretation will be misleading. Because information is sifted through one's personal past and present knowledge, experience, and history, the woman may consider certain conditions as risk factors which the health team does not, or vice versa.

During the course of a pregnancy-illness the process of assessing and reassessing the risk factors in response to informational signals is ongoing. Both the woman and the health team are constantly alert to signals which confirm or disprove their assessment and indicate a change in the status of the pregnancy-illness. The process for assessing data may remain the same or change during this period and, in either case, follow-up control will vary accordingly.

Risk Contexts. How a woman comes to define her risk situation in response to her assessment of physical, interactional, objective, and temporal cues as she progresses through the course of a pregnancy-illness occurs within a risk context. The pregnancy-illness progresses along a

course. The progression may be interrupted at any point along its path by destabilizing factors. The level of the morbidity and mortality risks to woman and/or fetus are on a continuum that may vary from low to high at any given time. The constellation of variables, including severity of the illness, experience, personality, and time, is the basis upon which the woman defines the risk context. For purposes of this research, the risk situations are categorized into four contexts. These contexts can be described as: 1) an on-course, lower-risk context; 2) an on-course, higher-risk context; 3) an off-course, noncritical context; and, 4) an off-course, critical context. During the course of the pregnancy-illness, her definition of the context may change in response to a change in cues. Definition of her risk context will not only influence her management of the physical risk factors affecting the self and fetus, but it will also have consequences on her ability to perform emotional and social tasks.

Balancing Alternatives. The life and health of mother and fetus are at stake in a pregnancy complicated by illness. There may be times when, in order to keep a pregnancy-illness under control, or to bring it back under control, certain measures must be undertaken that, of themselves, can jeopardize the life and/or health of the mother and/or fetus. A situation requiring such a life-threatening measure might be the administration of a high dosage of prednisone for treating a maternal disorder but which dosage can have a deleterious effect on the fetus. There are options that must be carefully weighed before a choice is made. The process of giving weight to alternative measures, in terms of outcome, and making a choice is termed balancing.

While the health team is principally concerned with the life and health of the woman and fetus, the woman has more at stake than that of

her physical well-being and that of her fetus. She also has considerable concern for her emotional and social needs and deems them as important bases for making her judgments. Very often the health team, in deciding among its options, is unaware of the many factors that a woman must balance when making her choices and of how these choices will ultimately influence her management decisions.

How a woman manages to minimize the risks of harm and/or loss that are associated with her pregnancy-illness is explained in this study through the analysis of the primary social process of protective governing as administered in the home, the clinic, and the hospital. Her protective governing is implemented by means of the three interrelated and major processes of assessing, balancing, and controlling.

## Section D: Consequences of Management

The primary consequences of successful or less than successful management by means of protective governing are for the life and health of the mother and baby, referred to throughout this study as a positive outcome. However, since the woman is a total person with emotional and social tasks as well as those tasks related to physical management of the pregnancy-illness, there is a potential range of consequences to those aspects of her life as well. How a woman comes to assess, balance, and control the pregnancy-illness may have consequences for the physical and emotional preparations she makes for baby, her level of fear for self and baby, her attitudes towards labor and delivery, her perception of the pregnancy experience, and may even come to affect her future childbearing career. Her family life, work and social activities outside the home may also be affected by her management of the pregnancy-illness.

## Summary

If the outcome of a pregnancy complicated by a chronic illness is to be positive, it is imperative that the physical risks of morbidity and mortality to the mother and the fetus or neonate are minimized. Physical, emotional, social, interactional, and structural forces interact to either facilitate or constrain the woman's management task of protective governing. If the interplay among these forces is balanced, the course of the pregnancy is constructive and unhindered and the outcome is generally positive; if the action among the forces is unbalanced, serious problems develop which require creative and diligent resolution before a positive outcome can be approximated.

# Chapter 7.

# ACTION CONTEXTS OF PROTECTIVE GOVERNING

Women with high-risk pregnancies assume active roles in the management of their pregnancies and illnesses. Their actions, and those of the health team, are aimed at minimizing the imposed risks by maintaining some measure of influence over the outcome. This chapter explains how women, within varying conditions, align their efforts with those of the health team to manage the risk factors by means of protective governing and its implementing processes of assessing, balancing, and controlling. The chapter is organized around the four risk contexts, as designated in Chapter 6., and differentiates among the management tasks peculiar to each context.

## Section A: On-Course, Lower-Risk Context

> You see, when I was here two to three weeks ago, the lady in the bed next to mine, her baby had a heart murmur. I heard that and thought, my God, anything could go wrong. In the back of my mind, I thought things could happen. Maybe the diabetes would....because you are not as healthy. I mean, there is always that extra chance of something going wrong, more so than for others, a little higher risk. (Excerpt from fieldnotes, Janet and Frank.)

With a pregnancy complicated by illness, as Janet relates, there is that increased chance of something going wrong with the pregnancy because of the illness, "a little higher risk." She, as with women with conditions similar to hers, defines her pregnancy as an on-course, lower-risk context. She does so because she assesses her pregnancy-illness to be on-course,

i.e., it progresses according to the culturally and medically defined pregnancy expectations, but with the risks to the fetus and to herself greater than if it were an uncomplicated pregnancy.

The outstanding characteristic of women in this context is their sense of confidence that they can control their illnesses and pregnancies in a manner that will minimize the risks.

> I knew if I took care of myself, with my working and the help of the doctors, that everything was going to be fine. If the baby was going to be retarded or malformed, it would be that way because of the way things were when it was conceived not because I didn't take care of myself. I do my things, take my shot, and then don't think about it. It is a way of life. (Excerpt from fieldnotes, Janet and Frank.)

Assessment of the risks as on course and on the lower end of the high-risk continuum may or may not correspond to the placement the health team assigns the risk, particularly, if the context changes during the course of the pregnancy because of a change in conditions.

Conditions Leading to Her Assessment of the Context. One of the essential requirements in the assessment of the risk level is an awareness of the possibility that the level can fluctuate. Some of the women in this study are aware of the risks before becoming pregnant; others do not become aware of the involved risks until they are actually into the pregnancy. Those that were aware before the pregnancy had learned of the potential risks as they lived with their illness, from what they may have read, from talking with others with similar conditions, or, as Janet and her husband Frank, from talking with the health team before the pregnancy.

> I received a lot of guidance when I went to see Dr. C about a year and a half ago. He told me about the kind of problems there could be. I was referred to him by my sister. She had heard that they took care of diabetic pregnancies all the time. It was good to hear that when I did get pregnant, this and that would or could happen. (Excerpt from fieldnotes, Janet and Frank.)

Those that do not become aware of the possible risks until they are into the pregnancy either do not develop the illness until pregnant or they simply are not informed. In those cases, they become aware through the implicit or explicit comments of the health team once they enter the health care system. It was not until after Tara's initial examination that she was given an unexplained appointment with the high-risk clinic.

> I was surprised they put me in a high-risk clinic. They didn't tell me they were going to put me there. They just made an appointment for me one day, so I went. I asked them why after I got there. (Excerpt from fieldnotes, Tara and Bill.)

When the health team explicitly presents the involved risks, the couple is told of how the illness can affect the pregnancy and how the pregnancy can affect the illness. Susan was told what could happen when she and Bob, her partner, visited the physician caring for her medical problem.

> Since I wasn't sure of the pregnancy at first, I was four months along when I went to see the doctor. He gave me a good talking to. I decided I wanted the baby before we went, but we wanted to hear what could happen so that we could play out all the options. (Excerpt from fieldnotes, Susan and Bob.)

Once aware of the risk to themselves and fetuses, there are several conditions that guide the women in assessing if the pregnancy-illness is proceeding on course and if the risks are at the lower range of the high risk level. They perceive the illness as stable and not as life-threatening. They experience few symptoms. If there are symptoms, they are expected and are related to the causal effects of the pregnancy upon the illness, e.g., episodes of hypoglycemia in early pregnancy or slight joint pain. Test results are usually within the normal range, indicating that the illness is under control. There is little need for hospitalization to

regulate or control the illness. The women perceive themselves as generally healthy. They incorporate the measures designed to manage the illness into their daily routine, to whatever necessary extent, and then forget about them, as did Laura.

> They do a thyroid test but everything has been within the normal range. I think the amount of drug that I am taking is what my body needs. I take it and then don't think about it. (Excerpt from fieldnotes, Laura and James.)

The women speak of their illnesses as being relatively easy to control, as responsive to treatment, as not having caused many past problems, and as not being a considerable problem during the pregnancy. They have strategies available for managing the illnesses, they are able to interpret their symptoms, and they know the signs warning of possible complications. They do not consider the prescribed drugs as especially harmful to themselves and/or fetuses; rather, they tend to view them either as replacement for substances normally found in the body or as nonharmful (dosages were low).

The women are also able to assess their risk levels through interaction with the health team and other professionals. Doctor's appointments are, for the most part, scheduled only every three weeks in early pregnancy though more frequently during the latter months. The information and counseling given by the health team is generally positive in its content. Jennifer was told by her neurologist that she was taken off the normally prescribed drugs for managing her epilepsy before they could harm the fetus. Her pharmacist concurred with the physician.

> I was on Tegretol for a while and this concerned me. Tegretol destroys white blood cells. I got off it as soon as possible which was one week past the time of my usual menstrual period. The neurologist and the pharmacist said getting off of it so

> soon should not have caused any damage to the baby [because I stopped taking the drug so soon, there certainly should be no damage to the fetus - Ed.] . (Excerpt from fieldnotes, Jennifer and Larry.)

Wilma sensed her pregnancy was on-course because of a comment made by a member of the health team.

> The last time I was here they said, you must be doing something right, you are keeping your blood pressure down. (Excerpt from fieldnotes, Wilma and Isaac.)

At her request, Wilma was allowed to return to the regular clinic towards the end of her pregnancy because her blood pressure remained within normal limits.

Positive cues from the fetus also indicate an on-course pregancy. The fetus is active, growing according to schedule, and remaining in utero. The heartbeat is within the normal ranges during auscultation. Movement is felt and the heartbeat is heard at the appropriate gestational stages. Tests, such as the oxytocin challenge test, indicate fetus well-being.

There are few pregnancy complications although one woman had mild preeclampsia. When comparing this pregnancy to previous pregnancies, the women perceive themselves to be in the same or better condition. Weight gain is within the normal ranges and the pregnancy follows a normal course to the end. Janet, along with most of the other women, reflected a real sense of optimism about this pregnancy.

> I figured that if the baby were born at seven months, it would have to go to the intensive care unit. At eight months, I figured it had a better chance of living, but still, there was always that chance. Now, in the ninth month, I figure I am home free. (Excerpt from fieldnotes, Janet and Frank.)

The Problem. Under conditions in which the pregnancy-illness is defined as on-course and the risks to be within the lower limits of high

risk, the problem is one of keeping it on-course and the risks at a low level. To minimize the risks of a pregnancy complicated by an illness, the women must be willing to invest time and effort and assume responsibility for the well-being of themselves and fetuses beyond that normally expected of an uncomplicated pregnancy.

Their motivation is the desire for a healthy infant and self. The desire for a healthy infant is not to be confused with the desire for an infant. Among the women in this study, only a few of the pregnancies were planned at the time of conception. However, once the women accept the pregnancy they are, for the most, willing to make the necessary and personal investments that increase their probabilities for healthy selves and infants.

> I wouldn't be going through this if it were not for the baby. I had a strong desire for a baby, not just any baby, but a healthy baby and not one affected by my illness or the medications I was taking to control it. (Excerpt from fieldnotes, Marsha and Gary.)

Janet reflected the mutual bond between the women and their fetuses. The task of caring for the self is perceived as caring for the fetus.

> I know I can take care of myself, but I've got something in there that is dependent upon me and needs to be taken care of. (Excerpt from fieldnotes, Janet and Frank.)

The health team also has an investment in the pregnancies. They invest their time and effort and assume considerable responsibility for the well-being of the women and their fetuses. They are in part motivated by the desire to give the women the infants they so badly want.

> I believe that this is a group of women who want children and we should give our expertise and service to see that they have at least one or two children within the place of their type of abnormality [their medical problem - Ed] . These women sincerely do want children. It is up to us to give them the stability, or whatever, to do it. (Excerpt from fieldnotes, interview with physician A.)

Adjunctive Control in Managing Risk Factors. If the pregnancy is assessed as on course and the risks within the lower ranges of high risk, the influencing conditions are stable and the women perceive their capability for keeping the pregnancy and illness under control. Susan indicated this ability to control.

> I went almost long enough to have a full term pregnancy with no medication when the disease was going full blast and had been developing for, God knows how many, years. And here I had more or less a clean break. My blood was acting nice, my blood pressure was good, I felt good. They took me off all medications. I felt I should be able to push nine months without any problems. (Excerpt from Fieldnotes, Susan and Bob.)

Within this context, the women perceive the role of the health team to be one of assistant support. The team performs those tasks for which the women lack the knowledge or experience for carrying out themselves. However, on a daily basis within the home, the greater share of the responsibility and expended effort for management belongs to the women. This combined effort, with the women assuming the greater responsibility for securing a positive outcome (healthy infants and selves), is termed adjunctive control.

The stability of the illness and pregnancy is the fundamental variable affecting the women's ability to maintain adjunctive control with the health team. The state of stability is determined by conditions such as severity and duration of the illness, the extent of the physiologic involvement of the illness, the women's past and present medical and obstetrical histories, and the interactive effect of the illness and pregnancy.

Another important variable in maintaining adjunctive control is the extent of the women's self confidence. She must believe in her own ability, that along with the support of the health team, she can keep the pregnancy and illness under control and on course. Her self confidence is derived

from her ability to keep the pregnancy and illness under control now and in the past, to cope with the problems as they arise, and from knowing that her fetus is progressing well. Even when Janet developed a mild case of preeclampsia, she was confident in her ability to adequately cope with it.

> I overheard the doctor say there's not...we're not worried about the baby. They kept telling me the baby's fine. I heard the doctor say it is the patient that we're worried about. I thought, I can take care of myself. I don't feel sick. I don't feel a loss of control. I was basically able to do everything that I had been doing before except that I was in bed. It was good. I was able to give my own shots, test my own urine. Half of the battle is having the confidence that you know what you are doing and that they know what they are doing. (Excerpt from fieldnotes, Janet and Frank.)

Overseeing the Well-Being of the Woman and Fetus; A Health Team Strategy. The health team's strategy in adjunctive control is that of systematically overseeing the well-being of the woman and fetus during the pregnancy, during labor and delivery, and during the readjustment stage. In managing by overseeing, the health team uses assessing, prescribing, and evaluating tactics.

The women cooperate with the health team by taking responsibility and making the effort to appear at the clinic for regularly scheduled appointments every three to four weeks during the early part of the pregnancy and more frequently during the last trimester. The pregnancy and illness are generally stable enough that they have no need to be seen more frequently. Each prenatal visit includes an assessment of weight, urine, blood pressure, edematous condition, a McDonald's measurement to determine fetal growth, and fetal heart tone (when audible). An assessment of the individual illness is also made. The women are questioned regarding their history and present symptoms and are physically examined, if appropriate. If warranted,

tests are secured to determine the status of the illness, the pregnancy, and fetal size as related to pregnancy duration. If a woman has a particular problem, it is discussed with available consultants at the time of her visit or during the pre/post clinic conferences. Based upon the health team's assessment, a management plan for assisting the woman to control her illness and pregnancy is prescribed. Whenever possible, alternative treatment is presented, e.g., potentially toxic drugs replaced by those known to be less teratogenic. On each subsequent visit, the woman is reassessed and the management plan is reevaluated with changes made accordingly. In addition, there are occasions when the health team may provide information about the illness or pregnancy, discuss potential labor and delivery problems, and offer suggestions for relieving minor discomforts of pregnancy. When the woman is hospitalized for delivery, members of the health team continue their overseeing of labor by monitoring, delivering the infant (in one instance, a woman delivered her infant in the car on the way to the hospital), and keeping the immediate postpartum stage in check. Her final examination is made four to six weeks after delivery.

Overseeing With Restraints. The task of overseeing the well-being of the woman and her fetus, within the clinic setting, is not always an easy one for either the health team providing the services nor for the woman seeking the services. The volume of clinic patients is generally high and the time allowed for each patient is relatively short. Complicated cases require a considerable amount of management time; as a result, there is less time available for those with less complicated pregnancies. Should a resident need to discuss a patient's condition with a consultant who, at the time, is involved with another patient, the resident and patient

must wait. In one particular clinic setting, the women rarely see the same resident on any two consecutive visits, making it necessary for her to repeat her medical history on each visit and for the resident to preview the chart before seeing her. The resident physician often consumes valuable time calling for laboratory results. A further restraint on optimum care is that the women are seldom delivered by the residents who attend them in the high-risk clinic so that the chance of familiarity with their medical histories is uncertain. One of the physicians reflected on this problem of care continuity with a great deal of concern.

> It would certainly improve the continuity of care that the patient receives if we evolved into a private office type situation. Then they [the residents - Ed] would see the same person and then it would take less time. You become more efficient if you see the same patient. The few times that I have been able to follow a patient for a month, or even two consecutive visits, means that I didn't have to pick up the chart and preview it. The conversation gets into other areas. I get to know the patient better. She gets to know me. I can sense her expectations for the pregnancy and maybe the delivery. She can feel out my philosophic attitudes. The meeting of minds improves the care, I think. It also makes it a lot more fun. I think we all do better work when we are enjoying it. (Excerpt from fieldnotes, interview with physician B.)

Residents often feel the pressure "to do a good job" within their limited time. Many lack the expertise and knowledge of the more experienced faculty and consultants. Because of insecurity, there is a rigidity in their approach to patient care (as compared to the more experienced physician) and they are less willing to modify the regimen to fit individual patient's needs. One consultant explained the problem as he perceived it.

> In the earlier stages of their training as residents and as students, without a background or experience, they're not very comfortable and have this need to feel that they are doing everything just right. And "just right" constitutes doing that which somebody else has done. And the only

> trouble with that, at least philosophically, is that the people who reported their experiences have never seen your patient. And so my feeling is that if you can use the information that they have learned from dealing with theirs [experience - Ed] and you look very carefully at yours, then you can tailor a program to fit the needs of your patient. That's, in a sense, the difference between treating a disease and treating a person. (Excerpt from fieldnotes, interview with physician D.)

The focus of management tends to be more on the illness than upon the pregnancy. This may be due to the nature of a pregnancy that is combined with an illness, to the lack of available time in the clinic, or to the lack of experience on the part of some of the residents.

While the women are willing to often drive the long distances to receive the specialized care and the advanced technology offered by a high-risk center, the one-sided emphasis upon the illness is frustrating to some women. Since they are aware that their pregnancy is on-course and the risks low, they are not preoccupied with consideration of the risk nor, because of the nature of their illness, find it necessary to spend undue time keeping it under control. Within this context, the women are more apt to focus upon the "normal" aspects of the pregnancy than upon the illness. They are far more interested in fetal growth and development and the mood changes that accompany pregnancy. During prenatal visits, it is these aspects they want to discuss. Jennifer changed facilities for some of these reasons.

> I didn't like the idea of going over my years of being epileptic every time I went to the clinic and never hearing about my baby. It was as if the pregnancy had nothing to do with it. I go to a neurologist for my epilepsy. (Excerpt from fieldnotes, Jennifer and Larry.)

Investing in a Healthy Baby and Self: The Woman's Strategy. The focus of the women's management by adjunctive control is, in this context, the investment in a healthy infant and self. This control occurs largely

in the home. It is here that she is responsible for carrying out the prescribed regimen and for assessing changes in the status of her illness and/or pregnancy.

The strategy of investing in a healthy infant and self consists of several tactics. Some women regulate their illness with a more strict adherence to the medical regimen. A diabetic will carefully watch her diet and test her urine four times daily rather than once or twice. Some take their medications to keep their illness under control while others resort to positive thinking or relaxation techniques. Others take the initiative and ask for diagnostic tests at the prenatal clinic. Wilma learned to keep her blood pressure within normal limits by responding to bodily cues. She counteracted with such tactics as watching her diet, resting, maintaining a calm attitude, and engaging in diversional activities.

> I've cut down on salt. I rest when I can. If I don't, I notice that after dinner I start retaining water. That is the hardest part of the day for me. I try to lie down, or read, and not do too much at the time. I've learned not to let things bother me. I can tell when my blood pressure is up. In the evening I get more upset. My head hurts, my heart pounds. I feel the sensation all over. I've learned to let things go by, to slide over things. (Excerpt from fieldnotes, Wilma and Isaac.)

Investing in a healthy infant and self involves more, however, than this overall strategy for keeping the illness under control. The women also require tactics for protecting the pregnancy itself. Some quit smoking while others restrict their coffee intake. Several avoid over-the counter drugs such as aspirin. Susan, for the sake of her fetus, made the choice to avoid all drugs even those which might be useful in keeping her illness in better control.

> They said they didn't think there would be any effects from the drug, but they don't really have that much data, you know. They

> were honest enough with me to tell me, this is the way it is and this is what we're basing it on. Most of it was studies on rabbits or rats. And I'm saying to myself, oh well, then I have as much information as you do except the medical knowledge. So really, I have as much as you do because I'm the one carrying the baby. I just kind of made my own decision to avoid it because I didn't know. (Excerpt from fieldnotes, Susan and Bob.)

The diets of all of the women are improved by consuming more protein and vegetables and supplementing their diet with vitamins and iron.

While adherence to the prescribed medical regimen is an important tactic for keeping the illness under control, not all of the women follow the regimen consistently. Some have an occasional lapse because they "forgot" or have a "taste for something." When a woman takes issue with a specific aspect of the prescribed regimen, she may attempt to negotiate with the health team for modification. Marsha did just that because she considered the medication dosage too high.

> They would have me taking 20 mg a day and I thought that was a lot. So I sort of convinced them I could manage on a lot less, so they cut it down. But, I only did it because of the baby. If it weren't for the baby, I wouldn't have minded taking it as much. (Excerpt from fieldnotes, Marsha and Gary.)

Managing at Home. In this context, with the illness and pregnancy in stable state, the women are able to maintain an organized home, care for their children, and control the pregnancy and illness without a great deal of assistance from family and others even though that support is appreciated. Marsha felt strong cooperation from her family even though she was managing without difficulty.

> Personally, I think I am doing very well because I've managed to keep the pregnancy at a very good level. I haven't become depressed and I know that my family is doing everything they can to keep up with me because they have had to slow down quite a bit. I think they humor me sometimes. I'm sure they do. Like when I start to have an asthma attack, everybody runs for the medication. So it's a co-effort and that is what is making it so easy for me. (Excerpt from fieldnotes, Marsha and Gary.)

Watching Over His Investment: The Partner's Strategy. Not all partners are equally involved in the actual pregnancy experience. However, most tend to watch over their mate and her fetus to supplement her managing efforts. Some express concern about the risks associated with the pregnancy. In some cases, he and his partner seek out information either before or at the beginning of the pregnancy. Bob, Susan's partner, was very tuned-in to her needs.

> I figured I could handle just about anything that comes along as long as it is not life-threatening. There are some things you cannot reach unless you take precautions ahead of time, that is what you have to do. I am a pretty observant person. I don't miss too much of what goes on around me, medical signs or anything. So, I just kind of watch. I watch for specific change. I can't name one, but I know how she usually functions and if there is any deviation from that on one side or the other, you can pick it out. (Excerpt from fieldnotes, Susan and Bob.)

Whenever questions about medication and treatment are raised by their partners during the pregnancy, the women either give a direct answer or seek answers from the experts. Women keep their partners informed of their progress by relating that which occurs at each prenatal visit or, whenever possible, they bring them along.

Tactics for watching over their woman and her fetus differ among the male partners. Some have concern for proper rest and food. They make certain that she has a rest period during the day and that she cooks special foods high in iron such as liver and spinach. Others encourage her to attend prenatal visits and put pressure on her to quit smoking. Some lay out her vitamins and scold whenever she fails to take them. Donald, for instance, reminds Sarah, his wife, that she must now eat enough for two with the remark, "Now that was for you, what are you going to eat for baby?"

Balancing: A Choice of Options. The multiple conditions of the women within this context are less threatening so that they generally feel they have more available choices for management of the pregnancy-illness than do the women in less stable contexts. They usually have some option in determining their drug intake for keeping the pregnancy and illness under control, i.e., choosing not to take certain medications, taking a less potent drug, or taking a lower dosage. The balancing process occurs at the point of fetus safety versus the woman's comfort and is always influenced by each woman's personal priorities and beliefs. Jennifer generally weighted the balance in favor of the fetus.

> I knew I had to be on medication and I trusted what the neurologist, obstetrician, and pharmacist told me about phonobarbital, that is, it is not known to cause birth defects. I knew that if I didn't take the medication, the chances of having a seizure would be very high and that would be worse on the baby. The phenobarbital made me sleepy, but I would rather be sleepy than have a deformed baby. (Excerpt from fieldnotes, Jennifer and Larry.)

Sarah chose the traditional health care system during the pregnancy over the alternative system she usually utilized because of the fetus. She said "What is right for me is right, but it may not be right for the baby."

Consequential Concerns. If the women perceive their pregnancy-illnesses as on-course and the risks low, the related and moderate conditions provide them with opportunity to manage their emotional and social tasks without difficulty. Many of the women begin making preparations for the infant's arrival during the second trimester. They name their infant, imagine its appearance, shop for baby clothes and accessories, and take their partners out to select baby furniture.

Jennifer, among others, is particularly aware of the normal psychological changes that accompany pregnancy.

> I've never been an emotional person, but the pregnancy has changed that. I cry, I keep finding myself crying over something that normally wouldn't bother me. I'd be surprised, much less [more - Ed.] my husband. It catches me off guard. (Excerpt from fieldnotes, Jennifer and Larry.)

Most women have no difficulty in properly caring for their other children nor assuming their normal job responsibilities if they work outside of the home.

They naturally fear for themselves and fetuses because of the combined illness and pregnancy; however, they have the normal uncertainties associated with any pregnancy. Some women, including Laura, worried about whether their protein intake was sufficient enough so as to prevent retardation or whether their fetus was developing normally.

> I had the amino because of the age [amniocentesis test to determine of the fetus is at term - Ed.] . Knowing is better than the shock of deliverying, not knowing. But actually, we really know very little from all of these tests. We don't really ever know if the baby is okay. It is not like we had seen through cellophane over the abdomen. The possibility of something going wrong is always there. (Excerpt from fieldnotes, Laura and James.)

The illnesses of women in this context are sufficiently stable so they are not restrained in choosing the type of birth experience they desire. Many of them, including Sara, attended prenatal classes and planned for natural childbirth.

> We "had been pregnant together," Donald and I, and we wanted this to be a good experience not only for us but for the baby also. We planned a Lamaze [a technic devised to reduce tension during labor - Ed.] and LeBoyer [intrauterine environment in the delivery room - Ed.] birth. We want it so that not only do we enjoy the experience but that the baby does too. (Excerpt from fieldnotes, Sara and Donald.)

Janet attended prenatal classes even though she knew that, as a diabetic, labor would probably be induced the 38th week. However, the health team considered her chances for having a vaginal rather than a cesarean-section birth as quite good and held open this option.

When Perceptions Differ: Tactics and Countertactics. Each individual involved in the management of a high-risk pregnancy brings his or her own biography of experience and knowledge to the context. As a result, there is frequently a discrepancy in the manner in which the risks are perceived. The perceptions of the health team or partner may differ from that of the woman. The management tactics associated with the task of risk minimization are determined by the individual's perception of the risk level. If the health team views the risk level higher than does the woman, to bring about a change in her management, they first need to bring about a change in her definition of the risk level. They accomplish this with tactics such as providing pertinent information, emphasizing the seriousness of the problems associated with the risks, and the importance of proper and precise management. After the thirtieth week of gestation, the health team noted that Janet's fetus was small for its gestational age, perhaps due to her hypertension. As a result, management plans were altered. Her clinic visits were changed to weekly intervals and she was asked to plan for regular rest periods throughout the day so that perfusion to the placenta would increase. She did faithfully keep her weekly appointments, but she always appeared either confused or embarrassed. There was obviously a difference of opinion as to the cause of the small fetus. Janet may have been resorting to denial; on the other hand, she was able to rationally explain that she could not agree with their diagnosis because this pregnancy corresponded favorably with two previous pregnancies to the extent that those fetuses were also small in size. She felt a discrepancy in the causative factors as perceived by her former physicians and the physician presently attending her.

> This was the worst pregnancy I've ever had. They kept after me all the time saying that the baby was small. No one ever told me that before with my other babies. I never had all these tests before, either. The blood pressure may make it a little smaller, maybe a pound or so, but small babies run in our family. My mother's babies were small and my other two were small. (Excerpt from fieldnotes, Janet and Frank.)

As a countertactic to the health team's emphasis on small fetal size, Janet asked them to review the records from her previous pregnancies. In terms of fetal size comparison, she made note of the fact that one fetus, at approximately the same gestational age, was even smaller than was this one. She also pointed out that while her blood pressure is quite high when it is initially taken on each clinic visit, when it is retaken after she has had time to relax, it is considerably lower. In spite of the health team's best efforts, they failed to convince her otherwise. By Janet's definition, the pregnancy-illness was on-course and at a low level of risk because the size of this fetus was comparable to that of her other two. Although she rested when it was feasible, it was not a priority in her busy life of caring for two small children and driving her husband to and from work. She was not about to interrupt her life and alter her management routines for, what she considered, erroneous health team perceptions.

Change: Losing a Measure of Control Over the Outcome. There are occasions when the adjunctive control process is inadequate for maintaining the risk level within the low range. A pregnancy-illness combination produces interactive effects which can create status changes in either the illness or the pregnancy. If this occurs, the women and those who work with them lose a measure of influence over the outcome. Changed symptoms signal changed internal conditions. A change in the illness and/or a change in the medication dosage may, because of possible adverse affects on the woman or the fetus, cause the risk level to rise, producing greater

uncertainty regarding the outcome. There is then a probability that the risk context may require redefinition.

Wilma became increasingly concerned when she passed the fortieth week of her pregnancy because, when overdue in a previous pregnancy, she developed toxemia.

> The more overdue I became, the more I worried about the baby. It is funny, we went to church on Sunday and I really paid attention to the children with problems, retarded or Mongoloid. I thought, I hope that this doesn't happen to me. (Excerpt from fieldnotes, Wilma and Isaac.)

Marsha found her illness more difficult to control as her pregnancy progressed. She had difficulty breathing and she wondered if the fetus was receiving sufficient oxygen. She feared this might increase the risk level for the fetus.

> That is what worries me now, the baby. Every once in a while now, I have attacks that last maybe for an hour or so. I just sit there and wait for the medication to start working. There is nothing else to do. But it is the baby. How does the baby breathe? It can't get enough air either. (Excerpt from fieldnotes, Marsha and Gary.)

The Outcome: A Healthy Baby, "That's the Payoff." Relating a specific outcome to a context can be difficult because of potential instability of conditions and the tendency of some women to move among contexts during the course of their pregnancy-illness. However, a broad general outcome can be given for each context.

Within this context, on-course and low risk, the outcome is generally positive. Women who remain within this context throughout their pregnancy have situational conditions that are conducive to a positive outcome. Each had a vaginal delivery, some with natural childbirth. The readjustment stages for mothers and infants were without major complications. All of the infants were of approximate normal size for gestational age.

The women demonstrated attachment behaviors to their infants such as positive verbalizations about the infant and behaviors of smiling at, holding close, looking in face, and tuning-in to noise and expression cues. All women were willing to keep open their options for future childbearing. Janet, and the others, generally viewed the pregancy, labor, and delivery as a positive experience.

> That's what makes me glow over everything else. With having diabetes, that I could bring something into the world that was just as healthy as the next child. That's the payoff. (Excerpt from fieldnotes, Janet and Frank.)

Section B: On Course, Higher-Risk Context

> I am frightened. The doctors seem concerned about the children inheriting the disease but that is not so much a concern of mine. I worry about the child being retarded or malformed, things that never happened in my family. I guess every mother worried about those things, but I worry about the drugs I take because of my kidney, the prednisone and Imuran. I wonder if I am not taking too much of a risk. (Excerpt from fieldnotes, Darlene and Corey.)

The most important characteristic of this context is the feeling of uncertainty regarding the outcome. In this context, the pregnancy-illness is also perceived as being on course. However, the risks are in the higher range due to the severity of the illness or to the medications and/or treatments necessary for controlling the illness but possibly deleterious to the developing fetus. These women are more apprehensive concerning their ability to control their pregnancy and illness and, thus, of securing a healthy infant and self.

Some women enter into pregnancy aware of the high risks. Others do not comprehend the risks as high until a threatening condition of the illness creates an awareness. As in other contexts, their perception of the risk level may or may not be congruent with the medically defined risk levels.

Conditions That Lead to the Women's Assessment. The illness, in this context, is usually severe. There is considerable physiologic involvement with a tendency toward instability and occasional life-threatening events. Darlene (referenced in this section's introductory excerpt) and one other woman had more than one illness or problem complicating their pregnancies. Darlene had both diabetes and a transplanted kidney. Other illnesses require the use of potent and/or large dosages of medication to control the symptoms.

Most women consider the control of their illnessess, during the pregnancy, as a continual effort. They speak of their illness as having been somewhat difficult to manage in the past or as having given them problems in previous pregnancies. Before the pregnancy, most feel confident in their ability to manage their illnesses because of long experience and developed manipulative skills. When pregnant, Diane and others feel less confident because they are aware of the potential complications.

> I read some about the problems and complications of being pregnant and diabetic, some of the realities about it like large babies, but I don't know enough to have any confidence in my being able to prevent them. (Excerpt from fieldnotes, Diane and Alex.)

Assisting in their own situational assessment is interaction with the health team. The fact of risk is stressed either by word or action. Diane was referred to the clinic's high-risk center because her gynecologist refused to provide her with pregnancy care.

> When I first found out I was pregnant, I was miserable because my gynecologist said he wouldn't take me. (Excerpt from fieldnotes, Diane and Alex.)

Lucinda was counseled not to become pregnant; once pregnant, it was suggested that she abort.

> They told me not to get pregnant. They wanted to tie my tubes. Downstairs in the medical clinic they stress the risks. That is their opinion and I won't let that interfere. When I was hospitalized in December for my blood pressure, they wanted me to abort. They stressed the importance of it. Last Thursday they had a conference about it in the medical clinic. All the doctors felt I should abort because my blood pressure is so high and the lupus active. They said it wouldn't be good for me or for the baby. (Excerpt from fieldnotes, Lucinda and Peter.)

Angie, concerned about the outcome, sought direct information from the health team.

> I've been asking quite a few questions. The baby usually comes out fine. It is the mother that usually gets sick of someone is going to get sick. And, if someone is going to die, it is

> the mother, not the baby. Every time I go to the doctor, they tell me the baby is doing okay. That makes me feel good. (Excerpt from fieldnotes, Angie and Henry.)

Supplementing the women's perceptions that the risks are in the high range is the scheduling of appointments in the high-risk clinic on a weekly or bi-weekly basis throughout the pregnancy. Greater emphasis is generally given to the condition of the illness than to the normal aspects of the pregnancy. The women undergo frequent tests to determine the status of both the illness and pregnancy.

Data for assessment is also derived from the extent of fetal activity and from the fact that the fetus remains in utero and continues to grow. For Karen fetal movement was a form of response to her concern.

> Once I decided that was the baby moving, I was very happy. It does make you realize that there is something there and if it is moving, the chances of it being healthy are pretty good. Especially since the fetus has been very active. I really feel delighted every time it moves. I've almost felt like I have a mental communication with it because sometimes I get kind of worried if it hasn't moved for a couple of hours and I start thinking about it and all of a sudden it moves. It is strange, some people think it is strange, but it works for me. Some people find fetal kicking uncomfortable but, to me, every time it moves, it really is a good feeling. (Excerpt from fieldnotes, Karen and Lou.)

The Problem. The presenting problem for women with pregnancies defined as on-course and within the higher range of high-risk is designing a management plan that can increase the probabilities for maintaining the pregnancy and illness on-course and restraining the level of risk. The motivation is the desire for healthy infants and selves. Obviously, the women cannot control the fact that they have an illness or take medications to keep it under control, but there are actions they can take to increase the odds in their favor. These control strategies are similar to those undertaken when the risks are perceived as lower. However,

within this context the strategies have added dimensions. There is greater intensity of performance, an increase in the number of them, more frequent use, and they are of a type designed to protect the fetuses and selves from any dangers that may compound the risks already at stake. Karen very much wanted to exercise such control.

> Before the pregnancy, it was nothing for me to enjoy a meal with desserts, whatever, and not worry about the consequences. But with the baby, you know that if you don't take care of yourself, there is going to be something wrong with it. It is something you can't get away from. There is also myself, in that if the baby does get here and is okay, I want to continue living to enjoy all the experiences of having a child. The anxiety is there and it is kind of discouraging not to be able to wipe out all the possibilities. If there is anything at all I can do that I have control over, I am going to do it. Even with the diabeties, in as much as possible, what control I do have over it, I try to take over and handle. (Excerpt from fieldnotes, Karen and Lou.)

Cooperative Control in Managing Risk Factors. Confronting the conditions that give a basis for their assessment of an on-course, higher-risk context, the women realize that considerable responsibility for their care must be assigned to the health team. Maintaining the pregnancy and illness on course and holding the risk level steady requires the management expertise of those with specialized knowledge. The process of protective governing is now one of cooperative control primarily between the health team and the women. Only with this form of control can the risks be minimized and a healthy infant and self be secured. The focus of cooperative control is the protection of the fetus and the woman from additional dangers that can potentially compound the risks.

The basic components of management by cooperative control are knowledge and support. For recognizing which symptoms are significant, and which are not, requires basic knowledge that is either experiential or

acquired. It enables the woman to know her limits in how far she can go and what she should avoid. Knowledge is her source for devising a strategy and tactics for keeping the illness and pregnancy under control. Experiential knowledge gives her models for coping with complications because she has "been through it before" and knows what to do. Knowledge better prepares her for anticipating problems and taking preventive measures. Knowing may also have negative aspects. For some women, knowing what is ahead creates considerable anxiety. Other women's or her own past experiences have a tendency to color her interpretation of present events so that she is unable to perceive the situation realistically.

The second component in cooperative control is support. The women need to be sustained and receive help to relieve the strain imposed by the stresses of a complicated pregnancy. The health team provides support in the form of medical expertise, gives assurances concerning the internal status of the woman's and the fetus' physiologic condition, or administers proper treatment when the condition of either is less than stable. She also requires physical help about the home and psychological support of comfort and encouragement. She obtains this by devising a network of family and friends to whom she delegates certain aspects of home and illness-pregnancy management. Religious faith is an essential support and comfort source for several of the women.

Looking Out for the Woman and Fetus: A Health Team Strategy. In this context which requires management by cooperative control, the health team's strategy is directed and responsible for looking out for the woman and fetus. The basic tactics of assessing, prescribing, and evaluating continue, but because her condition is more complex, the team's work is more concentrated.

The women are seen more frequently in the clinic, weekly or bi-weekly. The visits consist of a routine prenatal examination and an in-depth assessment of the illness status. The team is constantly on the alert for signs of present medical or obstetrical complications and aware that they should anticipate future problems. Frequent diagnostic tests are made, particularly in the final months, because they are important and supplementary assessment tools. There are many factors to be taken into consideration when establishing a management care plan. Because of the severity of the illness, it is difficult to keep it and the pregnancy on course. In this context, consultants are called upon more frequently to provide specialized data for assessment and the decision-making process. The regimens are more frequently evaluated for their effectiveness and are modified as necessary.

Because the high-risk prenatal centers are often located within an university teaching setting, the health team receives consultative assistance in their tasks from other health-related personnel such as other physicians, nurses, pharmacists, dieticians, and social workers. They also have the most advanced technology and the most recent research findings at their behest. Available laboratories are well equipped to perform detailed and sophisticated diagnostic tests.

Protecting the Fetus and Self from Harm: The Woman's Strategy. The health team performs a vital role in high-risk management; however, they could not engage in cooperative control with the women without their full and willing joint action. Karen realized that cooperative control required her initiative as well as the team's directives.

> The doctors can tell me what to do, but they don't have any control over whether or not I do it. It is up to me. (Excerpt from fieldnotes, Karen and Lou.)

The physician's efforts are of no avail unless the women, at home, expend the effort to implement and enforce the regimen and monitor symptoms for signs of complications.

In this on course, higher-risk context, the control tactics differ from those in the lower-risk context primarily in commitment to carrying out the tasks rather than in the type of task, per se. In other words, the woman must be more deeply motivated if she is to keep the illness and the pregnancy in control. To secure this objective, her overall and large-scale strategy has to be commitment to the physical and emotional tasks of her prescribed regimen. She must, with diligence, take medications, avoid strenuous tasks that might cause the illness to flare, get sufficient rest, take extra precaution with her diet and urine testing (if diabetic), engage in mental relaxation exercises, and remain in good spirits. For maintaining the well-being of the pregnancy, attention must be given to eating nutritious foods and supplementing them with vitamins and iron. Lucinda understood clearly that those tasks were vital to cooperative control.

> I do my part, eat the right food, come to the clinic, and take my medications. I go to church and come right home and rest. I always get up early enough so that I don't have to rush. I lay around, eat my breakfast. (Excerpt from fieldnotes, Lucinda and Peter.)

Some of the more independent women, on occasion, have doubts about what they are told, or not told, and sense better ways of protecting themselves and their fetuses from possible danger. Karen felt that perhaps she was not being told enough.

> I was constantly questioning, was everyone being as honest with me as they could be about what complications were possible. I was afraid that they kept trying not to worry me, like they wouldn't tell me because they didn't want to worry me. (Excerpt from fieldnotes, Karen and Lou.)

Some women, such as Diane, modified their regimens to care practices they felt to be more favorable to the well-being of themselves and their fetuses.

> The doctors told me to increase my exercise and to cut down on calories. When I went to the dietician for counseling, the foods she cut out were the ones with protein. I was concerned about that because I know in pregnancy you are supposed to increase your protein intake. So I added some extra milk and an egg to my diet. It also helps me from getting hypoglycemic. (Excerpt from fieldnotes, Diane and Alex.)

Angie and other women were constantly on the alert for more accurate information that would facilitate their task of controlling the illness, the pregnancy, or both.

> One of the things they say causes the illness to flare up is getting emotionally upset. It is important to stay in good spirits. Hopefully, having a natural childbirth will help. I've been taking classes so that we can go into labor knowing what will happen and how we can make it easier on me. Some medications can cause lupus to act up. If I don't have to have lots of medications, I think my chances will be better. If I know what I am doing, of course I am going to get tired, but I am not going to drive myself. (Excerpt from fieldnotes, Angie and Henry.)

Marsha, who is conscientious, wanted to protect her fetus by controlling her asthmatic attacks. However, though she understands its effects, she feels powerless in controlling its occurrence.

> I had no control over whether or not I would have an attack. No matter how careful I was, I couldn't prevent them. All I could do is know. (Excerpt from fieldnotes, Marsha and Gary.)

The health team always encourages the women to continue their management efforts. They freely praise those who make an effort to keep their illness under control and those who maintain daily records as a control technique. They invite the women to listen to the fetal heartbeat and detail recent fetal growth. The women thus come to realize the efficacy of their efforts. The team redefines expectations regarding the woman's

management role and chides, or even threatens, them with the possible adverse outcome should they renege in their efforts.

The women, by the same token, have their expectations of the health team. They anticipate that the team with its expertise will be on the alert for complications or status changes and prescribe a regimen and management plan that is exactly right for them. In this sense, both the women and the health team are accountable to the other for carrying out their respective responsibilities for management by cooperative control.

For the most, the women cooperate and follow the plan laid out for them by the health team; however, at times, they fail to comprehend the need for a particular medical intervention. Marsha, as an example, simply could not understand why her medication dosage should be decreased when her symptoms were, in fact, more severe. She felt let down because her idea of shared management was one in which the health team would at least acknowledge her experience and individual needs when establishing a plan of care.

> When they should have been keeping the medication down, they weren't. That is when they were giving 30 to 25 mg daily. That is when I was concerned about the baby. The pregnancy is so far along now and the baby well developed that I don't really think it is going to make any difference. So I really don't understand at this point when I need more oxygen that they would cut down on it. I have a really good chest doctor, though. She listens to me. She says if you need more, okay take more. She's not to dictate what I should and shouldn't do. Some doctors won't listen to you. (Excerpt from field-notes, Marsha and Gary.)

Protective Governing in the Home. Daily management within the home is facilitated by the support of family and friends. Family members generally provide help with the household tasks and with the care of other children, enabling the woman to obtain needed rest, plan and shop for the infant, or

attend the clinic. Occasionally, a family member or friend accompanies her to prenatal visits or listens when she wants to share and talk. Darlene who fears being alone in the event she has a reaction and there is no one available to help, appreciated the presence of another person.

> Sometimes I would be afraid to take a nap. In the daytime, I was afraid to really relax because I was afraid I wouldn't wake up. If I were alone and had one of those bad reactions, I wouldn't make it. There wouldn't be anyone to get out of it. (Excerpt from fieldnotes, Darlene and Corey.)

Protecting His Investment: The Partner's Strategy. Most of the women's partners develop an investment protection strategy as their contribution to cooperative control. In some instances, such as Karen's, the need of the partner to protect the woman and her fetus often overshadows his enthusiasm for the pregnancy itself.

> My husband's immediate reaction to the pregnancy was not one of happiness. He was immediately worried about me and the baby, both. He was greatly concerned about whether it would turn out to be a disappointment and he knew how much it would affect me if anything happened. He has since gotten over it. His immediate reaction was one of worry and not joy. It was disappointing for me because I wanted him to be as happy as I was. (Excerpt from fieldnotes, Karen and Lou.)

here the partner's fear for the woman's safety supercedes his blissful njoyment in anticipating the infant, the woman needs to reassure him that ne problems associated with a high-risk pregnancy can be managed. She ovides him with information about the illness and pregnancy to allay s fears. She assures him by demonstrating her ability to keep the pregncy and illness under control and involving him in pregnancy experiences ch as feeling the shape of her abdomen or the fetal movement. She assures n that she and the fetus are carefully attended by the health team and res her prenatal clinic visits, telling him what is said and about test ults. Angie and Henry, along with several other couples, find that

sharing mutual fears and concerns associated with a high-risk pregnancy brings them closer together.

> I think the experience of the pregnancy has made our marriage closer. We were always pretty close, but now even more so. He is shaking his head so I guess that means "yes." (Excerpt from fieldnotes, Angie and Henry.)

As necessary, several partners protect their investment by assuming such chores as housecleaning, grocery shopping, washing dishes, or caring for the children. Some provide supportive presence if the woman undergoes tests that they find frightening or potentially painful. They hold their hands or speak softly to them. Corey directly involved himself in cooperative control of the illness when providing Darlene with sugar during a diabetic reaction.

> The worst problems I had was the reactions in the middle of the night. I'd pass out. My husband says I started flopping around. It's funny. I know the Lord is looking out for me because he [the partner - Ed] is hard to wake up. And he says that I just start moving funny and start perspiring. And he gets orange juice or Seven-up, whatever, down me. I don't even realize it. Sometimes in those early morning reactions I would be very frightened when I woke up and I didn't want him to leave me. But he had to. I managed, but I couldn't have done it alone. (Excerpt from fieldnotes, Darlene and Corey.)

Balancing When There are Fewer Options. Within this context, balancing options is an important part of the three way process aimed at protecting the fetus and self from harm. However, there are fewer options than in the lower-risk context. A woman may not have a choice between taking a potent or less potent drug for controlling her illness because the less potent drug, or a lower dosage of it, is simply ineffective. There is the constant balancing of options in terms of the potential harm in taking a medication or treatment against the harm imposed on self and fetus in not doing so. Darlene was willing to take one drug considered as potent, but not another, equally potent.

> Well, like the immunosuppressant. I have to take that for the kidney, the rejection stuff. I figure I have to take it or I couldn't have a child in the first place. I wouldn't be alive. I have to look at it that way. Now with something like this, I have to weigh the discomfort. Is it bad enough compared to what taking the drug might do to the baby? I talked to the doctors and they said they were questionable risk drugs. Right now it seems like the medicine would be more harmful than the problem. (Excerpt from fieldnotes, Darlene and Corey.)

Some balance the fear and discomfort associated with certain tests for maternal and fetal well-being against the benefits of knowing, derived from these tests. It is as if they are weighing their fear of needles and pain, of possible injury to the fetus, or of stimulating early labor against an immature fetus. Karen displays that perplexity associated with that type of option when she had to undergo the amniocentesis test.

> It seems to me I wouldn't want to go taking a chance. I'm even afraid of how you can feel the baby's back or leg, and I'm afraid to push on it very hard because I might hurt it. Just sticking a needle in there is kind of frightening. During the pregnancy, I just feel protective of that whole area. You know, I don't want to get bumped or anything. (Excerpt from fieldnotes, Karen and Lou.)

In some cases, balancing of options begins before conception when the woman is faced with the decision to conceive or, not to conceive; or during early pregnancy carry a child when the odds against her are so high. Darlene considered the risks for her from an emotional and value bias.

> It is hard to talk to someone that just sees it from a strictly medical viewpoint on what is risky. There is a lot more to it than that of just the medical side. The children mean a great deal to us and we get a lot of joy from them. (Excerpt from fieldnotes, Darlene and Corey.)

When it was suggested to Lucinda that she have an abortion because of the risks, she responded that she had thought it over and after weighing all the factors decided that she could carry a fetus at this time.

> I believe the risks are worth it to have a baby. However, I wouldn't have entered into it if I felt I wouldn't live to see it or be too ill to care for it. Like five years ago, when my lupus was really acting up, I wouldn't have thought of getting pregnant. (Excerpt from fieldnotes, Ludinca and Peter.)

Associated Consequences of this Context. A deeper level of fear is commonly associated with a higher-risk context. Yet, the women need to find ways of coping on a daily basis to prevent these fears from preoccupying their lives. Factors other than fear frequently challenge the women's capability for engaging in normal and daily activities of living. Some have to be especially watchful of overexertion so as not to activate illness symptoms or raise blood pressure. Others find that the combination of an illness and pregnancy drains their energy so that extra activities such as church work are impossible. Several women had to take a leave of absence from their jobs earlier than they had intended because they required extra rest, had to be available for the many and frequent tests, and required time for the closer supervision of their pregnancy-illness as term approached. Marsha noted an added consequence of a high-risk pregnancy. Her daughter grew resentful because of interuption in the normal routines that she shared with her mother.

> It's starting to show at home. My daughter is getting very impatient. She tries to understand about the baby and stuff. Going to the park or playground, things like that I can't do. She wants us to do things together. I can't very well. I watch her and pay attention, but I can't play with her like before. As understanding as she's been, it's getting to her and it shows. (Excerpt from fieldnotes, Marsha and Gary.)

Exceptional concern for the pregnancy has a tendency to also influence e women's attitude toward labor and delivery. While a few women, in s context, attended prenatal classes, there was a certain feeling of ignation frequently expressed as, "It is not a normal pregnancy." The

diabetic women, with overtones of pessimism, usually expected three days of labor induction, terminating "most likely in a cesarean section."

For most of the women, a high-risk pregnancy did not deter them from making active preparations for the infant's arrival. They readily share what having a child means to them and they fantasize about the infant's appearance and personality. There is the usual preference for one sex over the other; however, Angie expressed a very definite preference for a boy because of the greater hereditary susceptibility of her illness for a female child.

> I worry that if it is a girl there is a greater chance that she will have lupus. That is why I want a boy. I know some guys that have it, from the lupus group I started. But I know a lot more women that have it and so do their daughters. It seems more women have it than men. Hopefully, I would snap out of it, but I might always feel that it was my fault that I went ahead and had the child. I know what you have to go through and how miserable it can be. You feel that you are putting your child through this. It is your fault. I have it and your child has it, then you accept the responsibility for it. (Excerpt from fieldnotes, Angie and Henry.)

Typical of most pregnant women, these women have the same concerns bout their weight gain, the same emotional changes, and the same aware- esses of how the child is likely to change their lives.

Dealing with Uncertainty of the Outcome: Fears and Controlling Fears. e uncertainties associated with any pregnancy are a common phenomenon. e women tend to worry that their infant will be deformed or retarded relate these problems to factors such as smoking, insufficient intake proteins, taking of drugs (e.g., aspirin), and genetic mix-up. They ically fear the pain of labor and delivery, particularly if they are nowledgeable about pain reduction by means of relaxation and proper thing techniques. However, women who are in a high-risk category

because their pregnancy is complicated by an illness have still another area of fear with which they must cope. They fear the consequences of measures designed to get their illness under control, the obstetrical complications the illness may incite, and the possibility that their infant may inherit their disease or illness. They fear that the control measure of medication may cause a retarded, malformed, or premature infant. The diabetic women, particularly, fear that the infant may develop postpartum medical complications such as hypoglycemia or respiratory distress syndrome. There is the very real lurking fear experienced by Terrie that the infant may die in utero, during labor, or during/after delivery.

> There is always the anxiety of having a stillborn or a baby with lots of problems. To be so close, inches away, and having it gone. Seeing things happen to other women can really make you anxious and it is hard to verbalize your fear for baby. You can never be sure. (Excerpt from fieldnotes, Terrie and Barry.)

The women also have illness-related fears for themselves. They fear the illness might destabilize, become more severe, or cause permanent or additional physical damage. They also fear that their illness may, in some way, complicate labor, delivery, or the postpartum stage so that they would not survive. As typical of women without complications, their fears intensify as the time for labor and delivery approach. When asked how their fears differ from those women without complicating illnesses, most replied "that their fear was more real or easier to get in touch with."

A variety of tactics are employed for counteracting their fears. One woman was "extra strict" in adherence to her regimen. Some sought reassurance from the health team or from maternal and fetal well-being test results. Those with faith prayed and deferred responsibility for the

outcome to God. Those without religious faith hoped for the best or left the outcome to fate. Some used substitutional technics of keeping busy, denying, or talking about their fears.

Learning to Control. The ability to manage the risk factors varies according to the experience and acquired information of each woman. Some have had experience with a previous pregnancy-illness and others have not. Most of the women had experience managing their illness before entering the pregnancy; two developed the illness during the course of the pregnancy and needed to obtain information on how to control the illness. Some had the experience of a previous pregnancy and some had not. Regardless of past experiences with a pregnancy-illness, each pregnancy combines differently with the illness. Even the experienced women found that there were occasions when they lacked vital information for keeping a certain aspect of their illness, pregnancy, or both under control. When encountering this situation, they had to learn how to manage it. They had to learn how to follow and carry out a regimen; how to differentiate among the medications and learn the purpose of each; how to recognize, interpret, and determine the significance of the symptoms; and, how to recognize which signs are indicative of pregnancy complications. Marsha, having developed asthma during her pregnancy, reflected that necessity for additional learning.

> During the pregnancy I learned a lot about asthma and how to manage. I didn't know anything about it before, but I read up on it and asked questions. The biggest problem was learning about the medications, what they were and how they worked, especially how they worked when they were combined. The doctors told me a lot. I got pretty good at it and learned a lot about asthma, but not by choice. (Excerpt from fieldnotes, Marsha and Gary.)

Marsha, as did most women, learned many of the necessary management skills from reading books, newspapers, pamphlets, and magazines or from watching

television specials about childbirth. Many women questioned the health team and/or other women with similar conditions. A feeling, such as a contraction,simply had to be learned by experiencing it.

Moving Off Course; Losing More Influence Over the Outcome. The conditions that determine an on course, higher-risk context assessment do not necessarily remain static throughout the pregnancy. Although the woman and the health team work in cooperative effort to maintain the pregnancy-illness in a state of control, there are times when the conditions inexplicably change and reassessment of the situation is imperative.

A change in conditions is often signaled by findings such as protein in the urine, a rise in blood pressure, general malaise, or premature labor. There are also temporal changes. As the diabetic nears term, there is that increased chance of fetal mortality. When this temporal risk factor is accompanied by a change in an objective signal it can raise anxiety. Lou, Karen's husband, was deeply concerned when the couple was confronted with an unexpected change in conditions which might well prove threatening to the fetus.

> We didn't stumble into the pregnancy blindly. We knew that it would require a great deal of medical attention. It put us at ease to know that we were here and this was the best place to get the kind of care she would need. For the most part, it was as expected. But when she was admitted to the hospital, that was different in that it was sudden and unexpected. She had her check-up that day and suddenly there was a drop in the estriol level. That was more cause for concern because it wasn't something we had anticipated. Suddenly there was a possibility of something wrong. (Excerpt from fieldnotes, Karen and Lou.)

Women for whom the risks are already perceived as high feel deeply inadequate to further influence the outcome whenever there is a serious change in their physical condition.

The Outcome: "I Am Glad We Did It." Whenever the risks are perceived as high, but the pregnancy-illness as remaining on course, the outcome is generally positive. The deliveries are either vaginal or planned cesarean section. The readjustment stage is without complication for both the mother and infant. All of the infants were of the appropriate size for gestational age except for one which was larger. All of the women displayed attachment behaviors toward their infants. The options for future childbearing were held open. The women's perceptions of the pregnancy, labor, and delivery were positive or ambivalent. A positive outcome for each of the mothers and infants appears to make the considerable effort required to manage the pregnancy as worthwhile. Darlene pointedly reflected this common post-pregnancy attitude.

> I was tired. I don't want to go through another for a while. Now that it is over, I'm glad we did it. (Excerpt from field-notes, Darlene and Corey.)

Section C: Off-Course, Noncritical Context

> They said because of the infections, it could cause me to go into premature labor, which wouldn't be good for the baby because it was only what....six months. I was having light contractions. I hadn't gained much weight and they said the baby was so small that it wouldn't stand much of a chance to survive if I went into premature labor. After I got out of the hospital, I started coming to the doctor once a week. They wanted to keep a close eye on me so that I wouldn't go into premature labor, and if I did, they could stop it right away. I made sure I took my pills every day, and the antibiotics. That would prevent further infection. (Excerpt from fieldnotes, Louise and Christian.)

The off-course, noncritical context is one in which the women perceive that their pregnancy-illness has the potential for interruption from an acute period in the illness, from certain medications or treatments, or from the development of obstetrical complications. Risk factors that previously had only been threatening now become more of a reality even though the situation has not yet reached a crisis proportion. The work of controlling the risk factors, in this context, focuses on maintaining control of the pregnancy and illness or bringing it back under control to prevent the reality from occurring.

Unlike the former two contexts, the women usually do not enter the pregnancy with it or the illness defined as off-course. Rather, they arrive at that assessment during the pregnancy in response to a change in conditions. If the conditions are variable, the context is not a stable one and it has a tendency toward change either upward or downward. As in the former contexts, the women's assesment may or may not be congruent with that of the health team.

Conditions Leading to the Women's Assessment. A change in the status of the illness or pregnancy leads the women to assess their pregnancy-illness

as off-course, but a noncritical situation. For many women, the changes are physiologic changes that normally accompany pregnancy. The effects of increased blood volume and cardiac output in a woman with cardiac disease is a physiologic change. However, combining this physiologic change of pregnancy with a cardiac problem may cause an increase in the symptoms and make them more difficult to control even with medication, rest, or dietary change. Carol, for example, could no longer engage in simple routine activities without increasing her pulse rate.

> I was usually able to do what I wanted, but now I can't. Even if I move a little bit my heart beats very fast. I lie down, take my pulse and it is over one hundred. (Excerpt from fieldnotes, Carol and Darrell.)

Terrie noticed that symptoms of her illness had not only changed during pregnancy but became more difficult to recognize.

> I was always able in the past to tell when I was hypoglycemic, but since I've been pregnant, I can't tell. It seems to come on me slowly and I can't tell when it is coming. I never saw my diabetes as a handicap before, but now I do. I always thought to be an epileptic or something was worse because they could lose control. The other day I had a hypoglycemic attack that took a long time to go away. I missed my bus and didn't have lunch. I did bring along some raisins and nuts and ate them. But, it took a long time to go away. I felt spaced out. I had no concept of time. I was awake, but I wasn't awake. It was frightening. (Excerpt from fieldnotes, Terrie and Barry.)

Those women who develop obstetrical complications such as premature labor, bleeding, or preeclampsia symptoms have lingering uncertainty about fetal status even when those symptoms are in control. Because of bleeding, Diane feared she would lose the fetus. Because of the illness, several women, as with Carol, experienced more severe problems with this pregnancy than did they with previous pregnancies.

> I've had some problems every time I've been pregnant. This is my fifth pregnancy. It seems like it gets more dangerous for me with each pregnancy. This time was worse than any of the others. Each pregnancy I was hospitalized, but it didn't

> flare up like this before. I didn't have to have a blood transfusion or have a fever that they had difficulty breaking. The doctors told me they thought they were going to lose me. (Excerpt from fieldnotes, Louise and Christian.)

The health team generally emphasizes the seriousness of this situational context; on the other hand, their messages are sometimes contradictory. Carol was told by her obstetrician that she needed to be careful or she might require another operation. This frightened her. Whereas her cardiologist told her that the condition of her heart was such it could withstand the stress of pregnancy and labor. This left her perplexed. Some women as with Heather, failed to receive the reassurance they wanted from the health team, leaving them with their fears.

> I kept thinking of having an abnormal baby, you know, one with a missing part or a sick baby, the kind of things that are prevalent with women taking macrodatin. When they first put me on the medication I didn't realize the seriousness of it while pregnant. My grandmother had books on antibiotics and it said it [the medication - Ed.] shouldn't be given to pregnant women and things like that. It causes slow development of the fetus. That is when I started to worry and the doctors couldn't reassure me. They couldn't say yes, the baby will be born normally. Yes, the baby will be fine, you will be fine. (Excerpt from fieldnotes, Heather and Edward.)

Some were told that their weight gain was inadequate; or, that the fetus was small for its gestational age. Heather, after ultrasonography, learned that her fetus was small and was concerned that the fetus would be a "five months size at seven months if it were born early."

There were also positive signs that encouraged the women. Indications of fetal heart tones and of movement conveyed to Louise that the fetus was active and alive. "Regardless of what they are telling me, as long as I feel movement, I know it [the fetus - Ed.] is okay." The lack of movement causes some women to doubt the reality of a living organism within them.

The Problem. The essential problem of a pregnancy-illness that is off course, but not critical, is the designation of a plan that will draw it back on course and, once on course, to hold it there. This is a vital process for reducing the probability of risk. Faced with the very real possibility of not achieving a healthy infant or self, most of the women are willing to take whatever measures are necessary to draw the pregnancy-illness back and maintain it under control so as to secure a positive outcome. Heather was willing to take potent drugs and give up enjoyable activities to keep her pregnancy on course.

> I just kept thinking, it is a baby and I want it to be healthy and it is going to be there. That was my goal, that's what I was looking forward to. People would say, let's go shopping; I would say, well, I can't go, I have to stay home and rest because I'm going to have a healthy baby. (Excerpt from fieldnotes, Heather and Edward.)

Entrusted Control in Managing Risk Factors. Within this context, the conditions are serious and extensive enough that the possibility of harm to self and fetus is perceived as very real. To alter these conditions so as to minimize the risks, the women need to assign to the health team an even greater share of responsibility for managing than did the women in the former contexts. They have to rely on the team to initiate the necessary measures for drawing the pregnancy and illness back under control and maintaining it there. Once the team delineates these measures for the women, the women do their share as a form of coordinated effort. This form of control whereby the women confidentially surrender the initiative for managing to the health team is termed entrusted control. The focus of entrusted control is getting the pregnancy-illness back on course and keeping it there by means of initiating activity.

What influences the women's willingness to entrust control to the health team with a sense of confidence and trust? Essentially, they trust in the team's knowledge, expertise, and experience to initiate a management plan for which there is a high probability that the women will successfully secure a positive outcome for herself and her fetus. As Karen discovered, it takes continual interaction and time with the health team for grounding trust.

> I have a lot of trust in everybody around here. That is one of the most helpful factors. Well, it wasn't like that at first, but I have gained trust the more I've been here and seen and talked with people. (Excerpt from field-notes, Karen and Lou.)

The health team must demonstrate its knowledge of and skill in management. The women mention factors that foster trust in the health team as honesty, a willingness to answer questions, praise for its efforts, listening to what they had to say, incorporating their suggestions into the management plan, and attentiveness to individual needs. Having this sense of confidence in the team gives the woman and her partner comfort. They know there are experts upon whom they can depend to take over aspects of management they can not control. When Marsha developed premature labor after a severe asthmatic attack, her husband, Gary, felt a deep sense of security in the team's ability to control the obstetric complication.

> The doctors seem confident that they are able to stop it and let the pregnancy continue as it should. That takes a burden off me. I feel relaxed knowing they can calm things down and make it work. (Excerpt from fieldnotes, Marsha and Gary.)

Increasing Their Efforts: The Strategy of the Health Team. Within this context, dependent upon entrusted control, the basic plan of the health team is an intensification of managing effort that will restore the pregnancy-illness to on course and maintain it there. The women are

seen in the clinic weekly rather than biweekly. Although the routine obstetric and medical assessments continue, the dimension of discovering and treating the problem is added. The women assist the health team in making a diagnosis by accurately and fully reporting their symptoms. The health team makes more frequent and careful observations. They study the results of diagnostic tests and more freely consult with other health professionals. Regimens are readjusted according to changing needs. The team emphatically stresses the consequences if the women fail to adhere to their recommended plan of management. Louise was afraid of premature labor if she were not strict in her management.

> All I ever heard was if I don't take this, this will happen. If I don't do that, that will happen. They always talked about premature labor. That had me scared to death. For the past three and a half months, I've been thinking I am going to have premature labor. I've got to watch this and watch that because the baby might not live. (Excerpt from fieldnotes, Louise and Christian.)

Heather had not always followed the regimen because she felt it was not beneficial and could be possibly harmful. It was necessary for the health team to convince her of its importance.

> I was more concerned about the effects of the medication on the baby than the infection. It is so difficult, all you have to go by is what they say. They really had to do a lot of talking to convince me that it was beneficial for me to take the medication so that it would be healthy. (Excerpt from fieldnotes, Heather and Edward.)

When efforts to manage the pregnancy-illness on an outpatient basis are inadequate, or close supervision is required, a woman may be hospitalized.

Taking the Necessary Measures: A Strategy of the Women. In coordinating their efforts with those of the health team in entrusted control, the women follow the prescribed regimen and take whatever measures are determined to be necessary for securing a positive outcome. Their tactics include the reporting of unexpected physical symptoms, of taking medications and treatment, modifying the nature and extent of their activity,

watching their diet, and intensifying their watch over themselves and fetuses for changes in the illness and signs of pregnancy complications.

Some women find it difficult to follow the regimen because it is in conflict with their habits and individual tastes. Carol, when advised to refrain from using salt, reacted to the fact of saltless food and tailored their advice to simply taking less salt. However, later in the pregnancy when symptoms of edema and shortness of breath continued to interfere with her activities, it was necessary for her to sacrifice all salt as a measure for getting her pregnancy back on course.

Restraints to Managing Within the Home. Some women lack both the confidence and motivation for taking the necessary measures that would maintain their illness and pregnancy in control. Management capability within the home is dependent upon the variables of extent of their applicable knowledge, the stability of their emotional and social conditions, the availability of support from others, and adaptive skills. When one or more are not in operation, management is greatly hindered. When Diane's mother-in-law was in the hospital with terminal cancer, she visited her daily. At the same time, she and her husband were remodeling their new home. Due to the emotional stress and physical strain imposed by these conditions, she felt run down, caught the flu, and had problems in stabilizing her blood sugar. When the health team wanted to hospitalize Terrie to regulate her blood sugar, she resisted because it would cause her social and interactional problems at home.

> They want to put me in the hospital to regulate me, but I can't go because my husband yells at me about who will take care of our little boy. When I come home he makes it very difficult for me for several days. It just isn't worth it. This pregnancy has been very stressful for me. (Excerpt from fieldnotes, Terrie and Barry.)

Another problem that hinders home management is the difficulty in finding time from routine responsibilities to maintain a twenty-four hour watch over the fetus and self as they neared term. Some had concern that, because of distance, making it to the hospital if something happened could be a close call. Some women find their problems too serious to deal with at home or they lack the necessary skills for coping. MaryBeth, finding the restraints in the home too great, took refuge in the hospital. When she was given the choice of learning to manage her illness at home or in the hospital, she chose the hospital.

> By coming to the hospital, it doesn't frighten me as much as if they had just turned me loose and told me to take a shot. I feel here they will have taught me what I need to do when I get home. Then, I can follow it. To show me in the clinic and then have them say, go home and do this, and not have them check out the amount of food and such, it would worry me. Just turning me loose, I feel, was taking a risk. (Excerpt from fieldnotes, MaryBeth and John.)

Dealing With Hospitalization. While hospitalization is sometimes necessary for stabilizing the pregnancy-illness or for monitoring the course of the pregnancy, the women find they must relinquish most of their responsibility for control to the health personnel. Karen particularly found this to be true when discovering errors in their carrying out of her regimen.

> It is not easy to control what happens to you under hospitalization. You know, you don't choose your roommates and don't choose the different situations that you're put into and it's stressful to have things go wrong. That was frustrating. Like they had me explain my diet to them and then they brought me the wrong things. Or, like having a heparin lock put in and having to explain from my own experience how to care for it. If I had three hands, you know one hand on the heparin lock and two to work with, I could have done much better myself at taking care of it. (Excerpt from fieldnotes, Karen and Lou.)

They frequently feel the loss of emotional and social control because of separation from family, constant interruption, a lack of privacy, and feelings of boredom and frustration. How do the women compensate for this loss of control? They resort to such tactics as preparing the family before their hospitalization to ease the separation, maintaining contact with home by telephone, handling minor crisis as best they can from a distance, and inviting friends and family to visit. Some involve themselves in hospital activities such as finding fault with personnel, overseeing the care provided by the health team, involving themselves in the lives of other women as advocates, or teaching baby care to other women. Some women read, watch television, or do handwork.

Retaking Over Control: Conflict Over Management. What does a woman who has entrusted control to the health team do when confidence in them is lost? As did Marsha, she took back control.

> That morning I got up and dressed. And the nurse said, "Where are you going?" I said, "I am going home." She said, "Are you sure?" The resident came in. I didn't know who he was, there is such a big turnover. He said, "I hear you are going home." I said, "Yes, I am going home. I don't feel good and I want to go home." He said, "You can't leave." I said, "Yes, I can." He felt because I had the iv in I couldn't leave. They had to take it out. What else could they do? If I wanted to leave there was nothing they could do to keep me there. They found out I was leaving and I had good reason to. They weren't about to challenge me. (Excerpt from field-notes, Marsha and Gary.)

It is not clear why Marsha abruptly left the hospital. Perhaps there was an unresolved conflict with health personnel with which she could not cope or an inner loneliness for her family. Regardless of her specific reason for taking back control, it can be determined that her condition was not acute, for if it had been, she would not have been willing or able to bear the responsibility of control, alone.

Retaking control occurs in stages. It begins with several small or one major incident that incites the woman to question the plan of management laid out for her. The health team responds, as they did with Diane by trying to reassure her and/or convince her that they were taking the proper measures for bringing the illness or pregnancy under control.

> They tried to convince me I was having some kind of stress episode. I said, "I know what an insulin reaction is, I've had diabetes for years. I know what it is, either that or I am losing my mind." They almost convinced me that I was going crazy, that I wasn't having insulin reactions. Then, when I finally got through to them that they were insulin reactions, they said, "Well, you better stop having them. It's bad for the baby." (Excerpt from fieldnotes, Diane and Alex.)

She counteracted with reason and attempted to explain to them that which she knew from experience worked or did not work for her. Failing to convince those with power to alter her regimen, Diane felt helpless, upset, and a loss of confidence in her managing abilities.

> I guess it upset me because I know what is going on with my diabetes and nobody would listen to me. That is what made me feel powerless, that is what made me feel so helpless. Even though I knew what was going on, nobody would listen to me. The nurse listened and one of the interns did, but the doctors wouldn't. (Excerpt from fieldnotes, Diane and Alex.)

When a consultant was called in and he concurred with her judgement of the situation, she felt vindicated. However, when the health team continued to manage her illness in a manner she felt inappropriate, Diane felt she could not longer tolerate the situation, and took back control by leaving the hospital. She refused to cooperate with their plan of managing her illness. Though she felt confident about taking back control of her illness, she still wanted their help in managing the pregnancy.

> Like I told the doctor, all I want from them is to take care of my baby. If I have a big baby, well let me have a big baby.

> At least I will know what my blood sugar is doing. It was either that, according to what they were doing, or have insulin reactions from now until the baby is born. I thought, this can't be so, it can't be right. (Excerpt from fieldnotes, Diane and Alex.)

In this type of impasse, there is usually a loss of trust in those individuals with whom there is conflict. After establishing a distance between herself and the situation, the woman is usually able to find others with whom she can satisfactorily work and to whom she is willing to entrust control.

Balancing Options: Making a Trade-off. The management focus for a pregnancy-illness that is off course but noncritical is the exercise of all the available options for drawing it back on course and holding it there. The options available are few and of those available, some are risk factors in and of themselves; other options are not but may have physical, emotional, and social consequences. It becomes a matter of establishing priorities from among the potential consequences, making a choice and following through with whatever measures are necessary for securing it. For choosing the most advantageous and yet safe option, the women need information about the available options and their consequences. This information she usually obtains from the health team or from other independent sources. The women generally entrust the option-balancing process regarding the well-being of themselves and fetuses to the health team. She, however, assumes the responsibility for balancing their options with her social and emotional needs, sometimes at considerable cost.

Noreen and Kenneth encountered this kind of balancing problem, in terms of trade-off in her pregnancy-illness. In addition to the expected child, they had two preschool-age children and two of school age.

Kenneth, an educational consultant, worked out of the state during most of the pregnancy. As a result, Noreen was left to weigh and balance her options without his input. While he was away, Noreen developed symptoms of premature labor after an episode of acute pyelonephritis and required hospitalization. Following a period of hospitalization, she was placed on terbutaline and bedrest. To comply with this regimen, she took a leave of absence from her position as teacher and removed the two older children from school. Because her home was considerable distance from the medical center, she moved in with her family who lived in its vicinity. Her history indicated that her previous deliveries had been early (32-34 weeks). She anticipated an early delivery for this birth which would allow her an early return to work and the boys' return to school. However, she did not have an early delivery, as expected, and had to rebalance her options and make a trade-off between the well-being of herself and fetus and the needs of the rest of the family.

> My husband felt that it wasn't just the baby that we needed to worry about. It was the entire family situation, which was true. I seemed like he [the infant - Ed] had gotten along further than the rest of the kids and would not have been as sick as they were. They had minimal residual problems and so we felt we could handle his [the infant's - Ed] being early. The frustration came from not being able to take care of the needs of the rest of my family and job. That was hard on me. My husband and I were not convinced that the baby would have no lung problems, anyway, because all our babies had. And so we envisioned having to wait forever and keep on getting negative tests. (Excerpt from fieldnotes, Noreen and Kenneth.)

Noreen chose to balance her options in favor of the well-being of her fetus over those of her family's needs because of her deep commitment to the health of the new child.

> Actually, you are caught in it [the pregnancy - Ed] and you have to continue to invest in it. That is the way I feel. You just can't change your mind at eight months. I didn't

> think I would be comfortable with any other decision because the baby would have problems. Depending upon how severe the problems are, that I would be personally responsible for having deliberately done it. Whereas, if I did what was necessary and it came early, I wouldn't have to feel guilty. (Excerpt from fieldnotes, Noreen and Kenneth.)

Her balancing in favor of the baby, however, had consequences for her social life. Her boys missed a considerable amount of school, affecting their performance. Her prolonged absence from her teaching position affected the quality of instruction her pupils received.

Becoming a Temporary Caretaker: The Partner's Strategy. In this context, the partners are active participants in entrusted control. The women place confidence in them that they will give physical, emotional, and social support in their various management tasks. Some, such as one husband who was left to care for his eight children when his wife was hospitalized, assume all the responsibility for maintaining the home and caring for the children. His wife would call home five to six times a day to give him advice and verbal assistance in his management task.

Some partners show their deep interest for the women's welfare by intervening on their behalf whenever they are unable or unwilling to make requests that would serve their well-being. Other partners serve as conduits of information, relaying information from the health team or others to the women. When, during his wife's hospitalization, Gary felt convinced that management by the health team was not in her best interest, he had no qualms about taking over control and removing her from an environment he no longer considered safe.

> After she became stable, they kept giving her that stuff in the same quantities and she was just getting sicker and sicker all the time. After she kept telling them and refused to do anything about it. I mean, if somebody is getting poisoned,

> what are you going to do, let them poison her or cut it off? So, I told her to get dressed, I was coming to get her and take her home. (Excerpt from fieldnotes, Marsha and Gary.)

Not all partners understand the concept of a high-risk pregnancy. Their assistance can hardly be enlisted if they have only little awareness of the seriousness of the woman's situation. Heather found it most difficult to convince her partner of the specialized management a high-risk pregnancy requires. She finally enlisted his support by convincing him of the seriousness of her condition through open and honest communication.

> We had a really rough time at first because he would look at other pregnant women and see how happy they were and say, "Why can't you be that way?" It was hard for me to explain. We both had to sit down and talk about it and be honest and talk about the things the doctor said could go wrong. Once he understood, it made it a lot easier. He helps me and does things because he understands the conditions now whereas, in the beginning, he didn't. (Excerpt from fieldnotes, Heather and Edward.)

Context Consequences. As in former contexts, certain of the conditions that qualify this context as off-course frequently provoke emotional and social problems. The fear of not achieving a healthy infant and self is often intense if the women have difficulty in maintaining the pregnancy-illness on-course. These additional and directed efforts generally provoke considerable stress and strain for themselves and for those who have concern for their welfare. If the illness is off-course during the last trimester, there is a real fear of extended and complicated labor, of cesarean rather than vaginal delivery, or of simply not making it through labor and delivery.

Another consequence of an off-course illness is the requirement of extended bedrest. This situation produces a variety of problems that contribute to emotional stress, as it did for Noreen.

> Actually, it was the time of waiting that was the real strain, probably more than staying in bed. I am used

> to staying in bed with my pregnancies, though it is hard when you have two little kids. I feel very useless and helpless. It was hard to wait because of the emotional things with my sons and how much they needed which I couldn't consider giving them with my being down. I think that was the hardest part. It was also hard for me to be in someone else's home all the time, their doing things for me. If I feel I can pay them back by doing a similar thing, then I can handle it better. (Excerpt from fieldnotes, Noreen and Kenneth.)

Holding Back: Protecting the Self Against Loss. Some women within this context make active preparations for their infants such as deciding on a name and buying furniture and clothes. Others hold back from these preparatory activities. Holding back in this situation serves as a protective tactic of control against the possible loss of the fetus. As with Diane, many women are reluctant to make an emotional investment in their infant until it is born.

> It is kind of funny, everyone said once you feel movement, you get real attached and everything. Maybe it is because I've had problems and stuff. I don't think I will feel attached until the baby is born. Maybe I am just trying to psych myself out just in case something happens. Maybe because I've had problems with the diabetes and the bleeding. It is not that I wouldn't do everything to keep the baby, it is just that I won't let myself get too excited. (Excerpt from fieldnotes, Diane and Alex.)

As Diane indicated, it is not so much that the women did not continue to take the measures necessary to maintain the pregnancy, but that they did not want to become too emotionally attached to an infant that might not live nor be healthy.

> I think anyone who has complications with their pregnancy, there has to be that certain amount of doubt because the doctors are telling us things like that and we tend to put doctors right up there. Maybe there is an element of truth, there is a possibility that I won't have a normal child. I am not getting my expectations up too high. I want to be able to turn my life around regardless of the situation with the baby. (Excerpt from fieldnotes, Heather and Edward.)

Conditions that lead to holding back are a poor obstetrical history, medical problems during the pregnancy that are perceived to be so severe so as threaten the life of the self or fetus, the development of obstetrical problems such as premature labor and bleeding, or a fetus that is reportedly small for gestational age. With a change in one or more of these conditions such as the progression of the pregnancy to a state of viability as the date of delivery approaches or weight gain of the fetus, there is a noticeable change in the women's attitude. They begin to speak about the fetus and make the necessary physical preparations. Carol, as she began to feel better, gave considerably more thought to the child within her than did she when she felt so sick. Because Heather's fetus gained weight so slowly, she didn't commit herself to the reality of an infant until about two weeks before her expected date of delivery. At that time she finally went out to buy a baby crib.

> It is the fact of knowing that the baby is now gaining weight. You know, it was so little, little, little. Then, all of a sudden, they said she had reached six pounds. It is kind of like climbing a mountain and reaching the top. It is not that you can't have a small baby and have it survive, but I just felt that the extra weight would give it a better chance. I felt better about myself and everything, knowing that it was gaining weight. (Excerpt from fieldnotes, Heather and Edward.)

Only Noreen, who had a poor obstetrical history, continued to demonstrate signs of holding back right up to the time of delivery. Her response when asked if she felt more encouraged about the fetus as term approached was negative.

> No, because there was a lot of potentials [for problems - Ed.] around. And since we have had all kinds of problems in the past and with this pregnancy, we just kept not planning on it. Because once you plan on it and it doesn't happen, then you have to be much more upset than if you prepare yourself for the worse. We all recognized that there might be a chance that it would be okay, but we didn't want to plan on it. (Excerpt from fieldnotes, Marybeth and John.)

Noreen was also one of the women who expressed reluctance to name her infant before birth because if one "names the baby, you really plan on it and so, in terms of your psychological set, it is harder if the baby doesn't make it."

Regaining Some Measure of Influence Over the Outcome. It is recalled that in an off-course, noncritical context there is a tendency toward instability because of the more serious nature of the conditions. Any change in the condition causes the woman to redefine the context upward, as off-course and critical, or downward, as on-course with high or low risks. Significant changes causing them to reassess the risk downward include the acquisition of new information which enables them to more accurately interpret symptoms, an accommodation of the body to the physiologic changes taking place because of the pregnancy, an increase in fetal growth, and the restabilization of the illness and/or pregnancy. A change in their definition of the context is usually accompanied by a concomitant change in management. Reassurance from her cardiologist regarding the significance of her symptoms, along with a decrease in symptoms, changed Carol's outlook toward the pregnancy and her willingness to take a more active role in the controlling process.

> I put less salt on my food, I've really cut down. I've also started to put protein powder in my milk and to crush my pills in the morning. Also, I've talked with the cardiologist. Before I was worried that I might die. Now, I am not as worried. When I have a pain now, I think, it will go away. Before, whenever I had a little pain, I thought, oh, oh, there is something wrong with me. I am not thinking about my heart all the time now. Instead, I am thinking about other things. (Excerpt from fieldnotes, Carol and Darrell.)

A change in assessment of the risk level is also accompanied by a change in other behaviors. The women become more actively involved in the tasks of every day living, caring for their home, and shopping. There

is also more involvement with the fetus, thinking about it and making preparations. One woman even began to occasionally babysit for a friend so that she might gain more experience in child care. Another went to work. Overall, there tends to be less preoccupation with the illness and/or pregnancy problems than before. With a change in conditions, it is as if the women had gained a measure of influence over their outcome.

Losing Some Measure of Influence Over the Outcome. While for some women the probability of risk apparently decreases, for others, the probability tend to increase. Despite their efforts, and those of the health team to manage by entrusted control, conditions worsen. When the fetus' life and/or her own is threatened, it is as if she reaches a cutting point in her ability to control. No longer does she feel able to take the necessary measures to bring and keep the pregnancy and/or illness under control. If she is to retain some measure of influence over the outcome of the pregnancy, she will now have to delegate her share of the effort for controlling the pregnancy and illness to the health team whom, at this time, she perceives as having the ability she lacks.

The Outcome: "A Fantastic Relief." Within this context where the nature of the conditions determines the assessment of the pregnancy-illness as off-course and noncritical, there is a tendency toward instability with the risk factors downward when the pregnancy-illness moves back on-course or upward when it tends toward the critical context. If, during the course of a pregnancy, there are periods when the pregnancy is off-course and then moves back on-course before delivery, the outcome is generally positive. There are both vaginal and planned cesarean section deliveries. There are no major complications during the readjustment state. Two infants were within the lower range of normal size for gestational age, the

remainder were of normal size. While some women held back from making emotional and physical preparations for the infant-to-be during the pregnancy, all demonstrated positive attachment behaviors toward the infants after delivery. Some women chose to keep open their options for future childbearing, others felt the risks were too great so that they did not plan for more children. As within the former context, the women's perceptions of the pregnancy, labor, and delivery experiences were either positive or ambivalent. Noreen's perception was certainly positive and considered worth the considerable physical, emotional and social investment she made.

> Since we did wait [for delivery - Ed.] until the baby was fine, it is very exciting. It is a fantastic relief when you have a baby that is able to go home with you. You know, I've never had that happen before. I've never had a baby that came into the room to visit with me before. (Excerpt from fieldnotes, Noreen and Kenneth.)

Section D: Off-Course, Critical Context

> I was in labor for 15 to 16 hours, hard labor. I think it was Wednesday, the fourth time they tried to induce. It is hard for me to remember, it was so awful that I try to forget. It was then that they said I wasn't making fast enough progress and that there was too much risk to the baby. They did a cesarean section. By that time, they could have done anything. I was ready for a cesarean section. I was so afraid. I went into the cesarean section shaking like a leaf. I was so tired by then, I wanted a general. I had no control. It was much too painful. All I wanted was to go to sleep. I couldn't stand it anymore. I was worried about the baby. My husband was pacing around. He didn't know what was happening. I felt so sorry for him. I just gave in. (Excerpt from fieldnotes, Diane and Alex.)

In this context, Diane and other women perceive the risk to their fetuses and to themselves as very high and life threatening. The risk factors are so pervasive and severe that the women no longer have the ability to control them. The characteristic of this context is its relatively short duration as compared to the other contexts. Its primary strategy is decisive action by both the women and the health team.

Conditions Leading to Assessment. There are usually a combination of physical, interactional, and temporal conditions that provide the basis for an off-course and critical context. Physical and temporal conditions include early signs of preeclampsia that gradually worsened for two of the women and, suddenly, for one woman. Karen, a diabetic, passed the usual delivery point for diabetics (37 weeks) and reached her 39th week without delivery. For one woman, complications caused a drop in the fetal heart tone; for another, meconium staining. Lucinda's oxytocin challenge test was positive (associated with a high incidence of neonatal death) and her illness was found to be out of control, as indicated by x-ray that showed fluid around her heart.

The risk factors are usually set forth explicitly by the health team and the situation is described as one in which the woman and/or her fetus are in jeopardy. The team will then sometimes advise immediate delivery, as they did for Lucinda who was told that "her fetus would do better on the outside where they could do something for it than to have it where they couldn't." At this point, most of the women perceive themselves to be ill, fatigued, ineffective, or uninformed and fearful, as was Sandi.

> I really didn't know what was happening. At 7 cm, my water broke and it was a funny color. And, my body was jumping, that is my legs, my reflexes. They decided to do a cesarean section. They then brought me into the room. They started sticking that catheter or whatever you call that thing, into me. And, I was in labor. I said, "Just put me to sleep first and you can do what you want." (Excerpt from fieldnotes, Sandi and Henry.)

Karen perceived herself as ineffective in her control of labor.

> Like after the second day, the doctor came in and he said, "You know, you didn't do anything." And, I felt like....me!!!! I mean I didn't have much control over what was happening. It didn't work. (Excerpt from fieldnotes, Karen and Lou.)

The Problem. When the pregnancy-illness is assessed as off course and critical, the problem is that of finding a way to contain the menacing risk factors. After months of continual and arduous effort in controlling her illness, Diane was ready for delivery by cesarean section if that meant having a healthy infant and self.

> My blood pressure kept going up. I was retaining so much fluid. They said they wanted to get the baby out while it was still well and not when there was some problem. I'd been through so much, I didn't want that to happen. I wouldn't want the baby to up and die now. (Excerpt from fieldnotes, Diane and Alex.)

Relinquished Control in Managing The Risk Factors. Faced with the problem of having to take action to contain the risk factors but perceiv-

ing herself as unable to any longer do so, the women generally relinquish control to the health team. Consequently, controlling the pregnancy and/or illness is no longer the responsibility of the women. Efforts to control the pregnancy-illness are delegated to the health team. The focus of relinquished control is containment of the risk factors. Because of the critical and impinging conditions, time is an important variable within this context. Whenever either of the two lives are threatened, regardless of the immediacy factor, rapid decisions must be made and quick action taken to contain the elements of risk.

Taking Over Control: The Health Team's Strategy. In this critical context, the health team's and the woman's jointed and united activity of pregnancy-illness management is, for all practical purposes, dissipated. Conditions are so threatening to the life and health of the woman and her fetus that only the expertise of the health team can be counted on to maximize her chances of a positive outcome. The health team literally takes over for the woman. Major tactics in taking over control so as to contain the risks include the tasks of assessing, monitoring, decision making, and intervening. The situation usually requires immediate and accurate assessment upon which action decisions are made that will minimize a jeopardous situation. Lucinda, it is recalled, had a positive oxytocin challenge test and fluid around her heart. It was quickly decided to deliver the fetus even though Lucinda was only in her seventh month of pregnancy. There was also a diabetic woman with elevated blood pressure and edema for whom the health team attempted to induce labor, but their monitoring of her indicated no progress. They then decided, that for the safety of her and her fetus, to intervene and perform a cesarean section.

Giving Over: The Woman's Strategy. In this context of relinquishing control, the woman's efforts to control her situation are no longer safe nor effective. The conditions constantly require medical assessment and intervention. It is in her best interest to give over the work of controlling to the health team. Karen, however, continued to actively and prayerfully watch over the status of her fetus and self until the time for delivery.

> After he told us that, even the few hours between then and the time the baby was delivered was really a torment because they had convinced us every minute....the baby was being monitored constantly at that time ... and we constantly watch the baby's heartbeat, praying that it would go on the way it was. (Excerpt from fieldnotes, Karen and Lou.)

Standing Watch With the Woman: The Partner's Strategy. The role of the partner is also a less active one because within this context the conditions are far too serious for other than expert control. However, he can still put forth psychological effort. He stands watch with the woman, he assists her with decisions that remain within her realm to make, he watches over her and promotes her well-being in whatever form he is able, and gives her his supportive presence. Diane and most of the other women were aware that it was also a difficult time for their partners, but their support was nevertheless important to them.

> I guess it was so hard on him because he just lost his mother and was worried that something might happen to me. He is normally devoted, but he's been even more so. He has spent all his time here. I hated to see him go through so much, but it was good for me. I needed somebody with me. He put up with a lot. (Excerpt from fieldnotes, Diane and Alex.)

Balancing: Having "No Choice." When her life and that of her fetus is threatened, the woman is faced with a "no choice" situation. There is no time nor opportunity for alternative or palliative measures if one or both are to survive. It becomes a matter of choosing that option which

is most likely to reduce the immediate threat and contain risks. In less critical situations, that particular choice may not have been considered at all because of its potential to be a risk factor in and of itself. Delivery of a fetus before it has reached maturity and the surgery of a cesarean section are threatening risk factors. When Karen felt the life of her fetus threatened by two days of induced labor and newly developed complications, she lost no time in giving her permission for a cesarean section.

> The baby's heartbeat started showing signs of stress even under light contractions. It was like the baby's heartbeat, rather than accelerating, had leveled off. They put me on oxygen and had me roll on my side. It was a very stressful and alarming type of thing. It straightened out but it was like you've got to make a decision right now, what do you want to do. After they explained everything, it didn't take us long to decide on the cesarean section. They didn't do it right away though because the woman across the hall had an emergency cesarean section for a breech, so they waited until morning. (Excerpt from fieldnotes, Karen and Lou.)

The Consequences: Feeling Helpless, The Inability to Control the Risk Factors. The major consequence for the women and, in some cases, for their partners is the feeling of helplessness intermingled with fear and frustration. When Diane's condition worsened, it was difficult for her to finally give up the control that she had exercised for so long.

> I don't know what I was afraid of. I knew they would get the baby out okay. I guess it was fear of the unknown, of not knowing what to expect. I'm sure my blood pressure went up. I was shaking. I really feel cruddy about it. I felt out of control at that time and that was hard for me. I guess it was from all of the fear and the pain. I was tired. All I wanted was to go to sleep. (Excerpt from fieldnotes, Diane and Alex.)

Karen's frustration and helplessness was magnified. Not only were she and her partner unable to any longer control the factors of risk, but they felt failure on the part of the health team to responsibly manage the con-

trol relinquished to them. She felt the delay in performing the amniocentesis and in obtaining its results when the pregnancy was already in the 39th week as irresponsible.

> And here it was. The baby was just about full term and with this much additional time, we were extremely worried. First they couldn't get any fluid from the amniotic sac and that was one delay. We waited a whole day for another doctor. Then, the second day they messed up the test and that was another full day of delay. And, if for some reason during those two days something would have happened, that would have ruined our chances of having a healthy baby. I wouldn't have forgiven them. I'd feel like it was their fault. I mean, that is uncecessary, just a plain screw-up. After my attention for nine months, the least they could do was get things right. (Excerpt from fieldnotes, Karen and Lou.)

Karen and Lou's perceptions of the dangers were reinforced by the health team who explained to them that, even in the hospital, the risk factors could not always be controlled. The couple was left with no recourse but that of prayer.

> Actually, they didn't tell us until the last few days when I was being induced how quickly it could happen. They sat down and explained it in detail. We knew there were risks but felt fairly confident that in the hospital they could take care of it. But they said things could happen so fast that even in the hospital they might not be able to do anything. The monitor might give an indication but it doesn't always....sometimes for no apparent reason and very quickly babies of diabetic mothers just up and died. After he told us that, the few hours between then and the time the baby was delivered was really a torment. It was really a torment to know that and to be full term and knowing the longer we waited the more increased the chances of something going wrong. I prayed to [by - Ed.] myself, it was all I could do. Like there was nothing we could do to cope. It raised our anxiety a lot but there wasn't anything we could do. (Excerpt from fieldnotes, Karen and Lou.)

Movement: A New Phase. Since the dangerous conditions within this context necessitate intervention within a relatively short period of time, if not immediately, the duration of this context is usually short. Intervention for bringing about a change in the conditions that will reduce the

threat to the life of the woman and/or her fetus is followed by a re-definition of the situation. In cases where intervention is in the form of delivery, the woman and her infant quickly move into the readjustment stage of the pregnancy-illness and begin to cope with all of the changes that accompany that stage.

The Outcome: "I Wouldn't Have Felt it was Worth It" if the Baby Had Not Been Healthy. If the pregnancy-illness is off-course and critical at the time of delivery, the outcome is less likely to be positive. All of the deliveries in this context were by unplanned cesarean section. During the readjustment stage, there were several instances of complications for both the mother and infant. One woman had to be placed in the intensive care unit for the first two days following delivery. Infection and convulsions required that she be hospitalized on two different occasions during the readjustment stage. Another woman was kept sedated with phenobarbital the first three days following delivery because of elevated blood pressure. One woman had a puerperal infection.

The outcome for the infants were varied. There was one neonatal death, one infant was large-for-date and had episodes of hypoglycemia and mild respiratory distress syndrome, and another infant was small-for-gestational age.

All of the women demonstrated a positive relationship with their infants at six weeks postpartum. Several women were undecided regarding future childbearing plans; however, for two women, this option was closed because of the type of problems encountered during the pregnancy. The women's perceptions of the pregnancy, labor and delivery were either ambivalent or negative. Karen felt the outcome to be positive beyond all of her expectations.

> Now that everything has turned out all right, it was worth it. But, I certainly wouldn't have thought it was worth it if after going through nine months and having the baby, for some reason, be a stillbirth or something. Of course, I wouldn't have felt it was worth it, by any means. Also, if there had been any real permanent damaging problems with the baby, it would not have been worth it. It was a relief when it was over and everything was okay. The only thing, I wasn't anticipating one as healthy as he was. Under no circumstances did I think we would get out of this pregnancy as well as we did. (Excerpt from fieldnotes, Karen and Lou.)

## Summary

For maintaining some measure of control over the outcome of the pregnancy, action is taken by means of the implementing processes of protective governing; assessing, balancing, and controlling. If after assessing conditions the pregnancy is defined as on-course and the risks at the lower end of the high-risk continuum, control takes place through adjunctive control. In adjunctive control the woman retains the greater share of the responsibility and effort for controlling. The health team's role is one of assisting the woman with her work. The focus of the woman's management is upon investing in a healthy baby and self. Within this context, a choice of options is usually available for controlling the pregnancy and illness. Balancing involves weighing the safety to the fetus gained from such measures against the discomfort they may create for the woman. The outcome, when management is effective and the risks remain low, is positive.

When the pregnancy is defined as on-course and the risk in the higher range on the high-risk continuum, the process of assessing and controlling takes place by means of cooperative control. In cooperative control, the focus of management is upon protection of the fetus and the woman from

additional danger which might compound the risks. The number of options available for controlling the pregnancy and/or illness are fewer than in the lower risk context. Balancing involves weighing the options in terms of their potential by taking a measure against the harm imposed from not doing so. If by means of cooperative control the management is adequate, and conditions remain stable, the outcome is generally positive.

If after assessment of conditions the pregnancy is defined as off-course and the situation noncritical, control takes the form of entrusted control. To alter the conditions leading to the risk situation, the woman must rely on the health team to initiate the measures necessary for drawing the pregnancy and her illness back under control and for maintaining them there. Options available for managing are few and balancing involves establishing priorities from among the potential consequences, making a choice, and following through with whatever measures are necessary to draw and maintain the pregnancy and illness under control. If management by entrusted control is effective so that the risk level remains steady, the outcome is generally positive.

When assessment of conditions defines the pregnancy as off-course and the situation as critical, the woman relinquishes control to the health team for containing the level of risk. At this time, only they are perceived as possessing the necessary expertise to reduce the immediate threat imposed by the higher risk situation. Balancing becomes a matter of choosing that option which is most likely to reduce the immediate threat and risk level. The outcome, because of the nature of the risk situation, is less likely to be positive.

# PART THREE

# THE CONCLUSION

# Chapter 8.

# SYNOPSIS AND APPLICABILITY PROPERTIES OF THEORY

Peculiar to the research endeavor is the tendency to filibuster closure of the issue under study. One always suspects that discovery of new data or a further analysis of the old will be the substance of a new revelation. When the researcher can finally suspend these dilatory tactics and can mentally adopt the notion that the issues be brought to conclusion (i.e., the conceptual framework now forms a systematic theory), the question of direction can be addressed. Doubt about a matter is seldom put to rest until a course or direction has been established.

## Section A: A Synopsis

The confirmation of a pregnancy is generally accepted as a joyous event for most women in this society. At least initially, the pregnancy seldom interferes with the woman's daily activities and she may, or may not, experience only minor physiologic discomforts. If the pregnancy remains on-course as term approaches, she plans and prepares for the delivery of a healthy infant and does not anticipate residual effects for herself.

Of all confirmed pregnancies, however, between ten to twenty percent are classified as at increased risk because of either internal or external factors that increase the probabilities of morbidity and mortality for the women and their fetuses. In this study, the women were at high-risk due to a chronic illness either present before or acquired during the

pregnancy. Chronic illness poses a wide range of physiological, psychological, and social problems for any individual; if the individual is a pregnant woman, the problems are compounded and their dimensions broadened.

This study has investigated a group of women with pregnancies at high-risk and has chronicled some of their daily experiences in living with these problems. If the illness remains stable so that the pregnancy remains on-course and the level of risk low, the pregnancy-illness tasks are routine and the problems minimal. If the illness destabilizes, but the pregnancy remains on-course, the level of risk rises, the tasks are more numerous, and the efforts to control the illness are intensified. When the illness becomes critical, the pregnancy is generally affected adversely, effecting a multiplication of psychosocial consequences for herself and those who participate with her in the management work.

As a result of the study, variations and dimensions of the psychosocial problems associated with the interactions in management work were discovered. The study makes evident how these settings and their organizational structures affect interaction between the women and their partners or health team. Each of these variables continue to influence the women's ability to manage her regimen, identify and control symptoms, prevent crisis, and maintain a relatively normal life style.

From the data evolved an explanation of the psychosocial aspects of management of a pregnancy at increased risk as protective governing, the integrated theory. Though grounded in the substantive data, it is only one explanation of these aspects and the management behaviors associated with the work of minimizing the pregnancy risks. Obviously, there are other theoretical explanations that might well have evolved. The theory as protective governing is characterized as a process involving the

diligent attempt to guard self and fetus from the potential hazardous consequences of a high-risk pregnancy by steering and directing the courses of the pregnancy and illness through the turbulence of changing conditions within the various structures. While there is more involved in protective governing than that delineated in the study, most of the study, nevertheless, touches on some aspect of governing as it affects and is affected by interaction among the various participants. Analysis of protective governing strategies reveals that productive and successful accomplishment depends upon the woman's ability to define a situation and assess its inherent level of risk, to balance the options available for minimizing the factors of risk, and to subsequently control the conditions that keep the pregnancy-illness on-course; or, if off-course, to control conditions that will restore it to on-course status.

The efforts expended by the women, the health team, the partners, and recruited others are essentially focused on the attainment of a positive outcome, a healthy infant and an unimpaired mother. However, even diligence and determination by all participants cannot always prevent the unexpected and drastic physiologic change of conditions that may result in a negative outcome for the woman, the fetus, or both. At times, nature imposes uncontrollable limitations on the women's finest intentions and skillful control strategies.

It must be noted that one should not conclude from these findings that all women with high-risk pregnancies (or any pregnancy) had an outcome goal of a healthy baby as second priority to their own health. Some women may choose to weigh their management measures in favor of their other children, other personal needs, or the needs of their partner.

## Section B: Establishing the Theory's Properties

Completion of a study, based on a method which evolves a theory during the analytic process, is a humbling intellectual experience. Theory development, one has been trained to believe, belongs to the domain of the world's Newtons and Einsteins whose theories have concrete power for application. Can one's own "private" theory, generated from interview and observation data, really have meaningful application so as to change the operational modes and minds of individuals for whom it might be suitably brought to bear? Glaser and Strauss (1967) think so if the theory, grounded in the substantive area under study, includes the four essential properties of fitness, understanding, generality, and control.

Fitness. For emphasis and comparison, it bears repeating that a woman with a normal or typical pregnancy may have certain minor psychologic and physiologic problems, but her life isn't generally consumed with giving them much notice nor do they interrupt her daily activities to any considerable extent. In contrast, a woman with a high-risk pregnancy associated with chronic illness is very much beseiged by problems.

Most of the women in this study, prior to their pregnancy, already faced discomforting, multitudinous, and varietal problems just in managing their illness. Then comes pregnancy, yet another physiologic force straining at her body and another psychosocial force competing for her energy and effort. What happens when she attempts to manage the problems in center stage of an on-going life beset with its own independent problems?

The women whom I observed and to whom I listened in these same circumstances were exceptionally busy women. As a group, they expressed a full

range of emotions and engaged in all types of tasks. They were at work managing a pregnancy, an illness, and a life. Their managing efforts had a quality not typical of a woman managing a pregnancy or an illness, separate one from another. I didn't have to watch and listen for long to derive a sense of similarity in the women's actions or reactions and words or silences. There was a consistent quality in their (and partners') attitudes, words, and behaviors which, it appeared to me, were characterized by guarding, fostering, defending, watching over, caring, preventing, sheltering, or shielding. It was evident that their measures for managing were like those of one protecting a meaningful object, that all of these measures were aimed at a goal (the lives and health of selves and fetuses), and that intentions and actions were being steered on an accomplishing course. I determined that their management was of a governing quality because it was goal and direction oriented and that the strategies for accomplishment were protective by their nature.

The theory is essentially and realistically grounded in the real managing activities of real people who, all in their own way, are caring for a high-risk pregnancy. Managing the psychosocial aspects of a risk pregnancy as protective governing fits and corresponds to these process actions.

Understanding. The grounded theory of protective governing is the action strand throughout the findings of this study. Any individual who knows of the attendant problems and the often difficult work associated with managing a high-risk pregnancy will immediately be sensitive to the evolving drama of this theory. A reading of the findings by nurses who intervene and attend these women in the clinic or hospital, by physicians

who prescribe and treat them, by psychologists and social welfare persons who counsel and arrange, and by partners who help and care, will inevitably solicit the readers' "that's right, that's the way it really is." It is right and that is the way it is because facts are real and are very much embedded in the "living" data. With that kind of affirmation and understanding, most anyone of these involved individuals will want to "get on with it" in their area of contact with these women, many of whom are confused and burdened by the complexities of their risk pregnancy.

The developed conceptualizations and certain tentative explanations also facilitate understanding because the theory corresponds to reality. Any questions that might be raised regarding the conceptualized problems and resolving management tasks by those who work with these women may be answered through interpretation of protective governing. Or, should any who attend the women have their private explanations of how the women manage their pregnancy problems, these explanations can be tested at such time that he or she begins to apply this theory.

If, for instance, women new to the risk-pregnancy situation want to put to test whether or not it is prudent to relinquish control, temporarily, to the health team under certain threatening conditions of their pregnancy-illness, they can translate that intended behavior in terms of the actions contexts of protective governing as well as by the kinds of responses they receive from the health team in doing so. Or, if a physician attending a hospitalized woman wants to determine whether or not it is a good idea to change a medication dosage for a woman, who through experience "knows" the dosage that will keep her illness under control, his response, too, can be interpreted in terms of the theory's action contexts and/or by the

woman's response to that alteration. In both of these examples and, certainly, in others arising out of the risk pregnancy situation, the theory provides abundant hypotheses and concepts that can fit those situations under varied but specific conditions.

Generality. The theory of protective governing certainly has the characteristic quality of generality required of a substantive theory because it has applicability to many different situations. This flexibility is most evident in Chapter 7. where protective governing is found to be applicable to four different situations of risk pregnancy care.

Each of these four contexts represents a different situation that occurred in response to changing conditions in the pregnancy, in the illness, or in both. Yet, protective governing and its implementing process of assessing, balancing, and controlling were sufficiently flexible enough for application to each context. For instance, in the off-course and critical context where the conditions of both were not only more severe and the pregnancy further off-course than were they in the former contexts, the theory was just as operational. The woman assessed the status of the illness and pregnancy to determine the new imposed level of risk and decided from among her alternatives the protective strategies she would engage. Within the first context, a changing situation, where the conditions differed, risks were at a low level and the pregnancy holding a steady course because the interplay of internal forces differed. Here again, she governed by assessing and balancing but the strategies taken to maintain control were different from those in the more severe context, yet nevertheless, protective.

Because of the theory's generality, it can be adapted to situations not occurring in this study but which possibly could happen in a hospital,

clinic, or home setting as it relates to management of the risk pregnancy. A hospital nurse, intent on improving a situation, can reformulate this theory and apply its process to a hospitalized patient whose pregnancy is at risk but which risk is due to factors such as economic variables or age rather than to chronic illness. Only application in other settings will reveal if sufficient categories have been discovered that will cover most of the diverse situations that can occur in the protective governing work.

Control. The protective strategies for carrying out the necessary management tasks in this study depend heavily on control processes, it is literally "built into" the theory. The data revealed that the work of managing was consistently realized and furthered by control of theory variables, if not by the women themselves, by their partners, the physicians, the nurses, and important others. Who was in control under what conditions, how was that control acquired, how was it applied and by whom, and what interactional problems did it produce, are well documented throughout the findings, particularly in Chapter 7.

The entire chapter explicitly reveals how the women under varying conditions engaged in control, shared control, and sometimes, even relinquished control. Because this control property, requisite to theory applicability, is inherent to the theory and gives it direction, it will not be further reasoned and elaborated in this section.

# Chapter 9.

# IMPLICATIONS OF THE SUBSTANTIVE THEORY

What can be concluded as a result of this study? Discovery by inference from the substantive theory and other findings and by association of embedded ideas, reveals some important connections, relationships, and conclusions not yet realized.

## Section A: For Women With High-Risk Pregnancies

Many women, when discovering themselves pregnant, are frequently not cognizant of the many physiologic, psychological, economic, or social problems (singularly or in combination) that have potential to interactively and adversely affect the progress and/or outcome of their pregnancy. Even fewer are alert to the fact that a great many aspects of these problems are factors which could place their pregnancies at increased risk for impairment, death, or both, for themselves and fetuses. Some women, if they have a pre-existing problem in one of these areas, particularly physiological, may have a notion that their pregnancies are not the normal or typical phenomena they are for other women. However, for most, the classification of "high risk" with its attendant potential consequences for harm, is an unfamiliar concept. Unless they have the good fortune to live in proximity to a university medical center as did the women in this study, they may be totally oblivious to the need of a highly specialized nine-month management program.

The presence of two physiologic conditions (pregnancy, illness) in combination is a very serious situation. It is clearly implied in the data that the chances for survival and unimpairment for the woman and fetus are in ratio to the woman's capability and interest for complicated and dedicated management. That quality of management found necessary for a positive outcome, further implies a woman who is willing and capable of learning new skills, who is willing to share responsibility for her welfare, who can diplomatically solicit support as required, who knows how to negotiate conflict, knows how to handle interfering social problems, has emotional equilibrium, and who believes in her ableness to work through a difficult situation. These are qualities of a successful manager.

Section B: For Husbands or Partners

In this study, the partners have an active role in management of the women's risk pregnancy. They seek information important for her managing, they help her to carry out the regimen, they are alert to her symptoms, they participate in her decisions, they maintain the home during crisis, and they give her emotional support when she is overcome by fear and helplessness. Some gave of themselves totally in performing these behaviors, others were more reluctant in one or another of the tasks. Some were consistent and dependable in their performance, others were not. Their role was one of giving support. The extent, the quality, and the nature of the support given by the partners to the women differed.

Implied for partners of these women is that they need to be made aware that a positive pregnancy outcome is very dependent on their presence in

the home, their accessibility, their willingness to assist, their capabilities, their sense of responsibility, and their capacity to empathize.

Section C: For Attending Physicians

Traditionally, physicians have primarily concentrated on the medical components of high-risk pregnancy care and management. They characteristically perceive their management tasks as those of diagnosing symptoms, prescribing treatment, monitoring the well-being of fetus and the woman, and advising the women how to proceed with the regimen amd monitor symptoms. Physicians are often unaware of the many problems with which a woman must cope as a result of her two physiologic conditions. They usually know very little of how she manages her life around these problems. Unless told by the woman, they may not give thought or attention to the psychosocial problems that often develop as a result of her protective tasks or of the influence that the psychosocial problems have on accomplishing her protective tasks.

These findings implicate for physicians the need for cooperative approaches when dealing with high-risk pregnant women. This study showed some of the complex medical and socioenvironmental conditions under which the women assessed, balanced, and controlled, and how these conditions affected and were affected by her ability to manage. The findings suggest that outcome is influenced by a woman's ability to carry out the medical components of management and thereby keep the illness stable and the pregnancy on-course (though there are times due to conditions beyond her control, that even with careful management the illness may destabilize and

the pregnancy move off-course). Consultation with the woman when designing a management plan may avoid later conflict over its components or methods of carrying it out. A woman who has a long history of living with and managing an illness may loose trust in a physician who attempts to institute a management plan that does not hold with her perceptions of how the illness should be managed, and thereby disrupt the alignment of efforts that is crucial for maximizing the chances of achieving a positive outcome. Allowing a woman to express her feelings about her perceptions of her chronic condition and listening to what practices she has found through experience to be helpful in controlling her illness, along with some of the problems she has encountered in doing so, will provide the obstetrician with insight into how a woman comes to assess, balance, and control her pregnancy-illness. She has a history of protective governing of her health with a chronic illness prior to the pregnancy. In most instances she desires to continue to protect herself and fetus during the pregnancy, therefore she considers management a joint process, an alignment of efforts, and, as such, expects to have input into the decision making process.

The findings also suggest that a physician's management perspective would be facilitated by an awareness of the extent to which a woman's, and her partner's, belief systems and cultural backgrounds affect management methods and priorities; and an awareness of the particular conditions that make her vulnerable and fearful. Familiarity with the protective governing theoretical framework helps provide the physician insight to the conditions and structural interactions that affect the woman's success at managing.

The physician has an essential role in the management and successful outcome of a high-risk pregnancy; however, from experiences of women in

this study, there are implications for revised considerations. There is a need for sensitization to the fact that the women's home experiences are not incidental to the design of a management plan nor are the many aspects of the women's social and psychological lives peripheral to essential considerations in providing care.

Section D: For Hospital or Clinic Nurses

The data of this study does not document direct interaction in the clinic between a nurse and any of the women unless she is considered as a member of the health team or as their functional assistant. As some clinic systems are now structured for the management work associated with high-risk pregnancies, there is little opportunity for a nurse to actively participate in the planning of management care or to be instrumental in the joint process of control. When nurses are involved, however, the recognition of the woman as a colleagual participant in "protective governing" is paramount.

Whether nurse-patient interaction takes place in the clinic or office setting, or when the woman is in the hospital for delivery or for treatment and care when critical change occurs in her pregnancy-illness status, a nursing history is crucial and care plans may be made with the patient. Had this been done in the case of the diabetic who was used to high blood sugars, she perhaps would not have undergone the stress of thinking she was going "crazy" when drastic alterations were being made in her diet or insulin dosage. While nurse participation in assisting women in the control process is for the most part minimal, except in a peripheral sense, there are many practical applications a nurse can make from the study's findings. (See Chapter 10).

Section E: For the Health-Care System

The nature of certain experiences that some of the women had with the health-care system (the hospital and clinic facilities), implies that the organization as now structured for delivery of its services, is not designed to accommodate true cooperative control between the women and health professionals. Though change in purpose, structure, and practice has been advocated for years by researchers and members of the holistic health movement, the organization tends to remain monolithic and impenetrable. Hospitals and clinics are essentially the private domains of administrators and health care practitioners. They are designed as authoritarian edifices in which standards of practice and functional use of space and time control, to a great extent, determine what will be accomplished and how it is to be done.

The fetus and the woman are in a continual precarious state for nine months (and some weeks later) and are very dependent upon the advanced technology and specialized knowledge provided by the institutions for increasing the outcome probabilities of health and life for herself and fetus. She often requires specialized care, particularly for labor and delivery, but also for interim hospitalization when her illness and pregnancy are severely destabilized. At the same time, a woman wants an active role and wants to share responsibility for control of her pregnancy-illness even when under the jurisdiction of the health-care system. She wants the pregnancy to be a good experience. She also knows her idiosyncratic responses to the chronic illness and its treatment, at times better than the health professionals who see her only once in passing. The need for continuity of care and the establishment of mutually trustful relationships between the health team and the woman have been highlighted in the data.

The social structure of the hospital and clinic is a very important variable influencing the woman's governing process. If the idealologies of those in charge are contradictory to her beliefs so that control of her pregnancy-illness is taken from her, she feels fearful and helpless. If the health team advises hospitalization but she resists, if they want a particular drug dosage and she believes it should be another, if they want her to rest and she fails to see its importance, these are conditions that may cause interactional conflict and affect the quality of her management.

Perhaps the hospice movement has implications for the goals and practices of the conventional health-care system. The essential purpose of the hospice is to provide a haven for those with chronic illness and disease. It is purposed and designed to allow patients to have some control over their care and treatment. Although in the off-course critial risk context a woman is not capable of having and does not want this degree of control, involvement and control in the management process would appear to profit greatly women with lesser degrees of risk.

## Summary

Implications of the substantive theory certainly exceed those elaborated in this chapter. Some important inferences have been made, but the reader and critiquer will, no doubt, discover many other relationships critical to the care and management of high-risk pregnancies.

# Chapter 10.

# RECOMMENDATIONS FOR APPLICATION

A researcher, after months of analytical procedures and writing, takes considerable pride in his or her finished product despite its imperfections and omissions. It is typical and natural to appraise the final work as having potential for practical application to many different user forms. The hypotheses and concepts provided by the theory have been shown to fit, to be general enough, to be understandable, and to give control (see Chapter 9.) so that application can be accomplished, albeit with some qualification.

The reason for recommending application is the hope that the results of this study, translated into different forms, will ultimately lead to reduction of the morbidity and mortality rate and social problems associated with pregnancies at increased risk because of chronic illness or disease.

Recommendations for application will be made for different areas of the substantive theory by form of application (e.g., as guide to intervention, as data for questionnaire, as curriculum for nursing education, as sensitizer, and as data for further research), showing rationale but not delineation of action programs and designating potential users. Further recommendation will be made for application to situations for which protective governing would be appropriate but not in the area of the substantive theory.

As Guide to Intervention. If the theory truly describes the important aspects I found to exist in each of the women's lives, it is credible and can be recommended as a predictive guide for intervention. It can help determine the type of intervention required, which women are likely to achieve a positive outcome without intervention, and which will need a plan of close supervision and intervention. It can be used to determine the conditions that will lead to a woman's successful mamangement, to predict her possibility of a positive outcome, and to help her reach her potential for a positive outcome. It will also show to those who work with the women the management processes (assessing and balancing) they engage to determine the proper strategy for accomplishment of specific control tasks.

Nurses, perinatal specialists, counselors, and an ombudsman are the likely users of an intervention guide.

As "Sensitizer." A perusal of the integrated theory and other detailed findings by women with high-risk pregnancies (not including those who were subjects in this study), by registered and student nurses, social workers, counselors, sociology students, physicians, researchers, and the general public, will enhance their sensitivity to both the physiologic and psychosocial aspects of management. A reading just for interest will inevitably leave the reader with an impression. The realities of each situation are so readily understandable that the interested reader will apprehend that there is more to management of a risk pregnancy than the medical components. Undoubtedly, it will be sensed that the responsibility for management work clearly belongs to the woman though she may, as necessary, delegate control to the health team. It can be "seen" that it is she who must confront the ever present problematic realities and make adjustments, accordingly.

Increased awareness of the plight of these women, the range of consequences of their management ability, will not only develop empathy but a desire to find new methods for facilitating management of their hazardous situation.

Clinical Counseling. Management competency varied among the women in this study. The variations were related to the amount of experience with the illness, the extent of relevant information, her support network, the stability or severity of the illness, the status of the pregnancy, her emotional stability, the extent (or absence) and nature of social problems, and her perceived sense of control. Of course, the women themselves were not aware, as they entered their pregnancy, that these factors were associated with successful management.

With these factors isolated, it is important that those who counsel, attend, or treat these women, ascertain the extent to which these conditions exist for her. This could be determined by means of a questionnaire. For instance, the extent and quality of her knowledge essential for assessment and choice of options might be determined by questioning how much she knows about the illness, the pregnancy, and the impact of one upon the other; the sources of her information; and, the amount of confusion she experiences because of too little or conflicting information. Also, the make-up of her support system can be ascertained by seeking answers to such questions as: Does she attend the clinic and trust in the health team? Does she have a partner, family members, and friends to assist her in management? Questions, such as these, can be derived from the dense findings pertaining to all the conditions underlying successful management. In whatever domain there is the obvious need for help, she can then be given assistance to acquire strategies that have power to maximize her probabilities for a positive pregnancy outcome.

From the responses to this kind of questionnaire, a profile for each woman could be devised and kept with her records. Then, working and responding to her in normal or problem situations would not be on an ad hoc basis. Perhaps problems of social crisis and disruption could be prevented if there is an initiation of a sincere attempt for "knowing about" and helping these women.

This same material could possibly be used as a basis for group learning sessions designed to meet the highly specialized needs of women with risk pregnancies. They could be attended by a representative of the health team and by nurses wishing to be better informed regarding the needs of these women. A number of these regular sessions, besides being a reliable source of information, could serve as a means for mutual support. The women would also discover that others in their curcumstances fear the unknown, but from one another they would learn new strategies appropriate for the changing and uncertain conditions.

A prenatal class for women with risk pregnancies would be a particularly effective avenue for instruction and support. Whereas this type of class traditionally places instructional emphasis on the medical components (sometimes on the emotional aspects) of normal pregnancy, the instructor could stress the interaction of a pregnancy-illness and explain how this situation produces a new set of symptoms and different measures for control, how labor may have to be induced, and that delivery may be by cesarean section.

A questionnaire for determining needs, a profile for fast reference, and a class or group for instruction and learning new strategies should certainly facilitate protective governing of pregnancies at increased risk.

As Curriculum for Nursing Education. As it has been previously pointed out, nurses often take responsibility for only the medical components of intervention for women with risk pregnancies. Management is not planned and carried out as a joint process between the nurse and the woman. In addition, the pregnant woman, at risk, is not always viewed as a total person whose medical problems are not independent of a total complex life, or that her physical symptoms may be related to the stress of social or emotional problems in her larger environment. Management of a high-risk pregnancy is very difficult in its physiologic aspects and the governing processes are very much affected by and affect her social and emotional conditions.

The theory clearly implicates the need for change in nursing education and training. While clinical competence and sound judgement are essential to quality nursing care, nursing education should also emphasize the role that the woman plays in the management process and the importance of considering management as a joint process. Women with risk pregnancies will be better served when nursing intervention includes not only consideration of the role the woman plays, but also considers how her management is affected by socio-economic, cultural, social, and interactional factors. It should also give consideration to the impact created by the settings in which management occurs.

As Data for Further Research. Because the theory evolved out of comparative analyses of the data in the substantive area of high-risk pregnancies, complicated by chronic illness, the theory of the psychosocial aspects of management of these pregnancies as protective governing can be extended to formal theory for which probabilities can be stated. Analysis of other substantive areas, for initial formulation of a formal theory of

protective governing, would be facilitated by categories already coded in this study or by new categories that would be generated to even further its scope.

When there are new conditions or settings, the theory can be altered to limit or extend knowledge that has evolved from this theory because the kind of protective governing relates, in part, to these structural settings and to these psychosocial aspects of managing a pregnancy at risk due to chronic illness. The integrated substantive theory are the events that happen in relation to governing a pregnancy and illness with protective measures. For example, women attending high-risk prenatal classes designed to assist them to acquire the knowledge, support, and strategies necessary for them to carry out the task of protective governing may be compared for outcome against those women attending conventional prenatal classes and those who fail to attend either.

Section B: For Areas Other Than the High-Risk Pregnancy

The conceptual framework of protective governing is certainly general enough for applying to situations other than that of high-risk pregnancy. If it can be applied, if it has fit to other structures even though the social structure and conditions are different, the validity of protective governing can be established. It can be appropriately applied to arenas where protective governing is important and can explain the action.

It could possibly explain how one can cope with any threat where the individual, alone or in collaboration with others, takes action to control the conditions leading to that threat. It can be applied to pregnancies that are at risk because of conditions such as premature labor or substance

abuse. Here risk factors must be assessed, priorities established, and benefits and limitations of options weighed. The theory is also applicable to the control of any stress-producing event in an individual's life; however, the structural contexts and management processes may differ.

Chronic illness or disease (not in conjunction with pregnancy) is also amenable to protective governing because the conditions are in many ways similar. Each new situation in the illness can be defined by means of physical interactional, temporal, and objective cues. Even the structural conditions characterized as joint participation can be applied. A goal of chronic illness management, as in risk pregnancy, is retaining control over one's life as long as possible so as to maintain the self-esteem that is often decreased when one loses control over his or her life.

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It is sincerely hoped that this study and its ramifications, independent of its interest for the interested reader, will not only help to assuage the uncertainties of the thousands of women with risk pregnancies threatened by chronic illness, but will also provide insight to those health professionals upon whom their critical medical care depends.

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# APPENDIX

# APPENDIX A

## Forms for "Consent to Act"
## (University of California at San Francisco)

(1) Consent to Participate, Pregnant Woman

(2) Consent to Participate, Pregnant Woman's Partner

(3) Consent to Participate, Health Professional

(4) Permission to Interview Patient Participant

(5) Permission to Review Patient Records

University of California San Francisco
Consent to Act as a Participant
in the

Study of "Adaptation to Pregnancy in Women With a Pregnancy
Superimposed Upon a Chronic Illness

I agree to have Ms. Julie Corbin, a nurse in the Doctor of Nursing Science Program at the University of California, San Francisco, asks me questions about my pregnancy. I have been informed that the purpose of this research is to explore those factors in a pregnancy superimposed upon a chronic illness which influence a woman's adaptation to her pregnancy. The questions will be asked in the form of an interview. I understand that the interviews will take place in my home, or in another mutually agreed upon place and will last approximately one hour. I realize that there will be about 4 interviews and that there will be phone calls between interviews.

I understand that the interviews will be taped, transcribed, and the tapes destroyed. Code names will be used in the written copies. My responses will be kept confidential and every effort will be made to protect my anonymity.

I understand that there will be no physical risks to me or to my child, however, some of the questions may cause psychological discomfort. I understand that I can refuse to answer any question or withdraw my participation from the study without jeopardy to my care or that of my child. I also understand that Ms. Corbin may decide to end an interview or my participation in the study without jeopardy of any kind to me or my child.

I understand that should any complications, physical or emotional, arise during the course of the interviews my physician will be contacted by myself or the researcher. I further understand that there may be no benefits to me personally, that the information received furing the study will mean a better understanding of the needs of other "high-risk" pregnant women.

If I have any questions regarding this study before or during the interviews I may contact Ms. Corbin by calling (415) 666-4771 and leaving a message.

Date:_____ Signature:_____

Signature of husband (if available)

Consent form: Pregnant Woman (1)

933407-01

University of California San Francisco

Consent to Act as a Participant

in the

Study of "Adaptation to Pregnancy in Women With A Pregnancy Superimposed Upon a Chronic Illness

agree to have Ms. Julie Corbin, a nurse in the Doctor of Nursing Science program t the University of California, San Francisco, asks me questions about my wife's regnancy. I have been informed that the purpose of this research is to explore those actors in a pregnancy superimposed upon a chronic illness which influence a woman's daptation to her pregnancy. The questions will be asked in the form of an nterview. I understand that the interview will take place in my home, or in another ctually agreed upon place and will last approximately one hour. I realize that there ill be one interview and that there may be a follow up phone call to elicit other ecessary information to complete the study not obtained in the interview.

understand that the interview will be taped, transcribed, and the tape destroyed. ode names will be sued in the written copies. My responses will be kept confidential nd every effort will be made to protect my annonymity.

understand that there will be no physical risks to me, however some of the questions y cause psychological discomfort. I understand that I can refuse to answer any estion or withdraw my participation from the study without any kind of jeopardy me or to my wife's or child's care. I further understand that if my wife is not esent during the interview, Ms. Corbin will not discuss my answers with my wife or rs with me, however, I am free to do so if I wish.

understand that there will be no benefits to me personally, however, the information ceived furing the study will mean a better understanding of the needs of "high-risk" egnant women.

I have any questions regarding this study before or during the interview, I may ntact Ms. Corbin by calling (415) 666-4771 and leaving a message.

te:_____ Signature:_____

nsent form: Husband one time interview (2)

University of California San Francisco
Consent to Act as a Participant
in the

Study of "Adaptation to Pregnancy in Women With A Pregnancy Superimposed Upon A Chronic Illness"

I agree to have Ms. Julie Corbin, a nurse in the Doctor of Nursing Science program at the University of California San Francisco, ask me questions about the medical management of women with a pregnancy superimposed upon a chronic illness. I have been informed that the purpose of this research is to explore those factors in a pregnancy superimposed upon a chronic illness which inluence a woman's adaptation to her pregnancy. The questions will be asked in the form of an interview. I understand that the interview will take place in my office, the clinic, or in another mutually agreed upon place and will last approximately one hour. I realize that there will be one interview and that there may be a follow up phone call to elicit other necessary information to complete the study not obtained in the interview.

I understand that the interview will be taped, transcribed, and the tape destroyed. Code names will be used in the written copies. My responses will be kept confidential and every effort will be made to protect my anonymity.

I understand that during the interview I can refuse to answer any question or withdraw my participation from the study without any kind of jropardy to me.

I understand that there will be no benefits to me personally, however, the information received during the study will mean a better understanding of the needs of "high-risk" pregnant women.

If I have any questions regarding this study before or during the interview, I may contact Ms. Corbin by calling (415) 666-4771 and leaving a message.

Date:_____ Signature:_____

Consent form: Health professional one time interview (3)

I understand the aims and procedures of the research study entitled " Process of Adaptation to Pregnancy in Women With a Pregnancy Superimposed Upon a Chronic Illness", conducted by Juliet M. Corbin, R.N., M.S., Doctoral student UCSF School of Nursing. I have no objection to Ms. Corbin contacting patients under my care to participate in the study.

Signed: _____

Date: _____

P.I. Juliet M. Corbin, R.N., M.S.
1595 Oakhurst
Los Altos, California 94022
(415) 965-0724

University of California San Francisco

I understand the aims and procedure of the research study entitled "Process of Adaptation to Pregnancy in Women With a Pregnancy Superimposed Upon a Chronic Illness, conducted by Juliet M. Corbin, R.N., M.S., Doctoral student UCSF School of Nursing. I understand that Ms. Corbin has agreed to keep confidential all information found in patient's records and, therefore, give her permission to screen the records of women in the "High-risk" Clinic for elegibility to participate in her study.

Signed:_____

Date: _____

P.I. Juliet M. Corbin, R.N., M.S.
1595 Oakhurst
Los Altos, California 94022
(415) 965-0724

Consent form: Permission to review patient records (5)

Appendix B

Demographic Data

Case #_____

Date Accepted into study_____

Age_____ Race_____ Occupation_____

No. grades completed_____ Occupation of husband_____

Ordinal position in family _____

Pregnancy Confirmed_____ E.D.C._____

Chronic Illness Year diagnosed_____

Diabetes _____
Heart Disease ____
Hypertension ____
Renal Disease ___
Other _____

Usual Medical Regimen for Chronic Illness

Medication _____
Diet _____
Rest _____
Other _____

Multiparas only

Gravida _____ Para_____ Previous fetal loss_____
Abortions T.A.B_____ S.A.B._____

Complications with pregnancy Yes No Medical Obstetrical

---

Treatment Medication_____ Diet_____ Rest_____ Other_____

---

Complications with delivery Yes No Medical Obstetrical

---

Condition of infant at birth Good Fair Poor

Did infant have extended hospital stay? Yes No 1-2 weeks 2-4 weeks
4-8weeks over 8 weeks

---

Complications Post-partum Yes No Medical Obstetrical

---

Medical treatment other than routine postpartum Yes No

Present Pregnancy

Planned Yes No

Problems with Conception Yes No

Number of physical complaints during pregnancy related to chronic illness

Very numerous numerous moderate mild none

Number of general complaints during pregnancy related to chronic illness

Very numerous numerous moderate mild none

Number of complaints related to pregnancy

Very numerous numerous moderate mild none

Medical regime during pregnancy related to chronic illness

Medication _____
Diet _____
Rest_____
Other_____

General mood during pregnancy

Very happy happy neutral unhappy very unhappy

Predominate: feeling at quickening

Very happy happy neutral unhappy very unhappy

General appearance during pregnancy

Excellent good fair poor very poor

Attending Childbirth Classes Yes No _____

Labor and Delivery

Date of Delivery_____ Type of Delivery: Vaginal

Length of labor_____ Ceserean Section

Analgesia Yes No _____

Anesthesia Yes No _____

Pitocin Augmentation Yes No _____

Complications Yes No Medical Obstetrical

_____

Support person in delivery room Yes No _____

Sex of infant: Male Female

Weight_____

Apgar _____

Breast_____ Bottle_____ Feeding

Infants overall condition in nursery

Excellent good fair poor very poor

Extended hospitalization of infant Yes No

---

Postpartum

Complications Yes No Medical Obstetrical

---

Predominate general mood

Very happy happy neutral unhappy very unhappy

General description of pregnancy _____

---

General description of labor and delivery _____

---

Status of chronic illness Stable Unstable

Present Medical regimen

Medication_____
Diet _____
Rest_____
Other_____

Hospital stay extended Yes No

---

If mother observed with baby

Positive comments about baby _____
Refers to baby by name _____
Holds baby close _____
Looks en face _____
Other--- Describe _____