THE UNBORN ONE: A PROFILE OF
THE HUMAN EXPERIENCE OF MISCARRIAGE

by

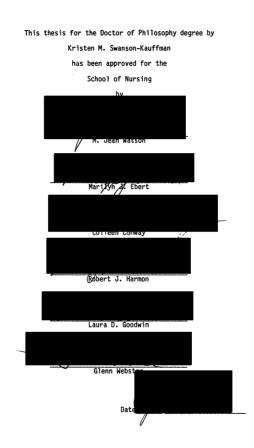
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The Unborn One: A Profile of the Human Experience of Miscarriage
Thesis directed by Professor M. Jean Watson

The purpose of this dissertation was to describe the human experience of miscarriage and the caring needs of the women who miscarried. A qualitative (modified grounded theory) research design was chosen for its compatibility with the research purpose and its methodological fit with the valuing of nursing as a human science. A convenience sample of 20 women who had miscarried within 15 weeks prior to study entry were interviewed twice about their experience with early pregnancy loss and the associated caring needs. The taped open-ended and transcripts were qualitatively for recurrent themes/categories that would aid the description of the phenomena. The categories were evolved using a constant comparative method in which each informant was compared to all other informants; all informants were compared to each emerging category; and finally, all categories were compared to the study's underlying assumptions as well as the literature reviewed.

The six experience categories developed were: 1) Coming to Know: describes the confusing painful process of balancing the mounting evidence of impending loss against hopes for a healthy pregnancy outcome; 2) Losing and Gaining: depicts the multiplicity of perceived losses and gains amongst the informants; 3) Sharing the Loss: summarizes the amount of recognition and support the women received throughout their loss; 4) Going Public: describes the process of letting others know about the loss and the price paid at

miscarriage for having (or not having) gone public with the pregnancy; 5) Getting Through It: compares the grieving patterns of the informants; and 6) Trying Again: discusses the decisions made related to plans for future pregnancies and identifies the related ongoing fears of future loss. The five caring categories developed were: 1) Knowing: identifies the woman's desire to be understood for her personal experience; 2) Being With: illustrates the woman's need to have others feel with her; 3) Enabling: depicts the need to have her grieving facilitated; 4) Doing For: describes the need to have others do for her (i.e., physical care); and 5) Maintaining Belief: focuses on the need to have others maintain belief in her capacity to get through the loss and to eventually give birth.

The significance of this study for nursing is that it: 1) enables nurses and other health care providers to more clearly understand miscarriage in particular and perhaps human loss in general; 2) provides information which is of potential use to the diagnosis and treatment of human responses to the actual and potential health problem of miscarriage; 3) lends support to Watson's Therry of Caring; and 4) offers a methodology that is compatible with the valuing of nursing as the science of human care.

The form and content of the abstract are approved. I recommend its publication.

Signed Faculty Member in charge of thesis

#### DEDICATION

I dedicate this dissertation to Chuck and J.C., the two most important people in my life. I love you both very much and thank you for being with me every step of the way.

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#### CHAPTER J

#### THE QUEST

My main purpose in pursuing this dissertation is to attempt to understand and describe the meaning of miscarriage as perceived by the woman who lives through an unplanned fetal loss in early pregnancy. Furthermore, I hope to be able to describe some of the behaviors of others (spouse, nurse, family, physician, etc.) which are identified as "caring" by the woman who miscarried.

This study's proposed outcome is a written narrative that offers a plausible theoretical description of 1) the human experience of miscarriage in early pregnancy, and 2) the caring behaviors of others which are described as helpful by the woman who miscarried. This study will utilize a combination of qualitative methodologies which will ground the description of the phenomena in the statements of the women who spontaneously aborted. The methodologies to be employed include aspects of grounded theory, ethnography and phenomenology. This combined methodology was decided upon for two main reasons: 1) these methods share an underlying philosophy which emphasizes the researcher's need to study with the individual who experiences an event in order to facilitate the researcher's description of that event; and 2) this combination will allow me to balance my goal of understanding the experiences of my informants with my goal of generating useful theoretical descriptions of the phenomena. It is my quest, not so much to offer a complete picture of the human experience of miscarriage, but rather, to point a finger in the direction of a clearer understanding of this human condition.

#### Significance of the Study

It is generally estimated that 10 to 20% of all pregnancies will end abruptly in unplanned fetal loss (Cavanaugh and Comas, 1982). In fact, it has been speculated that 20% is a conservative estimate due to the fact that these estimates are generally calculated based on hospital admisssions. This figure does not account for all of those miscarriages that either go unreported or which are dismissed by an unsuspecting mother as a "late heavy period." Furthermore, with the advent of more sophisticated lab/blood tests which make diagnosis of pregnancy possible even before a missed menstrual period, it will be interesting to note if there will be an even higher upward adjustment in this 10 to 20% estimated rate of spontaneous abortion (Page et al., 1981).

Given this rather frequent rate of occurrence, it is somewhat surprising to realize the amount of ignorance that surrounds the whole issue of miscarriage. Why it occurs, when it will occur, and to whom it will occur remains, for the most part, quite a mystery. Consequently, treatment and prevention tend to be based more on speculation than fact. Still, even less is known about the impact of fetal loss on the mother who miscarries. The whole process of the human experience of miscarriage has, as yet, to be adequately described. Little is understood about what it means to see that first blood-stained piece of toilet paper, to decide to call the doctor, to view the still ultrasound, to agree to a dilation and curettage, to put away the unused maternity clothes, to "go public" with the "non-pregnancy," and to eventually move onward with one's

life. Basically, we do not understand the human response to this health problem of spontaneous abortion. Even less is known about the caring needs of the woman during such an experience.

A Denver based obstetrician recently referred to miscarriage as "the most highly unscheduled obstetrical event." Unlike birth, there is no nine-months-give-or-take-two-weeks estimation of timing of occurrence. Miscarriage is no respecter of either the client or caregiver's dinner plans, sleep needs, vacation schedules or life goals. The same obstetrician further suggested that given the spuriousness of this event and the fact that obstetricians are limited to a day of 24 hours, there has to be a point at which the obstetrician is faced with curtailing the amount of time and energy available to any one client. Unfortunately, this has traditionally meant that the woman is pretty much left on her own to deal with the emotions she experiences as a result of her unplanned fetal loss.

In a pilot study (Swanson-Kauffman, 1982), a 21-year old mother of twins shared with me the following statement about her three miscarriages:

It really hurts. Even a few months later you still think this baby would have been this much older. And you wonder what the baby would have been like, how it would have grown up. Each time you lose a baby. It's, It's still, even though you're, even though you haven't seen it or anything, it's still something of the future.

This poignant testimony illustrates that there is a need for understanding and support throughout the experience of fetal loss. It is a major premise of this study that the person who should logically provide professional care on the occasion of this stressful event is a nurse. The 1980 ANA Social Policy Statement (p. 9) states: "Nursing is the diagnosis and treatment of human responses to actual or potential health problems." Similarly, in defining nursing as a caring science, Watson states: "Nursing is concerned with knowledge and understanding of 'care,' which is different from but complementary to the knowledge and understanding of 'cure,' which is the domain of medicine" (1979, p. 8). Both nursing and medicine hold as a central concern the health needs of the clients of their care. When working in complementary roles, each will to some extent both cure and care. The difference lies in degree of emphasis and area of expertise. For example, in the case of miscarriage, the physician's care emphasizes diagnosis and treatment of the spontaneous abortion. Whereas, the nurse's care should emphasize the diagnosis and treatment of the woman's responses to her fetal loss.

Human responses may be viewed as the reactions, meanings, feelings, or experiences that surround the health problem. For the purposes of this study, the health problem is the miscarriage. The human response is the experience. The relevance of this research to nursing is basically twofold: 1) it seeks to describe the human experience of miscarriage, hence, adding to the nursing knowledge which is necessary to diagnose human responses to miscarriage; and, 2) it also seeks to identify the caring behaviors that women would like to receive throughout their miscarriage experience, hence, adding to the knowledge of possible interventions for the human responses to the health problem of miscarriage.

## Statement of the Questions

The main question to be addressed in this study is: What is the human experience of miscarriage in early pregnancy? An additional related question which this study will explore is: What are the caring behaviors of others that are identified as helpful by the woman who miscarried?

Key terms in these two questions are defined as follows:

- The <u>human experience</u> of miscarriage is defined in this study as the woman's communicated perceptions of her spontaneous abortion. It includes her expressed personal cognitive, affective and physical/behavioral responses to the unplanned, abrupt ending of her pregnancy.
- 2. Miscarriage is the lay person's term for a spontaneous abortion which is the unintended ending of a pregnancy before the time the fetus could survive outside the mother. There is some controversy about when a fetal loss is termed a spontaneous abortion versus a stillbirth. According to Pritchard and MacDonald (1980), in many states a birth certificate (i.e., stillbirth) is prepared for any pregnancy at 20 weeks gestational age or more, or for any fetus that weighs 500 grams or more. The World Health Organization defines a spontaneous abortion as a premature delivery of a non-viable fetus before

- 28 weeks of gestation. The cutoff point appears to vary from study to study as somewhere between 18 and 28 weeks (Borg and Lasker, 1981; Pizer and Palinski, 1980; Javert, 1957; Pritchard and MacDonald, 1980).
- 3. Early pregnancy is defined in this study as being up to the point at which fetal movement is reported by the mother. This cutoff point (i.e., as opposed to a first trimester cutoff) was decided upon because the psychology-of-early-pregnancy literature describes a shift in maternal perceptions of pregnancy occuring at about the time fetal movement is felt which is generally at 18 or more weeks (Colman and Colman, 1971; Turrini, 1980; Raphael-Leff, 1980). It therefore seemed logical to limit the study to pregnancy disruption prior to the time fetal movement is reported by the mother.
- 4. <u>Caring behaviors of others</u> is defined as any actions (words, gestures, ministrations) that may be performed by others (spouse, physician, nurse, neighbor, etc.) that is perceived as helpful by the woman who miscarries. The study seeks to identify not only those caring behaviors which the woman <u>did</u> receive, but also, those behaviors she <u>would have liked to have</u> received in order to aid her through her miscarriage experience.

 A <u>recent miscarriage</u> will have occurred no more than 15 weeks prior to the time of the interview.

Within this study, I will try to answer my two research questions by going to the experts: those women who have lived the human experience of miscarriage. The women who have miscarried will be my informants. I will be their student. Through the guidance of my informants and a combination of qualitative research methods, I hope to facilitate the emergence of the answers to my two research questions. Parts of the ethnographic, phenomenological and grounded theory methodologies will be utilized so as to allow me to obtain the understanding which will shape my description of the human experience of miscarriage and the caring needs of women who miscarry.

## Theoretical Background

The decisions about what to include as theoretical background for this research reflect some of the basic assumptions which underlie this study. These assumptions are:

- Nursing is a discipline which should be studied as a human science.
- Caring is a phenomena which is of major concern to nursing.
- The Lazarus Stress and Coping Paradigm (1978) may provide some insight for understanding the myriad of responses to miscarriage.

- Familiarity with the psychology of early pregnancy is necessary to understanding the human experience of miscarriage in early pregnancy.
- The caring needs of the woman who miscarries will be individually defined depending on how the woman perceives her loss.

In this section of the paper, each of these assumptions will be individually explored.

# Assumption One: Nursing is a discipline which should be studied as a human science.

Assumption One gives rise to two major questions: What: constitutes the discipline of nursing? and, Why should nursing be studied as a human science? Webster's New Collegiate Dictionary briefly describes a discipline as "a subject that is taught: a field of study" (1980, p. 322). Laudan (1977) describes a discipline as being characterized by the fact that its "disciples" typically work within a research tradition. Laudan defines a research tradition as "a set of general assumptions about the entities and processes in a domain of study, and about the appropriate methods to be used for investigating the problems and constructing theories in that domain" (Laudan, 1977, p. 81). Donaldson and Crowley likewise state: discipline...is characterized by a unique perspective, a distinct way of viewing all phenomena, which ultimately defines the limits and nature of its inquiry" (Donaldson and Crowley, 1978, p. 113). They further state that an identifiable body of knowledge will consist of a given structure that will identify the substantive area of interest and the syntactical rules by which to study that substance (Donaldson

and Crowley, 1977; 1978). Donaldson and Crowley's "substance" of a discipline is referred to by Laudan as the ontology of a research tradition; whereas, the discipline's syntax becomes the research tradition's methodology.

The substance of nursing. At present, nursing seems to be more firm in its ontological than in its methodological commitments. Flaskerud and Halloran (1980) have offered a strong argument for the fact that most nursing theorists (recently and in the past) have focused on four basic concepts: person (man, patient); nurse (nursing); health (illness); and environment (society). The various theorists have mainly differed in their focus on the interrelationships among these concepts (i.e., stress, adaptation, complementarity, etc.). The observations of Flaskerud and Halloran have been recently supported by a number of other nurse metatheorists, i.e., Fawcett (1978, 1978, 1980), Newman (1983), and Chinn (1983).

My conceptualization of the four phenomena of concern to nursing. Since this dissertation is a nursing study, I believe it is imperative that I articulate my beliefs about these four concepts. Both Martha Rogers (1970) and Jean Watson (1979) have heavily influenced this humanistic conceptualization of the four nursing phenomena:

 The person is a wholistic individual who is in the process of becoming and who deserves to be known and

- appreciated for her\* uniqueness. Both nurse and client are first and foremost person.
- The environment is basically any situation (social, physical or otherwise) in which the person exists.
- Health is the optimal state of well being which the individual chooses to attain given her personal/environmental demands, constraints, and resources.
- Nursing is the diagnosis and treatment of human responses to actual or potential health problems.
   (A.N.A. Social Policy Statement, 1980, p. 9.)

The person and the environment co-exist in mutual and simultaneous interaction (Rogers, 1970). Each person is part of the other's environment, hence, nurse and person also experience mutual and simultaneous interaction (also knows as transaction). Optimally, the person should be studied in her own context. The notion of health is individually defined in terms of one's own life processes. Nursing practice occurs when a nurse cares for a person/client in the client's environment in relation to the client's health needs.

Figure 1 depicts the interrelationships among these four phenomena. The central shaded area may be considered as the core of nursing practice where the persons as client and nurse come together in a given environment for the purpose of meeting the client's health needs. For the sake of research, any quadrant of the figure or relationship between (among) quadrants may be studied.

<sup>\*</sup>For the sake of parsimony, feminine pronouns/nouns will be used throughout this dissertation since the topic of inquiry has been limited to a woman's perspective.

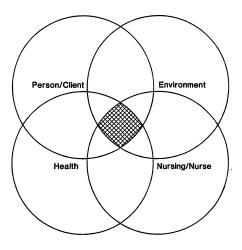


Figure 1. A diagram of the interrelationships between/among the four main phenomena of concern to nursing.

Nursing's syntax is presently under a considerable amount of controversy. There are those who believe the phenomena should dictate the methods, and then there are those who say the scientific methods should be used to structure the phenomena. Carper (1978), McKay (1977), Shlotfeldt (1977), Smith (1981), and Watson (1983) have suggested that in addition to empirical inquiry, nursing should explore alternative methods of knowing (i.e., esthetics, ethics, knowledge of self, intuiting, philosophical, literary and historical inquiry). The question of our methodological commitments will be elaborated upon as the following discussion of "human science" is pursued.

The notion of a "human science" is a term described by Giorgi (1970) in his attempt to find a niche for the so-called "Third Force" psychology. Third Force psychology is committed to the study of the person as a whole as opposed to the more restricted psychoanalytic or behavioristic views of psychology. This humanistic view of psychology shares with nursing some substantive, methodological, and historical concerns:

- There is a realization that there is a strain between the organismic concept of person as a whole and the traditional reductionistic assumptions of science.
- There exists a quandary as to the alternative methods with which to study the main phenomena of concern.
- Both disciplines struggle with strong historical ties to its "parent" discipline (philosophy for psychology and medicine for nursing).

- 4. Both are relatively young disciplines having their histories dating back to the mid-to-late nineteenth century; hence, both are susceptible to the temptation to follow the rules of the older natural sciences.
- There exists within the discipline a constant struggle to balance the theory-research-practice triad.
- 6. There exists a sensitivity to the dichotomous charge that those who are "wholistic" are the more "soft-clinicalpractice types" (art) as opposed to the "rigorousresearch types" (science).

Since nursing studies the whole person in relation to health concerns, it seems logical to use Giorgi's arguments for a "human science" for nursing also. Giorgi states:

Moreover, it is precisely the prejudice that Third Force psychology [nursing] must be either antiscientific or non-scientific that we would like to challenge. Consequently, both the term "human" and the term "science" are important to us. We would insist upon the relevance of the term human to those who want to build a psychology [nursing] of the human person according to the conceptions of science as developed by the natural sciences and who adhere rigidly to that concept despite changes in subject matter. We would insist upon the relevance of <a href="science">science</a> for those who want to study the humanistic aspects of man without any concern for method or rigor whatsoever (Giorgi, 1970, p. xi).

In essence, the notion of a human science embodies the valuing of the person as a whole <u>with</u> the need for rigor in study. The idea of rigor does not mean that the human sciences need adhere to the accepted rules and assumptions of the natural sciences; rather it means the human sciences should explore how to best study its own concerns. A science of humans will seek to generate those methods which allow us to study and value persons as wholistic, unique

individuals who are in the process of becoming and who must be studied in their environment.

The innappropriateness of limiting nursing's methodologies to the so-called "received" rules of the natural sciences has been recently discussed by a number of nursing scholars (Chinn, 1983; Tinkle and Beaton, 1983; Omery, 1983; Newman, 1983; MacPherson, 1983; Munhall, 1982; Oiler, 1982; Watson, 1981; Webster, Jacox, and Baldwin, 1981; and Stern, 1980). These authors have pointed out that in nursing we have traditionally valued the uniqueness of the individual, wholism, and the importance of studying the person in her context (environment). In contrast, the natural sciences stress objectivity, reductionism, and an ahistorical and acontextual approach to understanding the world (Munhall, 1982). Watson sums up this concern as follows:

This ethic of [natural] "science" is recognized by nursing's adherence to a research tradition that is so trapped in the world of objectivity, facts, measurement of smaller and smaller parts, and issues of instrumentality, reliability, validity, and operationalization that nursing is in danger of exhausting the meaning, relevance, and understanding of the very values, goals and actions that we espouse in our heritage and in our values. Indeed, if we continue along this path, nursing is in danger of losing its very soul, and in turn losing both its scientific and social contribution to humanity....[This] path is a path of limited thinking; a limited view of human life, person, nature and health...This path disengages nursing's ultimate meanings and intuitions from its aesthetics, ethics, science and its practice (Watson, 1983, p. 3).

As a young science, we are faced with a quandary: do we reject science with its somewhat successful record for generating knowledge, do we reject humanism with its logical fit with our phenomena of concern, or do we learn to live with some conflict and

accept elements of both - in the form of a human science. Gortner offers the following advice:

The profession would be unwise to reject scientific techniques now because of fear of dehumanization or concerns about the validity of analytic approaches. The hypothetico-deductive athods of science can be as much a part of nursing rese. The repetoire as are the descriptive, inductive, and theory generating forms. The refession surely can accommodate multiple paradigms (anaiplic, humanistic) and modes of inquiry (naturalistic, experimental, historical) (Gortner, 1983, p. 6).

In sum, perhaps the rule-of-thumb for increasing nursing knowledge should be: let the question guide the method, while being ever aware that the method will shape the answer.

# Assumption Two: Caring is a phenomena which is of major concern to nursing.

Watson offers seven basic assumptions for the science of caring in nursing. The first one is that "caring can be effectively demonstrated and practiced only interpersonally" (1979, p. 8). This assumption reflects Meyerhoff's emphasis on the importance of knowing another in order to care (1971). Such knowing involves an understanding of and appreciation for the other's plight. Brown (1981) states, "This kind of knowledge requires of the knower the ability to experience and be with the other as a separate, independent being rather than an an extension of self" (p. 15). Interpersonal caring implies that not only must the nurse be able to "give caring," but so must the client be desirous of the care offered to her. This leads to the second assumption which states, "Caring consists of carative factors that result in the satisfaction of

certain human needs" (p. 9). Watson emphasizes that these needs must be identified by systematic use of the nursing process.

The third assumption of Watson is that "Effective caring promotes health and individual or family growth." This assumption reflects Meyerhoff's description of caring as a process which facilitates development and actualization of the self (1971). Meyerhoff stresses the importance of patience on the part of the caregiver in order to allow the "cared-for" to grow and move within her own timeframe. Such patience will be based on the humility of the caregiver. This humility is described by Carper as involving a "continuous learning and awareness of the uniqueness of each new situation regardless of how extensive one's previous experience has been" (Carper, 1979, p. 15).

A fourth assumption which underlies Watson's model of caring is that "caring responses accept a person not only as he or she is now, but as what he or she may become" (Watson, 1979, p. 9). Basic to this assumption are the notions of trust and hope as described by Meyerhoff. Trust involves the appreciation of the uniqueness of the other and the other's ability to make wise judgements. Hope is described by Carper as "an expression of a present alive with possibilities and plenitude....[It] implies that there is or could be something that is worthy of commitment and that mitigates against despair" (Carper, 1979, p. 15).

Watson's fifth assumption states: "A caring environment is one that offers the development of potential while allowing the person to choose the best action for himself or herself at a given point in time" (1979, p. 9). The capacity to allow the other to choose frequently involves courage on the part of the nurse. Carper describes this courage as the capacity to take risks and to test one's secure boundaries. For the nurse, this frequently means challenging the norms of routine care in order to facilitate the client's individually defined needs.

A sixth assumption of Watson is that caring is more "healthogenic" than is curing. This places an emphasis in caring on the restoration, maintenance, and promotion of health. Caring is seen as complementary to curing which focuses on the amelioration of illness. The final assumption of Watson is one that is shared by this paper. That is: "The practice of caring is central to nursing" (1979, p. 9). This assumption expands upon the importance of knowing about caring and encourages nurses to utilize this knowledge in humanistic practice. Nursing practice which focuses on caring is based on a valuing of the uniqueness, rights, and capacities of the one for whom care is provided.

Carper (1979) suggests that the need for caring in nursing today is paramount. The move towards specialized health care and the rapid growth of space-aged technology has led to a tremendous tendency to depersonalize health care. Nurses and doctors are frequently seduced by the lure of machines, medicines, and procedures. Without caring, the person gets lost in the middle. She gets reduced to the limited status of patient: one who is viewed as needing a prescribable amount of physical curing interventions.

Caring acts and decisions make the crucial difference in effective curing consequences. Therefore, it is caring that is the most essential and critical ingredient to any curing process (Leininger, 1977, p. 2).

Assumption Three: The Lazarus Stress and Coping Paradigm (1978) may provide some insight for understanding the myriad of responses to miscarriage.

There are four major tenets which underlie the Lazarus Stress and Coping Paradigm, the first of which emphasizes the need to study the person in her natural environment. The natural environment refers to the person's own real-life situation versus a laboratorystaged study. The lab based research is rejected in this paradigm for five reasons: 1) the lab cannot provide full descriptive data on sources of stress in people's lives; 2) nor can it provide descriptive data on the full range of coping strategies used in stress related situations: 3) the lab is limited to short periods of time, thus not allowing for stress and coping to be studied as a process over time: 4) for ethical reasons researchers cannot subject humans in the lab to the kinds and degrees of stressors that are part of life; and, 5) the lab may offer illusion in the belief that the researcher "controls" extraneous variables, and furthermore, the relevance of the findings in such a "controlled" situation may be limited (Lazarus, 1978, pp. 6-10).

The second major tenet underlying the Lazarus Paradigm is that the person and the environment relate to each other in a transaction that involves process. A transaction implies that in the course of an encounter, the person and environment mutually and simultaneously interact (Lazarus, 1978; Rogers, 1970). Both the

person and the environment serve as sources of stimuli for each other where causality is multi-directional. Furthermore, when studying about stress (i.e., threat), Lazarus and Launier state:

Threat cannot be described in terms of person or environment alone, but must be defined by both. For example, a person may be threatened because the external demand seems very taxing and the resources for managing it weak, or the threat may arise from a weak demand that nevertheless appears stronger than the available resources for managing it. Both sides of the equation are necessary to the appraised relationship...(Lazarus and Launier, 1978, p. 288).

Lazarus refers to the environment as an "external situation." The situation brings to the transaction certain demands, constraints, and resources to which the person can attend and react (Klausner, 1971). The person brings "characteristics...[which are] forged over a lifetime and nestled in a genetically shaped physical constitution" (Lazarus, 1978, p. 10). These characteristics include personality, beliefs, values, commitments, skills, etc. A transaction-in-process implies that a person experiences an event as happening over time and Life does not proceed as a series of "time-dots:" rather, time passes as the past melts into the present in a continuous motion. Yet, historically, the problem has been that when traditional, deterministic scientific methods have been used to study stress as a static trait, the idea of stress as arising from a process between person and environment has been lost (Lazarus and Launier, 1978). The solution is that both the person and the environment acting over time together must be taken as the system of analysis.

The third major tenet of the Stress and Coping Paradigm is that stress may be measured on three separate but independent levels.

These are the physical, social and psychological levels. This tenet simply cautions the researcher to avoid measuring one level of stress (i.e., physical) and using it as an indicator of another level (i.e., psychological).

The final tenet underlying the Lazarus Paradigm is an emphasis on the ipsative versus the normative ways of studying people. This means that the shift in study is away from a search for "principles that apply to all humans alike" and toward an attempt to understand "the many facets of the same person or how that person functions (e.g., coping processes) in a variety of contexts or encounters" (Lazarus, 1978, pp. 21 and 23). This shift requires that emphasis in "sample size" not be on numbers of subjects, rather it be on amount of information available across time per individual.

These four tenets underlie the Lazarus Stress and Coping Paradigm. The paradigm is based on the belief that stress is a cognitively mediated emotion. This paradigm was selected to be of possible use to this study because it emphasizes the fact that people will react in different ways to the same event (i.e., a miscarriage) depending on the meaning this event has for their life. An event will derive its meaning in terms of a person's life experience, life goals, abilities, values, beliefs, etc.

Stress is said to be perceived when a person appraises an event as either harmful (a loss), threatening (impending loss), or challenging. Lazarus states:

Psychological stress, overall, refers to demands (or conflicts among them) that tax or exceed available resources (internal and external) as appraised by the person involved. The key element is that a person senses in some way, consciously or unconsciously, that he or she is in jeopardy. In a parallel fashion at the social level, stress involves demands from without or within that tax or exceed the resources of a social system. And at the somatic level, stress consists of proximate physical demands (even when they originate distally at the social or psychological level) that tax or exceed the resources of a tissue system (Lazarus, 1978, p. 26).

The appraisal process referred to in this paradigm operates in the following manner. In the primary appraisal, a person evaluates an event (i.e., miscarriage) as either stressful or non-stressful. A non-stressful event is dismissed as being either benign/positive or irrelevant (i.e., a miscarriage which was appraised as being nothing more than a late heavy period). An event which is appraised of as stressful would be one that the person perceives to be either threatening, harmful or challenging. The primary appraisal is followed by an ongoing reappraisal in which the individual continues to monitor the transaction and to evaluate the meaning of the unfolding event for one's well being (Lazarus and Launier, 1978).

The primary appraisal of stress is rapidly (perhaps even simultaneously) followed by a secondary appraisal. In the secondary appraisal the person cognitively reviews and selects among the coping resources available to her. These resources may be either personal or social/environmental. Lazarus describes two functions of coping: these are the problem-solving and the emotion-regulating functions. There are four modes of behavior that contribute to either or both of these functions. These modes are: information seeking, direct action, inhibition of action, and intrapsychic process (Lazarus, 1978, p. 36). Information seeking involves soliciting knowledge about the event so as to make a decision about course of action (a

problem solving function) or so as to rationalize decisions already made (emotion regulating). Direct action involves activities aimed at handling the stressful transaction; whereas inhibition of action involves holding back impulses to behave in a manner which would only exacerbate the stress-producing problem. Intrapsychic processes involve all the things a person "says to herself" to help her deal with the stressful transaction. Some of these "things" include denial, avoidance, intellectualizing, doing an undoing, etc.

The Lazarus Stress and Coping Paradigm has been reviewed for its potential relevance to understanding the myriad of responses to miscarriage. It is assumed that this paradigm may provide insight as to why different women experience the same event (loss of pregnancy prior to fetal movement being felt) in different ways. This paradigm stresses the fact that each woman will appraise her loss in terms of her own life experience. Furthermore, the paradigm stresses individuality in choice of coping strategies.

# Assumption Four: Familiarity with the psychology of early pregnancy is necessary to the understanding of the human experience of miscarriage in early pregnancy.

Zajicek (1981) views pregnancy as a major transitional stage in a woman's development. It is a time of rapid biological, social and psychological changes in a woman's life. In a short span of nine months, a woman experiences a forced need to deal with a new image of herself as a biological/sexual being capable of bringing forth life. Furthermore, she must also begin to come to terms with all the social and psychological rites, privileges and obligations that accompany motherhood.

Colman and Colman discuss one of the major tasks that a woman faces during pregnancy. That is the dealing with the relationship that unfolds between a mother and her fetus/infant in pregnancy. They state:

Some professionals have defined the changing psychological tasks of pregnancy as a process of incorporation, differentiation, and finally separation of the fetus from the mother. That is, the woman must first accept the fetus as present in her body (incorporation), then realize that, although it is there, it is actually not part of her (differentiation), and finally to prepare to give up the fetus (separation) (Colman and Colman, 1971, p. 32).

Likewise, Deutsch writes of the multiple polar strifes of pregnancy in which there are continuous struggles between the present and the future, between life and death, and between the desire to expel and retain. She writes:

To make it the being that is outside her, the pregnant mother must deliver the child from the depths of herself, and thus she discharges herself not only of it, but with it, of herself. This, I think, is at the bottom of that fear that every pregnant woman has, and this turns the giving of life into the losing of life (Deutsch, 1945, p. 160).

Frequently, the woman views her pregnant self as a link in time, she becomes not only that which "is," but also, that which "will be." Her act is not simply placed in time and space, rather she is the one of many, a bearer of fruit that will give rise to the future. The decision to become pregnant, which may or may not be consciously made, answers many needs both intra-psychic and interpersonal. Turrini has listed the following as some forces that may come to bear on that decision:

- The seeking of pleasure and the gratification of biological-physical-sexual needs;
- The meeting of grandparents' wishes;

- Answering a perceived biological timeclock "before it's too late:"
- Conforming to the cultural models (i.e. the ideal one boy - one girl family);
- Resolving of guilt associated with one's own childhood or one's hedonistic present: and
- 6. Fulfilling one's desire to mother for whatever reasons be they conscious or not (Turrini, 1980, pp. 138-9).

During the first trimester of pregnancy, the woman in some way comes to know that she is pregnant. Frequently, this leads to a constant monitoring of her health and the health of her fetus. The bodily changes of early pregnancy serve as a confirmation of the life hidden within her. Turrini states:

A critical conflict develops: should she think about being pregnant or not. When the healthy ego, fueled by self-protective functions and ideals of the maternal ego wins, the good enough mother enters into a constant monitoring of her health and the health of her fetus. On trips to the bathroom, for example, the woman watches for staining, one signal to her of the safety of the fetus. A life and death detection process goes on in the conscious experience, privately, and alone in the bathroom (Turrini, 1980, p. 140).

The link to the inner world of the womb is the obstetrician. Typically, the woman becomes very dependent on her physician, as he/she is her only means of access to the life within her. Until the point of quickening, the monthly verdict of the physician provides crucial confirmation for the woman that the life within her is prospering.

Raphael-Leff (1980) states that the first maturational stage of pregnancy lasts from the awareness of conception until the first felt movement of the fetus. She describes four tasks this stage bears upon the woman to come to terms with: 1) the realization that

this is the beginning of an irrevocable mother-child relationship; 2) coming to terms with conflicting feelings towards the baby; 3) increasing investment in the "foreign body" and making it into an integral part of her own being; and 4) adjusting to a new and rapidly changing body image.

Seventy-five percent of all fetal loss takes place in the first trimester and it is estimated that at least 20% of all women will have some symptoms of a threatened abortion during the first few months. Of these 20%, half will go on to lose that life (Berezin, 1982). Given the psychological challenges that take place in early pregnancy, it is no wonder that a loss at this point is going to have a unique multi-faceted meaning for each woman who spontaneously aborts.

Deutsch acknowledges that early fetal loss robs the woman of "the joy of anticipation, the pride of achievement, the anxious tension and its mastery, the dreamlike peaceful introversion, and the joyous preparatory activity" (Deutsch, 1945, p. 164). This, of course, says nothing of the fact that miscarriage denies a future in that it robs the fetus of a life, and the mother of a child.

As mentioned previously, early pregnancy involves an incorporation of the fetus as a part of the mother. At this point, there is little differentiation between the mother and her child. The fetus is one with the mother. When early fetal loss occurs, the woman perceives a loss of self. If the pregnancy were to go to term, at least then, the woman would come to know the life within her as another person. Deutsch write: "For separation is death, and only when the mother's love again receives the child in the outside world

are the specters of death banished" (Deutsch, 1945, p. 161). With spontaneous abortion, there is no child-life. There is only loss-death.

# Assumption Five: The caring needs of a woman who miscarries will be individually defined depending on how the woman perceives her loss.

This assumption actually encompasses two main thoughts. The first one is that miscarriage may be studied as an instance of loss. The second part to this assumption is that within this loss a woman will define her own needs for caring. Miscarriage as a form of loss will be explored first.

Marris (1974) has constructed a theory of loss and change based on multiple observations of people in "crucial life transitions." Some of these transitions included relocation, death of spouse, and changes in occupation. Marris identified that the commonality underlying each of these transitions was that each event represented a break from the familiar and a venturing into the unknown, hence, they called into action a need for readjustment.

Marris believes that as humans, we have a conservative impulse, "a tendency of adaptive beings to assimilate reality into their existing structures" (Marris, 1974, p. 4). This means that we all have a tendency to find and maintain a structure of meaning in life that makes sense to us. Marris defines this structure of meaning as an "organized structure of understanding and emotional attachments" (Marris, 1974, p. 4). Unfortunately, when loss or change occurs, our conservative impulses are challenged and we find that what previously had meaning to us may be suddenly rendered

useless. As Engel states: "The smooth, more or less automatic, taken-for-granted aspects of living are interrupted. The grieving person suddenly becomes aware of the innumerable ways in which he was dependent, often quite unconciously, on the lost object (person) as a source of gratification and as an essential influence for his feeling of well-being and effective functioning, his sense of self, so to speak" (Engel, 1964, p. 94). Grieving ensues when loss forces us to realize that that which we cling to no longer holds true. Marris refers to this grieving as a "psychological adjustment to loss" (Marris, 1974, p. 4).

Kushner's (1981) book When Bad Things Happen to Good People contains an excellent example of a structure of meaning being challenged by loss. Kushner shares his inner struggle with some basic religious beliefs he strongly clung to. Kushner, a rabbi, lost a 14-year old son to death and found himself raging against God. He questioned how it could be that God, whom he believed to be just, fair and all-powerful, would let his innocent son suffer and die. Kushner struggled with the loss of two very crucial meanings he had structured in his life: an attachment to his son and an attachment to his God. Kushner shares his grieving in the form of a book in which he attempts to restructure some very important "meanings" in his life.

Freud (1917/1957) described grieving as a series of attempts on the part of the bereaved to gain proximity to the lost object. Resolution of grieving is said to occur when the energy tied to the lost object is progressively withdrawn or "decathected." Similarly, Lindemann (1944), in a classic study of 101 bereaved individuals,

described the following characteristic signs of grief: somatic distress, preoccupation with image of the dead, guilt, hostile reactions, loss of normal behavior patterns and (less frequently) the appearance of traits of the deceased in the behavior of the bereaved.

An important aspect to Marris' theory of loss and change is that the outcomes of grieving need not be all negative; in fact, most loss will eventually end up in growth. The grieving process has been described as a series of necessary stages/phases that one goes through in adjusting to loss. For example, the phases described by Engel (1963) are: 1) shock, disbelief, denial; 2) development of awareness (where an intense range of emotions are experienced); and 3) restitution (where one learns to deal with the loss and get on with the business of living).

To what extent Engel's phases of grieving or Freud's description of the need to "decathect" will apply to miscarriage is as yet unknown. When a woman miscarries, what it means to lose a fetus can only be described by the woman herself. The pregnant woman's loss will be individually defined depending on (among other things) the meaning that the pregnancy had for her. Watson states that losses "may take many different forms and meanings depending on:

1) the individual, 2) the extent of loss or change, 3) the extent to which the object lost was valued, 4) the manner in which the object lost was valued, 5) the number of previous losses, and 6) whether adequate coping and resolution occurred" (Watson, 1979, p. 279).

Watson also describes loss as occurring on any or all of three levels: psychological, physical and sociocultural (Watson, 1979). Psychological loss involves a loss in meaning which one has of the self (i.e., self esteem). In the case of miscarriage, conceivably this loss might take the form of doubting in one's own femininity (i.e., Why can't I carry a baby? What kind of a woman am I?). Physical loss includes the obvious bleeding, pain and weakness; however, it might also include the perception of a loss of a body part since the woman in early pregnancy might not yet have fully separated out a sense of self and other (fetus). Sociocultural loss could conceivably occur in many ways, i.e., actual loss of the role of pregnant woman and future loss of the role of mother. Sociocultural loss also occurs when the woman is consciously avoided by others who don't know what to say, or unconsciously "avoided" by those who offer "distancing platitudes" (i.e., It is nature's way of taking care of things.).

Given that there is such variability in the meaning of loss, the type of care or support a woman who miscarries might need is often hard to predict. Watson emphasizes the need for caring to be based on an assessment of "the person's perception of the stressful event in his or her own life" (Watson, 1979, p. 299). This admonishment is congruent with the Lazarus Stress and Coping Paradigm previously discussed. How the woman perceives her loss (stressful or non-stressful) and how she prefers to cope (information seeking, direct action, inhibition of action, intrapsychic processes) will dictate what her caring needs are. Similarly, whom the woman prefers to be comforted by or how she prefers to seek solace must be valued.

Therefore, the caring role of the nurse in assisting the woman through her loss will have to be defined based on a thorough assessment of the woman's perceptions. Watson suggests that eventual

interventions will be based on an attempt to promote constructive coping mechanisms. She states: "The interventions that best promote constructive coping are those that assist the individual according to his or her strengths and weaknesses" (Watson, 1979, p. 300). Finally, Watson also suggests that an appropriate role for the nurse is to promote situational supports. Situational supports include physical and social resources available to the person. For example, if a woman who miscarries identifies one of her caring needs as a desire to be held and comforted by her spouse, an appropriate nursing intervention would be to encourage the woman to verabalize this need to her spouse and to include the spouse when the nurse prepares the woman for the process of adjusting to her loss.

#### Summary and Restatement of the Questions

Five major assumptions which underlie this study have been shared and explored. These assumptions reflect my beliefs about reality and therefore, will influence the way I gather and analyze data for this study. Once again, these five assumptions are: 1) nursing is a discipline which should be studied as a human science; 2) caring is a phenomena which is of major concern to nursing; 3) the Lazarus Stress and Coping Paradigm (1978) may provide some insight for understanding the myriad of responses to miscarriage; 4) familiarity with the psychology of early pregnancy is necessary to the understanding of the human experience of miscarriage in early pregnancy; 5) the caring needs of a woman who miscarries will be individually defined depending on how the woman perceives her loss.

Finally, the questions which are to be answered in this study are:

- What is the human experience of miscarriage in early pregnancy?
- 2. What are the caring behaviors of others that are identified as helpful by the woman who miscarried?

#### CHAPTER II

#### PROFILES OF PERINATAL LOSS

The review of the literature will proceed in a funnel-like fashion; that is from the global to the specific. Initially, some of the classic studies on grief in general and its concomitant caring needs will be explored. Secondarily, literature which refers to perinatal loss will be examined and finally, studies which specifically address miscarriage will be reviewed. Within the section on miscarriage, the findings of the pilot for this study will be presented.

## Grief in General

As stated in the introductory chapter, Freud (1917/1957) addressed the issue of the reaction of an individual to the loss of a loved one. For Freud, "mourning involved: a profoundly painful dejection; loss of capacity to adopt new love objects; turning away from any activity not connected with thoughts of the lost person; and loss of interest in the outside world - insofar as it does not recall the lost one" (Siggins, 1967, p. 420.) Freud stressed that there was a normal necessary reaction of mourning and a prolonged pathological reaction of melancholia. This attempt at describing and distinguishing normal versus pathological grieving has been the focus of the subsequent studies of Lindemann (1944), Marris (1958) and Parkes (1965).

Bowlby (1980) has cautioned that these three (as well as other) classic grief studies are somewhat limited in their focus and that their findings must be carefully applied in clinical and research usage. Bowlby points out the following limitations to these grief studies: 1) an imbalanced ratio of more widows to widowers; 2) a bias towards younger adult age groups, thus, children and the elderly may not be typified by the findings; 3) participants in all studies were volunteers; and 4) subjects of these studies come exclusively from the Western world.

Lindemann's study. Lindemann (1944) analyzed the interviews of 101 individuals' descriptions of their experience of loss of a loved one. He identified a "remarkably uniform" syndrome of the symptomatology of acute grief. The somatic experience of grief included "sensations of somatic distress occurring in waves lasting from 20 minutes to an hour at a time, a feeling of tightness in the throat, choking with shortness of breath, need for sighing, and an empty feeling in the abdomen, lack of muscular power, and an intense subjective distress described as tension or mental pain" (Lindemann, 1944, p. 141). In addition to somatic distress, normal acute grieving was said to include preoccupation with the image of the deceased, guilt, hostile reactions, and loss of patterns of conduct. Lindemann also identified a sixth behavior which he felt "bordered on the pathological" that was the tendency of the bereaved to incorporate into their behavior the traits of the deceased.

Lindemann further attempted to define the course of a normal grief reaction. He emphasized that resolution of grieving depended

"upon the success with which a person does grief work, namely, emancipation from bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships" (Lindemann, 1944, p. 143). It is unclear in Lindemann's study just what he considered to be a "normal" schedule for unassisted "grief work." However, he does state that in "eight to 10 interviews in which the psychiatrist shares the grief work, and within a period of four to six weeks, it was ordinarily possible to settle an uncomplicated and undistorted grief reaction" (1944, p. 144).

Lindemann distinguished normal and morbid grief reactions. He emphasized that with therapy, the morbid may be transformed into the normal. Included in the morbid reactions are delayed and distorted reactions. He described distorted reactions as: 1) overactivity without a sense of loss; 2) acquisition of symptoms belonging to the last illness of the deceased; 3) development of a psychosomatic medical disease (i.e., ulcerative colitis); 4) alteration in relationships to friends and relatives; 5) furious hostility against specific persons (i.e., the doctor); 6) schizophrenic-like behavior (i.e., a wooden formal affect); 7) lasting loss of patterns of social interaction (i.e., lack of decision and initiative); 8) activities detrimental to one's social and economic existence; and 9) agitated depression/suicidal tendencies.

Marris' study. Marris (1958) studied 72 London widows who ranged in age from 25 to 56. He found that common symptoms displayed

by some of these women were: deterioration in health; sleep disturbances; a loss of contact with reality related to an inability to release their loss; obsessive memories; a sense of their dead husband's presence; and behaving as though the husband were still alive. The women also complained of: being apathetic; withdrawing from people; trying to escape from all reminders of the loss; having a need to blame; and experiencing guilt.

Marris compared grief to a mental wound. He stated:

Once the numbness of shock has worn off, the pain is at first acute; gradually the attacks of sharp distress become less frequent, the despair duller, until at last grief is recalled only on rare occassions (Marris, 1974, p. 27).

Marris stated that "the acute phase of loss seems to last for several weeks if the loss is severe, only slowly and intermittently abating for as much as a year or more." Marris' widows took up to two years to recover, while some of the women claimed they would never get over it (Marris, 1958; 1974).

Marris distinguished two major patterns of grief: normal and abortive. Abortive grief is of three types: delayed, inhibited and chronic. Delayed grief tends to involve grief that is not expressed at the time of loss, rather it typically shows up much later, often in response to a trivial loss. Inhibited grief seems to be more typical of children and the elderly; it involves not fully expressing grief, but rather, displacing it into "physical disorders or neurotic conditions" (Marris, 1974, p. 27). Finally, Marris described chronic grief as "an indefinite prolonging of the acute phase of yearning and despair" (1974, p. 28).

Parkes' study. At the Bethlehem Royal and Maudsley Hospitals, Parkes (1965 I and II) collected data by interviewing 21 recently bereaved adult psychiatric patients and by a case notes review of an additional 94 recently bereaved adult psychiatric patients admitted between 1944 and 1951. The purpose of Parkes' study was to "systematize the various types of reaction which follow a major bereavement" (1965, p. 1). Parkes examined his notes and interviews to distinguish the occurrence of typical and atypical grief reactions. He claimed that the typical reaction to bereavement varied with the closeness of the relationship to the deceased.

Parkes arbitrarily set an upper limit of six months for a typical grief reaction. He drew heavily upon the works of Lindemann (1944) and Marris (1958) to develop the following description of a typical grieving pattern:

At first the full reaction may be delayed; there may be a period of numbness or blunting in which the bereaved person acts as if nothing had happened for a few hours or days up to two weeks. Thereafter, attacks of yearning and distress with autonomic disturbance began. These occur in waves and are aggravated by reminders of the deceased. Between the attacks, the bereaved person is depressed and apathetic with a sense of futility. Associated symptoms are insomnia, irritability with occassional restlessness, outbursts of anger directed against others or the self, and preoccupation with thoughts of the deceased. The dead person is commonly felt to be present and there is a tendency to think of him as if he were still alive and to idealize his The intensity of these features begin to decline after one to six weeks and is minimal by six months, although for several years occassional brief periods of yearning and depression may be precipitated by reminders of the loss (e.g. at anniversaries) (Parkes, 1965I, p. 3).

In classifying bereavement types, the first main subdivision used by Parkes was: I. The stress specific grief response and its variants; and II. Non-specific responses. In Type I, "it is the

nature of the loss and the peculiar significance which this may have for the individual which are likely to be important, whereas in the latter type, other factors will probably be found and the loss may be no more than a precipitating factor" (Parkes, 1965II, p. 13). Parkes summarized the classification of bereavement reactions as:

- I. The stress-specific reactions-grief and its variants
  - (1) Typical grief

  - (2) Chronic grief (3) Inhibited grief (4) Delayed grief
- II. Non-specific and mixed reactions. Any of the above along with:
  - Psychosomatic reactions

  - (2) Psychoneurotic reactions (3) Affective disorders not resembling grief
  - (4) Other conditions

(1965II, p. 14)

The non-specific and mixed reactions will not be reviewed however, the stress-specific reactions will be briefly mentioned. The brevity of this review is based on the fact that Parkes' description of the stress-specific reactions does not significantly differ from the descriptions of Lindemann or Marris. Parkes' version of typical grief has been stated above. He sees chronic grief as involving a prolonged typical grief with a picture of deep and pressing sorrow and ideas of guilt, self blame, identification symptoms, and/or aggressive-delinquent behavior. describing inhibited grief, Parkes quoted Deutsch (1937) who referred to the fact that unexpressed grief typically exhibits itself in some other form (i.e., recurrent depression, identification symptoms,

affectlessness, and the tendency to vicariously share in the grief of others).

Delayed grief involves a typical or chronic reaction which occurs after a period of time in which full grief expression was inhibited. Parkes also noted that the delay may simply represent a prolonged extension of the numbness phase.

This has been a general introduction of the reactions to the loss of a loved one. Three classic, often quoted sources were reviewed. The similarity in description of the grief process among these three studies has been noted. In summary, it may be stated that typical grief-work seems to take about six months to a year; it is a necessary, healthy process, and it generally involves four stages: numbness and shock; yearning and protest; depression; and recovery (Parkes, 1964).

## The Needs of "Grievers in General"

Before identifying the caring needs of the bereaved, it is worthwhile to consider for a moment what it means to care for the grief stricken. Engel (1964) has suggested that perhaps the reason we have little research on some (all?) aspects of grieving is that loss and death are topics that are too painfully real for all of us. Higgins has suggested that there are two major components of grief: separation anxiety - a fear of response to separation from a significant other; and existential anxiety - the fact that "grief will awaken anxiety about our own death, a condition that is impossible to imagine and painful to conceive" (Higgins, 1977, p.

692). Both separation and existential anxiety may be cause enough for the caregiver or researcher to establish "a shell, to insulate ourselves, to avoid engagement, to make out it does not occur or it is not our concern" (Engel, 1964, p. 93). Yet, in spite of the painfulness of the topic, Engel insists that we must reach out, we must care for those who suffer a loss - if for no other reason - the fact that unresolved grief will typically later exhibit itself in a physical/mental disease state (Engel, 1961).

Engel notes that knowledge of the stages of typical grieving is essential for the caregiver in order that an assessment may be made of whether the "healing process" is taking place, and so that a judicious selection of well-timed interventions may be chosen. It is paramount that the caregiver remain sensitive to the fact that grieving cannot be accelerated. Grief must have the needed time to take its course. Engel's review of the stages of grieving and his suggestions for caring needs will be the topic of the following paragraphs.

In the first stage of grieving, a feeling of shock and disbelief predominates. The survivor typically yells out, "It can't be" or throws himself at the body of the deceased upon first hearing the news of death. This outburst may then be followed by a stunned, numb feeling which exhibits itself through sitting and staring blankly or, perhaps, a sudden burst of "surface-busywork-behavior" or even an extremely calm <u>intellectual</u> discussion of the death. All of these behaviors must be recognized as the individual's way of protecting "oneself against the effects of the overwhelming stress by raising the threshold against its recognition or against the painful

feeling thereby" (Engel, 1964, p. 95). Engel states that this stage will last anywhere from a few minutes to a few days. During this phase, the caregiver must simply be aware of this protective process and be careful to not make an inappropriate judgement of the meaning of the survivor's behavior.

During the second stage of grieving, awareness of the loss The awareness is acutely painful and is frequently develops. perceived of as an experience of emptiness: physically as an emptiness in the chest or epigastrum, emotionally as a realization that something valued is lost, and environmentally as a frustrating void in that it no longer contains the beloved. Often the bereaved person will try to place blame either on the self where guilt and self destructive actions may ensue; or on another (i.e., the doctor) where disparging remarks will be made at the assumed evil-doer. Outward emotional displays are typical of this stage. Awareness often brings on crying, swearing, fist pounding, chest beating and other such emotion-laden behaviors. Engel suggests that at this stage, the caregiver must be very cautious of a tendency to judge, especially to prejudge in the form of the caregiver's cultural expectations. There are cultural variations in expected behavior connected to mourning that must be respected and facilitated. Culturally valued activities must be allowed to take place. Finally, Engel warns that a failure to exhibit emotional behavior (i.e., not cry) may be a symptom of failure to grieve, which at the very least bears watching.

In the third stage, restitution, "the work of mourning" takes place. It is at this time that institutionalized forms of public

mourning occur. Usually, in our society this means a wake, funeral or prayer service takes place. Engel states:

First, it involves a gathering together of family and friends who mutually share the loss, although not all to the same degree. At the same time, there is acknowledgement of the need for support of the more stricken survivors whose regression is accepted. In this setting, overt or conscious expression of aggression is reduced to a minimum (1964, p. 95).

Institutionalized forms of mourning serve the important function of clearly recognizing that a death has occurred. It acknowledges there was a life, there is now a death. A funeral allows for a group sharing of the loss and a means to reassure the survivors that perhaps a reunion in the afterlife will ensue. Finally, a funeral usually begins the official period of mourning in which close, significant mourners are allowed to assume outward signs that identify them with their lost loved one (i.e., sackcloth and ashes, the wearing of black, widow's veil, etc.). It is important that caregivers recognize the meaning of these institutionalized rituals in order that they may allow for and facilitate planning of such events with either the dying or the survivors.

Engel states that the final stage of grieving is resolution of the loss. This stage involves several aspects which appear to incorporate Parkes' (1964) final two stages of depression and recovery. Engel states, "First, the mourner attempts to deal with the painful void, the awareness of the loss, which is felt also as a defect in the sense of intactness and wholeness of the self" (1964, p. 96). During this time, the bereaved person is rarely able to enter into meaningful relationships with others or to fully accept a new "love object" (i.e., remarry or have a replacement child) without

doing injustice to that new relationship. It is during this time that the mourner turns inward to the physical sensations of grieving as described by Lindemann, to the preoccupation with thoughts of the lost one, and occasionally a brief assumption of disease symptoms or personality characteristics of the deceased. This preoccupation with the loss proceeds from a focus on what has been personally lost in the survivor's life to a predominance of thoughts of the deceased's life.

The slow, painful rumination of the loss will usually contain an element of idealization of the deceased. In order to idealize the deceased, all negative thoughts (past and present) about the dead person must be overcome. Engel states, "Such repression may lead to fluctuating guilty, remorseful, and even fearful feelings with regrets for past acts or fantasies of hostility, inconsiderateness, or unkindness, recollection of some which may be exaggerated. Sometimes, there may be a haunting preoccupation with feelings of responsibility for the death" (1964, p. 96). The caregiver is admonished to recognize the need for idealization and to monitor closely when overly-exaggerated self-reproachment may be occurring. Furthermore, the caregiver must be aware that this is a process that takes many months and that signs of successful grieving are the capacity of the bereaved to be comfortable with the more realistic ambivalent feeling towards the deceased and a reduction in the amount of sadness felt when the deceased is mentioned.

The outcome of successful grieving will be the capacity to reenter life in its fullness, to turn away from the death and towards life. A full expression of living will involve the capacity to give more fully to others (i.e., the surviving children or the other parent) and to enter into a meaningful relationship with a new love object (i.e., another baby, a new spouse). Engel points out that many factors will influence the outcome both in terms of rate and resolution of grieving. Some of these are:

- The importance of the lost object as a source of support for the bereaved (i.e., a more dependent relationship is harder to resolve);
- 2. The degree of ambivalence toward the deceased;
- Age of the deceased (loss of child generally being more painful than loss of a parent);
- 4. Age of the mourner;
- 5. Number and nature of other meaningful relationships;
- Number, nature, and recentness of previous losses and their resolution;
- Degree of preparation for the loss (acute losses are generally more profoundly felt); and
- 8. The physical/psychological health of the mourner at the time of the loss (1964, pp. 96-97).

In summary, Engel's description of the stages of grieving was offered as a means to structure the exploration of the caring needs of the grieving. He calls upon the caregiver to practice sensitivity to the needs of the survivors. In closing, Engel offers the following practical interventions in caring for the bereaved: 1) whenever possible, share the news of death with the family as a group so as to have together a natural support group. 2) Facilitate the chance for the survivors to see, touch and be with the dead person as they may desire. 3) Recognize the meaning of, and allow for, the need of the survivors to express feelings, anger at caregivers, and emotional behavior. 4) Expect variability in initial response to

death and be cautious of personal/cultural biases of appropriate mourning behaviors. 5) Be aware of variability in expressions of grief, learn to include information about recent loss in assessing a new client. 6) Be aware of variability in grieving styles due to age. 7) Recognize the poignancy of meaning in the loss of a child. Finally, once again, Engel admonishes us to move past the pain we experience in confronting death. He suggests we, as caregivers, seek and give support to each other so as to facilitate our capacity to care.

### Perinatal Loss

In most studies, perinatal loss refers to stillbirth and neonatal loss up to about one month of life. As stated in Chapter I, stillbirth usually means delivery of a fetus after 28 weeks gestation. In some studies reviewed here, the researcher has included fetal loss prior to 28 weeks. Most commonly when this is done, only those subjects who have experienced fetal movement are included. Rarely is the woman who spontaneously aborts prior to 20 weeks gestation included in the articles (research and clinical papers) which address perinatal loss. In this review, if and when early fetal loss is included, it will be noted.

Elliot (1978) has provided a first-hand account of what it means to grieve through the loss of twin boys who died at one week of age. As an introduction to this section of the literature review, excerpts from her article will be given on the right while my interpretation of Engel's grief stages will be shown on the left. It

must be noted that in spite of the way I have presented these excerpts, these statements did not occur in the order shown here, and Elliot's own description seemed to indicate that stages overlapped, sometimes totally out of order. This lack of succinct, ordered stages is described by Kirkley-Best and Kellner (1982) as typical in perinatal grieving. Elliot's personal experience follows.

#### Stage

#### Elliot's Experience

Shock, disbelief

Everytime I closed my eyes, I relived the experience in the nursery. I could see each of them and wanted them. Nothing else in my life mattered. I felt very alone and was not able to care about other people. I ate only because food was put in front of me...My husband, Tom, was as numb as I. He suffered the same shock at the babies' deaths.

Development of Awareness

Everyday I spent part of the time trying to answer questions: Why did this happen? Why me? Why wasn't I able to produce a child that lived? Why couldn't the doctors cure their disease? What did I do to deserve this pain? Why was God doing this? I was trying to blame someone for my loss...I felt completely drained and empty...It was easiest to be angry with myself, and the anger became guilt...No answers came, just frustrated, angry tears.

Restitution

Our parents...came and helped by caring for the children and the house. They cried with us too, we all shared the emptiness. Friends sent flowers and cards. Some came to be with us for brief visits, and many called with offers to help. We had a close friend make the arrangements with the funera! home...Then it was time to write thank you notes. That point seemed to mark a change for me...I no longer thought it was just a bad dream. I knew they were dead and were never again going to be a part of my family. It was time for me to try to pick up the pieces of my life.

Resolution

Each of us wanted relief from the emptiness. We found ourselves clinging to each other for comfort. We made love Resolution (Cond.) for selfish reasons, but it was a losing battle at first. When we relaxed, our thoughts would return to the result of sex - babies. Then we would both sink back to the bottom, thinking about our loss....We had trouble relating to our children. too....Some people called to talk about what happened, but we were not ready for that yet. I felt completely drained and empty....Clearly the hardest part of becoming active again was having contact with people....The time I spent at home with my children was fine as long as I was busy....There would be a string of bad hours or days, ending with tears, and then a time of relative quiet. At first the cycles were one or two days apart, then three days, five days, a week and so on....Now a year later, my time is spent following a normal routine and looking forward to tomorrow. relationship with Tom is deeper than it was....Our children bring us joy and pleasure....Our conversations are now the possibility of baby....What is really important in my life is clearer now, and I look forward to living each day (Barbara Elliot, 1978, pp. 100-102).

Elliot's sensitive sharing of her grief work provides an introduction for the remainder of this literature review. It must be noted that the state-of-the-art in literature related to perinatal loss is such that meaningful articles are not limited to quantitative research studies. In fact, the majority of this literature review will cover books and articles that have been typically written based on: an analysis of the experience of clinical caregivers, "witness" of lay people who have suffered a loss, and qualitative interview-type research studies done by nurses, sociologists, psychologists and physicians. It is probably safe to say that most of the perinatal

loss research available to date is at a descriptive level with considerable speculation about appropriate interventions.

Articles which tend to be more research-oriented will be individually reviewed in the immediately following section. After that, I will summarize a number of clinical-review articles in order to provide a picture of: signs, symptoms and personal experiences associated with the grieving of perinatal loss; caring needs of the woman who experiences a perinatal loss; reactions and feelings of health care providers; and suggested care strategies for assisting the woman in her adjustment to perinatal loss. The first article reviewed here is by Kennell and associates. My critique will be fairly long and detailed since this study has been influential on most of the perinatal loss literature which followed it.

## Review of Perinatal Loss Research Articles

Kennell, Slyter, and Klaus (1970). Kennell et al. set out with the assumption that "length and intensity of mourning after a loss is proportionate to the closeness of the relationship prior to death" (Kennell et al., 1970, p. 345). Given this assumption, 20 women who had experienced neonatal loss were interviewed by the researchers with the objectives: "to determine whether early tactile contact between mother and infant leads to unduly upsetting reactions after a baby's death; to investigate the importance of various factors, particularly tactile contact in the establishment of an affectional bond between mother and infant; and to observe

systematically the reactions of a group of parents to the loss of a newborn infant" (Kennell et al., 1970, p. 344).

Data were collected over a one-year period (January, 1968 to January, 1969). At the same time the premature nursery site for this study was being used, it was also the site for a long-term maternal separation study that had a three-month cycle which allowed women to either touch their infants or to simply view them through the window of the nursery. There were 21 women whose neonates (one hour to 12 days of age) died. Of these, 20 mothers agreed to participate in the study. Whether or not the mother had contact (touch) with her infant reflected the three-month cycle in which her delivery took place. Each woman had at least one living child and socio-economic background was said to be "wide." Three of the infants who died had a twin who survived.

Tape recorded one-hour interviews were conducted three to 22 weeks after infant death. Interviews were semi-structured and designed to cover three periods: prenatal experience, the postnatal experience, and experience surrounding the death. At the end of the interviews, 13 of the mothers were asked to fill out questionnaires related to the same topics. It is not reported why the other seven did not do this. It must be noted that autopsy results were shared with the mothers during this meeting between the interview and the filling out of the questionnaire.

Choice of variables for the questionnaire was based on the studies of Parkes and Lindemann. A mourning measure with a five-point Likert scale (0 = never a problem to 4 = major problem for greater than four weeks) per item was developed. The six items in

this measure referred to sadness, loss of appetite, inability to sleep, irritability, preoccupation with the lost infant and inability to return to normal activities. The six items together gave a numerical mourning score. This score was averaged with the mourning score of two raters who had independently rated the interview tapes. Raters looked for a presence of three or more grief signs. The nature (interval, ordinal) of the rater's score was unclear. Reliability was established by comparing the scores of the two independent raters. Inter-rater reliability was reported as 89 per cent agreement. Measure to rater reliability was said to be "the same or within one point of the interview evaluation 85 per cent of the time" (p. 345). Internal consistency or test-retest reliability measures were not reported. Validity was not mentioned.

Before results of this study are reviewed, some major criticisms of this very often quoted study must be given:

- One cannot help but wonder about the confounding of results between the two studies which were said to have simultaneously occurred in one setting.
- Convenience assignment (based on constraints of the larger study) limits the validity of findings.
- Receiving autopsy results between interview and questionnaire and then comparing the two measures seems questionable.
- Limiting the mourning score to six items seems insufficient, especially when two of the items

- were sadness and preoccupation with thoughts of the infant. It seems hard to imagine that there would be much variability found in either of these items.
- 5. If the scale for each mourning symptom ranges from never a problem to a major problem for greater than four weeks, and some of the women were interviewed at three weeks post-loss while some were 20 weeks post-loss, it seems highly debatable as to whether scores have a meaningful use for comparison (i.e., a woman three weeks post-loss was still quite pregnant four weeks ago; whereas, a woman 20 weeks post-loss may possibly be three to four weeks past the acute phase and its symptoms).
- 6. A low mourning score could indicate multiple meanings: a resolved grief, a failure to grieve, or an innappropriate measure of a particular woman's grief (i.e., a tendency to overeat rather than undereat when upset).
- 7. While not a critique of this study per say, it bears mentioning that if as Bowlby (1980) stated, the studies of Lindemann and Parkes were characterized by an imbalanced ratio of younger females (widows) to other population groups and if Kennell et al.'s scale is based on Lindemann's study, then it would seem logical to be concerned

about the meaningfulness of this tool in measuring grief in fathers and adolescent mothers as has been typically done in subsequent studies.

The authors did drop the three week post-loss mother for the reason cited in my critique, and another mother chose to drop out for fear of dredging up unpleasant feelings. The remaining 18 women were arbitrarily divided into low and high mourning score groups of nine each.

All mothers reported definite sadness and preoccupation with thoughts of the dead baby. All but two experienced insomnia and a disturbance of their usual patterns of daily life. Fifteen had increased irritability and 12 had a loss of appetite. Every mother had problems in at least three of the six items and 15 had problems in five or all six items.

Using a Fischer Exact Probability Test, the high and the low group were compared on a number of the prenatal, postnatal, and loss variables. High mourning was associated with the previous loss of a baby through miscarriage or neonatal death (p less than 0.05). High mourning was also associated with having positive feelings about the pregnancy (p less than 0.05). High mourning was suggestively associated with touching the infant before his death (p less than 0.1) and failure of communication between mother and husband, or in husband's absence, her own mother. No apparent relations were found between mourning score and length of baby's life, a mother's expectation of her baby's chances to live, and number of living children.

All three mothers with living twins had low mourning scores. Again the meaning of this finding is debatable. Only one case of post-partum depressive psychosis was reported. This was in the case of a woman who had touched her infant, but who had not touched her previously born infant after whose death she had <u>also</u> developed post-partum psychosis. This woman had a long history of psychiatric hospitalizations.

It must be reiterated that the discrepancy in meaningfulness of scores severely impedes this study. A high mourning score after touching an infant may be due to the fact that the woman is more intensely grieving a real human being whom she has met. While this high score may seem somewhat disconcerting immediately, it may eventually be looked back at as an indicator of the woman's capacity to more rapidly move through the grieving stages. Furthermore, the scores might more highly reflect the timing of the interview in relationship to time of loss than any other variable due to the range of measurement times.

Finally, if length of baby's life did not significantly associate with mourning score, but having positive feelings about the pregnancy did, one has to question if Kennell et al.'s original assumption about "closeness of the relationship prior to death" might best be interpreted as the mother-infant <u>gestational</u> relationship. And if this is the case, it would seem logical that the authors would have pursued a study of gestational attachment (i.e., bonding prior to birth). It is interesting to note that in future publications (Kennell and Klaus, 1971; Kennell and Trause, 1978; Speck and Kennell, 1980; Klaus and Kennell, 1982), the authors went on to

assume, "Many women develop affectionate feelings toward their unborn infants following the onset of fetal movement" (Speck and Kennell, 1980, p. 59). The potential for attachment prior to movement seems negated.

Wolff, Neilson and Schiller (1970). Wolff et al. (1970) reported on a prospective study of 50 women who experienced stillbirth or neonatal death. Subjects were randomly selected from the inpatient maternity service at Presbyterian-St. Luke's Hospital in Chicago. Forty of the 50 women were followed over a one to threeyear span (dates not reported) in order to observe their loss resolution over time. Ages ranged from 14 to 38 years. Thirty-eight of the subjects were from a low-income group, 12 were middle income. Thirty-one were married and living with spouse, 37 were multiparas, 17 of these had a previous stillbirth. Interviews were conducted postpartum at two days, four days, and (for the subsample of 40) at one or more times in the subsequent three-year period. Half of the sample requested six-week postpartum interviews, five were accompanied by husband or relative during visits. All but the 14year old were reported to have "talked freely in all areas of the searching interviews" (Wolff et al., 1970, p. 74).

All but two patients were said to have displayed the usual grief pattern. The two who were atypical were said to have been previously (and continued to be) participating in psychotherapy. The women universally asked why their baby died. Feelings of guilt and blame of others, self and God were frequently expressed. All expressed a preference to be informed of the death by a doctor and

some wished to have a supportive person present (whether or not this occurred was not reported). Most women reported that they were satisfied with the timing of when they were told of the infant's death (when they were told was not reported).

Forty-six were placed in the maternity unit, 27 were said to have desired this. Four women were placed in a general ward, three by request, one for sepsis. Sixteen women stated they would have desired a general ward. Those who saw a chaplain considered it to be helpful. The large majority expressed a desire for unrestricted visiting hours for family and friends.

Wolff et al. did not report on the amount of medications women received, however, they stated the majority were satisfied with some wanting more and two wanting less. They also stated, "Most of them thought they behaved well and that the experience was not much different from what they expected" (1970, p. 4). This statement was not elaborated upon.

Twenty-two women refused to discuss their attitudes toward health care providers. The 28 who did reported warm feelings toward (doctors = 13, nurses = 10, attendants = 10); cold feelings toward (doctors = 10, nurses = 11, attendants = 11); and neutral toward (doctors = 5, nurses = 7, attendants = 6). Doctors and nurses were said to have elicited stronger feelings than the attendants. In a later article, Wolff reported that 50 per cent of these women changed physicians (Wolff, 1971).

Of the 16 patients who stated in their earlier interviews that they had definite plans for subsequent pregnancies, eight became pregnant. Of the 19 who stated they would not desire to become

pregnant, eight did, and of the remaining 15 who preferred to focus future plans on "other activities" (i.e., job, school), two became pregnant. Of the 20 who did not become pregnant, eight were adamant against having a baby and four of these chose to be sterilized. The authors also noted that previous pregnancy loss did not appear to affect whether or not women became pregnant again.

This study's report was characterized by a tendency to reduce all information to a count of number of subjects who experienced symptoms, expressed needs, or behaved in given ways. The "numbers" tended to lose meaning (i.e., "some" wanted "more medication"). Qualitative data would have strongly enhanced the usefulness of data (i.e., satisfaction with and reaction to subsequent pregnancies; what distinguished "cold" from "warm" nurses). While this study is one of the few prospective studies of perinatal loss, it suffers from a failure to substantiate numbers with meaningful interpretations and a tendency to offer unsubstantiated statements (i.e., "All reacted with a typical grief reaction. None developed other significant psychiatric difficulties. [What happened to the two who were said to have continued in psychotheraphy?] In 50 per cent, the resolution was in becoming pregnant again" (Wolff et al., 1970, p. 73)).

Bruce (1962). One of the earliest published studies on caring for women who experience stillbirth was done by Bruce in 1962. This qualitative nursing masters thesis provided a striking example of the incongruency between nurses' and clients' emotional needs. Comparisons were made between the interview data of a convenience sample of 25 maternity nurses and 25 women who had experienced

stillbirth. This report of the thesis failed to give background information pertaining to characteristics of the sample or research methods. However, it was rich in poignant examples of incompatabilities between the mother's need to be cared about emotionally, to be heard, and to be understood for her pain <u>and</u> the nurses' need to maintain a professional armor.

Through her interviews with the nurses, Bruce found that the nurses really did care about and feel for these women. Much of the nurses' uncaring demeanor reflected not so much a lack of concern as an inability to allow themselves to truly feel their own or the mother's needs. This was said to be based on a self-defensive reaction to guilt around the loss, a self-protective mechanism against the intensity of their own sadness at participating in birth-death, and finally, a need to conform to a professional role to which they had been socialized. This role highly valued a need to appear professional, knowledgeable and ever-ready with a scientific technological explanation for every occurrence. The usefulness of this study for caregivers in general, and nurses in particular, is striking.

Giles (1970). Giles conducted a descriptive study of a convenience sample of 40 Western Australian women who delivered at the King Edward Memorial Hospital for Women during 1968 and 1969. All 40 women were public patients and had "just lost babies in the perinatal period" (p. 207). The purpose of the study was to have the women suggest ways in which their doctors could have helped them.

Interviews took two to three hours and were spread out over several days in the <u>early</u> puerperium. If, indeed, the first phase of mourning involves numbness and shock, one has to wonder how much this would have influenced the mother's capacity to share her feelings. Furthermore, the women's ability to articulate her caring needs might well have been influenced by the fact that doctors had "prescribed sedatives liberally" (p. 207) during the woman's hospitalization.

The results reflected the timing of the interview. Emptiness and numbness were said to be the two most prevalent reactions. Women also discussed their reactions to previous pregnancy losses (these losses were said to have been more traumatic). Thirty-three of the 40 women were said to have been only mildly interested in autopsy findings. Women also expressed concern about the timing of when they were informed of the infant's death. Many would have preferred some warning of impending death. When asked, only 16 of the 40 gave an opinion as to cause of the infant's death.

In terms of the care they received, 18 said they felt a doctor could have helped them bear the loss, especially by explaining cause of death. "Five complained that junior doctors had not answered their questions, but had left them to be answered by senior doctors who, in fact, never visited them" (p. 208). Twelve felt they had been helped mainly by their visitors, 10 by a doctor, and 10 by nursing staff. There were mixed feelings expressed about choice of ward versus private bed. Other complaints included not being given information, not having their husbands called in when the baby died and being subjected to meaningless hospital procedures (i.e., routine blood pressures). The most poignant finding related to the women's

reactions to the routine practice of sedating these mothers. Two would have preferred more sedation, two asked for limiting meds to sleeping aids, two would have preferred heavy medication for just a day or so, and  $\underline{14}$  felt "their loss ran its own course and that the sedatives that they had had only confused them" (p. 208).

The main contribution of this research was as Giles pointed out: "Doctors managed bereaved mothers in the present series by treating physical symptoms and by prescribing sedatives liberally, but they avoided discussing the baby's death in about half of the cases," p. 209). One has to wonder whose needs were really being met.

Bourne (1971). Bourne, like Giles, reported on an overwhelming tendency of physicians to place "distance" between themselves and the emotional impact of stillbirth (on both the doctor and the patient). The original purpose of Bourne's study was to "discover the psychological effects of stillbirth on the mother and her family." Bourne was quite concerned about the prevalent tendency to dismiss stillbirth as being like a spontaneous abortion in early pregnancy. He stated "an abortion is commonplace and may be more successfully denied: the gestation is brief, investment and disappointment less, the product is tiny, almost unrecognizable, the experience is private and not notifiable" (p. 333). While Bourne's sensitivity to the impact of stillbirth is commendable and his realization that there is a difference in meaning between the two losses is creditable, his dismissal of miscarriage seems rather presumptuous.

In 1962, 100 women who experienced stillbirths were matched with 100 women who experienced live births. All names were randomly chosen from different parts of one London county. questionnaires were sent to their family doctors who were unaware of the survey's purpose. The 1971 article reported on the results of the doctors' survey. Reported findings ended up being quite unrelated to the study's original purpose, but none the less When the researcher discovered that the general practitioners reported that women who had had a stillbirth were no more anxious in subsequent pregnancies than women who had not experienced such a loss, the researcher began to suspect something Bourne decided to take a closer look at the doctors was askew. themselves (rather than the doctors reports on the women). discovered that: 1) more of the stillbirth doctors did not return the questionnaire; 2) two wrote long letters explaining they neither wanted to or had the time to fill in the questionnaire: 3) many more of the returned stillbirth questionnaires were blank; and 4) that on those stillbirth forms returned there was "a much higher proportion of don't knows and a general poverty of information or interest. some questions, the differences were at the 0.001 level of significance" (p. 334).

Bourne states, "The doctor whose patient has had a stillbirth does not want to know, he does not want to notice and he does not want to remember anything about it. This must mean doctors under strain and a group of patients are in danger of neglect" (p. 334). This study has since been widely quoted in stillbirth publications although it has sometimes been mildly criticized for studying general

practitioners versus obstetricians. (Apparently obstetrical care by general practitioners is common practice in London County.)

Cullberg (1971). Fifty-six of the 62 women who experienced perinatal death in one year in a Stockholm maternity clinic and who were able to be contacted participated in one to two-year follow-up interviews. Cullberg conducted the one to two hour taped interviews in the same clinic. The purpose was to obtain follow-up information on the women's reaction to her loss. Most of the women reportedly expressed gratitude for the chance to share their feelings.

# Cullberg stated:

The main reactions in all mothers (except nine, who denied any reaction) were grief, apathy, feelings of emptiness and inadequacy. These reactions developed a few hours to some days after an initial shock reaction. During the second or third month, most women had returned to their usual work and at the time of the interview, most of them seemed to have gained their mental stability (1971, p. 326).

One-third of the women reported marital conflict or "other social complications" after the loss. Eleven women recalled denial or supression of feelings initially in order to conform to the expectation of hospital staff or family members. Chi-Square analysis showed that this enforced supression was significantly related to a longer grief process and a longer time to return to work (p less than 0.05).

Nineteen of the 56 were said to have reported more serious symptomatology. Of the 19, nine experienced attacks of acute death anxiety, one experienced psychotic delusions of an impending castration, one a psychosis with pseudocyetic fantasies. Two women

feared uterine cancer, one believed she was to be sterilized, and two feared death of a family member.

There was no pre-crises information available on the women (i.e., history of psychiatric illnesses). Symptomatology was said to have  $\underline{\text{usually}}$  culminated a few months after the infant's death and then subsequently subsided. A few symptoms were said to have persisted as maladaptive behavior (n = ?).

Cullberg remarked about the extreme sensitivity of the women to their doctors. She also stated that nine women seemed to have been given reasonable opportunities for emotionally working through their loss. In four cases this was due to the caring of a nurse. No further information about the doctor-patient relationships of this sample was shared.

Cullberg's study has been frequently quoted, often inappropriately. People have referred to this study as having found 19 cases of psychosis or pathological grieving (one-third of Cullberg's sample). In actuality, Cullberg referred to psychosis only once, and psychotic symptoms once also. She referred to her subsample of 19 as experiencing more "serious mental symptoms than the rest." Furthermore, few (if any, Cullberg included) have tuned into the seriousness of the fact that nine women reported no reaction. This indicates either delayed or inhibited grieving both of which one to two years past loss may be considered pathological. Therefore, a rather striking outcome of this study is that if the nine "non-symptoms" and the 19 cases of "serious mental symptoms" are combined, then 50 per cent of Cullberg's sample may be characterized as having experienced a troublesome grieving process.

Jensen and Zahourek (1972). In a small clinical study done by Jensen and Zahourek (1972) at two days post-partum, 25 women who had experienced either neonatal loss or stillbirth completed the Zung Self-Rating Depression Scale. This scale was filled out again at six weeks by 15 of these women and at one year by 10. After the study year, a control group of 12 women whose infants lived completed the same protocol. (The control group was said to have been matched as "closely as possible.") There were no significant differences across all three time measures when the control was compared to the group of 10. However, T tests between the original group of 25 and the control group at two days, and the subgroup of 15 and the control group at six weeks revealed significant differences at the 0.05 level (two-tailed alpha). Depression scores in both cases were higher in the loss group.

This study was overwhelmingly fraught with statistical, methodological, and practical problems (i.e., the original protocol called for interviews and the administration of two depression scales). The authors' sole conclusion was that the data tended to support their original hypothesis that women who experienced perinatal loss were at risk for depression.

<u>Grubb (1975 and 1976).</u> A case study of a 32 year-old black woman who experienced intra-uterine death at 34 weeks gestation was reported on by Grubb (1975, 1976). The woman carried the dead fetus for 22 days before spontaneous labor began. The fetus was macerated with a knot in the umbilical cord, and two tight loops of cord around

the fetus' neck. The woman had a history of postpartal hemorrhage, three spontaneous abortions, and two live births.

A brief summary of Grubb's elaborately reported findings are given here. First, the woman exhibited tremendous concerns about the threatened loss of body intactness. This was especially obvious in her pre-delivery fear of exsanguination. Secondly, the woman's concern about incarceration by death within was clearly evident in her tremendous concern about her upcoming labor and her belief that having something "rotting away" inside her body would result in the pollution of the living body surrounding it. Thirdly, the woman was tremendously concerned about the future of her body-self, that is the security of her future as a fully living, fully functioning person and woman. The woman's fourth and final concern was said to center on a distinct effort to differentiate and liberate her own body-self from that of the fetus which had died. This concern was demonstrated in the woman's trying to make real a separate personality for the fetus.

In Grubb's 1976 publication about the same woman, she explored the woman's efforts at receiving validation as to whether or not the fetus she was carrying had died. The woman was said to have sought out three sources of validation: her own inner sensations, the medical opinions and technologically-based diagnostic procedures, and a social source (i.e., opinions, hopes, and doubts of friends and family). The woman was said to have used all three sources simultaneously and at differing times to support her conclusions about the viability of the fetus.

The two articles by Grubb were fascinating, rich, and highly useful for identifying the need for further research in the way women perceive and attempt resolution of their losses. The implications for the need to be heard and constantly supported throughout the tragedy are most apparent.

Kowalski and Bowes (1976). A brief case study of the delivery of a stillborn by a 30-year woman with a history of one abortion (nature = ?) was shared by Kowalski and Bowes (1976). This woman's loss was said to have stimulated an interest in studying reactions to stillbirth at Colorado General Hospital. The woman's uncomplicated pregnancy led to spontaneous labor at 42 weeks gestation. Upon rupture of the membrane, meconium stained fluid was noted. Twenty minutes later the fetus was said to have died. The woman and her husband continued after the death with a long, difficult labor. Both parents held the infant in the delivery room. The father cried and the mother went through the usual bonding behaviors described by Kennell and Klaus. At a later time, the couple were once again given the chance to hold the infant. At this point, the mother cried. The couple's perception of the event was said to have been one of sadness, love and support from one another as well as the staff.

Kowalksi and Bowes used this as well as past clinical experience and a review of the literature to generate suggestions for care of the women who experience stillbirth. Their suggestions will be included in my summary of interventions which will follow the review of the subsequent research studies.

Benfield (1978). Benfield (1978) interviewed and administered a grief response questionnaire to 50 mother-father pairs. The parents had experienced loss of neonate betwen 1974 and 1977 in an Akron, Ohio regional neonatal intensive care unit. The nature of participation was voluntary. The interviews occurred at the time in which parents chose to be scheduled for report of autopsy findings (11 to 97 days post infant death). Interviews came after the questionnaires but preceeded discussion of autopsy results.

The grief questionnaire was designed by Benfield and had two parts. The first seven-item Likert type scale was meant to measure the parents' grief response. The items were: feelings of sadness, loss of appetite, inability to sleep, increased irritability, preoccupation thinking about the baby, thinking one had done something to cause the baby's death (guilt), and feelings of anger. The scale read "was never a problem" (0) to "was a big problem" (3). The second half of the questionnaire asked for dichotomous answers to whether or not the parents' grief reaction involved the following: episodes of crying, praying for the baby, depression, disbelief, and wanting to be left alone. Reliability and validity concerns were not mentioned.

Results were analyzed using T tests, Chi-Square analysis, and Pearson product moment correlation coefficients where applicable. Findings were that the mean maternal grief score was significantly higher than the father's (p less than 0.0001). In 11 instances, the father's score exceeded the wife's. In two cases fathers denied experiencing any grief and their scores were zero. Unfortunately, Benfield did not publish the correlation between parent's scores,

however, he did provide a distribution graph (histogram) which illustrated a fairly strong positive relationship between the parent's grieving scores. Of the seven item-to-item comparisons of parents' interval measured grieving symptoms, only one showed a significant difference: significantly more mothers reported guilt (p less than 0.001). Likewise only one of the dichotomously measured grief symptoms was significantly different between parents: the mothers apparently cried more (p less than 0.005).

Grief scores were not significantly related to birth weight, duration of life, extent of parent-infant contact, previous perinatal loss, parental age, or distance from the hospital of birth to regional NICU. Paternal grief scores were related positively to pleasure with pregnancy (r = 0.28, p less than 0.02) and inversely to interval from death to autopsy discussion (r = -0.32, p less than .01).

A subsample of 18 families who elected to discontinue respiratory support for their infants were compared to the other 32 families. There were no significant differences between mother or father overall grief scores between groups. Significant differences were found between parents in the two groups on the following items: mothers in the subsample experienced less anger, irritability, and wanting to be left alone. The subsample fathers experienced less problems with sleeping, loss of appetite, irritability, crying and depression. Significance levels for the above findings ranged from p = less than 0.01 to p = less than 0.001 using Chi-Square analysis. There was only one case of pathological grieving reportedly found.

This was in a woman who was continuing with psychiatric care which began in early pregnancy.

Interview data revealed that the majority of parents felt anger and guilt. Criticism was directed at God and the physicians. Many parents expressed some form of disbelief. Frequently the families found themselves involved in awkward situations which were brought on by inappropriate actions of others (staff, family, and friends). Families also expressed concerns about finding a cause for the death, inappropriate advice of others, and fear of having somehow been involved in causing the death. Several families shared how painful it was to bring themselves to the office to discuss the autopsy results.

Benfield's study of parental reaction to neonatal death provides a very useful summary of some of the feelings parents experience in the case of loss of neonate.

Rowe, Clyman, Green, Mikkelsen, Haight and Ataide (1978). In a retrospective phone survey of 26 families who had experienced perinatal death, Rowe et al. (1978) found six cases of prolonged (12 to 20 month) grief reactions. The 26 families had experienced a perinatal loss (stillbirth at greater than 20 weeks gestation and neonatal death) between September, 1974 and September, 1975 at the University of California San Francisco Medical Center. Of the 26 mothers, 75 per cent were married, 30 per cent had had a previous abortion and 50 per cent were primigravidas.

Open-ended interviews were conducted by Rowe, a female physician, who had no previous contact with the families. Fifty per

cent (13) of the 26 mothers had become pregnant in the months prior to the interview. It was found that women who had no children were significantly more likely to be in this group (p less than 0.05, n = 11). Six of the 26 women were judged to have morbid grief reactions. The only factor the researchers could associate with this reaction was the presence of a new infant in the home. This finding is in keeping with the reports of others (Poznanski, 1972; Richardson, 1973; and Horowitz, 1978) that have found when a so-called "replacement child" is sought out too soon after the loss of a previous child, outcomes may involve delayed parental grief which may be quite severe upon final expression, idealization of the lost child which leaves "a hard act" for the replacement child to follow and possibly neglect or abuse of the replacement child.

Positive and negative sources of support included friends, religion, school or work, husbands and family. One woman sought professional counseling. The authors stated, "No mother mentioned a pediatrician, obstetrician, or other physician as a source of support and some were critical that their physicians had never contacted them about autopsy information" (p. 168).

Thirteen of the mothers received information about cause of the infant's death and risk of reoccurrence only during the hospitalization. They were never contacted again by a physician. The other half of the group received information both in the hospital and through physician follow-up (i.e., by phone or in person). Those mothers who had had contact with a physician following the death had a higher level of understanding about the cause of the infant's death and risk of reoccurrence than those mothers who just received

information during hospitalization. Only seven of the mothers were satisfied with the information they received. Of the nine women who were judged to have inadequate information, six were said to exhibit a morbid grief response. Of the 17 women who were said to be adequately informed and to have had no morbid grief response, 10 complained of some dissatisfaction with the information they received and the way they received it.

In summary, this study once again highlighted the inadequacy of health care providers in recognizing and meeting the needs of a woman who experiences perinatal loss. This study illustrates the need for re-evaluation of our assumptions which underly care of the grieving mother.

Helmrath and Steinitz (1978). The purpose of Helmrath and Steinitz' study was "to explore the events and personal interactions that helped or hindered the parents following their infant's death" (1978, p. 785). At the Edward W. Sparrow Hospital NICU, agreement to participate in the study was obtained from seven out of 10 couples who met the following criteria: 20 to 35 years of age, white middle-class, college educated, no serious marital problems, and a wanted pregnancy. Taped interviews were conducted at four to eight months post loss of infant. (All infants were live born and survived two hours to 21 days.) The semi-structured interviews done by the authors covered: 1) the couples' view of pregnancy, labor and delivery; 2) the events in NICU, particularly the death; 3) characteristics of the grief of both parents; 4) responses of family and friends; 5) relationship between the couple and how they helped

each other mourn; and 6) attitudes toward future pregnancies. The tapes were examined for common views and experiences.

All couples were inexperienced with loss and were surprised about their depth of feelings. All parents rated high on the Kennell scale previously described in this paper. There was no discernible difference in grief response based on presence or absence of a previous living child.

Men and women were said to grieve differently. The woman grieved longer and more acutely. The woman frequently complained of feeling cheated out of the chance to cuddle an infant. Each woman described a dire need to talk about the infant. None of the women were judged to have pathological grief. All women did feel some degree of responsibility for the death. Guilt was rampant. Men tended to resolve their guilt and self-blame sooner than the women. For each family, the opportunity to discuss autopsy data seemed to have abated some of their guilt. The fathers felt a need to be strong for the mothers especially right after the death. The fathers had held their infants prior to death and had positive feelings toward their babies.

All parents complained of extreme isolation. Typically, they were told "you're young, you can always have another one." Each couple expressed a need to talk about the loss and their grief. Three couples received no condolences. Each father found that people at work never acknowledged their tragedy. This "conspiracy of silence" was quite detrimental to all the couples. Typically the couples began to question the appropriateness of their own responses in the light of no external support or acknowledgement.

The acute grief phase was said to last approximately six months to a year with all couples being either past or close to the end of this stage. The biggest factor in this resolution was the support between spouses, although the incongruence of grieving patterns initially proved to be frustrating. For all couples, their relationship was said to have deepened as a result of the shared loss. Five couples even came to view the death as an opportunity for growth in their lives. Of the three couples who had children, all acknowledged a deepening in their appreciation of their children.

This study briefly summarized the common experiences of seven couples who experienced perinatal loss. Its findings are somewhat more optimistic than other studies (i.e., all marital couples deepened their relationships). This may well be due to the limited size of the sample and the "privileged" socio-economic picture of the participants.

Lewis and Page (1978). Lewis and Page (1978) presented a case study of a mother who failed to mourn the stillborn death of her son. She was referred to the researchers one year after the stillbirth because she was unable to care for her three and one-half month old daughter. A social worker who had seen the couple right after the stillbirth reported that other than some anger against the hospital, the couple appeared to be effectively dealing with their loss.

During the second pregnancy, the stillbirth was not discussed until two days prior to the daughter's birth. The mother's anticipatory terror of a repeat stillbirth changed to joy at the

birth of her daughter. Upon discharge, the woman's spirits once more swung low. She complained to her doctor and social worker of being suicidal, hating her baby, and fearing that she would abuse her new daughter. The pediatrician, fearing for the child's safety, had the baby admitted to the hospital and referred the family to Lewis and Page for counseling.

It was revealed in psychotherapy that the mother felt inadequate to handle her new daughter. Apparently the father's ease of parenting only served to enhance the mother's frustration. When asked about the stillbirth, the father, who had not been present during the birth-death, reported that he had cried briefly immediately after the loss and not since. He claimed to be through with mourning. The mother became quite upset (sobbing convulsively) as the therapists pursued a rather detailed line of questioning about the loss. Initially the father was upset with the forceful questioning, but eventually stated, "We're finally getting somewhere." The couple agreed to take their baby home after the first visit. Psychotherapy continued for six more weeks. The mother never opted to take the researchers up on their offer to call in between sessions as needed.

The follow-up sessions focused on the mother's feelings of inadequacy and resentment and the couples' related sexual difficulties. Progress was felt to have been made in the six-week course of therapy. During a follow-up visit 18 months later, the mother was able to freely discuss her feelings about the stillbirth and her previous failure to mourn it. She could not recall the depth

of her pain in the first session. Rather, she stated that her memory of it "felt right."

The replacement-child syndrome was discussed earlier in this literature review. This case study serves as a vivid example of the danger of rushing into pregnancy prior to the opportunity to adequately grieve the lost child. Implications for counseling are obvious when caring for a family that experiences perinatal loss.

Cohen, Zilkha, Middleton, and O'Donnohue (1978). Cohen et al. reported on their clinical experience at the Downstate-Kings County Hospital Medical Center perinatal mortality bereavement clinic which opened in 1974. The clinic involves a multi-disciplinary approach to follow up on women who experience perinatal loss. Teams consisting of a psychiatric resident or an obstetrician, a psychiatric nurse and a nurse-midwife met with parents during the mother's hospitalization and approximately one month later. The taped interviews focused on issues which surround the loss and grieving of the loss. A few of their experiences were shared in a 1978 publication.

Apparently since this hospital is in an economically depressed area, many of the couples end up allowing the hospital to handle the remains of their child. The authors stated: "During the course of the study we found that the question 'What have you done to my child?' was either the nidus of a mixed hostile/pleading diatribe, or more frequently lurked unvoiced, subtly coloring many of our interactions." This confusion of parents as to where the hospital disposed of their children's body was soon found to be an equal

source of confusion for most staff members. The staff had to piece together bits of information from multiple sources before they could finally become knowledgeable enough to provide families with this essential information.

The authors also reported on the evolution of the staff's policy regarding allowing the mother (and others) to have contact with their dead infants. Their present policy is simply for the nurses to offer all mothers the opportunity to touch or view their infant. Physicians have been minimally involved in this policy. Interestingly, the authors stated that of 17 mothers recently admitted to the center's psychiatric service, seven had not viewed their dead infant.

This article pointed out an important, often overlooked concern that is the need for staff to be aware of and to share with the parents just what it means to have the hospital or the county "dispose" of the infantile corpse. Unfortunately, this article is somewhat poorly written. "The study" referred to throughout is never fully described and the statistical data which refer to the viewing/holding of the infant are incomplete and confusing.

clarke and Williams (1979). Clarke and Williams (1979) shared the preliminary findings of a sub-study of a larger investigation of perinatal mortality in Leicestershire, England. Two groups of over 300 women each were asked to complete a Beck Depression inventory scale at 48 hours, six weeks, and six months postpartum. The purpose of the study was to investigate if there was a difference in prevalence of depression between women who had

experienced live birth and those women whose babies were stillborn or died before seven days of life.

Concurrent criterion validity was established by having all women whose Beck score was greater than 15 at six months and an equal number of women whose scores were less than 15 at six months seen by a psychiatrist and assessed on the Hamilton rating scale. A rank order correlation of 0.67 was established using Kendall's tau. No further reliability or validity data were mentioned. A Beck score of 17 or above was used to indicate moderate depression.

The results were reported as: 1) at all three time measurements, about four per cent of the women who had live births were moderately depressed; 2) among women whose infants died, 20 per cent were depressed at two days and 13 per cent at six weeks and six months; 3) when data were broken down by age, there were no differences in prevalence of depression between age groups in the perinatal loss group; but, 4) an age effect did show up in the live birth groups with younger women being more depressed than older women; 5) young women who had live births were as depressed six months postpartum as were those whose babies died perinatally; 6) prevalence of depression at six months was significantly higher in older women (24 years and over) whose babies died than in older women whose babies lived (p less than 0.001); 7) the overall difference in relationship between birth outcome and depression at six months was significant with the perinatal loss group being more depressed (p less than 0.025 but greater than 0.01); and, 8) the highest six-month mean postpartum depression score was exhibited by the women who were less than 19 years of age and who had experienced a live birth.

These findings are useful in identifying populations at risk for depression in the postpartum period. The young and those who experience perinatal loss appear to be the most vulnerable.

Peppers and Knapp (1980, 1979, 1980). Peppers and Knapp published a book in 1980 entitled Motherhood and Mourning. It was reportedly written based on data gathered from interviews with 42 women contacted through AMEND (Aid to Mothers Experiencing Neonatal Death) and hundreds of lengthy letters, questionnaires and interviews with women who volunteered to be in the study. The women had all experienced fetal/infant loss through miscarriage, stillbirth or neonatal death. There were no limitations placed on length of time since loss which may serve to obscure some of the findings. Also, the voluntary nature of the sample selection and the fact that many of the participants were contacted through AMEND may tend to make the findings not representative of all women who experience perinatal loss.

Peppers and Knapp drew seven major conclusions from their study. The first finding was that all women mourned regardless of their loss although the expression of grief differed with type of loss. Generally women who miscarried tended to grieve for shorter lengths of time, but just as intensely. Also, feelings of guilt and failure strongly characterized the miscarriage group.

The second finding was that every woman had an acute, vivid remembrance of the details of the events surrounding their loss. Thirdly, the women shared the fact that communication channels were closed to them. People were not open to talking with the women about

their loss. Related to this was the fourth finding that breakdown in communication between spouses led to marital strain. This breakdown tended to be due to the incongruent grieving patterns between husbands and wives.

A fifth finding which was reported on earlier by the authors (Knapp and Peppers, 1979) was that many women had unsatisfactory relationships with their physicians. Apparently, few doctors expressed much concern about the loss these families experienced and of the few who did attempt consolation, they often fell into the trap of saying the wrong things. Many of the women switched physicians as a result of their dissatisfaction. A sixth problem was that many mothers' stories demonstrated that unyielding hospital staff and inflexible rules often hindered the resolution of grief.

Peppers and Knapp's final conclusion was that total resolution of grief surrounding perinatal loss may never occur. They claim "portions of it will always remain tucked away appearing from time to time when they least expect it. We believe that 'shadow grief' as we call it is that 'something' these mothers speak of, a burden that most of them will bear the rest of their lives" (Peppers and Knapp, 1980, p. 47). Shadow grief is hypothesized to be due to two factors: 1) the mother desires to never let go of the loss, she wishes to remember; and 2) the general inability of the mother to find legitimate avenues for expression of her grief leads her to believe that if she doesn't remember no one else will. The mother's task is to keep alive a memory of her child.

In another study by Peppers and Knapp (1980), a convenience sample of 65 women who experienced "involuntary fetal/infant death"

(miscarriage, stillbirth, or neonatal death by the self-report of the mother) were asked to complete a questionnaire. The measure had three parts: socio-demographic data, data related to the loss itself and an expanded (15-item) version of Kennell and associates' grief scale. This scale, as described and critiqued earlier, was based on Lindemann's descriptions of acute grieving symptoms. A drawback to this study is that range of time from loss to study participation ranged from six months to 36 years with a mean of 8.1 years. Needless to say, time may have colored the responses. The women were asked to respond to the grief scale twice. First, as they remembered feeling at the time of their loss, and again as they felt at the time of study participation. An analysis of variance (ANOVA) demonstrated significant difference in the two mean grief scores between/amongst the three losses (miscarriage, stillbirth and neonatal death). When two-way ANOVAs with the background variables were run, only two were reported as approaching (p = ?) statistical significance: where subsequent children had been born (less intense reaction) and when previous complications in pregnancy had been experienced (more intense grief reaction).

A strong point of this study was that Peppers and Knapp are to be credited for their sensitivity in going past the prevalent assumption that mother-infant attachment did not occur prior to fetal movement having been felt. Their attempt to seek out evidence of early maternal attachment is to be credited. They claim to have simultaneously collected interview data. It will be interesting to see them expand on their findings. In spite of the fact that the report of intensity of grieving symptoms may not have been

significantly different, one cannot help but wonder about the different routes (experiences) the women took towards their intense grieving.

Stringham, Riley, and Ross (1982). Stringham et al. (1982) interviewed a convenience sample of 20 women who had experienced stillbirth six months to 10 years prior to the study. The semi-structured interviews lasted two hours and took place in the subject's homes. The purpose of the study was to have the women describe their stillbirth experience. Subjects were white, married, and 23 to 35 years of age at the time of stillbirth. At the time of the interview, 10 had had successful subsequent pregnancies, seven were trying to conceive, four of which complained of infertility.

All 20 women reported they were devastated by news of their baby's death. Other concerns of the women were the uncaring manner in which they were handled, the tragedy of carrying a dead baby and the silence in the delivery room. Eleven of the women reported they were never offered the opportunity to see or touch the infant. Some of these women were afraid to ask for fear of being judged crazy. Of the 11 who did have contact with their infant, all were glad to have done so. Of the nine who did not touch/see their babies, four regretted it, four were satisfied with their decision, and one still seemed unclear.

Sixteen autopsies were performed. Two couples had requested it and one of these was refused. Those who knew their autopsy results reported that the infants were normal, this was reassuring to most couples although some were angry that their normal infant could

not have been saved. More than half the families arranged their own burials and most of these families were satisfied with the funeral. Of those who had a hospital arranged burial, most were dissatisfied. Five couples did not know where their babies were buried. The need to be involved in decisions around the burial were reported as important by many couples.

Nearly all the families remembered their anniversary birth dates, however, those whose babies died in-utero tended to refer to the day the fetus died as the anniversary date. Other reminders of the baby included date of conception, a drive past the hospital, and other children the same age as their child would have been. Several families shared with Stringham et al. their Memory Box which included such things as the hospital record, death certificate, autopsy report, photographs, footprints, newspaper announcement, and sympathy cards and letters. One woman reported having thrown away her cards when she thought she had resolved her loss and how much she later regretted it.

Many of the women reported grief symptoms (as described by Lindemann). For most women, these lasted from six months to a year, although, some stated it lasted longer. Some women complained of having been expected to be back to normal far too quickly, in some cases within a month. When asked what aided their resolving the loss, women listed birth of subsequent children, spousal and family support, self-help groups, own inner strength, religion, professional help, and time having passed. Five of seven women who sought psychotherapy reported it as useful.

In comparing stillbirth to other losses, many of the women complained of the loneliness and isolation of their grieving. Another complaint was of the seeming injustice of stillbirth. Lastly, the women stated that with stillbirth, the grieving was due to what might have been versus what already was.

Harmon, Glicken and Siegel (in press). Harmon et al. interviewed 38 women whose infants had died in the regional NICU at Denver's Childrens Hospital between late 1979 and early 1980. Nineteen of the mothers experienced neonatal loss prior to the onset of a hospice program. The other 19 losses occurred post-hospice. Phone interviews of all mothers were conducted at three and nine months post loss by health professionals who had no previous contact with the families. Descriptive data of nine grieving symptoms in the combined sample of 38 indicated that grief work took place with symptomatology being higher at three months than at nine months. Additional findings indicated that for most of the sample, the husband was identified as the most supportive person throughout the grieving period with 55 per cent of the mothers reporting a closer relationship with spouse at nine months. Similarly 65 per cent reported a deepening of their relationship with their children. A few (29 per cent) even reported a deepening of relationship with their extended family. An additional finding of this study was that half of the mothers reported mild to severe financial difficulties post-loss. This very important finding has been overlooked in many of the studies which preceded this one.

In this and a previous article (Whitfield et al., 1982), findings related to outcome of hospice intervention were shared. Hospice intervention involved staff training in caring for families experiencing neonatal loss <u>and</u> the implementation of an off unit home-like atmosphere family room. The family room was available to families and staff to be used in private intimate encounters with the dying infants. It is interesting to note that of the first 103 post-hospice deaths, in 67 per cent of the deaths, the family room was used by family and staff. An additional finding was that post-hospice there was a greater willingness of families to participate in follow-up care (Whitfield et al., 1982).

In the pre vs. post-hospice study (Harmon et al., in press) significant differences were found between the two groups of 19 each on a variety of measures at nine months. The post-hospice group experienced less sleep disturbance and less irritability. More of the post-hospice group found their husbands helpful and more wanted to get pregnant again (100 per cent). The staff also experienced some change as a result of hospice participation. This was indicated by a greater tendency to contact families with autopsy information and to speak to the families about burial. Both of these interventions were deemed helpful by the mothers. (Significance levels ranged from less than 0.01 to less than 0.06).

Three additional findings shared by the authors were: 1) 73 per cent of the total sample of 38 expected the death of their child. This indicates that parents may be more ready to discuss impending neonatal death than we typically realize; 2) of the total sample, 73 per cent of the parents received photographs; all of the remainder

who did not receive a photograph wished they had; and 3) only 11 per cent of this sample opted for a hospital burial. This may reflect the staff's emphasis on the importance of a family-planned burial.

This study of Harmon et al. is to be valued for a number of reasons: 1) it provides data on maternal grieving post loss at three and nine months; 2) it is one of the few pre versus post-intervention studies on neonatal loss available to date; and 3) along with the 1982 article (Whitfield, et al.), it describes a promising intervention strategy to be used in caring for families who experience neonatal death.

# Summary of Clinical Articles

In order to summarize the multiple clinical-based articles, this section of the paper will mainly consist of tables. The tables will summarize the major categories which the perinatal loss authors promote as being essential to four separate topics around which I have chosen to center this review. The four topics are:

- Signs, symptoms, and personal experiences associated with the grieving of perinatal loss;
- Caring needs of the woman who experiences perinatal loss;
- Feelings, reactions and caring needs of health care providers; and
- Suggested care strategies for assisting the woman in her adjustment to perinatal loss.

Clinical-based articles are those categories of articles (and/or books) which I have so named in order to differentiate them from the more research-oriented articles. This is certainly not a dichotomous categorization. One could clearly argue my placement of case studies or retrospective studies of clinical data in the previous research section.

My choice of topics and method of categorization within topic were arrived at by my having read multiple perinatal loss articles and clearly recognizing a tremendous amount of repetition. In some ways one could compare my method of literature categorization to the Grounded Theory Methodology which underlies part of this study. Each article reviewed may be considered as a "case" to be sampled. Each sampled case was compared with all previous cases sampled. Every case was examined for similarities to and differences from the previous cases. I read to the point of saturation (until I seemed to be reading nothing new). I knew then it was time to stop "sampling cases of literature." It was at that point I returned to my voluminous notes and began to look for major topics and commonalities (categories) within topics. The products/tables which emerged are presented on the following pages.

The articles/books which were reviewed for these tables are: Bourne, 1972; Hildebrand and Schreiner, 1980; Hagan, 1974; Kennell, Slyter, and Klaus, 1970; Kennel and Trause, 1978; Kennell and Klaus, 1971; Klaus and Kennell, 1982; Peppers and Knapp, 1980; Scupholme, 1976; Seitz and Warrick, 1974; Wilson and Soule, 1981; Yates, 1972; Cohen et al., 1978; Dunlop, 1979; Elliot, 1978; Elliot and Hein, 1978; Grubb, 1975, 1976; Helmrath and Steinitz, 1978; Jensen and

Zahourek, 1972; Johnson, 1972; Kellner et al., 1981; Kowalski, 1980; Kowalski and Bowes, 1976; Lewis, E., 1971, 1976, 1979; Lewis, H., 1980; Speck and Kennell, 1980; Zahourek and Jensen, 1973; Bruce, 1962; Kirkley-Best and Kellner, 1982; Saylor, 1977; Stringham et al., 1982; Phipps, 1981.

### TABLE 1

# Signs, Symptoms, and Personal Experiences With the Grieving of Perinatal Loss

## Self Doubt/Blaming

Feeling contaminated
Fear of having caused death (i.e., through intercourse)
Fear of fantasies or previous negative thoughts having caused death
Seeing body as defective machine
Failure as a woman
Looking for a cause in ones own behavior
Blaming God, doctor, husband
Hating one's body
Loss of body-self

### The Missing Person/Death

Void inside and out Emptiness in arms and womb Feeling the baby moving, hearing the baby crying "I felt I had created death" There was no proof she ever existed The need to include dead infant when asked "How many children do you have?" There exists a fear of forgetting about the baby "I feel as though I'm still pregnant" Frequently mourning is prolonged if the infant was never seen or touched An intense frantic need to have another baby Painful anniversary dates Fearing the death within is killing the woman Inability to separate self from the dead infant A loss of what might have been Many women touch their dead infants in the typical bonding pattern

### Emotions/Feelings/Meanings

"I thought I was going mad"
Anger, irritability
Guilt
It all feels unreal
Why did this happen to me?
Some couples feel loss of newborn is worse than loss of older child
or adult
Turning inward/unable to give
I close my eyes and relive the whole thing
Sleep disturbances
Fearing the future

# Table 1 (Continued)

# Emotions/Feelings/Meanings (Continued)

"I fear that I can't keep myself from taking one of the other babies" Occasionally there are painful reminders A need to hide in shame

"I can't escape the pain when I'm home alone"

# Isolation/Reactions of Others

Avoided by others who do not know what to say, who fear contamination, and who desire to protect themselves from the loss Avoiding others (due to shame, guilt) Anger at those who make distancing comments "You're young, you can always have another" "At least it didn't live longer so you could get closer" Irritability/anger with actions of others Appreciate efforts of others to be helpful Some women turn their nurturance needs into protecting others (i.e., staff) from the mother's pain Avoiding others so as not to harm them too Strong envy of other women

## Timing

The pain is worst in the first two months Anxiety no longer at a high level after 7 to 9 months Laughing for the first time at nine months Some women never get over it: shadow grief Most women near resolution in 12 months

### Sharing the Grief

Insistent need to talk over and over again about the loss Sometimes the father holds back The father feels a need to be strong for the mother Incongruent grieving patterns Other parents who have had perinatal deaths understand

## Inability to Give

Turning inward Unable to care for the children or house Refusal to ever have another child Incapacity to support each other's grieving needs

## Table 1 (Continued)

# Signs of Resolution

A desire to help others
Some women say losing the baby gave more meaning to life
A closer relationship to spouse
Ability to discuss and feel loss with the children
Enjoyment of the family
Ability to make new friendships
Ability to accept a new pregnancy without mourning the previous one
To be able to dismantle the nursery with tears, but not great anguish
Ability to nurture another child without being over-protective

## Pathological Outcomes

Chronic grief (depression, inability to relate to others)
Absent grief (signs and symptoms of grief not exhibited, but
debilitating physical, emotional health may ensue)
Delayed grief (Typically will show up in future less meaningful lossor in the case of replacement child, an inability to parent the
new offspring)

TABLE 2

Caring Needs of the Woman
Who Experiences Perinatal Loss

Focus	Caring Need	Manifestation/Wants	
n the Hospital and To Be Recognized fo Follow-Up Care For Individual Want Needs			
	To Be Heard	I did not want to talk about the baby specifically, but I did want to talk To be heard, understood	
	To Receive Understanding/ Empathy	Need staff to all be informed of the loss Need staff to not be abrupt Not to be given reasons, rather to receive understanding "All I wanted to know was that someone at the hospital was interested in me" "I guess I see the hospital as a place to cry. Once I get cried out, I can go home and face things more realistically" To be given empathy/understanding Desires caring/concern	
	Information Needs	Reassurance that past deeds did not cause the death That emotions, feelings are normal part of grieving To be given the chance to ask	

Table 2 (Continued)

Focus	Caring Need	Manifestation/Wants
_	Information Needs (Continued)	To be told what to expect (grieving) Repeating of information Need to be told what is happening as it happens "Recovery would have been easier if I'd known why the baby died." Need to hear autopsy results as soon as possible from the doctor
The Baby	To Have Birth/Child Validated	To have named the baby To touch the baby To see the baby To care for the infant Desire to hold/cuddle Regretted having never held the baby Need to know what the infant looked like Need to have the baby baptized Need to have the baby baptized Need to have their labor/birth recognized as real Need to include dead child in number of children when asked, "How many children do you have?"
	To Have Death/Loss Validated	Most mothers desired to be included in funeral plans To have the dead twin mourned

Table 2 (Continued)

<u>Focus</u>	<u>Caring Need</u> Need For Information	Manifestation/Wants  Help needed with deciding what to do with the baby's things (i.e., nursery) Why the baby died/cause
Others	To Have the Death/ Loss Validated	Need to share the grief with spouse/family Need for others to realize their loss Need to talk, share the loss
	To Be Heard	Need to be encouraged to talk Need a sympathetic ear
	To Be Recognized For Individual Wants/Needs	Need for physical/emotional help Need for others to help the first few days home To be allowed to cry – just to get it all out
	To Receive Understanding/ Empathy	Hate to hear, "Try again, you're young" Anger at those who say it was better to not have a defective child Hate for others to remind them they should be grateful for their other children
	To Have Birth/Child Validated	Appreciative when others said the baby could never be replaced

Table 2 (Continued)

Focus	<u>Caring Need</u>	<u>Manifestation/Wants</u>	
	Need For Information	How to tell the children and help the children grieve How to tell others	
Subsequent Pregnancies	To Have Death/Loss Validated	Need to have previous loss recognized	
	To Receive Understanding/ Empathy	Need for emotional support Need for reassurance of progress	
	Need For Information	Genetic counseling Need to know chances of recurrence of loss	

 $\label{eq:TABLE 3}$  Feelings, Reactions, and Caring Needs of Health Care Providers

Feelings	Reactions	Caring Need
Threatened	Inability to admit own limitations Abruptness, anger, avoidance	To receive understanding/ empathy
Useless, Inadequate	Generate technological explanations so as to be able to do something Make meaningless admonishments (i.e., "There is another little angel in heaven now.") Quickly erase details of the birth	Information needs To be recognized for individual wants/ needs
Anxiety About Sharing The News of Death/Or Discussing the Loss	"Passing the buck" Offering terse, inadequate explanations Making flip comments Body language that conveys "Don't you dare cry, or ask me anything else." A "conspiracy of silence"	To be heard (professional, peer support) Information needs To receive understanding/ empathy
Fear of Being Emotional	Avoidance Channeling energy into "tasks" (i.e., making the bed) Telling the woman, "Be strong, chin up!" Acting busy, keeping busy Control mother's emotions through medications Shift attention to another less-likely- to-fail patient	To be recognized for individual wants/needs To receive understanding/empathy To have death/loss validated

Table 3 (Continued)

Feelings	Reactions	Caring Need
Defeated, Guilt	"Burnout" - Change Jobs Withdraw into self Show anger at the woman, God, other staff members Physical distress: diarrhea, headaches, etc. Conveying to the woman that she is the source of defeat	To be heard (professional, peer support) To receive understanding/ empathy
Uncomfortable	Refuse to allow woman to choose how she wishes to be cared for Making decisions which cause the provider less pain (i.e., early discharge of mother) Overly sedating the mother Promptly call in psych consultant for mother (passing the buck) Conspiracy of silence Separating mother and infant	To have birth/child validated To have death/loss validated To receive understanding/ empathy
Revolted by the Whole Event	Avoidance Tendency to judge the woman's behavior as bizarre, gross Removing self from the whole affair as rapidly as possible Attempts to dissociate self from the woman/infant/death	To be heard (professional, peer support) To be recognized for individual wants/needs

Table 3 (Continued)

Caring Need		To receive empathy/ understanding To have birth/child validated To be recognized for individual wants/needs Information needs To have the death/loss validated	To receive empathy/ understanding To be heard (professional, peer support) To be recognized for individual wants/needs
Reactions	Showing open revulsion at the woman's behavior Make jokes	Crying with the family Crying with the family Sharing the defeat/loss Sharing the defeat/loss Sharing the defeat/loss Anticipating the woman's needs Anticipating the woman's needs Allowing the woman to genuinely feel her emotions Realize the need to support other staff members Provide empstby-training opportunities for junior staff members	Ability to allow others (woman) to express their meeds Able/willingness to handle anger, complaints of family Know own limits, know when to seek help for others and self
Feelings	Revolted by the Whole Event (Continued)	Empathetic, Genuine	Confident With Self

TABLE 4

## Suggested Care Strategies for Assisting The Woman In Her Adjustment to Perinatal Loss

- I. Schedule of planned visits/optimally for husband and wife
  - A. Perinatal loss team
    - Obstetrician/pediatrician
    - 2. Midwife
    - Psychiatric nurse
    - 4. Social worker
    - 5. Spiritual counselor
  - B. Protocol for visits with some/all team members
    - 1. Immediately
      - a. Inform family of death (obstetrician/midwife or pediatrician)
      - b. Offer any information available
      - c. Offer chance to see/hold infant (reoffer p.r.n.)
      - d. Brief explanation of grieving
    - 2. Upon discharge
      - a. Offer any information available

      - Brief explanation of grieving
         Anticipate needs of woman at home (i.e., other children, informing others of loss, physical care needs)
      - d. Leave phone number of staff with family
    - 3. Ten days
      - a. Monitor grieving
      - b. Support
      - Share autopsy results if possible
      - d. Discuss contraception/caution against early pregnancy
    - 4. Six weeks
      - a. Continue to monitor grieving
      - b. Appraise need for psych consultant
      - c. Check on home life

- 5. Six months and one year
  - a. Continue to monitor grieving
  - b. Check on home life
  - c. Discuss plans for future
  - d. Psych consult p.r.n.
- II. Goals of caring (goals described by Phipps, 1981)
  - A. Making death a reality/forcing the non-event into an event
    - Give honest answers; provide facts; repeat facts; keep the family informed of events as they occur
    - Offer the infant to the parents as soon as possible; hold the infant on the delivery floor as long as possible; offer the infant more than once/allow the couple to decide.
    - When culturally acceptable, take a photograph of the infant, even if parents do not wish to have it immediately; years later, they may
    - Allow the mother to care for her infant as she desires (i.e., bathing, diapering, etc.)
    - 5. Encourage the parents to name the baby
    - If at all possible, encourage the family to hold some sort of memorial service for the dead infant
    - If the hospital handles the burial, keep parents informed of what this entails
    - 8. Encourage the family to delay the memorial service until the wife can participate
    - Offer condolences, sympathy, acknowledge that there has been a death
    - Allow the woman to describe/discuss her labor/delivery; acknowledge that there was a birth
    - Help the family make a memory box; fill it with the infant's bracelet, footprints, photograph; letters of condolences; death certificate; autopsy results
    - If possible, meet with grandparents, other family members for the purpose of providing information, offering counsel

- Be sensitive in timing when asking for permission for autopsy
- 14. Share autopsy results as soon as possible
- 15. Avoid tranquilizers and oversedation; the woman needs to fee!
- 16. Be with the couple as they sign the death certificate
- B. Anticipatory guidance
  - 1. Tell the family about the grieving process
  - Warn that there will be days you will worry about your sanity or losing control
  - Remind couples to work at sharing the loss; warn about incongruent grieving
  - 4. Prepare the couple for others/how to handle
    - a. Uncaring remarks
    - b. Informing others of the death
    - c. Seeing/being with other mothers/other babies
    - Running into people who don't know of the death and ask about the baby
    - e. Receiving in the mail unsolicited "free new baby stuff"
  - 5. Utilize visiting nursing services p.r.n.
  - Encourage the family to get help as needed in the early days at home (i.e., watching the other children)
  - When families don't make it to follow-up visits, try to contact them (calls, social worker)
  - Discuss with the couple how they plan to handle returning to work/school
  - Plan with the women the dismantling of the nursery, the putting away of maternity clothes
  - 10. Allowing/encouraging the children to grieve
  - Discuss how to deal with the isolation/trying to get back out again
  - 12. Caution about becoming pregnant too soon

- 13. If pregnant again
  - a. Warn about replacement child problems
  - Anticipate the woman's needs for reassurance; see more often as needed
  - c. Ask the woman if she has any fears or needs to discuss her last pregnancy
- C. Acknowledge parental feelings and assure that feelings are normal
  - 1. Encourage expression of feelings
  - 2. Validate that the intenseness of their pain is real
  - 3. Suggest parental support groups
  - If possible, put couple in contact with another couple who have shared the same loss
  - 5. Warn parents of shifting of emotions
  - 6. Assure that time will someday heal
  - Warn that even when life seems back to normal that there may still be unexpected painful reminders
  - Be real; share your feelings; do not wear professional armor
- D. Observe that normal grief reactions are carried through
  - Encourage the family to share their feelings with the health care provider
  - Ask about occurrence of specific feelings/behaviors that are known to be a part of normal grieving
  - 3. Inquire about specific family members and their behavior
  - Be suspicious of too rapid or too prolonged progress; make psych referral if necesary
  - 5. Ask about family interactions
  - Ask parents to tell about their ability to re-enter the social-world (i.e., ask about activities, work, outings, etc.)

- E. Meet the specific needs of individual patients
  - 1. Ask the couple what they would like from the staff
  - Include the couple in decisions about care (i.e., need for more follow-up care)
  - 3. Facilitate cultural differences in mourning behaviors
  - Do not force on parents that which they do not want (i.e., autopsy, autopsy results)
  - 5. Relax visiting rules/allow the husband to room in

## Spontaneous Abortion

This section of the literature review will be considerably briefer than the previous two due to the fact that there is such a scant amount of literature available on the human experience of miscarriage. The caring needs of the woman who miscarries will not be addressed since I could not find any studies which addressed this topic. I will begin by very briefly addressing some of the literature related to the cause of miscarriage. This will be followed by a critique of four research articles, a brief review of four books which have been recently written on loss in pregnancy and which address miscarriage, and lastly, a summary of the pilot study for this dissertation.

## Causation

The late 50's and early 60's were characterized by multiple studies which attempted to isolate (and treat) the noxious stimuli. Spontaneous abortions were causally linked to vitamin, bismuth, or hormonal deficiencies, malposition or incapacity of the uterus, incompetency of the cervix, blood group incompatibilities and more. Curiously, while most the studies reported successful subsequent pregnancy rates of up to 75 per cent with previous habitual aborters, few of the studies were able to be replicated. It was concluded that the only commonality to each of these cures was the caregivers' belief in their own strategy. Hence, many began to suggest an underlying psychological basis to miscarriage. As is typical with so many gynecological problems, this suggestion was followed by a rash

of attempts to link miscarriage to emotional factors (i.e., rejection of motherhood, a poor relationship with the woman's mother, or her weak father) and to treat the habitual aborter with intense psychotherapy in order to bring her to term (Weil and Tupper, 1960; Grim, 1962; Clyne, 1967; Rothman, 1973; Michel-Wolfrom, 1968; and Hertz, 1973). Again, these psychotherapeutic studies claimed success rates as high as 80 per cent.

More recently, studies have been done to link spontaneous abortion to cigarette smoking, diabetes, thyroid malfunctioning, and possibly even previous induced abortions. (Himmelberger et al., 1978; "Digest" in Family Planning Perspectives, 1981; and Pizer and Palinski, 1980). The present state of the art is to focus on possible genetic defects and on an immunologic blocking agent as potential causes of early spontaneous abortions, and consideration of structural fetal/maternal incompatibilities as the stimulus for late spontaneous abortions. Pizer and Palinski report that increasing age has also been linked to a rise in the incidence of miscarriage: whereas 41 per cent of the pregnancies in 42-year olds end in miscarriage, only 12 per cent of the 20-year old women will not go to term. They also report that a woman with a history of one spontaneous abortion has the same 20 per cent chance of a subsequent abortion as the rest of the population. It is only after two spontaneous abortions that her chances increase to 33 per cent. and after three abortions to 50 per cent. It is generally advised that after two spontaneous abortions, a couple seek genetic counseling as well as thorough physical examinations to rule out a few of the more highly suspect causes of spontaneous abortion (i.e., incompetent cervix, possibly some viral strains) and to evaluate the health practices of the couple.

Simon, Rothman, Goff and Santuria (1969). Simon et al. compared 46 women who experienced spontaneous abortion (SAB) to 32 women who underwent therapeutic abortion for the reasons of medical illness, psychiatric illness or possible fetal damage. Two-thirds of the therapeutic (TAB) group had diagnosable psychiatric illness prior to the time they came for abortion. Given this preponderance of psychiatric illness in the TAB group and the fact that the TAB group was prospectively studied (1955 to 1963) while the SAB group was retrospectively studied, it seems a waste of time to compare the findings of the two groups. Therefore, this review will focus only on the discussion of findings in the SAB group.

The first five women who were hospitalized for spontaneous abortion in December of 1955, 1957, 1959, 1961 and 1963 were selected to be interviewed about their miscarriage (the years were chosen to match the TAB group - why December was chosen was not reported). Thirty-two women agreed to participate. They were asked to complete a battery of questionnaires and psychological tests (MMPI and Loevinger Family Problems Scale) and to agree to a one to two-hour semi-structured interview.

It is not clearly indicated when this retrospective study took place. It would appear that the women would have miscarried somewhere between six and 13 years prior to the study. At the time of follow-up, 15 women were diagnosed as having neurotic reactions, five as having personality trait disturbances, and 12 as having no

psychiatric diagnosis. What these diagnosis mean and their etiologies are unclear. Thirteen women reported depressed feelings at the time of the abortion. In most cases, depression began at the time miscarriage was suspected. Nine remembered being disappointed, six remembered being relieved or glad, two felt both disappointment and relief, and it was said that the last two women could not be categorized. Eight of the 13 who reported depression connected with the loss had diagnosable psychiatric illness at follow-up. Depression was said to have been more common in those whose pregnancies had been planned.

Twenty-five (78 per cent) reported either very little or no guilt related to the spontaneous abortion. The other seven were said to have guilt for quite a few months after their loss. Thirty-one women completed the depression scale on the MMPI; when compared to a large normal population group from another study, no significant difference in depression scores were found (N.B. this was a measure of the SAB's group six to 13 years after their loss). There was a significant difference in the PD scale (trends toward psychopathology and acting out behavior) between the normative and the SAB group. The SAB score was higher (p = 0.001). The MF scale measures concerns related to the sexual role. A high score indicates "trends toward resolving conflicts about sexuality by exaggeration of typical 'feminine attitudes'" (p. 108). The SAB groups mean MF score was higher than the normative group's at the p = 0.05 level.

Thirty-one women completed the attitude toward feminine biological role scale which is part of the Loevinger Family Problems

Test. This subscale measures attitudes toward feminine functions

(i.e., nurturing, child bearing). Ten women (32 per cent) had scores which indicated rejection of the feminine role. The rest were said to be within normal range.

The meaningfulness of this study seems pretty low. Criteria used for diagnosis are unclear. There was quite a gap between time of loss and time of interview; and, most pointedly, given the amount of time between loss and completion of psychological scales, one can't help but ask how the authors ever hoped to link the measure outcomes to the spontaneous abortion. History, maturation, selection, and, I would suspect, "effect of experimenter" (i.e., in terms of diagnosis of psychological disturbances at time of follow-up) were fairly large threats to the validity of the study.

corney and Horton (1974). Corney and Horton reported on a case study of a 23-year old married woman "who developed acute, disturbing symptoms several months after a spontaneous abortion" (1974, p. 825). She was referred to an outpatient psychiatric facility by her husband, a graduate student. The woman complained of recent, uncontrolable bouts of crying and feeling like there had been a death in the family. Additional symptoms were irritability, anxiety, and anger. Just prior to admission two possible suicide attempts occurred. The woman had no psychiatric history and an obstetrical history of one live birth (18-month old child) and one spontaneous abortion at four and one-half months gestation (four months prior to admission). Although the latter pregnancy was unplanned, the woman had grown to be quite pleased with it. Neither the woman nor her husband had connected the fetal loss with the

depression. The woman was said to have no signs of clinical depression.

During the interview, the woman herself connected her feelings with her loss. She relayed having been out of town and away from her husband and obstetrician when the loss occurred. She had held back on her feelings in the hospital for fear of being judged immature. Upon discharge, she was said to have appeared her usual vivacious, cheerful self. Some of the facade was apparently for her husband's benefit since he had not been too enamored with the pregnancy all along.

The woman was seen by the authors for eight more sessions. The delayed grief work was able to reach resolution with assistance and time. The authors labeled this as a case of morbid grief as it was characterized by a history of ambivalence toward the pregnancy, a sudden, unexpected death (the spontaneous abortion), external events which inhibited the expression of grief, an absence of mourning at the expected time, and a lack of public recognition of loss (i.e., burial rite of fetus).

<u>Seibel and Graves (1980).</u> Seibel and Graves (1980) had 93 female patients complete a self-administered questionnaire while in the recovery room following a D & C for an incomplete spontaneous abortion. In addition, a brief emotional-status inventory modeled after the Multiple Affect Adjective Checklist (MAACL) was included. The MAACL was specifically developed to measure immediate feelings of anxiety, depression, and hostility. The questionnaire surveyed such variables as why the client thought she miscarried, her past

pregnancies and medical or psychiatric histories, father's disappointment, if the pregnancy was planned, desire for more children, and the woman's desire for a hospital roommate.

Two-thirds of their sample were not married at the time of the survey and 72 per cent of the pregnancies were unplanned. Various reasons offered for the miscarriage by the women were: a medical problem, trauma and nervousness, sexual intercourse, the father's actions, lifting heavy objects, and something they personally did. Some feared that the miscarriage would lead to an inability to bear children, while others feared it would interfere with their capacity to enjoy sex. Twelve per cent of the sample said they were very, very happy, 32 per cent were neither happy or unhappy, and 44 per cent reported that they were unhappy, very unhappy. Twenty-nine per cent checked affect words that were generally positive; 53 per cent checked the words pertaining to depression; 51 per cent checked the anxiety words; and 41 per cent checked the hostility words.

This study is valuable for its efforts to describe miscarriage as an affect-laden experience that is individually defined by the woman who spontaneously aborts. However, given the fact that data were collected in the recovery room, one has to question if the findings are more representative of the woman's reaction to surgery and anesthesia than her actual feelings about miscarriage.

<u>Stack (1980).</u> Stack (1980) shared five brief case studies of women that he had known. Case number one involved a 30-year old woman whose miscarriage had not been mourned and whose health was deteriorating. Although she continued to function, anger and resentment were building. "She acknowledged an unfulfilled need to be comforted and to be allowed to assume the role of a grieving person" (p. 99). When therapy assisted grief work was finally done, her health subsequently improved.

In case number two, a 52-year old nurse was seen turning away from a friend in the emergency room who was admitted for dilatation and curettage for an incomplete abortion. The nurse had suffered a miscarriage 10 years previously and had to admit that she still grieved when reminded of her loss (i.e., anniversaries or when observing her friend's loss).

In the third case, a 48-year old woman spoke of her miscarriage which occurred 10 years previous. The woman remembered having bled heavily and having refused to stay in bed. Her denial at the time of miscarriage expressed itself in a subsequent sore throat and fear of throat cancer. Her physician said she was having a neurotic reaction. Her husband told her talking about it would not help. The woman remembered every detail of the event and complained of having felt angry and helpless.

A 50-year old psychologist relayed her experiences following a miscarriage 21 years ago. While discussing her loss, she reexperienced tense feelings. She recalled other hard times being after the birth of her next child and when her friend had a stillbirth. The psychologist related these tearful times to reliving the pain of her miscarriage.

In the fifth and last case, a 30-year old mother of three became pregnant with an intrauterine device in place. Upon loss of the pregnancy, she was encouraged to "Try not to think about it." Her impression was that miscarriage was a rather routine event for medical personnel. Upon discharge from the hospital, she had bouts of crying, lost 10 pounds in two weeks, and complained of fatigue. This woman was said to have grieved successfully. She acknowledged the healing effect of having another baby.

Stack concludes by offering 12 factors that may explain the development of delayed or pathological grief post spontaneous abortion. These are:

- 1. Usually people do not even know the woman was pregnant;
- 2. The woman is embarrassed to mention her loss;
- Unresolved ambivalence which is typical of early pregnancy;
- The fact that fetus is still incorporated as part of self;
- 5. There was no fetal movement, no sign of life to recall;
- 6. Usually the woman doesn't see the fetus;
- 7. There is no funeral;
- 8. Unrecognition of the event by caregivers;
- Others encouraged denial by not allowing the woman to talk;
- 10. A miscarriage is sudden and unpredictable;
- 11. Guilt is common; and,
- 12. Helplessness accompanies the bleeding (Stack, 1980, p. 101).

While Stack's case studies are brief, they do none-the-less lend credence to the assumption that spontaneous abortions can be stressful. Stack does not say how he collected his data or for what purpose. Stack's 12 factors which lead to a potential pathological grief reaction are useful and they are supported by his case studies.

# Recent Books Which Address Miscarriage

Pizer and Palinski (1980). Pizer is a medical writer and researcher who worked part-time as a physician's assistant. Palinski is a woman who after multiple spontaneous abortions finally carried a child to term. Together they wrote Coping with a Miscarriage, however, as Hai stated, "The book is more correctly titled: What You Should Know About Miscarriage: A Guide for Habitual Aborters" (Hai, 1981, p. 131). The book focuses on two main topics. The first one is Palinski's experience with habitual abortion, her eventual diagnosis of cause, and her subsequent successful pregnancy. second topic addressed is information related to the etiology and physiology of habitual abortion. While there is some information on the actual coping with miscarriage, it tends to be far outshadowed by the other two topics. Perhaps the authors assumed that having knowledge about cause is the preferred coping strategy of most women who spontaneously abort. This book is quite misleading because for most first or second time aborters, the cause is neither known or sought out. Furthermore, it offers the habitual aborter false hope since unlike Palinski, not all causes of habitual abortion are subject to medical intervention.

Additional problems with this book are that it does not use references throughout the text, and that it fails to draw on relevant theoretical knowledge that could serve to illuminate some of the emotions surrounding miscarriage.

The book does offer some useful information on the incidence of miscarriage (if only their references were cited!). What is given about emotions does offer the reader who has experienced fetal loss some validation for her roller-coaster emotions. Finally, the book does also use the experiences of a few other people they interviewed in order to enhance the authors' message. It is too bad that there was not more emphasis shifted away from Palinski and towards the others.

Borg and Lasker (1981). Borg, an architect, writer and consumer health advocate, and Lasker, an assistant professor who teaches in medical sociology and women's health areas, jointly wrote When Pregnancy Fails. Both women wrote from personal experience with perinatal loss, critical familiarity with the perinatal loss literature, and extensive interviews with other women who shared their grief. The book is well written, sensitive and informative. Actual excerpts from their interviews are used throughout the text to illustrate the deep meaning of loss in pregnancy.

The chapter on miscarriage includes information (causation, treatment, emotional reaction) on spontaneous abortion and unwanted therapeutic abortion for negative prenatal amniocentesis results. Both losses were viewed as physically and emotionally draining

experiences which were neither expected or desired. The findings related to spontaneous abortion will be summarized here.

First, most couples who miscarried reported being overwhelmed by the physical and emotional intensity of their loss. Couples said they were totally unprepared for the meaning of miscarriage until they experienced it. Another common finding was that guilt was rampant amongst women who miscarried. They frequently fretted over having somehow caused their loss. The authors sensitively point out that there is no basis in fact for this common misconception.

Thirdly, the authors equate the woman's reaction to loss of fetus to loss of loved one. They emphasize that the attachment between parent and child begins with the realization of conception. A fourth and related finding is that grieving does occur upon loss of early pregnancy and that as in other pregnancy losses, the husband and wife do differ in grieving styles. A fifth point made is that negative grieving outcomes and marital strain are also possible with miscarriage. A sixth and final finding was that "Although miscarriage is the most common type of failed pregnancy, the grief associated with it is probably the least understood" (p. 35).

<u>Berezin (1982).</u> Berezin, a writer in the area of woman's health, wrote <u>After A Loss in Pregnancy</u>. This book is written based on interviews and a review of literature from both the humanities and sciences which pertain to perinatal loss. Topics addressed include grieving by family members, caregiver's responses and the social support (or lack thereof) available to the couple who experience loss through miscarriage, stillbirth or neonatal death.

This book is written for the consumer and offers useful information on the fact that the emotions which accompany loss are normal and necessary. She does not separate out miscarriage to any great extent. She simply acknowledges that this loss is probably most subject to being dismissed by society as a non-event. This book might be a helpful reference for couples who experience perinatal loss; however, the fact that all losses are integrated throughout the book does make it difficult to look up information that pertains directly to one woman's type of loss. For some people, this having to ferret out information may not be the best answer to their needs.

Friedman and Gradstein (1982). Friedman, a psychiatrist, and Gradstein, a reproductive health counselor, collaborated to write Surviving Pregnancy Loss (1982). The book was written based on a combination of clinical experience, a review of literature, and a 46-item open-ended questionnaire which was completed by more than 60 women who had experienced one or more pregnancy losses. The book is broken down into four main topic areas: an overview of the emotional experience of pregnancy loss; types of loss (miscarriage, stillbirth, ectopic pregnancy, and multiple loss are separately addressed); the experience of family members; and options for the future (trying again, adoption, and choosing childlessness).

Miscarriage is referred to as an unrecognized loss. They state that typically few people realize the meaning of it until they themselves experience it. They discuss the warning signs of miscarriage and the different ways in which women respond to these. The stress of the uncertainty of the waiting for confirmation of

miscarriage is emphasized. Information is offered on the causes of miscarriage, the physical experience of miscarriage, and the different types of spontaneous abortion (i.e., incomplete, habitual, missed). Their discussion of the hospital stay includes six suggestions for care: 1) to have the husband available to the woman as much as possible; 2) to be hospitalized on a ward other than maternity; 3) preferably in a private room; 4) to be part of the decisions about her own care (i.e., type of anesthesia for D & C); 5) to decide in advance whether or not to view the fetal tissue; and 6) to be involved in the decision of how to dispose of fetal tissue.

This is a well written, well researched book. Information is clearly presented and validated with clinical examples. Its use for consumers and providers is well recommended. I was particularly intrigued with the similarity between their findings and the findings from my pilot study of the emotional impact of miscarriage. A summary of the pilot for this dissertation follows.

# Preliminary Investigation of The Emotional Impact of Miscarriage

In the summer of 1982 I utilized a Glaser and Strauss Grounded Theory (1967) approach to interview five women who had experienced miscarriage in the previous three and one-half months. The purpose of the study was to answer the question: "What is the meaning of miscarriage to the woman who has recently experienced such an event?" (Swanson-Kaufmann, 1982, p. 2). Two of the women were friends of mine. The other three were contacted through the

University of Colorado Health Sciences Center Department of Obstetrics. Each woman had at least one or more living children and all but one had at least some college education. Ages ranged from 22 to 37, all were Caucasian, socio-economic status was described by the informants as either middle (n = 2) or upper-middle class (n = 3). Two had no previous pregnancy losses, two had one previous miscarriage, and one had two previous miscarriages.

<u>Data collection.</u> Data were collected via one-hour taped semi-structured interviews which took place in the women's homes. The protocol for the open-ended questions may be found in Appendix A. This protocol was developed from my reading of the Berezin (1982), Borg and Lasker (1981), Peppers and Knapp (1980) books and a variety of articles written for consumer magazines such as <u>Baby Talk</u>, <u>American Baby</u>, <u>Redbook</u>, etc. While the questionnaire provided guidance for the interview, it was flexible enough to allow the woman to bring up information that I, on my own was not "expert" enough to recognize as important. Part of the philosophy which underlay my study was that the real experts in the emotional impact of miscarriage were the women who lived through a fetal loss. I was merely their eager student. The tapes of interviews were transcribed directly on to the Boulder computer.

<u>Data analysis.</u> Data analysis was done using the grounded theory approach described by Glaser and Strauss in 1967. This analysis will be elaborated upon in the methodology section of this dissertation.

Results. Figure 2 depicts The Emotional Impact of Miscarriage Model which was generated from my pilot study. The perimeter of the model is made up of categories that have an influence on the meanings of the pregnancy, miscarriage, or both. The two most important categories here are spouse and Health Care Delivery System (HCDS) telling/caring. Spouse was of a major influence in all five interviews. Three spouses were positive influences (+) and two were negative (-):

- (+) ONE:\* He just put his arms around me and we didn't have to talk about it any further. He just knew.
- (-) TWO: He made no effort whatsoever to do anything. He comes over and gives me a little pat on the shoulder and then I was furious. He kept saying, "It's gonna be OK, it's gonna be OK." Goddamnit, it wasn't OK!
- (+) THREE: He was worried mainly medically about me. He said, "Honey, I'm here when you want to talk about it. I'm not gonna push it on you."
- (+) FOUR: I lean on Bobby. So Bobby and I talked about it. It was especially hard on Bobby and my 15-year old because they didn't know what was going to happen to me.
- (-) FIVE: I told him, "You weren't here. You're more married to your job than me because you weren't here." I can't make him see that I really didn't mean that stuff. It's just that I didn't have him here.

The category of <u>HCDS telling/caring</u> is so named because of FIVE'S fixation on the lack of information and care she received from

<sup>\*</sup>Informants are referred to throughout by number.

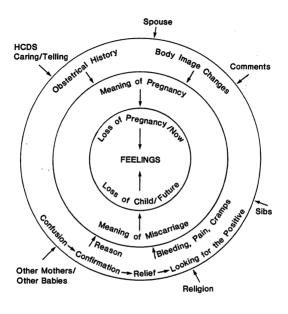


Figure 2. The Emotional Impact of Miscarriage Model.

her health caregivers. Yet, in the exact opposite direction, TWO and THREE were quite enamored with their care:

- ( ) ONE: (This was a fairly neutral category for ONE.)
- (+) TWO: She was real nice. Nice gal. That made an impression on me. At least he had it in him to turn around and look at me to see what a position I was in while I was waiting.
- (+) THREE: Because he knew what was going on, I felt much more secure and confident. The care I got at the hospital was excellent. He told me...He did explain.
- (+,-) FOUR: And the doctor, he didn't care for me at all. He had no compassion, no suggestions, anything. I've got nothing but praise for Colorado General. They were wonderful.
  - (-) FIVE: The doctor gynecologist was a witch. Her attitude stunk. And they don't tell you anything about that. It's really a cold feeling you get. There's nobody there. It's like you're the only one who cares.

The other categories that peripherally influenced the meanings of pregnancy, miscarriage, or the woman's ultimate feelings were: religion, sibs, other mothers/other babies, and comments. Of these four, religion seemed to be the most important for four of the women. In fact, for ONE, religion may have been the central influence: "Religion is our lives completely...It was such a source of comfort to know the Lord was there right by me with His arms around me." Sibs were usually addressed in terms of their capacity to make up for the loss. FIVE stated, "These guys don't make up for my first two." FOUR stated, "Like Bobby said, 'We got Nancy and Peggy. We're happy.'" Other mothers/other babies were mentioned as

reminders of the loss. ONE stated, "There was this real pregnant captain and that just reminded me of me cause that's what I would have been come November or December...And you see a lot of these babies that are around and women that are pregnant. It's really depressing." Finally, comments refers to remarks made by people that were either helpful or hurtful. THREE shared these comments with me. "My aunt said 'I know exactly where you are since I've been there. Is there anything I can do?!" THREE was also subjected to some negative comments. "Well, you know, it's for the best. You're young. You can have another."

The next sphere of the model depicts events that directly impact on the meaning of pregnancy or miscarriage. Obstetrical history and body image changes both seemed to serve as checkpoints against which the women would monitor their pregnancies. ONE stated, "The second time I was missing absolutely all the signs of being pregnant." "My uterus was smaller," said THREE. FIVE stated, "My breasts get really swollen." And FOUR said, "If I'd a been the type of woman who had several miscarriages, then I would think it was me." These categories were supported by the literature on the psychology of early pregnancy (i.e., monitoring, incorporation, body image changes, etc.).

The most common theme to all of the women was the recurrent themes of the physical signs and symptoms of miscarriage: <a href="bleeding.pain">bleeding.pain</a>, and cramps. The bleeding seemed to be the most obvious sign. In the case of THREE, bleeding was originally seen as benign due to her obstetrical history of bleeding with her previous pregnancy. FOUR was hemorrhaging up to two weeks after her miscarriage,

requiring two extra D & Cs. ONE stated, "The bleeding, that really bugs me. It really just emphasizes. It is almost like a mock-up."

The confusion-confirmation-relief-looking for the positive process was fascinating and ubiquitous. Each woman went through a time of inner strife waiting to hear which way the pregnancy was going to go once they started to bleed. THREE stated, "When the cramping started - I - I don't know - I couldn't decide which way to go because I figured I was miscarrying and then when the cervix was closed, I realized...I tried not to be too hopeful, but I tried not to give up either." FOUR stated, "Well, what if the baby is alright and you go home and lay down for six months. Is it possible that you might have a normal baby? Up until then, I was expecting a D & C, and what's that? It's basically an abortion." Relief finally was obtained for the subjects when at some point, confirmation of fetal demise was obtained. For each woman, that moment of knowing that it was inevitable was in some way a breakpoint, an end to the confusion.

#### Confirmation

ONE: As soon as I saw the blood, I knew I was going to miscarry.

THREE: I had enough knowledge of when they said the cervix was closed what that meant, and then when it began to dilate...

## Relief

FOUR: But once they looked at me at Colorado General and they told me it was no good, that was OK to go ahead and do it.

#### Looking for the positive

TWO: And I think then if it did anything to me. The miscarriage made me know that, yes, I really do want another baby.

nano anoma, babyt

FOUR: In a way, I'm glad that all this happened because we found out (about Colorado General).

One other category that impinged on the meaning of the miscarriage was the struggle to find a <u>reason</u>. TWO called upon a friend to analyze a piece of her fetal tissue. ONE and FIVE believed it was God's way of retrieving the imperfect. ONE also harbored guilt over a sleeping pill that she took in early pregnancy for fear that the pill had deformed the fetus. FOUR thought the miscarriage was her message that she was too old to have children and time to get her tubes tied. THREE stated, "It would be easy to try to find a blame. Fortunately or unfortunately, I'm more educated than to try and do that." FIVE was suspicious that her cyst was possibly "blocking her tubes."

The next sphere of the model depicts the overall <u>meanings of pregnancy and/or miscarriage</u>. As for the pregnancy, TWO said, "The first one was for Dave. This one was for me." FOUR stated, "It was good that I was pregnant because this time we were going to be together." ONE'S husband said, "Well, I think the reason you got pregnant is...the Lord wanted me to have a son." On the other hand, the miscarriage was interpreted by FOUR as a sign to get her tubes tied. To ONE, TWO, THREE and FIVE the miscarriage was basically seen as God or nature's way of saving them from birthing the imperfect.

Finally, the inner circle consists of the <u>feelings</u> surrounding the <u>loss of pregnancy/now</u> and the <u>loss of child/future</u>.

The two losses were definitely differentiated in ONE, TWO, and THREE'S conversations. Each one of them bemoaned their present loss which was the loss of the chance to be pregnant and to wear maternity clothes:

ONE: I was so mad that I didn't get to wear my maternity clothers.

TWO: I never got to be pregnant. I got pregnant and then to lose that.

THREE: It took me til yesterday to put my maternity things away. I just couldn't face them. It's hard to realize in certain ways that you're pregnant and it's harder to realize in other ways that you're not pregnant.

Loss of child was defined mainly in terms of the future. The pain was not as easy to place as losing the chance to wear maternity clothes. This loss seemed more elusive. There was nothing to bury, nothing to put away:

THREE: It's not kind of like a death you can mourn, something you can't see, that makes it more aching and continuing for a while.

FIVE: It really hurts even a few months later, you still think, this baby would have been this much older. And you wonder what that baby would have been like, how it would have grown up. Each time you lose a baby. It's, it's still, even though you're, even though you haven't seen it or anything, it's still something of the future.

ONE: You really had a little death there. Even if it was just an embryo or a little fetus at that point. It really was a little death.

Feelings is the last category. It is the central category of this study. All previous categories become variables that in some way contribute, either directly or indirectly, to this outcome variable. This category was, for the most part, arrived at by the responses to my final question: "If you had to describe this whole experience in one word, what would that word be?" The answer usually came after a long pause and each woman was able to elaborate on her response with prompting:

ONE: Anger. Mad because it stopped...You will just feel terrible, which is true, but you just can't help trying to find a reason for it. It helps so much more to know the reason because otherwise it seems like if there was no reason, than it would seem like such a waste of life to, you know, die.

TWO: Sad-loss. I don't know if I ever had time to really get into this and think about this as being my baby. But, I really felt like I lost something. I got to be pregnant and I lost that.

THREE: Aching-sadness. Sometimes I just kind of ache and feel real sad, and other times, I just feel, just a sad. But it's, it's not sad like "Oh, gee, I broke that favorite vase of mine or something."

It's kind of an aching sadness. Something you can't see. It's not kind of like a death you can mourn in certain ways. That makes it more aching and continuing for a while.

FOUR: Frustrating. Frustrating, the whole thing, frustrating. I didn't know, I didn't know what to do. I never had anything like this happen to me before. I didn't know what was causing it. I didn't.

FIVE: Cold. Cold, everything cold. There's nobody there. It's kind of like, you know, you're the only one that's caring about this baby that you're losing.

Painful. Painful, emotionally and physically. And you try again, you know, each time it hurts. And some people think that if you have other babies, it makes up for the ones you lost. But it doesn't.

Summary of the pilot study. While the pilot study may have been quite small in terms of sample size, it was quite rich in terms of data. The model which was generated is certainly in need of further refinement, however, it has proven to be quite useful for providing me with guidance, and moreso, the motivation to pursue this dissertation. It is obvious that there are some similarities between the pilot model and the literature reviewed earlier in this section. However, a noticeable gap in both is the caring component. There is a need for more information about just what type of support the woman would liked to have received from those "sources of influence" which are depicted in the outer perimeter of the model. This pilot study was invaluable in preparing me for this dissertation.

# Summary of the Review of the Literature

The review of the literature proceeded from a general overview of grief and the caring needs of grievers in general to a critique and summary of the literature on perinatal loss and concluded with a review of the miscarriage literature. The pilot study for this dissertation was included in the miscarriage section.

#### CHAPTER III

#### THE PROCESS

# The Multiplicity of Realities

I have chosen to begin the description of the research process by interspersing Johnson's description of the aim of psychology as an existential human science with <u>my</u> nursing emphasis:

Psychology [nursing] as an existential science drives us deeper into subjective reality so that we can describe it, encompass it, and make it our own. Psychology [nursing] as a human science does not ask us to cloister ourselves within the synthetic security of animal laboratories and normal distributions. It does not train us to objectify ourselves and others by an endless series of intellectual measurements and calculations. On the contrary...an existential science demands that we risk our personal being in a violent thrust down into the "flux and fire" of life. It is only at such emotional depths that we break through the intellectual symbols of scientism and grasp existence with the passion of our hearts. Psychology [nursing] as an existential science demands that the methods we use to study man be as ardent and as sensitive as the human subject matter which we seek to discover and understand (Johnson, 1975, pp. 16-17).

Based on Johnson's argument, it becomes clear that some of the dichotomous underpinnings of the physical sciences become moot points in the human sciences. For example, the distinction between researcher and subject is muddled by the fact that the researcher must accept her naivete and the subject's expertise on the phenomena under inquiry. The researcher/student is dependent on the informant/expert to guide her in her systematic attempt to understand and describe the informant's experience (Agar, 1980; Watson, 1981).

Equally unclear are the distinctions between percept and object and facts and values. Within the human sciences, it is accepted that there is more than one reality. One cannot view a fact/object separate from one's value-laden perceptions. For example, traditionally spontaneous abortion is viewed (valued and perceived) as little more than a somewhat disappointing, minor medical emergency. From my perspective, miscarriage appears to be a loss of life. Obviously, my lens will be more focused on the feelings, thoughts and concerns that are centered around such a loss. Which perspective is <a href="true">true</a>? Whose to say. Perhaps the only fact we can be sure of is that where human beings are concerned, there is nothing of which we can be totally sure (Dennis, 1982; Marton and Svenson, 1979).

One value that runs rampant in traditional science is the emphasis on the normative. The goal of the natural sciences is to describe law-like generalizations that have a broad range of applicability. By the very nature of their broadness, these rules tend to be very specific, applying to an extremely limited aspect of reality. The net result is that we know a little about a lot of people. The pragmatic clinical use of these normative "truths" is limited by the contextual (space) and historical (time) realities of the nurse-patient encounter. Thus, a nursing science which values reductionism (normative laws) must be ultimately judged for its usefulness in a unique setting.

On the other hand, a human science which values uniqueness must face an ultimate judgement of applicability of findings to the needs of the larger discipline. Whereas lots of data about "a little

bit of people" may be of heuristic interest, its judgement of worth for a clinical discipline must reflect our goals which involve meeting the health needs of society. It is my argument that if a study can open our eyes to a range of meanings that we had not previously realized, then isn't that study at least as useful to the growth of nursing knowledge as a statistically significant finding about effectiveness of a new method of tracheostomy care? Thus, in nursing, I argue we must be open to more than one reality with which to judge the "worthwhileness" of research outcomes.

In order to briefly summarize some of the predominant differences between traditional research methodologies and the combined qualitative methodology, Table 5 was designed. This table illustrates contrasts that underlie the actual methods and the philosophies upon which the methods are based. It must be made clear that these contrasts, while appearing dichotomous, are probably better understood as being on a continuum.

# The Nature of Reality

Mehan and Wood (1975) have described five features of reality, the understanding of which is crucial to our capacity as a discipline to accept multiple research traditions. The first feature of reality is that it is reflexive. We all see the world in terms of our own life experiences. Our perception of objects reflects back on our previous experience with those objects. We are said to have "object constancy assumptions." Without these assumptions, we would have no trouble accepting alternative viewpoints. For example, in a

TABLE 5
Contrast of Research Methods

	<u>Traditional</u>	Qualitative
Starting Point	Conceptual Framework	Data
Finishing Point	Data	Conceptual Framework
Description Focus	Units/Parts	Processes/Whole
Comparison	Indices to Total	Case to Case
Protoco1	Fixed	Constantly Modified With New Info
Process	Linear (i.e., Hypothesis Collection, Analysis	Matrix (All Steps Occur Simultaneously)
Issues	Reliability/Validity	Usefulness/Credibility
Relationship Researcher to Subject	Separate/Objective	Together/Subjective
Truth	Value Free Facts	Valued Perceptions
Setting	Lab/Controlled	Real World/Contextual
Instruments	Too1/Questionnaire	Researcher and Evolving Questions
Aim	Normative	Ipsative
Findings	Descriptive, Predictive	Descriptive, Interpretive

References: Stern, 1980; Dennis, 1982; Marton and Svensson, 1979; Watson, 1983.

world where miscarriage (the object of inquiry) is viewed as a basic non-event (no big deal - medically or emotionally), this study might be viewed as an emotional muckraker: a "big to-do" about a fairly benign event. Another example of reflexive thinking is that in a discipline which values normative science, the tendency will be for that value to be maintained. Thus, research projects that utilize more traditional normative methodologies will not only be more widely viewed as scientific, but it will be privy to wider acceptance and funding. Such acceptance and funding reflexively feed back into our valuing of such a notion of science.

A second related feature of reality is that it is coherent. We will accept something as true if it coheres with the rest of what we know to be true. In terms of this study, if the woman who miscarries experiences sleep disturbance and preoccupation with thoughts of the lost fetus, these symptoms are coherent with our notion of the nature of grieving. Thus, we will accept the fact that she is grieving a loss. If on the other hand, a teen-age mother returns to school within 24 hours of her loss and never again mentions her miscarriage, we might be led to refer to this as an incidence of non-grieving. Non-symptoms, thus, non-grieving coheres with our notions of the nature of grieving. If, however, we would be willing to accept the possibility that there might exist an alternative reality which describes different adolescent grieving patterns as suggested by Schodt (1982), then we would have to be open to a truth which is not totally coherent with our accepted reality.

In order to maintain our reflexive, coherent reality, we must live that reality. As Mehan and Wood's third aspect of reality

states, reality is maintained by interaction. This feature is apparent in the literature reviewed in the previous section. So long as psychologists viewed habitual abortion as caused by a cast of neurotic personality characteristics, they found validation for their beliefs. They maintained these beliefs by interacting in practice with women who displayed neurotic symptomatology and by interacting professionally with other psychotherapists who shared their beliefs. The possibility that habitual abortion was due to a repetitive genetic deviation or that the woman's symptoms may have evolved as a result of her repetitive losses was not coherent with the researchers' notions of the reality of miscarriage. Likewise, in nursing, so long as our professional journals and conferences focus on more traditional notions of science, interaction with these two vehicles for our scientific endeavors will serve to maintain the reality of a more traditional view of science.

On a more optimistic note, the fourth feature of reality is that it is fragile. Human beings have the capacity to be "moved out of their comfortable places." A reality that meets with a growing body of dissenting cases eventually has to break. A nursing science that continually experiences the inadequacy of traditional science for describing its phenomena of concern eventually has to question its assumptions. Herein sets the stage for this dissertation. A nursing science that values the depth of feelings that surrounds a woman's experience (be it pregnancy, miscarriage, menstruation, or mothering) can't possibly "ride" on a comfortable "received" notion of the non-significance of these events. As Benoliel notes, for too long "the male biases have determined not only what is selected for

study, but also how it is studied and subsequently how it is interpreted" (Benoliel, 1975, p. 25). The fragility of a reality that reduces miscarriage to a minor medical occurrence is apparent. Equally in my favor, as I have attempted to make a case for this dissertation, is the obvious fragility of the notion of science that requires quantification and reduction of findings. Since there is so little known on the human experience of miscarriage or the caring needs of women who experience such a loss, it would have been downright inapproporiate for me to leap to a quantitative study. Obviously, any quantitative tool I would have generated would reflect nothing more than my naive assumptions about the reality of the nature of miscarriage.

A fifth and final feature of reality as described by Mehan and Wood is that our fragile realities are permeable. "Every reality is capable of dissolution" (Mehan and Wood, 1975, p. 23). It was on this premise, that I pursued this study. I operated on the tacit assumption that the reality I had built up around miscarriage (see my five assumptions in Chapter I and the results of my pilot study in Chapter II) was capable of being permeated. The key was believed to lay within my capacity to critically reflect upon my notions of reality and the reality which my informants were able to share with me. I had no guarantee that my reality would be permeated by my informants or that nursing's reality will be permeated by my conclusions. My only hope was (and is) that by knowledge of the fact that my thinking and acting tend to be reflexive, coherent, and interactional, I could somehow leave myself open to the permeation of

my informants' reality. The methods I utilized to "tap" this reality are described in the rest of this chapter.

The reflexivity of my thinking is apparent. I do not deny it.

## Description of the Methodology

This dissertation utilized a combination of qualitative methodologies which would allow me to understand and describe the phenomena of study in the best way I deemed possible. Aspects of phenomenology, ethnography and grounded theory were melded together to form a qualitative methodology for research in nursing. Whereas I certainly had tried, I found that simply "receiving" any one of these three methodologies alone just was not sufficient for nursing.

Grounded theory which has its roots in sociology was limited by its tendency to ignore the individual who is the source of the data from which theories are generated. In the opposite direction, phenomenology, which has its roots in psychology, philosophy and socio-linguistics, was insufficient for use in describing commonalities amongst informants. This limited my goals of collapsing data across individuals in order to describe the categories pertinent to the phenomena. Lastly, ethnography which has its roots in sociology and anthropology, was deemed somewhat limited in its guidelines about how to best present findings in a succinct, useable format. As Agar (1980), an ethnographer notes, the capacity of the edic (a description of a reality from the outside) to become the emic (a description of reality from inside the culture) is

limited not only by the researcher's ability to permeate another's reality, but also by the capacity of the researcher to use her own words to describe the reality of the other's culture. The limitations of language as well as the strangeness of the informants' reality presents the researcher with an indexical dilemma: how to best present findings in a way that is useful and informative to the uninformed consumer yet meaningful in terms of the culture from which it was generated. The net result is that, typically, in order to achieve indexicality where there is a necessary amount of background knowledge shared so as to make the findings meaningful, the researcher ends up having to either write a book or simply share the superlative (best and worst) cases in order to get her message across. Thus, no one of the three aforementioned methods alone was deemed appropriate to my purpose.

On the other hand, each method did offer a contribution to my search. Phenomenology, as described by Alexanderson (1981), Giorgi (1970) and Oiler (1982), offered to this study a goal: to describe the human experience of miscarriage as it is lived. phenomenological perspective describes four premises on which this study is based. The first premise is that a phenomena is nothing more than how an object or event appears in the world. appearance of an object is simply the meaning we attribute to it (i.e., miscarriage as an event derives its meaning by how it is viewed). A second similar perspective is that objects/events derive their reality subjectively and perspectively. The subjective/perspective nature of the reality of miscarriage will be determined by who lives that experience (i.e., the way the woman

lives through her miscarriage and the way the nurse lives through the woman's miscarriage will certainly generate different perceptions of the reality). Similarly, the third assumption underlying phenomenology is that the world becomes real through contact with it. I believed the world of fetal loss would become more real to me by my contact with women who had lived through fetal loss. Finally, phenomenology emphasizes that truth is a composite of realities. As Oiler states, "The world is grasped in profiles dependent on an individual's perspective" (1982, p. 179). The profile of the human experience I describe in the next chapter reflects my perception of the reality of my informants.

Spradley's ethnographic developmental research sequence was used as a guide to interviewing in this qualitative study. Spradley (1979) emphasizes that ethnographic interviewing requires of the researcher an ability to balance her interviews in terms of structure and looseness. The interview must be structured enough so that the researcher can pursue lines of inquiry that she <u>believes</u> to be pertinent. Yet, it must also be loose enough for the informant to be able to direct her student researcher to the topics that she, the expert in experiencing miscarriage and its caring needs, <u>knows</u> to be important.

Grounded theory offered this study a goal of generating a theoretical description of the human experience of miscarriage and the caring needs of the woman who experiences such a loss. As Glaser and Strauss (1967) have described, the description should ultimately be grounded in the data. The sources of the data are the statements of the informants and to a lesser extent, the literature which

pertains to miscarriage. Within a grounded theory framework each source of data is considered to be a case which is available for comparison with all other cases. In a 1966 publication, Glaser and Strauss attempted to delineate the "in process" nature of qualitative research. They emphasized that no matter where the researcher starts, she will always begin with ideas or assumptions about the answer to the resarch questions she sets out with. These assumptions whether openly acknowledged or unconsciously experienced will influence the data the researcher attends to. In my case, having reviewed the literature and done a pilot study, I naturally had some ideas about that for which I was looking. My challenge was to try to remain open to miscarriage "concerns" which were not relevant to my assumptions. My assumptions are fairly well summarized in Chapter I and depicted in the theoretical model which was generated from the pilot study.

As within most qualitative research strategies, data collection and analysis proceeded simultaneously. Data was analyzed as it was collected both within each interview and between subsequent interviews. Statements were compared intra-informant for consistency and contrast during the interview and inter-informant for consistency and contrast between interviews. Each interview was a source of data for questions to be asked in all subsequent interviews and a case to be compared to all other cases.

By now, the central role of the researcher in this study should be obvious. I, the researcher, must acknowledge how much the study's outcome has reflected my decisions about every step of the research process. It has been my attempt thus far to share my biases

as fully as I am able to label them. It is the consumer's position to accept or reject the plausibility of my findings as they deem necessary. The ultimate test of faith in the researcher is faced in the capacity of everyone concerned (myself included) to acknowledge the researcher's right to decide when saturation is reached. Glaser and Strauss state that saturation is reached when the researcher:

may find that [she] is not learning anything new enough about [her] analysis to make the explicit procedure seem worthwhile.of course, explicit coding at the study's close can add further elaboration of details; but the question is always whether or not the additional effort is worthwhile since there is little chance that the core of the analysis will change, and details below the level of generality of the theory seldom add to its wider import and applicability (Glaser and Strauss, 1966).

To Glaser and Strauss' thoughts about category saturation, I add a thought of my own. It has been my suspicion that not only categories saturate, but so do researchers. There comes a time when the researcher must acknowledge her limits, a time which she can no longer absorb any further information about her phenomena of concern. Hopefully, researcher and category saturation occur somewhat simultaneously. By the very nature of qualitative research, any end point is a beginning point for future study. Therefore, the actual point at which I stopped to summarize the findings of this study is not so crucial so long as study of the phenomena is viewed as ever-in-process.

### Research Strategy

### Informants

Although an attempt was made to contact informants directly through a variety of convenience strategies (i.e., advertisements in

newspapers and newsletters), as it turned out, each informant was referred to the study through a mediator. Eighteen of the 20 informants were referred by their obstetrical care provider (private physician or midwife); one woman was referred by my parish priest and the final informant called me after a common acquaintance showed her the research advertisement in a Cesarean Birth Support Group newsletter.

Selection criterion for inclusion in the study were proposed as: that the woman reported having experienced miscarriage within 15 weeks prior to initial interview; that she reported not having felt fetal movement prior to her loss; and that she spoke English. As it turned out, two women reported mid-interview that they had felt fetal movement: SEVEN\* (a primiparous mother) reported she felt movement at 12 weeks gestation (it is interesting to note that the fetus was a 12-week size when aborted at 14 weeks gestation); and TWELVE (her third pregnancy) reported having felt movement just days prior to losing her son at 16 weeks gestation. Rather than dismiss these two excellent informants from the study, it was decided to build their perceptions of movement into the study.

Demographic data were collected using the Data Sheet which may be found in Appendix B. The informants ranged in age from 18 to 38 years (mean = 30, median = 31, modes = 27 and 34). Nineteen of the informants were married to the father; one informant was engaged to the father. For 12 of the couples, it was a first marriage for each partner; for the remainder of the couples at least one of the

\*As in the pilot, informants will be referred to by number.

partners was previously married. The length of time living together as a couple ranged from eight months to 19 years (mean = 6.2, median = 3.5, mode = 3). The fathers ranged in age from 24 to 48 years (mean = 32.85, median = 31.5, mode = 31).

The years of education for the informants ranged from 12 to 17 years (mean = 14.4, median = 14, mode = 16); and for their partners it ranged from 11 to 18 years (mean = 15.3, median and mode = 16). The annual family income level ranged from a low of \$18,000 to a high of \$65,000 (mean = \$40,750, median = \$40,000, mode = \$50,000). Five of the informants were not employed outside the home, four were employed part-time, and 11 were employed full time outside the home. One unemployed informant was a part time student. At the time of the first interview, all fathers were employed full time. At second interview one father had lost his job and was heavily involved in trying to start his own new business.

Of the 18 informants who claimed a religious preference, 11 were Protestant, one was Mormom and six were Catholic. There were 17 Caucasian, one Black, and two Hispanic women in the study.

Table 6 summarizes the number of children in each family and Table 7 summarizes the obstetrical history of the informants.

# Data Collection and Analysis

As described previously, data collection and analysis proceeded simultaneously. Each informant was interviewed twice: first interviews generally lasted from one to two hours and took place in either the informant's home or at a place outside her home to which she agreed. Most of the second interviews took place over

TABLE 6 Children in Each Informant's Family

Informant	Total # Of Children	Their <u>Children</u>	His by Previous <u>Marriage</u>	Hers by Previous Marriage
ONE	1	1		
TWO	0			
THREE	3		3*	
FOUR	1	1		
FIVE	0			
SIX	0			
SEVEN	0			
EIGHT	2		2**	
NINE	0			
TEN	0			
ELEVEN	1	1		
TWELVE	1			1
THIRTEEN	4	4		
FOURTEEN	2	2***		
FIFTEEN	1		1	
SIXTEEN	1	1		
SEVENTEEN	2	2		
EIGHTEEN	0			
NINETEEN	1		1****	
TWENTY	0			

<sup>\*</sup>Older children; none living in household; one deceased.
\*\*Half-time custody.
\*\*\*Mother has custody.

TABLE 7
Obstetrical History of Informants

Informant	Gravidity*	<u>Parity</u>	Infertility <u>History</u>	History of Traumatic <u>Birth</u>	<u>Stillbirth</u>	<u>TAB</u>	SAB*	Weeks Gestation For Most Recent <u>SAB</u>
ONE	3	1		X			2	9
TWO	ī	ō					ī	13
THREE	1	0	X				1	14
FOUR	2	1					1	7
FIVE	1	0					1	12
SIX	1	0	X				ī	7
SEVEN	1	0					1	14
EIGHT	2	0				1	1	12
NINE	2	0				1	1	12
TEN	2	1					1	11
ELEVEN	2	1					1	12
TWELVE	3	1	X				2	16
THIRTEEN	6	4			1		1	11
FOURTEEN	2	1	X				1	14
FIFTEEN	2	0	X				2	13
SIXTEEN	4	1		χ .	. 1	1	1	14
SEVENTEEN	4	2		X			2	13
EIGHTEEN	2	0				1	1	12
NINETEEN	1	0	X				1	10
TWENTY	7	0					7	8

<sup>\*</sup>Includes most recent pregnancy/SAB.

the phone and lasted from 15 to 30 minutes. The very first interview took place on June 10, 1983. By September 19, 1983, all second interviews were completed.

Table 8 summarizes the timing of interviews in terms of length of time between loss and interviews. The time span between loss and first interview ranged from one week to 14 weeks, five days (mean = five weeks, four days). The range of times reflected when the informant was referred to the study by the contact "go between" (usually the obstetrical care provider). The length of time between first and second interview ranged from four weeks, four days to 10 weeks, five days. An attempt was made to contact each informant four weeks after the first interview in order to schedule a second interview. The discrepancies in timespan between interviews usually reflected the informant's late summer vacation plans. The longest timespan (10 weeks, five days) was due to ONE's preference to wait until after harvest to meet again (they were farmers). Finally, the overall timespan from loss to second interview ranged from a low of five weeks, six days to a high of 23 weeks, four days (mean = 11 weeks, three days).

## <u>Interview Schedule</u>

The first interview was guided by the semi-structured interview schedule which may be found in Appendix C. The second interview was likewise guided by a short semi-structured interview schedule which may be found in Appendix D. Each interview schedule served only as a guide to me - the major research "tool." An attempt was made to keep the interviews open and to allow each informant to

TABLE 8
Length of Time Between Loss and Interviews

Informant	Miscarriage to Inverview #1 (Weeks + Days)	Interview #1 to Interview #2 (Weeks + Days)	Miscarriage to Interview #2 (Weeks + Days)
ONE	5 + 4	10 + 5	16 + 2
TWO	9	5 + 2	14 + 2
THREE	14 + 5	8 + 6	23 + 4
FOUR	1	6	7
FIVE	3	5 + 6	8 + 6
SIX	3 + 4	7	10 + 4
SEVEN	4	6 + 4	10 + 4
EIGHT	3 + 4	4 + 6	8 + 3
NINE	5 + 1	5	10 + 1
TEN	9 + 5	5 + 4	14 + 2
ELEVEN	4 + 1	5	9 + 1
TWELVE	1	4 + 6	5 + 6
THIRTEEN	8 + 6	5 + 3	14 + 2
FOURTEEN	6 + 2	5 + 2	11 + 4
FIFTEEN	7 + 1	5 + 6	13
SIXTEEN	2 + 2	5	7 + 2
SEVENTEEN	4 + 4	4 + 4	9 + 1
EIGHTEEN	10 + 6	5 + 6	16 + 5
NINETEEN	3 + 3	5 + 4	9
TWENTY	4	4 + 4	8 + 4
	X = 5 + 4	₹ = 5 + 6	$\overline{X} = 11 + 3$

direct the flow of discussion. The second interview provided an opportunity to clear up any misconceptions or discrepancies in the first interview as well as a chance to assess the woman's progress over time.

The first interview schedule for the initial semi-structured interview was originally generated based on my having read lay literature on the topic of miscarriage prior to the pilot study. During the pilot, questions were added based on the information provided by the informants. For example, Item 26 evolved as a central question to my pilot yet it was not part of the original pilot protocol. Upon analysis of the pilot findings, I realized some gaps in my line of questioning. A particularly pertinent gap was my failure to address the caring needs of the woman who miscarried. This need has been addressed in Questions 18, 24 and 25 of Appendix C. Item 17 was a new question in this dissertation which was added due to my discovery of the tendency of women in the pilot study to define their own ideas about gains and losses which accompanied their miscarriage. Items 18 and 19 reflect the grief literature which was reviewed for this dissertation.

The second interview schedule for the follow-up interview was developed toward the end of the first round of interviews. The questions on this form were asked of all informants. In addition, each woman was asked those specific questions which grew out of her particular first interview. The purpose of items 1, 2 and 8 were to evaluate the woman's progress over time. Item 3 was meant to find out the woman's perception of her follow-up health care visit. Items 4, 5, 6, and 7 grew out of an analysis of the original transcripts.

Item 4 reflected a few of the informants' experience with coming to know they were no longer pregnant. Item 5 was meant to validate their original thoughts on plans for the future. Items 6 and 7 were my attempts at arguing against Speck and Kennell's (1980) assumption about the lack of maternal attachment prior to fetal movement being felt.

## The Method: Step by Step

In response to Florence Downs' recent challenge (1983) that qualitative researchers frequently fail to share their workplan, this step-by-step research strategy is reported. It must be noted that a linear format is basically incompatible with the matrix-like nature of qualitative research; thus, this chart may not do justice to my actual research process.

## Step I: The Preliminaries

- A. Human Subjects approval was obtained for the pilot study on June 18, 1982. Updated approval was received for the dissertation research on May 31, 1983. See Appendix E for a copy of the Human Subjects Consent Form.
- B. Three assistants were trained in the use of the computer in order to prepare them for transcription of the interviews (May and June, 1983).

## Step II: Locating Informants

A. Advertisements were placed in a variety of newspapers and newsletters in order to locate informants (last week of May, 1983). B. Via the phone and in person, obstetrical care providers throughout the Denver-Metro area were asked to refer women to the study (first three weeks of June).

## Step III: The Interviews

- A. Informant ONE was interviewed (June 10).
- B. ONE's tape was dropped off at transcriber's house to be typed onto the mainframe computer in Boulder (June 11).
- C. Informants TWO and THREE were interviewed (June 23).
- D. In late June, tape ONE was transcribed and analysis began. From here on, transcribed tapes slowly "trickled in." Generally, I was about four interviews ahead of the transcripts (i.e., I was interviewing SIX before I had analyzed TWO's transcript).
- E. On July 7 an attempt was made to contact ONE to arrange for a second interview.
- F. First interviews were completed August 18, 1983.
- G. Second interviews were completed September 19, 1983. Before each second interview, the informant's first interview had been analyzed and questions about the unclear parts of the first interview had been formulated.

#### Step IV: Analysis

### A. Coding the Data

 As soon as ONE's raw transcript was received, I listened to the tape while reading the

- transcript. It was at this point that I penciled in corrections of transcription errors. (For an example of a segment of raw transcript, see Appendix F.)
- Penciled in corrections were typed into the computer.
- Using <u>The Ethnograph</u> (Seidel and Clark, 1983), raw transcripts were converted into formatted, numbered lines. (For an example of a numbered segment of transcript, see Appendix F.)
- Lines of the numbered transcript were coded by 4. hand. A code is a word that I used as an index marker that aided me in breaking the transcripts down by topics that were addressed in our conversation. A code is a word that was very close to the data. By that I mean I did not attempt to make any "leaps" between what was said and what I thought was meant. For example, if the woman talked about her physical relationship with her spouse, I coded it "sex." The purpose of the codes was to facilitate my analysis later on in the study. When I was ready to support my categories. I was able to sort through the long transcripts rapidly using the coded segments as index markers. In all, there were 84 codes. An example of a hand-coded segment may be found in Appendix F.

- The hand codes were typed into the computer. An example of a computer printed coded segment may be found in Appendix F.
- 6. The computer was directed to sort through each transcript for every occurrence of a given code, i.e., everytime a segment of ONE's transcript addressed the code "sex," it was retrieved and printed out on the sort page for the code "sex." For an example of a sort page, see Appendix F.

### B. Category Development

- Constant reflection on data gathered to date ensued throughout the entire dissertation process. (This goes back to before the pilot study even occurred in the summer of 1982.) I lived my study in my sleeping and waking moments. Obviously, the intensity of this reflective process (or the saturation of the researcher) increased as the data collection ensued.
- While reading some of the earlier first transcripts, I was struck with the fact that all the informants to date (pilot informants included) seemed to take a while to realize they were miscarrying. Thus, the category "Coming to Know" was seeded.
- 3. The remaining categories came over time. By the  $\mbox{time} \quad \mbox{I} \quad \mbox{had} \quad \mbox{completed} \quad \mbox{my} \quad \mbox{first} \quad \mbox{round} \quad \mbox{of} \quad \mbox{}$

interviews, I felt fairly comfortable with the fact that I had probably identified the six Experience categories. (The number six just happened. I didn't aim for six.) Second interviews provided the opportunity to ask questions that helped me to saturate each category and to better clarify the meaning of each category.

- The Caring categories were longer in coming. I could not seem to move past the simplistic codes (i.e., C/touch---caring was evidenced in touch). I was not able to identify the source of my problem until I realized my folly was in the question I originally asked. (What are the caring behaviors of others that are identified as helpful by the woman who miscarries?) It was informant SIXTEEN who corrected me when I asked her what was said to her that made her feel cared for. She pointed out I shouldn't be asking for words. I should be looking for messages. It was then I realized that the caring categories had to define the caring processes that underlie external caring behaviors. Once this insight was achieved, the five caring categories came quite easily when the data to date were reflected upon.
- The concrescence of the categories came as the final write-up of this dissertation was done.

Each category was supported by my returning to the transcripts of each informant for evidence. The return to the transcripts was aided by the fact that all transcripts had been sorted by codes earlier in the analysis.

It must be reiterated that this step-by-step format is limited in its usefulness for conveying the actual research process. It is very difficult to convey how much of the actual analysis (developing and "thinking through" categories) was done away from my desk or computer. The reflective nature of qualitative research must leave room for the fact that ideas are "intuited"; and by their very nature, "intuitions" come where and when they will which is not necessarily always where or when they were sought after. Finally, Johnson (1975) offers support for the appropriateness of intuition as a way of "doing science." He states:

Now it is clear that any new advance in science and psychology [nursing] demands a method that can give us direct access to the internal organization and existential reality of phenomena themselves. Bergson argues that intuition is the only method of investigation that can provide us such direct access to the mystery of existence and to the absolute nature of reality. He means by intuition, a 'kind of intellectual sympathy' by which one places oneself within an object in order to coincide with what is unique in it...(Johnson, 1975, p. 229).

### Research Issues

In a more traditional research study, this part of the methodology section would have been labeled <u>Reliability and Validity</u>. Whereas, in a qualitative study these points are not exactly applicable as traditionally defined, it does not mean that these issues should not be addressed. From a measurement standpoint,

chances of my generating a reliability or validity statistic are slim. However, from a conceptual standpoint, there is some meaningfulness in discussion of these issues.

If one thinks of reliability as the likelihood of getting the same answer twice from the same person (i.e., traditionally a <a href="test-retest-reliability">test-retest-reliability</a>), then my plan to interview the same individual twice may be viewed as an attempt to address this concept. However, this is not a readily transferable issue. Part of the very rationale for using a qualitative methodology for this study was my belief that grief was a process that was neither bound by space (context) or time (history). When I interviewed the woman a second time, there was a lapse in time between "measurement points." If she was indeed grieving and we know from the literature that grieving is supposed to change over time, then we certainly could not have expected the same response from the women when interviewed a second time. Grief is a process that involves time and is certainly influenced by one's environment.

As it turns out, this point was supported serendipitously in this study. When informant SIX's first interview was being transcribed, we (the transcriber and myself) realized the second half of SIX's interview was inaudible. SIX very kindly agreed to let me redo the missing part of the first interview when I returned to her house six and one-half weeks later to do the second interview. On our first interview, SIX was quite eloquent in describing her grieving period. She was quite emotional and cried freely. Yet, on the second interview when I repeated many of the same questions from

the first interview, SIX was pleasant, but brief in responding. So I asked her:

ME: As I remember when I was speaking to you the last time, you were kind of a lot more sad then. It seemed to me like you were.

SIX: I think I've gotten over it more now...I really

SIX: I think I've gotten over it more now... really don't think about it anymore...

Obviously, grief is a dynamic activity and the same questions asked at two different measurement points will not present the same answer.

Measures of internal consistency are likewise hard to generate. It is my suspicion that my protocol for the open-ended interview is replete with subscales. Perhaps being mindful of the fact that my questions may be able to be grouped into subscales based on similarity of responses will be helpful to my future research in this area.

<u>Inter-rater reliability</u> is perhaps the most applicable reliability concern for this study. Yet, even as close as it comes, it needs some reinterpretation in terms of a qualitative study. For the purposes of this research, inter-rater reliability was addressed by asking how likely it would be that someone else using my categories would evaluate a transcript as I have. Two raters (practicing Registered Nurses) were given a copy of the results section of this dissertation and were asked to independently look at a transcript for: 1) presence or absence of a category; and 2) if a category was present, an example of how the woman expressed herself in that category. For example, for the category "Coming to Know,"

the rater was asked, "How did the woman <u>come to know</u> she was miscarrying? What was her first sign? Was there a point of confirmation? What was it? What were her emotions throughout?" Each rater was asked to support her responses by listing the numbered lines in the transcript which supported the categories. A copy of the Inter-rater Reliability form is in Appendix G.

The raters claimed that the categories were easy to understand and insightful. They were in complete agreement that all categories were present in the transcript they were each given to review. In addition, they closely concurred in their assessment of the informant's expression of her experience in each of the categories. Lastly, the raters evaluation on the transcript very closely matched my original analysis of that particular informant's transcript.

Of course, given my central role in this study, I have to be viewed as perhaps the major tool in this investigation. The reliability and validity of the responses I was able to elicit is an issue of real concern. In order to gain some feedback on how reliable and valid an interviewer I was, a nurse ethographer was asked to review three tapes and transcripts from this study. The transcripts of ONE, NINE, and SEVENTEEN were reviewed. My questions to the reviewer and the reviewer's responses are summarized in Table 9.

<u>Content validity</u> was attempted in my method of generating the interview schedule. As stated previously, the protocol has been designed to reflect the lay literature, the pilot study, and the professional literature. For the pilot study, I asked women who had

TABLE 9

Nurse Ethnographer's Critique of Research/Interviewer

#### Mv Ouestion

- How good an informant was each woman? How good was the informant at teaching me about her loss?
- How good a researcher am I? How well do I "flow" with my informant? Do I pick up cues? Do I appear to be comfortable? Can I get at the woman's story without forcing an answer from her?

- Do you see change in interview format over the three interviews?
- 4. Do you feel that when all is said and done that you have a "gestalt"--an overall feel for what the informant's experience was?

#### Critical Comment

- Each was distinct...as they had had diverse experiences ...each was superb in telling their story.
- 2. You as a researcher-a good learner. The difference be-tween ONE and SEVENTEEN's interview is remarkable as vou moved from being a closed question interviewer to a patient learner...You had a certain amount of information you wanted and you directed their history telling to these points... The first tape was so directed I did feel you cut her off several times in order to move on ... Your informants seemed relaxed-certainly a clue to your own state.
- You are researching a specific event and it is appropriate in qualitative method to keep focused on the event...I felt you kept to the same format consistently...I believe you did allow each to individualize.
- I was absolutely shuddering as each told their story. If I hadn't listened, I would have doubted you could have gotten such rich descriptions.

miscarried (the experts) to review my interview schedule for comprehensiveness. I repeated this procedure for this larger study. An additional strategy that I used in the study was to end each interview by asking the woman if she felt there was anything about her experience which I failed to ask and that she thought I needed to know.

Construct validity or how close I really came to getting at the human experience of miscarriage and the caring needs of the women who miscarried, is considerably more difficult to establish. If we can accept that there are multiple realities depending on the perspective of the subject, then who can say that my perspective is any less real than any other perspective. The important point is that I need to make it clear how I established my reality. Perhaps if others can see the credibility of my method and conclusions, then they can decide for themselves whether or not I have done a worthwhile job of describing the phenomena I claim to have described. One way I attempted to check the credibility of my findings was to ask two people who are knowledgeable in the area of early pregnancy loss to evaluate my overall results as to how close I came to their experience with miscarriage. My evaluators included a lay expert who had miscarried three times and who was not previously involved in the study and a nurse-midwife who had done research in the area of perinatal loss.

These same two evaluators were asked to address the construct validity of the specific categories themselves. This entailed their reading a transcript and providing me with feedback as to how plausible they thought my categories were. Plausibility refers to

whether or not they could see how I might have derived the categories given that transcript.

Both "experts" offered support for the validity of the categories. The "lay-expert" validated the categories by reacting to the categories and evaluating herself and her experience according to the categories. The one major suggestion she offered was that the Coming to Know category was guite cyclical and that each new sign of impending loss has to be dealt with as almost a whole new "First Sign." Her comment is similar to my description of the hope-no hope cycle. The law expert stated although the transcript she was asked to review differed so greatly from her experience, she could definitely see how the categories managed to individually capture both her and the informant's experience. The researcher-expert who reviewed the categories "tested" their plausibility by using them to evaluate the transcript she was sent to review. She concurred with the validity of the categories and stated. "I find your categories creditable....The six experience categories well illustrate the grief experience of women with miscarriage. Losing and Gaining and Sharing the Loss. I believe, will be related to length and intensity of the grief experience. The five caring caregories include crisis intervention with an emphasis upon real empathy."

It should be noted that at one point I had considered attempting construct validity by having a couple of raters read a "raw" (uncoded) transcript and evolve their own categories. I quickly rejected this idea because I believe it would be unfair to me to compare my findings (which were based on the entire study) to the findings of a couple of raters whose only experience would be the

time spent in reading a couple of transcripts. This is one case in which I believe that I and the consumers of my study must be willing to recognize my expertise.

Related to construct validity is <a href="mailto:criterion">criterion</a> (concurrent or <a href="mailto:predictive">predictive</a>) validity. That is, how likely it would be that someone using a <a href="mailto:different method">different method</a> (i.e., a different interview protocol) would find results similar to mine. At this point in time, perhaps the best I can do here is to compare and contrast my findings to those of others who have written about miscarriage (i.e., Borg and Lasker, Friedman and Gradstein, etc.). This is done in the following chapter. Ideally, I would have been able to compare my findings to the results of quantitative measures which I had administered to my informants. Since there are no measures that get at all of my questions, this point will have to remain in the realm of the ideal.

A final research issue to be addressed is the <u>usefulness</u> of the theoretical model I generate. Glaser and Strauss have suggested four requisite properties for theoretical models which have been generated via qualitative study. The first requisite property is that the theory must closely fit the substantive area in which it will be used. This is similar to a construct validity issue; this was evaluated when I ask my professional and lay evaluators to rate how closely my categories came to capturing their experience.

A second property is that the theory must be readily understandable by the lay people and professional people to whom it will apply. This property was addressed via my construct validity and inter-rater reliability strategies. Both of these strategies

mandated that I describe my categories in such a way that they were sufficiently understandable for the raters to use.

A third requisite property is that the theory "must be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area" (Glaser and Strauss, 1967, p. 237). It is my hope that there was enough variability in my sample that the model I generated will have a fairly broad range of application in describing the phenomena of study. Admittedly, the lack of teenagers, single women and clinic patients in this study limits the generalization of findings to these groups. The final criteria of Glaser and Strauss is that the theory "must allow the user partial control over the structure and process of daily situations as they change over time" (1967, p. 237). I translate this criteria to mean that the theoretical model must capture process and be of use to clinicians who care for women who miscarry. Hopefully the findings of this study will be able to provide the practicing nurse with insight for assessment, intervention and evalution of the changing nursing care needs of the woman who experiences loss in early pregnancy.

### CHAPTER IV

### THE DISCOVERY

## Introduction

This chapter has to start with an acknowledgement of the 20 women who taught me so much about their experience with miscarriage. For the openness and warmth with which they took me into their homes and lives, I am forever indebted. It is my hope that in this chapter I will be able to provide a meaningful interpretation of their collective experience without doing a tremendous injustice to any one woman's unique experience.

## **Vocabulary**

As this study progressed, a vocabulary with which to operate emerged. In Chapter III the word "code" was defined. In this chapter, the meaning of the words "category" and "situational variable" must be conveyed. A category is akin to a process or an active meaningful sequence of events. In this study, two classes of categories are described: experience categories and caring categories. The experience categories capture the processes that each woman who miscarried seemed to go through - each in her own unique way. These categories are: 1) Coming to Know; 2) Gaining and Losing; 3) Going Public; 4) Sharing the Loss; 5) Getting Through It; and 6) Trying Again. The caring categories are the thought processes or meanings conveyed which seemed to underlie the external caring

behaviors provided by others. These categories are: 1) Knowing; 2)
Being With: 3) Enabling: 4) Doing For: and 5) Maintaining Belief.

The situational variables are similar to Klausner's (1971) individual/environmental demands, constraints and resources. The situational variables strongly influence the woman's perceptions and actions in any of the experience categories or in her perception of any of the caring categories. It is the situational variables that account for the unique way each and every informant lived through her loss. Situational variables include such things as obstetrical histories, religious background, relationship with spouse, sibs, family's desire for children, usual coping strategies, etc. In this study, situational variables will be discussed if, and only if, they help to better convey one of the six experience or five caring categories.

The experience categories (which are depicted in Figure 3) will be described first. These categories are believed to present a new profile of miscarriage. They represent six processes which each woman seemed to have to work through. These categories will be presented somewhat in order of occurrence although this is far from specifying a time line. Conceivably, aspects of all six experience categories could be simultaneously occurring at any point in time. They are probably not all inclusive of everything that a woman has to deal with in adjusting to early pregnancy loss; however, they do offer a perspective for understanding some of what is involved. Also, these categories are far from mutually exclusive. There will be a noticeable amount of overlap between categories. Some of the lack of clarity may be attributed to the "newness" of this research:

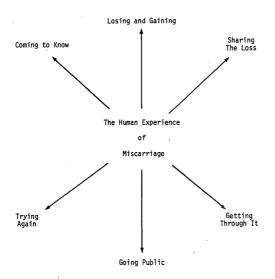


Figure 3. The Six Experience Categories which underlie the Human Experience of Miscarriage.

however, it must also be acknowledged that an equally large amount of the overlap is due to the fact that there are few (if any) human behaviors or thoughts that are able to be pigeon-holed as having one and only one underlying meaning.

## The Experience Categories

### Coming to Know

Stated briefly, Coming to Know is the confusing, painful process of balancing mounting evidence of impending loss against hopes of a healthy pregnancy outcome. As with all the categories to follow, Coming to Know is a process which takes place over time, the beginning and endpoints of which defy isolation. Generally, there did seem to be a sequence to this process: previous ideas, premonitions, first sign, waiting, confirmation, and realizing you are no longer pregnant.

Coming to Know preceeds all other categories in both order of occurrence and perhaps, order of importance. It describes the taking in, cognating, feeling and realizing that the pregnancy is no longer viable. Each informant in her own way had to finally Come to Know that she was no longer going to carry through on the path she began at conception. Whereas it is impossible to describe each woman's experience, an attempt will be made to convey a sampling of the ways in which Coming to Know occurred.

<u>Previous Ideas</u>. Preparation for one's own pregnancy loss and recognition of the first signs of miscarriage appeared to be

influenced by the previous ideas one held about miscarriage in general. Each woman was asked if she had any previous ideas (that is previous to their loss) of what miscarriage entailed. Situational variables which seemed to impact most strongly on this were the informant's obstetrical history, obstetrical history of women close to the informant (i.e., her mother, sisters, close friend) or knowledge of more distant acquaintances who had miscarried. For instance, FIFTEEN'S experience was:

MF:

And let me ask you this question. Have you ever given any previous thought to what it entailed to have a miscarriage?

FIFTEEN: No.

ME:

You haven't? So you had nothing to compare yours to? Just never was a thought to you?

FIFTEEN:

No, because I was always healthy. My mother had four kids. Never had any problems.

And THIRTEEN shared:

THIRTEEN: I don't think I'm explaining this very well. Before when I thought of miscarriage, I didn't think it would be as traumatic as having a stillborn. I though well, sure, you know, that is bad, but I've suffered the ultimate (stillbirth) - which really isn't the ultimate. I think that would be the poor women that have the S.I.D.S. thing happen to them. I think that would have to be...

And ONE stated:

ONE:

Yes. I talked about it with my friends before, you know, my girlfriends. I just told them that I could never imagine having a miscarriage, you know, I could just see what it could do to you. I couldn't imagine losing a kid, a baby, because one of my friends miscarried and she felt really bad. She hasn't gotten pregnant since. It can't be too good for you.

ME: From whatever v

From whatever you imagined a miscarriage to be, was it anything like what yours actually was?

ONE: Yes.

ME: It was?

ONE: It was what I thought it would be. (Teary-eyed,

looking down, wouldn't look up.)

ME: Hard?

ONE: Very hard to take.

<u>Premonitions.</u> Moving along from the global preconceived ideas to the more personal premonitions, I asked each informant if she ever feared that she might lose her pregnancy. This was an attempt to identify how prepared the woman was to accept herself as "a miscarrying-type." The situational variables that seemed to most strongly relate to premonitions were: the informant's and her mother's obstetrical history, some of the "unhealthy things" (i.e., smoking, drinking) the woman may have done early on in her pregnancy, and the woman's having heeded the old dictum to "not tell anyone until after three months have gone by because you never know what will happen." When I asked TWELVE if she had any premonitions, she replied:

TWELVE: I worried about it, yeah.

MF: You did?

TWELVE: Uh-huh.

ME: Worried because of the things you said you had

done earlier?

TWELVE: I guess because I have a tendency to miscarry. I think I was worried because of everything I had

done before I found out I was pregnant that something might be wrong with the fetus, you know.

ME: Was there ever a time when you kind of let the

worry go by?

TWELVE: When I passed, I think at about two and a half

months, maybe ten weeks or so, and I guess that's when I started feeling better, too.

ELEVEN worked as an ultrasound technician which professionally put her in contact with many women who miscarried. Our discussion follows:

ME: How about your girlfriends. Why did you not let them know you were pregnant?

ELEVEN: Well, because I know there's a high percentage of

miscarriage during the first three months.

ME: Did you suspect that you were going to miscarry?

ELEVEN: No, I did the same thing with my first pregnancy and I didn't miscarry. Also, my mother had told me that (short laugh) at one time. She said, "You know, it's silly to tell people you're pregnant during the first three months because so many

women miscarry."

When I asked SIXTEEN (who had a history of a stillbirth and a difficult labor) if she had any premonitions of miscarriage, she responded:

SIXTEEN: None whatsover. 'Cause I didn't worry about miscarriage...I worried about stillbirth, I worried about accidents of labor, I worried about problems with it, I don't know. I didn't really, I worried about it a little, but it wasn't my major fear or anything. I worried about it just because I was worrying about everything.

First Sign. The first true evidence of miscarriage occuring was coded as "first sign." Generally this first sign seemed to serve more as a threatening note than a full realization of loss. As in the Lazarus Stress and Coping Paradigm, the primary appraisal of the first piece of evidence took on different meanings depending upon the woman's perception of how serious the evidence was. Many of the women had or were able to "rally up" the "resource" of knowing that spotting or slight cramping was sometimes normal; hence, they could discount the sign as fairly benign. For example:

SEVEN: Well, I started bleeding on a Thursday, ever so slightly. And I called the doctor, and they said to let it go awhile. If it was just real slight, not to worry about it. She told me that sometimes after intercourse when you're pregnant, it'll cause bleeding a little bit.

ME: And had you recently had intercourse?

SEVEN: Yeah, so I though well that is a reasonable explanation. It was just the first time it had happened. And it did stop within a couple of hours. It was very slight, so I figured that was fine.

SIXTEEN referred the spotting back to her earlier pregnancy:

SIXTEEN: I was laying that tile floor back there which is no big deal really. Um, and on Sunday afternoon I

had a little spotting, you know, pink tinge, barely there, kind of spotting which really didn't alarm me that much because I had it with Kay, too, once or twice. And [the doctor's] attitude then, and I've even read a number of times that that often happens. It's not a big deal, it's rarely anything to worry about. Because it wasn't flowing. It was definitely spotting. And so I mentioned it to Mike, but I didn't call the doctor or anything on Sunday. And then there wasn't any more of it and I though well, I'll mention it at the next visit which was just a few days away.

NINE discounted her slight cramping as Braxton-Hicks contractions. She told me:

NINE:

I had been getting the usual Braxton-Hicks all along, on and off, and I understood those. They didn't scare me or anything. Well, I was getting the same thing that morning, but they never let And around noon I thought these haven't let These aren't going away. Well, I rode my bicycle to work, and I got to work and finally I said to the supervisor, you know, I'm having these Braxton-Hicks which I've been having, but they're not letting up. Very light sensation of cramping. I wouldn't even call it a cramp, light type feeling. And everybody said, "Oh they're just normal Braxton-Hicks." And I thought. "Oh vea. vea."

For some of the other informants, the first sign seemed a bit more ominous, more of a threat. It was as though their "antennae went up."

FOUR:

So I got back home here on Sunday and I still had a little bit of the discharge, but nothing heavy

or anything. It wasn't like bleeding.

ME: How did you feel emotionally during all of this? FOUR:

A little, just like nervous. Nervous and confused and just, I don't know, just kind of scared about the whole thing, like I didn't know what was going on.

ONE was perhaps a bit more aware, however, she chose to "forget about it."

ONE: I was bleeding and I went to the bathroom and a bunch of stuff came out.

ME: So that was the first sign when a whole bunch came at once? You didn't have just a little spotting before that?

ONE: No, I was really upset.

ME: Did you know then that you were having a miscarriage?

ONE: Um, well I was really wanting a baby really bad so I was afraid to tell my husband. So I don't know. I just didn't know what to do. I just kind of just wanted to forget about it so I didn't go to the doctor or nothing.

ME: 0.K. and then when did you finally go to the doctor?

ONE: Oh, it was, oh, I would say about a month after that.

TWENTY, who had had six previous miscarriages (and no children) was considerably more aware of what was going on, yet, even she didn't totally accept the first sign as final.

TWENTY: The first sign I thought I was miscarrying is when I would go to the bathroom and I would wipe and I'd see like little dark specks, and that started depressing me, you know. And then I had gone to the doctor, and he said everything was normal, and when he examined me, he did take out like a clot of dark mucus or whatever, you know. And he was

saying this was normal. I mean, for some people...I can't remember what he called it, but anyway he wasn't like, "Are you miscarrying?"...he was saying, "This is...your uterus is still closed up tight, and you still are carrying a baby."...But, then when he pulled that clot out, I...it just does something to me because I've been through that before, you know...You go through periods that (voice shaking here), you know, you stop, don't see anything, you think everything is O.K. Three days later, it just happens (crying).

Maiting. TWENTY's experience moves us along to the next phase of Coming to Know which I call "waiting." Waiting is that phase between the first sign and the point of confirmation. During the waiting time, hope and despair seem to vacillate. The husband, occassionally God, and sometimes the woman's mother were important influences on the woman during the waiting period. SIXTEEN's story is fairly typical and poignantly told:

SIXTEEN: The following day when it was more than spotting, yeah it really panicked me. And I called Mike and he came running home and um, it was just, it was a horrible night. You know. [The doctor] told me to lay down. Get lots of rest. Um, don't do anything until morning when he could get me in...Yeah, and we cried, both of us. And worried. I mean just even talking about it [now] we both get a little misty and, um, I was just absolutely terrified. There was this horrible feeling of just waiting for something to happen. There was a feeling of wanting to hang onto it somehow, you know. What can you do? I mean something's happening and you can't, you know, just wanting to say DON'T, don't do it. Everything's fine.

And then later in the evening everything started feeling so much more normal. I stopped, the flow sort of stopped. And we sort of went on about our evening...and when I got up in the morning, um, I hadn't had any flow all night. So it was, I don't know, all of a sudden it was morning. Everything

felt really normal. And too normal for anything to be wrong. There was just, life was, you know the sun came up, you know, everything was normal...and I really felt like you know obviously everything is O.K....I mean I hadn't completely stopped worrying, but I was feeling much more confident that everything must be O.K.

NINETEEN, a single woman who was engaged to be married, had been told as a teenager she could never get pregnant. She had never used birth control in her life. At 32, when she was told she was pregnant, she was incredulous, but ecstatic. She described her "waiting" as follows:

NINETEEN: I thought that, um, I guess I just thought all along, "Please, no," and I just knew. You know, it was 'ike somebody's fooling me, and I was saying, "Please don't, don't be a miscarriage, please don't"....The night of the spotting I finally got hold of my mom. She came over and stayed all night until Tom came home....And I was, you know...and he kept telling me, "You're thinking too negatively. It doesn't mean that for sure." But I think I knew. But then I had my hopes up because Friday, I wasn't too bad, and Saturday, I was still kind of spotting, but Sunday night, then I was bleeding more, and a little clotting, and the pain...and Monday...the test was still positive. I thought, you know, it was like my hopes were up.

NINE, who is an ultrasound technician, had an amazing story to tell.

NINE: At a certain point during work, I thought I had a feeling I'm losing this baby. And I immediately put it out of my mind and thought no I'm not, no I'm not. Well by four-thirty after everybody else leaves, I work 'til six. I filled my own bladder and I scanned myself at work with nobody else

there. This was really interesting. I'm really interested in what I learned about myself in this situation. When I looked in my uterus, my uterus was a twelve week size, and I knew that, and I looked at the baby and I can't believe I did this, but I convinced myself that there was a heartbeat, but that I thought it was a little irregular and that the baby was a twelve week size. And it wasn't. And I knew it wasn't. But I told myself everything's fine.

<u>Confirmation.</u> NINE continued to bleed, then cramp, until the next morning when her obstetrician sent her in to be scanned. This time NINE's supervisor/friend scanned her.

NINE:

They knew I knew. I was watching. They knew they didn't have to say anything like that. I turned around and said to my husband, "It's dead, Mark." [Later], I talked to the doctor on the phone...and I he said, did you have the ultrasound yet, and I said yes, the baby's dead. It's a nine weeker.

Three stories of the "waiting" have been told here. There are seventeen other equally rich sagas which will be left untold. Perhaps in the sharing of three of the other informants' point of confirmation, an appreciation can be gained for their experience. It must be noted here that what was finally accepted as confirmation really varied from woman to woman. For some informants, the ultrasound findings were sufficient. Others needed a physical sign from their own body. SEVEN felt it was O.K. to go ahead with the D and C after the ultrasound confirmed the fetus had died. She related the following:

SEVEN:

I think I had pretty much accepted it over the weekend because I did have that kind of delayed response there (short laugh) where there was a pretty good chance...that I was losing the baby, but I just kind of wanted to hang on to that little bit of hope that maybe everything was all right. And, then once I knew, I just wanted to get it done with.

ME:

The ultrasound was confirmation?

SEVEN:

Un-huh. Uh-huh. Um, yeah, it was, definitely. It was like if they had decided on Friday to go right ahead and do a D and C without knowing for sure, then I would have probably always had those doubts that maybe it would have been O.K. Or, if I had gone ahead like I did and naturally start, you know, to abort the fetus, then that would have been O.K. But, seeing that nothing was happening over the weekend but this bleeding, yeah, I wanted a definite confirmation.

TEN's experience was somewhat unique in that she more or less had her pregnancy and miscarriage simultaneously confirmed. TEN had never been to an obstetrician for this pregnancy. She had plans to go for her first OB appointment soon after her trip to St. Louis. (TEN was a flight attendant.) TEN was in St. Louis when the cramping and bleeding became guite heavy. Here she describes calling her

TEN:

husband from the hotel room:

 $\dots$ it was just a mess of emotions. I was trying to be strong and then being able to be weak around him, and then...and I couldn't even...I was crying.

TEN finally managed to get a flight back to Denver. She went to the obstetrician's:

TEN:

I'll tell you it was a relief to get to the doctor and I lost the placenta there. You know, all that stuff came blasting out in his office. Thank God I made it that far cause it was not, not a pleasant sight. But, um, I was almost relieved when he confirmed it. I mean I felt horrible about that, the fact that I was miscarrying, but I was so relieved that it was indeed a miscarriage and that I hadn't lost my head. It was wierd...the immediate relief, but then the loss.

SIX had a history of infertility. In fact, it was on Pergonal that she became pregnant. When she began to bleed, she was admitted to the hospital. She had been bleeding for several days when one Friday morning there was no bleeding. She told me:

SIX: Well Friday morning when I talked to the doctor and she said, "How do you feel?" and I felt really good. I couldn't believe it. I felt really good. And then I took a shower and I started getting cramps and I started bleeding, and then I thought, you know, I thought everything was fine, and all of a sudden...it wasn't and that's when it started...I felt so alone. I didn't want to think about it because at that point I thought I'm going to lose it. There's no hope.

ME: Is that the time you knew?

SIX: That's when I think I knew because I thought, this bleeding, this is not implantation. This is something else.

SEVENTEEN told me about an earlier miscarriage she had had within the year. With this earlier loss, SEVENTEEN never received confirmation. Her story was particularly enlightening in helping me to understand the importance of confirmation in the Coming to Know process:

SEVENTEEN: I spotted slightly...I went to ultrasound and [they] told me it was a missed AB...they were going to schedule me in two days for a D and C. I still felt very pregnant. I still felt like, actually, I felt like that there was a big mistake. I felt like that there was a big mistake. I felt like, what if they're wrong? I was scheduled three days, it was real hell. I kept wanting to get another opinion. I really felt that, I'll be honest with you, I just didn't feel that...how can you just run over for a little test and that's the end of it? It's over...and I felt like people can be wrong, tests can be wrong...

SEVENTEEN went on to seek a second opinion and was told the ultrasound was conclusive. She went on to have the D and C:

SEVENTEEN: Apparently all this was on my mind and during the time I was under the anaesthetic, I must have let all my feelings be known to him (the doctor) and when I woke up, all I did was cry. And I couldn't stop crying.

stop crying.

ME:

Did you ever achieve resolution or confirmation?

SEVENTEEN: I felt like there was no reason to continue to research anymore, or to even worry about it because it was not a point of...it was done. I couldn't turn back...you couldn't go back. If it was a mistake, I didn't want to know if it was a mistake because I couldn't have lived with a mistake.

About a year later SEVENTEEN had a second miscarriage (the one that brought her into this study). This miscarriage involved a hemorrhage, three weeks of spotting, a series of positive and negative pregnancy tests, and questionable ultrasounds. SEVENTEEN had even switched obstetricians in order to get a second opinion. Her new obstetrician suggested they do ultrasounds a week apart in order to see if any fetal growth took place; none did and finally a D

and C was scheduled for Friday. SEVENTEEN received her confirmation the night before surgery:

SEVENTEEN: That night I told Bob I was going to cancel the surgery...because it was a Friday...I said, "I'm going to wait until Monday. I want to think it over through the weekend." And see...let my body tell me what it's oning to do.

ME: 0.K.

SEVENTEEN: O.K.? It's really funny. My body did tell me because that night, I got up during the night and now the bright red blood had turned to kind of a dark brown...and it was thick, and I could tell that now I'm starting to expel...

ME: Was that your point of confirmation?

SEVENTEEN: That was my point of confirmation. I got up the next morning; I informed my husband that I wasn't going to cancel the surgery. I was going to go through with it. That I was fine. My husband felt that I had miscarried, but he felt that it was immortant for me to know.

SIXTEEN's confirmation came during her ultrasound; however, the news she received was quite disconcerting, confusing and unexpected:

SIXTEEN: And he started looking for things and he couldn't find anything. (Crying) I mean he couldn't find a baby. This was so freaky to me. I mean it was like, you know, I would have a dream something like this. I would have a dream where they start looking and the baby's disappeared. You know, you make things like that up. That doesn't happen. There's no baby. THERE WAS JUST NO BABY THERE! And oh, it's real upsetting. He called in the other doctor. He can't find anything either. I mean it sounds like a bad joke or something. Um, and you know, it's obvious at that moment that things are over. I don't have the details yet, but things are over.

ME:

Was that your point of confirmation more so than even the blood the day before?

SIXTEEN:

I mean people can bleed and still have babies, but when you can't find the baby, there's no baby there. I mean it's just, and it's this crazy, you know, where the hell did it go? What do you mean there's no baby? What have I been doing here for 15 weeks?...They said it was either absorbed back into the system, apparently that happens. Um, or it was a pregnancy...that their more likely theory they said was that there was a perfectly healthy placenta, a quote, "beautiful placenta."....Well, I'm not saying that it would have made me feel good if they told me the baby had just died the day before, but to have carried around NOTHING?....I mean I'm carrying around a baby inside and there's no baby there? I'm carrying around an empty womb, nothing....A fraud....There never was chance....That is too bizarre to handle....I didn't have a pregnancy. I didn't have a baby. I wasn't an expectant mother. I was somebody who had this strange medical condition going on in their uterus, you know....My body doesn't even do that right, you know. And it should have taken care of ...

It is interesting to note that SIXTEEN's husband took comfort in the fact that there had been no baby. Of equal interest is the fact that with SEVENTEEN's second miscarriage, she also received the news of no baby present on ultrasound. In time she also described this as somewhat comforting. The same news to two different women was perceived each in their own way. To SIXTEEN it was a source of confusion and pain. To SEVENTEEN it made sense and was ultimately comforting. The two different cognitive appraisals of the "no baby" information led to two totally different experiences.

Realizing You Are No Longer Pregnant. Every informant did go on to have a D and C in this study. Some women had oriented

themselves to the fact that they were no longer pregnant prior to the surgery and the D and C served as a "cap" to the Coming to Know process. Although for some of the other women it wasn't until after the surgery that the facts registered. Occasionally this delayed Coming to Know expressed itself in incidental events (i.e., thinking of the grandparents' trip to see the baby in late spring...and then saying, "Oh, no, no. There's no baby."); more often Coming to Know you're no longer pregnant was felt more deeply.

ELEVEN: Well I was depressed, but I didn't, I guess I was still trying to adjust to the idea that I wasn't going to have a baby any more.

EIGHTEEN: ...trying to tell myself that I was no longer pregnant, "Well, I may as well have a drink."....You know, I don't have to buy gallons of milk anymore...

NINETEEN: And it wasn't 'til Friday that it hit me that I was no longer pregnant...it started really hitting me...and I still think about it everyday.

NINE: It wasn't until after the D and C that...that was when, I woke up that morning and I didn't even have to look down. I knew it wasn't there anymore. I knew I was back to normal, and I never wanted to be more un-normal in my life.

Relevance to Assumptions and Pilot Study. The Coming to Know process was alluded to in the pilot study's "confusion-confirmation-relief-looking for the positive" process. The category ended up slightly different for the fact that the "relief" was denied by many

of the women. Looking for the positive shows up in the next category which I've entitled "Losing and Gaining."

These testimonies provide evidence for the meaningfulness of the Lazarus Stress and Coping Paradigm as an aid to understanding the human experience of miscarriage. The appraisal, reappraisal process was apparent in the hope-no hope cycles described here. A variety of coping strategies occurred: some intrapsychic (denying); some inhibition of action (resting); some direct action (switching physicians); and some information-seeking (reading, calling mom). Each woman was faced with the task of appraising the evidence that confronted her. Each chose to cope in her own manner; in time...all had to Come to Know.

## Losing and Gaining

Losing and Gaining depicts the multiplicity of perceived losses and gains amongst the informants. Each woman was unique in assessing the overall meaning of her early pregnancy loss. The differences seem to have their roots in a multitude of situational variables. Some of the strongest influences on perceptions of losses and gains were: history of pregnancy loss (especially recent miscarriages); having seen an ultrasound; relationship with spouse; family's desire for children (which was immeasurably strong especially in families with infertility); and degree of involvement in early pregnancy.

In Kirkley-Best's 1981 dissertation on maternal attachment and grief at perinatal loss, she found that the variable which most highly correlated to grief at perinatal loss was gestational age. Kirkley-Best viewed attachment as a lifelong process, the roots of which appeared in the unfolding maternal-fetal/infant relationship. She emphasized the need to focus in on the fact that there was attachment/grief at early pregnancy loss; rather than discounting it as less than the attachment/grief in late pregnancy loss. Two other findings of Kirkley-Best were: 1) that there was not a leveling off of attachment/grief scores at quickening which to her meant that, "Quickening itself may be only one aspect or milestone of attachment of which there are many"; and 2) Kirkley-Best's impression was that, "Grief responses to loss in the first trimester are indicative of grief at the loss of future plans and the "pregnancy," whereas grief at later loss is grief over the severing of an attachment to a particular child, an attachment already well-formed at birth" (Kirkley-Best, 1981, p. 86).

The findings of this study are that there was indeed attachment indicators and grief at loss in early pregnancy. Similar to Kirkley-Best's findings on quickening; the two women who felt movement in this study stated:

SEVEN: It just seemed to solidify the whole idea even more. It made it more real. Every little thing like that that happened made the baby more real and more...instead of, it seemed like, those little things...instead of making it feel like the baby was a part of me, made the baby it's own seperate little identity for us.

TWELVE: It just told me it was there. I really didn't know it was fetal movement that much. You know because it could have been gas, you know, moving around my stomach.

ME: So was the fetal movement any big event for you?

TWELVE: No. I think we were pretty attached to it.

Kirkley-Best's "impression" that early pregnancy loss involved present pregnancy loss and future child loss was quite similar to my pilot study speculations. However, I no longer fully concur with that impression. Some of the women in this study very strongly felt a loss of a particular child now. These informants focused in on the present relationship they held with their child prior to loss. They saw themselves as mother even in the earliest weeks of pregnancy. Obviously, the findings of Kirkley-Best, the pilot, and this study provide strong threats to Speck and Kennell's assertion that maternal attachment occurs only after fetal movement is felt (1980).

In order to present the category "Losing and Gaining" in a manner that will capture the diversity of experiences amongst the informants, it was decided to present the findings in the form of a table. Table 10 depicts Losing and Gaining as consisting of four parts. The first column indicates the woman's self-assessment of her attachment to the fetus/child. Column two lists the woman's losses and column three identifies her gains. The fourth and final column is provided as a means to convey the woman's overall assessment of her pregnancy loss. Each woman was asked to summarize the whole event in one word or phrase. The words chosen by each woman seemed to best convey the personal meaning her miscarriage held for her.

<u>Summary of Losing and Gaining</u>. It must be noted that a number of the women had previous abortions (elective therapeutic).

TABLE 10 Losing and Gaining

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
ONE	Yes, I just think that I had something in my body and I really loved it.	My baby, my childyou don't feel, you know, proud of yourself. It might happen again. My husband felt the same way.	Not that II never did.	Painful and a big loss. It just makes you feel like you ain't nobody.
TWO	We were both attachedwe'd always talk about it. When he'd leave, "Take care of Junior," you know.	A child and a part of myself, I did feel real empty afterlike something had left meThere will always be a spot for that baby.	Like say there was something wrong with the baby It helped our marriage relation- shipwe got a lot closerIt's just made both of us really grow up.	Mixed emotions helped me and hated itwe got closer lost the baby I was looking so forward tothe emotional pain.
THREE	(First Interview)  If I had made it to  like six months  where I wasn't big felt kicking  might have always  had a place	The chance to be a mother. I didn't really lose a personA blighted baby.	A lot of under- standing, more sensitivity A loss/gain, that is a sensitivity to the joys and losses	Painful more than any- thing, very unpleasant, feel you don't deserve itWhen I think about it, it hurts just as much.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
THREE (Con'd.)			that life can bringSensitivity to what it means to be a mother.	
	(Second Interview) Oh definitely, I just was ready to love that babyalready sort of making plans.	A child is a word I would use, a preg- nancy, a part of myself, not a fetus.		
FOUR	Yes, definitely, it was a part of me and Tony it was going to be our child.	A child, very con- fused, relief, sad, upset, didn't know what to feel. When I look at our daugh- ter and see what that child could be	Not to say grow up but learn more about yourself and losses and how you handle them.	Emotional-tearing apart time for me confusedhorrible the D and C to physically hear that and feel thatthe machine with the blood all coming outvery upsetting.
FIVE	We nicknamed him. He was firmly entrenched in our little family. Already, we talked to him like he was already there.	The pregnancy was a condition. The child is what it was all about. It was my secret something to smile about all the	The realization that once I have the baby, it will mean so much more. It brought us closer. I realized	Pain is the thing that keeps coming to mindNot loss, that could cover me losing my wallet. It hurts so much to get used

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
FIVE (Con'd.)		time. He will always be our first child a death.	how many friends we have.	to the idea that [he] is never going to exist except in our own memories.
SIX	I knew there was, something was there. I just was really happy I was pregnant. Maybe if I'd been farther along, then	A part of me, a part of Jim. Even if it wasn't really that big, it was still a part of us that died! knew it's not really a baby. It's just a thing. I lost a little of my own self-confidence there for a while.	At least I know I can get pregnant and I can try again. It made me understand he really does care. I think it brought me and Jim closer.	A lot of pain physical pain, your emotional pain, your feelngs are so mixed up, you don't know who to turn to. Why did it happen, why me?
SEVEN	Yes, I wanted it and accepted it immediatelythe morning sickness and all maybe made it more real. More to the pregnancy, didn't have a personality for the baby or anything like that.	Definitely a preg- nancyI can't say I specifically lost a child that way, but for the chance to have one.	I learned a lot about miscarriage, a lot of people have gone through them. It's not an abnormality. We gained. It brought us closer. Our first real crisis.	Two words, two parts, disappointment in the initial part and growth for what I have had to experience and learn and gain to get over it.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
EIGHT	Yeah, to a certain extent. Not to the point that I fell apart, butI don't see how you can't be attached to it. I guess, it's a little person.	A part of you (crying). It's just something you made together and its gone. I can't really say it's a child. It's not yours 'til it's there. Can't hold it	I can't really sayNo, no. I'd have to say it deepened our relationship in the respect that he really cared.	Anger, fear and a bit of courage at the same time, anxious about being in the hospital, definitely loss.
NINE	I feel like I knew that baby, but I was the only personand that's part of whyWhat makes you sad, hard to share that. He said I think when you start showing, it's going to hit me.	A memory of a child you never got to see. A sadness you carry with you always. A baby you never got to hold or take care ofour first child.	Learned a lot about myself, about my ideas as a mother. This is hell now, but in a couple of years, I'll look back and be glad I went through it. We really stuck together.	Enlightening. It opened my eyes to a lot of things. Lot more positive than negative. More sensitive at work.
TEN	If I'd felt fetal move- ment and things like that I would have put it into a little face, dress, bike	Hopes and dreams. The chance to be pregnant. I was thinking about breast feeding.	About ten pounds! All kinds of things, a sense of vulnera- bility, I was humbled. I thought	Just a lossof baby, pregnancy, going out, and buying maternity clothes, everything.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
TEN (Con'd.)			of a lot of my holier than-thou-attitudes.	<b>)-</b>
ELEVEN	No, actually I had done an ultrasound and had just started getting the idea I was pregnant.	I didn't really see a fetus, just membranes. I didn't really lose a living human being at all never formed into that.	It made me realize I should be thankful for what I have the familythe happiness.	Depressing. It just seemed like I was down for several days and that was probably the most lasting thing I experienced during the whole thing.
TWELVE	Yeah, at ten weeks, on ultrasound we actually got to see the fetus Actually seeing it made it more like a baby fetal movement, just let me know it was there. We have a picture from the ultrasound.	A child, a living thingIt's a death without a grave. You wonder did it think? We both cried. He told me it was a boy.	At least I didn't get to hold it. That would have made it worse. At least I know I can have more children.	Heartbreaking. To go through as much as I did to get pregnant. To know it was on the way and then to die.
THIRTEEN	I think from the moment she suspect's she's pregnantwhen she's trying to get pregnant I'm speaking for myself.	More than just a baby. A little bit of self, respect or esteem. I blame myselfa belief in	I can't think of anything that you could gain.	A lonely, helpless experience, you can't pay someone to care You have no control over the situation.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
THIRTEEN (Con'd.)	You know it's there, the way you feel physicallykicking names around	God. Little smiles, no open arms for mama or daddy.		It just comes out of nowhere and gets you.
FOURTEEN	Just beginning. It takes a while to get it in your mind there's really some- thing there. You'd have to be, but not like after you'd heard the heartbeat or felt movement.	We didn't lose a little Britain or a little Jessie. It could have been worsejust a baby and not a name. A fetus, more a physi- cal something that we created.	If I ever lost another one, at least I know what I'm going through. There's a reason for it. Someday I'll understand. Much easier than losing a child that was already here.	Growth experience, made us closer, maybe a first little thing to let us know everything isn't always goodNot a tragedy, not devastating.
FIFTEEN	It was our sole topic of conversation. Would it have my eyes, reading everything, every class, names, movement would have been just one more elation	Devastating on more of a whole basis. From childhood I wantedthe utmostchildrenhave to decide on another dream because your dream's not going to happen. A future child will not reclied the other trees.	Brought us a lot closer, more depen- dent, sensitive, slowed the pace of life, more time doing things, talking together.	Devastating. It destroys so many things at one time: your zest, your humility, the baby. It can happen again. Where does your life go from there?

place the other two.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
SIXTEEN	I thought about Kay's baby brother or sister. The visions were always two children. Fantasize. Dreams, planning, always thinking about the family, always, always. It was the new kid. He had a name.	A child, Kay's baby brother or sister that would only be 21 months apart from her and be her friend and play with her.	I can't think of anything. Not a thing.	Pain. It hurts. It's unfair. It comes out of nowhere. It's gone, boom. You can't have it anymore.
SEVENTEEN	Unborn oneAfter having two, yeah I would say so, I had all-ready imagined what it would look like, what kind of personality.	Future expectations. somehow I felt this one would not have been normalThe possibility of probably ever having another one.	Our relationship is probably better than its been in a long time.	It's like losing a child be it born or not bornIt doesn't matter. It's still a child and you know it's a child.
EIGHTEEN	We gave it a stupid name. Wy body was changing. I wouldn't look at the ultrasound, didn't want to become more attached.	A loss of life, a fetus/child, loss of control, plans, a lifestyle, all of a sudden, I wasn't pregnant any more.	Better that this would have happened than perhaps giving birth to a child that would die shortly after or be very deformedvery defective.	Loss of control encompasses it all the planning, all the hope, the one thing that you want so much to controlyou don't. It's just devastating.

Table 10 (Continued)

Informant	Were you attached? Why?	What did you lose?	What did you gain?	Can you sum it all up in one word or phrase?
NINETEEN	I wanted it so badly just real excited about being pregnant. Already picking out names it was like there was a person there already.	A child. I had names and every- thing. For a long time, it was "I want my baby back." I lost a life.	The knowledge that there's a lot of women besides my-self that have gone through it Just even our closeness and everything would be a gain.	Horrendous, going from one extreme of happi- ness to the other total unhappiness in a short and fast time.
TWENTY	I just felt something warm, and the thoughts and the love I could give itthe idea of something being part of you that's growing in you.	A child. It was something living at one time. A part of meit was growing in- side me.	Strength. Strength within yourself and strength in God. Each time you lose something, you grow. We've gotten closer.	Terrifying. It's a nightmare, unreal. It's something you hope for and all of a sudden, it's just wiped away from youand you don't have no cure for it. I've been through hell.

They all shared one common perception of it; that is, it was right for that situation in their life when they did it. Yes, it hurt some now, but it truly did not seem to be a major source of anguish. As a group, they admitted how surprisingly different it was to lose a desired pregnancy at a time in their life when they were ready to have a child.

In the assumptions for this study, it was noted that other recent losses might affect the perception of the miscarriage. In a few cases this was true. For example, TWELVE had lost a pet and a relative in the last two years and admitted she felt overwhelmed by all the deaths. On the other hand, SIX began to bleed at her grandmother's funeral and she saw no relationship between her feelings about the two losses. FIFTEEN and SEVENTEEN's recent miscarriages did seem to strongly affect their most recent loss. TWENTY's multiple miscarriages certainly enhanced her pain.

Losing and Gaining demonstrated that there are quite a range of meanings attributed to loss in early pregnancy. Basically, it appeared that perception of loss was closely associated to the degree of attachment to both the pregnancy and the child/fetus within. Table 10 served to summarize the commonalities and differences amongst the twenty informants. It has been shown that each woman's perceptions of what she lost and how she felt about that loss was uniquely defined by her own specific life situation. Finally, it must be noted that the three informants who were unable to identify anything that they gained in their miscarriage are probably the three women who I perceived to have the most trouble with adjusting to their loss.

## Going Public

Going Public is perhaps the most simplistic category to emerge out of this study. It describes the woman's experience in letting others know of her loss and the price she pays at miscarriage for having (or not having) gone public with the pregnancy. The price for "telling the world" you're pregnant is that the world has to be told you're no longer pregnant; the benefit is there are a lot of potential candidates for sharing the loss. For example, NINETEEN (who was single-engaged) was jubilant when she realized she was pregnant. "I wasn't, there was a little bit of like embarrassment, but I was real public. Everybody was super because I talked about it for years, and they all knew how I felt about having kids." Having gone public with the pregnancy made going back to work a little overwhelming in that everyone stopped by to say they were sorry. NINETEEN referred back to that time as a period of being in shock and as having too much attention. She described needing time alone at Weeks later when the attention wore off, NINETEEN found herself to be quite bitter about the loss and to be feeling it deeper then ever. Perhaps in NINETEEN's case, the initial overwhelming attention served as a buffer for her deeper feelings of loss.

ELEVEN was much more private about both her pregnancy and loss. It wasn't until one of her co-workers demanded to know why ELEVEN was making frequent trips to the doctor and why she was so down that ELEVEN finally told her workmates. Once the topic became public, ELEVEN admitted her need to go home and take time off. Going public also opened up the door for ELEVEN to discuss her loss at work amongst her friends and she did this comfortably from then on.

Previous to FIVE becoming pregnant, FIVE had overheard a workmate being very open about her new pregnancy. FIVE remarked that her workmate should be more cautious about "telling the world" when she was not too far along. A couple of months later when FIVE became pregnant, she did not heed her own warning and told everyone her news. When FIVE miscarried, her supervisor remarked how FIVE shouldn't have made that earlier comment. In fact, FIVE's boss suggested that FIVE had jinxed herself.

THREE was very private about her pregnancy and her loss. She claimed that she was happy she told no one she was pregnant because that meant there was no one to confront afterwards. However, weeks after her loss, when THREE finally told a few co-workers about her earlier loss, she was amazed to find how much she was comforted when others revealed to her that they had similar losses.

A recurrent problem in going public was the actual task of having to tell people you were no longer pregnant. EIGHTEEN had her husband make all the calls. SIXTEEN's friend took charge of informing all the other mothers in SIXTEEN's daughter's play group. FIVE referred to the call home to her mother as a crucial turning point for her. TWELVE's call to her mother was "the hardest part." TEN shared an interesting dilemma: how to tell the dry cleaner. Apparently a couple of weeks earlier her husband had bragged about their news. TEN claimed she would not return to the same dry cleaner until she figured out how to bring up in conversation (to a semistranger), "Oh, by the way, I'm no longer pregnant." Equally awkward was NINE's experience with her veterinarian.

TWENTY's previous experience with her husband's going public in her earlier miscarriages was so negative that she decided not to let her husband know she was pregnant this last time. TWENTY feared he would once again tell everyone. Consequently, she kept the news to herself. TWENTY described her previous experience with going public:

TWENTY: And, you know, so everybody knew. I had to go to the hospital and had a miscarriage. I had to come home with everything else and then call and say I had a miscarriage, and I couldn't deal with going through that part again.

As was demonstrated in the pilot study, a rather difficult public encounter for each of the informants was running into other pregnant women or seeing small babies. EIGHTEEN described an awkward experience:

EIGHTEEN: We have friends we haven't seen to this day who had a baby January 31st. Older kids I could see, you know. Infants I felt like I could not be around. I've gotten my feelings hurt because it got to the point where she called me once after it happened, and I felt like I was a leper on the phone. She could not get off the phone fast enough.

SIX, a Hispanic woman, explained that in her culture a woman is expected to have babies. She stated:

SIX: Is my husband going to listen to his sisters? They say, um, "Oh, look at us. We have out kids already, and you have nothing, and it's her fault." They're really funny. One of them, you know, she's got a little girl, and it's hard for me sometimes because I see her with her, and I want to have that...My sister just had a baby and that really hurt because I wanted one, and she had one. And I'd see my mom with the baby, and they were really excited, and I felt, really, why not me?

TWO had a couple of unsettling encounters with other pregnant women. The first one involved the day she lost her pregnancy:

TWO:

I went to the doctor the next morning and took all of it in a plastic thing and just took it in the office. But, I didn't think it was fair because there were all these women nine months along. And, I was having to take mine in my purse in a little plastic thing. That was probably the worst thing...putting it in my purses..., taking it with me, and then another thing that really hurt was leaving it there. I wanted to take it with me...I don't know why.

TWO's second encounter with "other mothers" involved her sister-in-law. At the time of our second interview, TWO related that her sister-in-law had recently found out she was pregnant. This same sister-in-law was the person who had accompanied TWO to her D and C (TWO's husband had been away on business). Two stated:

TWO:

That has been hard on me. Just because I don't know, they're...and I should be excited for her, but I can't be because it's hard on me. And I told, I just told her, don't expect me to be that happy. I says I'm not being rude or anything, but it's just a little bit hard...Probably because I'm envious, 'cause I want to be pregnant too, and then I had to lose my first one...

Another interesting dilemma in going public is that women who miscarry in early pregnancy don't look very pregnant prior to their loss; therefore, there is no real <u>outward change</u> pre to post loss. On the other hand, women who miscarry at around ten to twelve weeks have generally started to "spread" a little and certain clothes no longer fit. SIXTEEN's dilemma involved whether or not to wear a maternity bathing suit post-loss in front of a group of women who had already been notified of SIXTEEN's miscarriage.

SIXTEEN: The local pool over here has a mom and tot swimming hour that Kay and I have been going to. That second day, physically, there was no reason for me not to do anything. I had a brand new maternity bathing suit I'd been wearing...and I can't wear that cause people are going to be there and know I'm not pregnant. I just had a miscarriage and what am I doing out any way after I just had a miscarriage. I should be home crying. But, if I put on my regular bathing suit, I look like hell, and I don't need to look like hell. I feel bad enough already.

One final component of going public is the <u>comments</u> one is privy to post loss. THIRTEEN's "friends" suggested her loss was a blessing. Conversely, SIX's co-worker's condolences were integral to her recovery. EIGHTEEN and TWELVE stated they would prefer that people say nothing to them about their loss. EIGHTEEN viewed an "I'm sorry," as a prompt to which she had to respond - almost her turn to comfort the sympathisizer. TWELVE felt there was nothing anyone could do. "You can't change it, so why bring it up." Lastly, it would appear that depending on where a woman was in her grieving, she may or may not prefer comments. For example, an, "I'm sorry," too

soon after the loss may be all it takes for a woman to lose her control. The wound was too raw. Whereas an I'm sorry too much later on may prove an embarassment to a woman who is pretty much past her loss and desiring to put it behind her.

## Sharing the Loss

Sharing the Loss refers to the amount of recognition and support a woman received throughout her loss. The husband (or in NINETEEN's case, husband-to-be) was for the most part the significant other in sharing the woman's experience. Others with whom the loss was shared were other women who had miscarried, parents, family, close friends (usually a special girlfriend), health care providers, and the woman's God (religious affiliation). Not all women preferred to share to any great extent. For example, EIGHT and ELEVEN seemed to be most comfortable seeking the majority of their solace from their spouse and in quiet times along. THREE and EIGHTEEN emphasized how much they initially needed to withdraw. It wasn't until several weeks post loss that they were comfortable with expressions of sympathy.

A good rule of thumb was that if the woman saw her usual coping strategy as involving some "leaning on others" then she tended to behave in the same manner here. If, however, the woman tended to have few support systems available to her, then at the time of her loss, she once again found herself alone.

In order to portray some of the ways in which loss was shared, four women's experiences will be shared here. These same four women will be followed into the next category which is called

"Getting Through It." In that category an attempt will be made associate amount of support available and utilized with self-described recovery (or lack thereof). SEVEN's experience is described first.

SEVEN: (Re: Her obstetrician and the office nurse practitioner.) During the whole weekend that I was here at home, they called once and always made me feel like...never to hesitate to call...one o'clock in the morning, whenever. It didn't matter...when I went back for the check-up, he talked for awhile to make sure I was doing 0.K. I never felt like I'd just been processed through.

SEVEN: (Re: Her parents.)
Well, my parents were just real supportive during
the whole thing. I don't think they said anything
in particular...just the fact that they were here
was all I really need from them. And I knew it
was really hard for them. They were really sad.
This was their first grandchild.

SEVEN:

(Re: A girlfriend.)
And I had been having these little feelings about
seeing Timmy and Terry and everything. I thought
it would be a little bit hard. And just having
her tell me that she thought it might be hard for
me to be there with the babies. Then it was O.K.
I didn't have to feel guilty or selfish.

SEVEN: You know, I relied a whole lot on Bill to help me through it, on my parents to help me through it, or not to help me through it. I guess..there was no way they could help, but to understand and to let me talk to them about it..I guess the fact that people, I did get a feeling of how much people really did care for me and Bill, and I, what we were going through, and that other people were truly sorry that we lost a baby because they were truly sorry that we were going to have one. I guess that really made me feel kind of good that other people really would care that much.

In contrast to SEVEN's experience, THIRTEEN viewed herself as very much alone in her loss:

THIRTEEN: Oh I did go back to my other doctor about nerve medication a week ago. He really layed into me.

He said, well you should be over that by...He said that's been what...three months ago? He said, "You should be grateful that you didn't carry to term; it probably would have been deformed or ... " He made me start crying again. He said, "Oh, are

you crying again?"

THIRTEEN: (Re: Her older daughters.)

I mean I think they felt it was something that just concerned me, I don't know. Well, I've talked about it, but I don't see any great response from them so I don't talk to them about it....Oh I think maybe they didn't really feel that it was a loss. That, well they felt some

loss, but not that big a deal.

ME: Is there anybody who really did sound real sorry

for you?

THIRTEEN: No.

MF: Do you feel like anybody really knows your pain?

THIRTEEN: No.

Husband included? ME:

THIRTEEN: I try to tell him, but you can only bring it up three or four times and pretty soon you know he's thinking, "Well, here it comes again. She's going

to...we're gonna hear the whole tirade. The whole story." And then I figure why should I dump that on him.

THIRTFEN: I verv lonely...a lonely. experience...because there's not too many people that really care...and you can't find somebody to

care. You can't pay somebody to come and care.

FOURTEEN's experience was 180 degrees away from THIRTEEN's:

FOURTEEN: Everybody's all right there to help take care of the kids. Friends who just had a baby wanted to bring dinner down...just everybody's concerned. I was embarassed I had so many flowers...all from people my husband worked with that I don't even

know.

FOURTEEN. (Re: Her priest friends.)

We talked to John so he knew about it. Robert came walking into the hospital into the area where you're not supposed to be and I was in pre-on waiting. And then our priest here came down so there was that support. My God, we know so many people.

FOURTEEN: Friends who accompanied FOURTEEN and her (Re:

husband to the hospital.)

And then actually we didn't have a lot of time to think because our friends came right away and we all prayed together and talked together and cried together. They had been through a miscarriage several years ago between two of their kids. Like she said, "It does and it doesn't help to say that I've been through it, too, and I know what you're going through."

ME: Why those friends? Any particular reason?

FOURTEEN: Oh. we had, we, at our Marriage Encounter, there are so many people we could have called....We are

in a sharing support group with them and a priest

friend of ours.

TWENTY's experience was somewhat unique. Because of her multiple miscarriages and her husband's past inability to deal with that loss, TWENTY did not tell him she was pregnant. He learned of her pregnancy at the same time he learned of the need for his wife to go in for a D and C (and ultimately a tubal ligation).

MF : (TWENTY had just told me about the "gush" of bleeding that she felt while she was in the

bathroom.) You called your husband in?

No, because he didn't even know. He didn't know TWENTY: until I got ready to have surgery because he gets

too emotional.

ME: He knew you were pregnant though?

TWENTY: I didn't tell him. ME: You didn't tell him you were pregnant either?
Tell me what that was like.

TWENTY: Very hard (crying) because before we enjoyed the joy of me getting pregnant. He was so happy...and he was telling everybody and everything. The day after he called his folks, called my folks with the miscarriage and all, so I could...it's enough for me to deal with my own [emotions].

ME: Did you tell anybody else?

TWENTY: My boss knew cause I had to take off work. My sisters knew because I had to move and I couldn't be doing no lifting under the circumstances...so they knew.

TWENTY: (Re: Receiving the results of the ultrasound.)
My husband was here, and we were making a drink.
I wasn't alone. The doctor called and said he got
the results of the ultrasound, and I had to hide
because of my husband. I had to hide my feelings.
So I just kind of said that was Dr. Nevala. He
said that it looked like I was pregnant, and I
started bleeding and it looked like I was
miscarrying, and he's finally telling me to come
in for a D and C. And I just kind of let it go at
that...

ME: How do you generally handle tough times?

TWENTY: Generally I try to deal with them myself, you know, but then if it gets tough..because I don't want to put a burden on anyone else...and I may tell my sister a little bit, but not the whole story...and I pray. That's the only answer.

TWENTY: (Our second interview) Well I finally got to explain to him, and he really didn't understand what I go through. And like I never really explained it to him before, and he said, "Well, you didn't ever tell me." And we talked about it one night, and it's just going to take some time for me to really get myself back together because sometimes even I don't want him around. I just want to be by myself, alone. But, he's really been loving and really caring, you know.

Four women's experiences with sharing their loss have been described. There appeared to be two major factors in the sharing the

Loss Category: the first being the availability of support systems; the second being the capacity or desire to use those systems. Both SEVEN and FOURTEEN had a variety of supportive resources available which they were willing and able to utilize. THIRTEEN neither had resources nor the know-how to utilize any that might be open to her. (I offered on three separate occassions to put her in contact with some free counseling which, although THIRTEEN agreed she could use, she never followed through.) It was hard to tell if there were supportive people available for TWENTY. However, it would appear that coping on her own, or with her prayers, seemed to be TWENTY's preferred strategy. In the next category, how each of these four women described getting through their loss will be presented.

## Getting Through It

Getting Through It depicts the grieving patterns of the informants. This category attempts to describe a rough guideline for what might be considered the "normal-range" of grieving styles in early pregnancy loss. Getting Through It versus over it was chosen since quite a few informants claimed to believe you never get totally over it. Data for this category was gathered on second interviews when each informant was asked to define where they were physically and emotionally in recovering from their loss. They were also asked if they could identify a turning point in their grief (a time when there seemed to be more good times than bad in a day), and if they thought they would ever be over it. Table 11 very briefly depicts all twenty informants' responses to those questions.

TABLE 11
Getting Through It

How are you feeling   How are you feeling   Emotionally?   When was your turning   Mill you ever be over   It'n work that   It'n trying to have another one.					
everyday especially now that I'm trying to have another one.  TWO Fine. It's worse now that my sister-in-law is pregnant.  THREE Not good. (3 weeks of flu symptoms.) It'e not had a real "down" since the last time we spoke.  FOUR Fine, fine. I still think about it.  FIVE Fine. It amazes me how fine.  I still think I'm doing me how fine.  I seally good cause I know I week. Talking to my aunt, going back my about it.  Laking the birth control.  About it.  Sweeks. Putting away maternity clothes.  I'm still going to have to deal with this until I hit week to deal with this until I hit week to deal with this until I hit week to deal with this until I hit work full time.  FOUR Fine, fine. I still think about it a little everyday. I probably always will.  SIX Real good. Really good cause I know I can get want, going back it anymore.	Informant				
THREE Not good. (3 weeks of flu symptoms.)  Town's since the last time we spoke.  FOUR Fine, fine.  I still think about it.  FIVE Fine. It amazes me how fine.  SIX Real good.  Really good cause I know I can get my aunt, going back maternity clothes.  I'w naternity clothes.  It.  maternity clothes.  I'm still going to have to deal with this until I hit menopause or have a baby.  I'm over it, but I still think about it.  SIX Real good.  Really good cause I know I can get my aunt, going back it anymore.	ONE	Pretty good.	everyday especially now that I'm trying	taking the birth	
of flu symptoms.)  "down" since the last time we spoke.  "down" since the last time we spoke.  "training.  "training.  "have to deal with this until I hit menopause or have a baby.  FOUR  Fine, fine.  I still think about it.  FIVE  Fine. It amazes me how fine.  I think I'm doing on the doctor.  I think about it a little everyday. I probably always will.  SIX  Real good.  Really good cause I know I can get my aunt, going back it anymore.	TWO	Fine.	my sister-in-law is		
FIVE Fine. It amazes me how fine. It hink I'm doing 0.K. I think about it a little everyday. I probably always will.  SIX Real good. Really good cause I know I can get my aunt, going back it anymore.	THREE		"down" since the last	interview and EST	have to deal with this until I hit menopause or have a
me how fine. O.K. the doctor. little everyday. I probably always will.  SIX Real good. Really good cause I l week. Talking to know I can get my aunt, going back it anymore.	FOUR	Fine, fine.			
know I can get my aunt, going back it anymore.	FIVE				little everyday. I
pregnant. to work.	SIX	Real good.	know I can get	my aunt, going back	

Table 11 (Continued)

Informant	How are you feeling physically?	How are you feeling Emotionally?	When was your turning point?	Will you ever be over <a href="mailto:it?">it?</a>
SEVEN	Fine.	Fine. Things have gotten better.	2 weeks. Doctor's check-up.	(Not asked.)
EIGHT	Fine.	I don't really think about it at all.	1 day. When I woke up in recovery. I felt O.K.	I don't think about it at all.
NINE	Real good. Strong and healthy.	Now, it doesn't get me down.	3 weeks. I just found myself thinking about it less.	I'll always carry a sadness inside.
TEN	Not real good. Real slow getting back the energy.	Thinking about it a lot since I'm pregnant.	2 weeks. Talked with another woman who had miscarried.	I'll think about the miscarriage not the child per se.
ELEVEN	Very normal.	Totally over it.	1 week. Back to work.	I'm totally over it.
TWELVE	Fine.	A lot better. I still think about it.	1 month. Busy at work.	No, it was a child to me.
THIRTEEN	Fine, I have a cold.	I've still got some rough spots, more frequent than the last time we spoke.	At times it's worse. Now, I think it would have been this far along	I'll think of the child it would have grown into.

Table 11 (Continued)

Informant	How are you feeling physically?	How are you feeling Emotionally?	When was your turning point?	Will you ever be over it?
FOURTEEN	Fully recovered.	Recovered.	2 weeks. Just talking about it with my hus-band each evening.	I don't dwell on it, but if I get preg- nant, I might worry.
FIFTEEN	Pretty good. Not as able to endure phys- ical activity as long.	A whole lot better, but I have a hard time accepting the possibility we'll never have children.	I haven't come to a turning point yet.	I don't know the day would ever come that I'd have no whys left.
SIXTEEN	Completely recovered.	Fine. It seems like a hundred years ago.	3 weeks. The first interview.	I'm as over it as I'll ever be.
SEVENTEEN	Fine. Energy level back.	I'm doing real good.	1 month. Time away on vacation.	I'm over it as much as I'm ever going to be.
EIGHTEEN	All recovered.	Pretty good.	4 weeks. A trip home.	There will always be little reminders.
NINETEEN	Fine.	Worse than the last time we spoke. More bitter.	In the beginning there was support. I was in shock. Now I'm afraid I've blown my one chance to have a baby.	I don't think it will ever be totally gone.

Table 11 (Continued)

Informant	How are you feeling physically?	How are you feeling Emotionally?	When was your turning point?	Will you ever be over <u>it?</u>
TWENTY	Much better. Kind of exhausted at times.	I'm still recovering. Good days and bad daysbut not as often as before.	2 weeks. When I could get out of the house.	I don't think I'll forget it.

As Table 11 shows, 17 of the 20 informants were able to identify a time when the acute phase was over. For the 17, the times ranged from one day (eight claimed to do a lot of anticipatory grieving) to 16 weeks ( $\overline{\chi}$  = 3.8 weeks; mode = 2 weeks). There were three informants who claimed to have not yet reached a turning point: THIRTEEN who had a history of a stillbirth and no one to share her present loss; FIFTEEN who had two miscarriages in one year and no close friends in Denver; and NINETEEN who never thought she could have children and was afraid she had lost her one chance.

An average of 3.8 weeks and a high of 16 weeks falls considerably short of the typical six months to a year grieving pattern described by Lindemann (1944), Marris (1974), and Parkes (1965). In addition, the women who miscarried also appeared to differ from the women in the study of Harmon et al. (1981). In their study, some of the women who experienced neonatal loss at nine months post loss were said to be still actively grieving. It must be acknowledged that: 1) I had a rather "loose" interpretation of recovery (the good times in a day outweighing the bad); and 2) there was at most six months from loss to second interview (mean = less than 12 weeks), thus those who recovered more slowly may not have yet reached their turning point; and 3) that the "turning point" probably more closely equates to the end of the more acute phases described in the classic grief studies. Nonetheless, it does appear to be fairly safe to say that the "typical" grieving time for early pregnancy loss is considerably shorter than the grieving time for loss of an older person (i.e., spouse, born child). Shorter, however, does not discount the attention this human loss experience deserves. There is

no weight attached to human suffering, to assume "lesser pain" is to fall into the all too typical assumption that early pregnancy loss is a non-event.

The Getting Through It for the four informants described in Sharing the Loss will support the premise that no matter how brief the grieving of miscarriage is, it is nonetheless real. SEVEN's "Getting Through It" follows:

ME: Do you remember what you were thinking during all of it? (The D and C.)

SEVEN:

SEVEN:

SEVEN:

I just remember thinking that I was glad I was getting this over with. I hoped that they got everything and that there were no complications. I think by the time I was at the hospital I was pretty composed because it had been a long time, you know, several days happening already, and I was glad the pain was over...I guess relief was a big...you know, I was just glad that it was finally done.

(Re: Her husband.)
...for a few days afterward, I was still bleeding and still having...so it wasn't physically, it wasn't tute over with. So I think maybe that's why it took me a little bit longer to get over it. Um, his attitude towards the whole thing was very positive and very helpful to me. Because I got a little...I was depressed. I cried a few days afterwards, but his attitude was just so positive.

Emotionally, I had, it took me a while, the day that it, emotionally, it kind of guit for me and turned me around was when I went back to the doctor two weeks later for a checkup, and they told me everything was fine...I can just remember leaving the doctor's office that day and thinking that this...I just felt like a burden had been lifted up. Up until that time, I still had worries that maybe there was something really wrong still...and as soon as I knew that everything was fine, and that, yes, we could get pregnant again and all this, then I felt fine.

ME: Can you tell me when it went from more to less

intense?

SEVEN: Oh, um not a specific time, huh-huh. You know it was just kind of gradual. Maybe it took about six

to eight weeks.

ME: Do you think about it now?

SEVEN: Oh, on occassion, but not very often. If some, you know, it's usually if someone mentions it or

something.

THIRTEEN who perceived that no one shared her loss was not moving "through it." Her experience is summarized here:

THIRTEEN: (Re: The D and C.)

I've got to say this, they were really...they never mentioned that I was miscarrying or anything like that. They took really good care of me, but nobody wanted to say anything to me about...once in a while I'd cry and I'd say I want my baby, you know. Or I'd, I'm losing it, and they would just sort of pat you on the head type of thing. They

wouldn't talk about it.

THIRTEEN: (Re: The first few days.)

I think sort of numb, emotionally. I mean I lost it, it was over and I didn't really, I don't know what you call it, shock. Even though I knew a few days ahead of time that this was going to happen, it still hadn't quite sunk in. It really hasn't to this day quite sunk in completely, you know,

that there isn't going to be a baby.

THIRTEEN: (Re: Her follow-up visit to the obstetrician.)

I mean I was upset, I cried. I don't know why I

n mean I was upset, I cried. I don't know why I wanted him to give me something, tell me something, information...and I just felt like I got nothing out of that post operative visit.

Ten weeks post loss, THIRTEEN described watching the news and seeing a T.V. personality who had recently suffered a pregnancy loss: THIRTEEN: It was really too bad she lost her baby, and it just hit me like a ton of bricks again. This is how it sneaks up on you, just out of nowhere. And that happens with my other baby, too [her stillbirth]. That you might think you're doing just really terrific and...you start crying. I know it comes down to feeling sorry for yourself, but by God if I don't who is?

At 14 weeks post loss, THIRTEEN described herself as being in a worse state than when we spoke at 10 weeks. Her husband had lost his job in the meantime and she claimed to have never been able to speak to anyone but me about her loss. She attributed her increased depression to the fact that she would have been "that much further along" in her pregnancy at that point.

FOURTEEN'S Getting Through It was much smoother. FOURTEEN'S experience begins with a description of the weekend before her D and C:

FOURTEEN: I guess what we decided when this went on from Thursday to Sunday when I spotted heavily, we both made the decision that there was something wrong with the baby. You know we prayed all weekend especially when we went to church, we asked some friends for prayers and stuff. If there was something wrong, we'd lose it or if I was going to have to stay off my feet for the next six months, I'd just lose it now. First of all, I couldn't do that with little kids, and the two that I have are more important you know.

FOURTEEN: (Re: The D and C.)

On the way to the hospital, I kind of paniced all of a sudden because I didn't really know what a D and C was. I didn't know how much pain. Donald is not the strong one of the two of us so I was being real strong cause I didn't want to, you know, didn't want him to get upset.

FOURTEEN: (Re: 5 days after her D and C.)
And Thursday, it happened, Thursday it hit me.

Sandy had just learned how to say baby and point to my tummy. She woke up this morning saying that, and that was really hard...Everytime I turned around, I was in tears. I couldn't talk about it to one of my best friends who'd been out of town. Saturday was the first day that we had together. We had three things to do that weekend. We cancelled everything. We decided that we needed to stay home and just be together and have time to talk about it. And then like the next couple of nights everytime the kids were in bedwe'd talk about it as much as we could and cried about it. It's more like post partum blues. You've got to get it out.

On the second interview at 14 weeks post loss, FOURTEEN referred back to the week after her miscarriage as her turning point. She summed up her present feelings as "you know I'm sure I'll think of it from time to time, but it's not something that I'm going to dwell on or be upset about the rest of my life."

TWENTY's experience will conclude this section on "Getting Through It." Her experience is somewhat different from the rest of the informants in that she was a habitual aborter and she decided to have a tubal ligation at the time of her D and C.

TWENTY: (Re: Her point of confirmation.)

Well, first thing I thought, well, everything happens...happens for the best. And I felt like

God knows what's best for me.

ME: And that hit you, even right away?

TWENTY: Because I had been praying all the time. And I had kind of built up within myself to be prepared for the best or for the worst. Well, I said maybe this is for the best because I didn't want to bring a child into the world that was deformed or

whatever.

TWENTY attributed much of her "Getting Through It" to being busy with her new house:

TWENTY: And if it wasn't for us moving, like I said things work out for the best, but I'm quite sure...we lived over in the other house for 10 years, and

lived over in the other house for 10 years, and I'm quite sure I would have gone through a lot more depressing days, moments, and times over there than I had over here because of me, well,

staying busy....drapes....furniture...

TWENTY: I didn't grieve right after the D and C. No, but days later I did, when I was alone. I feel sort of lonely in a way...when you think about what

you could plan for a child, what you could do with a child and so forth. I just felt like empty.

Finally, on the second interview at 9 weeks post loss, TWENTY stated, "I'm still mending. I have good days, but not as...good days and bad days...but not as often as I used to."

In associating Sharing the Loss with Getting Through It, it becomes obvious that the more shared, the more rapid the recovery. SEVEN and FOURTEEN certainly grieved, but their loss was not prolonged. TWENTY, who seemed to prefer coping on her own, but also used her religion as support was mending slowly, but steadily. THIRTEEN whose loss was unrecognized by all was in a worse state 14 weeks post loss then she was at the time of her miscarriage.

# Trying Again

The final experience category is entitled Trying Again.

Trying Again focuses on the <u>plans for future</u> pregnancies and the related <u>ongoing fears</u> of future loss. It is interesting to note that the informants were all given a variety of pieces of medical advice

as to when to get pregnant again. Advice ranged from no advice, to wait at least one period to wait six months. Generally the women followed this advice only if it agreed with their plans. Informant after informant would look at me and smile and say, "Well he told me to wait X months, but we have kind of 'forgotten' quite a few times to use anything." Two of the informants who had a history of infertility (SIX and NINETEEN) got a good laugh out of their obstetrician's advice to use birth control. NINETEEN admitted with a laugh that at 32 years of age, she was not about to learn about birth control. SIX and her husband found real humor in the notion of using birth control after they had gone through close to three years of intense infertility treatments.

One other interesting piece of medical advice given to some women was the caution to delay getting pregnant again until the woman felt she could conceive without having it be "a replacement child." Obviously, this advice came out of the caregiver's assumption that the replacement child syndrome is of concern in early pregnancy loss. Whether or not this concern is real for women who miscarry is at this point in time an unknown. However, given the previous section's findings on a briefer Getting Through It, there may be clinical implications for the possibility that women who miscarry need not wait guite so long as women who experience later pregnancy loss.

The "count" at the time of the follow-up interview is fascinating. The number after each "name" (code number) refers to rounded off number of weeks post-loss each informant was at second interview:

Pregnant: 4 (FIVE, 9; NINE, 10; TEN, 14; EIGHTEEN, 17)

Trying to get pregnant: 11 (ONE, 16; TWO, 14; THREE, 24; SIX, 11; SEVEN, 11; EIGHT, 8; ELEVEN, 9; THELVE, 6; FOURTEEN, 13; ELEVEN, 13; ELEVEN, 13; ELEVEN, 14; ELE

12; FIFTEEN, 13; NINETEEN, 9)

Avoiding pregnancy: 3 (SIXTEEN, 7; FOUR, 7; THIRTEEN,

14)

Tubal ligation: 2 (TWENTY, 9-done; SEVENTEEN, 9-

soon to be scheduled)

Pregnant. Each of these four variations on the Trying Again theme will be individually explored. First, those who were pregnant shared one very common concern: an <u>ongoing fear</u> of recurrent problems. The problems feared usually went beyond just a fear of miscarriage in that the woman's previous loss made her cognizant of the fact that statistics of any kind of loss do mean something. These women now saw themselves as potential candidates for other losses (a gained sense of vulnerability). The women typically referred to the day of their previous miscarriage as "D-day" and felt tremendous concern about getting past that day in this pregnancy. NINE's experience pretty much summarizes the concerns of the newly pregnant group:

ME: Are there any carryovers from your miscarriage that has affected your feelings in this pregnancy that you can identify? Any ongoing fears?

shab you can radherry. Tany engoing real or

NINE: Yea, I was going to say, I'm not sure I'm really, really in touch, yet. I'm working that through, that all through. Let me explain it as best I can. Um, I'm real nervous.

ME: Hum?

NINF: I'm real nervous. I'm real nervous.

MF. More so then the last time?

NINE: Oh, vea, um-hum. One hundred percent more because

I know the possible outcome.

ME: Yea.

I'm not sitting here thinking it's going to happen NINF: again, but um, I'm afraid that it will. I'm just

real afraid that it will because the more miscarriages that you have the more you are going to start thinking that you can't have a child.

ME: Yes. um-hum.

NINE: So I'm kind of trying, I'm telling myself to have

fun with it and to feel good about it, and be happy about it, but at the same time I find myself holding back. I'm not telling anybody else about it or I'm not talking about it that much. I, I keep reminding myself that maybe my system's just screwed up and I'm, I'll be due in a week. You know. I'll be real disappointed. And it's just, I'm afraid of the disappointment if I weren't

pregnant.

MF . It sounds to me like you're describing in some

ways a loss of innocence that you had with the last one.

Yea. Yea, that's a good way of putting it. Yea, kind of if you want to say the first time I was naive to it, perhaps, as of having gone through it, naturally you learn something. You learn what it feels like to lose something that you really wanted. And this time I don't want it taken

again.

So this time it's a real threat, whereas the last ME: time it was not a real threat for you in

particular.

Not at all, not at all. No, but I do know also that I will relax. I feel like I'm in control. NINE:

I'm not crying about it or anything.

ME: Yea.

NINF:

NINE: I'm under control and I know that if I get through

the first trimester, will start to relax...And,

I'll start looking at it as fine. And I'll be

ME: Is it going to take the first trimester you think?

NINE: Well, yea, it probably will, because I went to 12

weeks the last time.

ME: You went to 12?

NINE: Maybe not, but I'm, I'm looking at now as it

probably will take another couple months.

ME: To get to that point?

NINE: Yea.

ME: And you have only shared it so far with your

husband and the friend that figured it out?

NINE: Yea.

ME: That's it?

NINE: Yea.

ME: No family?

NINE: No we're going back to see my family in a week,

and if I am pregnant for sure, I'll tell them...Yea, um, a big reason that I, I'm not interested in telling what I call peripheral

friends, meaning...

ME: Yea.

NINE: Friends that I hardly ever see or acquaintance-

type friends, is because it's a pain to have to tell them that you've miscarried. Now, now that's the reason I would prefer not to tell...the good friends I'll go ahead and tell. They'll find out

at work.

Trying to Get Pregnant. The group who were trying to get pregnant can actually be separated into two types in terms of their effort. TWO and FIFTEEN were actively trying to make sure they had intercourse on the "right nights," although for both of them this

presented an interesting dilemma in that both of their spouses had traveling jobs. One has to question if the reason they more freely admitted their concerted effort was that they were cognizant of the fact that they could have their spouses at home for only a limited number of the "right nights." The remainder of the trying-to-get-pregnant group claimed to be exercising a much more casual "if it happens, it happens" attitude. This group claimed their effort consisted of "not trying to avoid it." As opposed to TWO and FIFTEEN, the spouses in the "casual effort group" were much more readily available. EIGHT typifies the casual approach.

EIGHT: What can you do (laugh) except try again?

ME: O.K. Let's talk about trying agin. What are your

plans now?

EIGHT: We're trying.

ME: You're trying? You're actively practicing the

ritual?

EIGHT: I mean we're not taking temperatures and all that, it's just that we're not doing any birth control

either.

ME: Are you trying to do it on the right nights?

FIGHT: No. I didn't even think of all that before.

ME: 0.K., just this back to...

EIGHT: ...back to...I don't need, you know, neither of us

really needs to work at it that hard. If it

happens, it happens, but...

ME: When you say "need" do you mean you don't need to

be pregnant that much now, or...

EIGHT: No, not, just, if I can't conceive in a year or

something I think then we might go into the temperature and all that stuff. But I think you

can get to the point of ridiculous.

The three women who were avoiding Avoiding Pregnancy. pregnancy each had her own reason. FOUR thought she'd wait at least another year which had been her original plan back when she had found herself pregnant by surprise (at the time of conception, FOUR had been breast-feeding a four-month old daughter). SIXTEEN despised being pregnant so much so that she could not bring herself to have sex with her spouse. It had been at least nine weeks since her loss and they had not resumed their physical relationship. SIXTEEN was in a real tough spot. She stated at our first interview that she couldn't wait to get pregnant again. On the second interview, she admitted to desperately wanting a child, but just as strongly hating the thought of reliving the first trimester. SIXTEEN saw herself as weak, angry, emotional and unstable during early pregnancy. SIXTEEN stated:

SIXTEEN: Well some of it was an angry kind of feeling, but a lot of it was just being afraid to go through that again. As I said my pregnancies are so horrible...especially at the beginning. And all of a sudden, the pregnancy is worse than ever. I mean, you now, it's just...I mean, the association...it's not a fun way to be; it's a horrible way to be, especially when tragedies happen...I still want a child, very much want a child, but I dread getting pregnant again. Just dread it.

THIRTEEN (who is 38 years old) was also at a very uncomfortable place. She admitted to "secretly still wanting a baby." On our first interview, THIRTEEN had admitted that getting her tubes tied had been a point of discussion between she and her husband. It was obvious at our second interview that THIRTEEN was

still very much unsettled on Trying Again. Her husband had recently lost his job and was in absolutely no position to have another child. At our first interview. THIRTEEN described her feelings about sex:

THIRTEEN: When I am first pregnant, I don't want to have sex until at least three months along. And I try to put him off. Even though the doctors tell me it's perfectly all right - go ahead. I'm sure it's going to cause a miscarriage. So I just put him off as much as possible. And then after I had the miscarriage, I just, I don't want to be touched. It was, it's repulsive to me. I've had to submit..but I don't want it.

It is of interest to note that the only two women in this study to whom I felt a need to offer a referral for additional counseling were THIRTEEN and SIXTEEN. These two women shared three points in common: histories of stillbirths, an avoidance of physical relations post most recent loss, and being in the pregnancy avoidance group.

Tubal Ligation. The last two women to dicuss in Trying Again are SEVENTEEN and TWENTY. TWENTY had had her tubal ligation at the time of her D and C. She had considered having it done with her last miscarriage four years ago, but at the time her physician suggested she wait a couple of months in order to be more sure of her decision. With the latest miscarriage, there was no question, TWENTY, who was 38 years old, knew it was time. She admitted that recovery was painful and at times whe wondered if she had made the right decision, but overall felt at peace with her decision. She was planning to

reinstitute adoption proceedings in the next couple of months, her last attempt at adoption having been about ten years ago.

SEVENTEEN decided between our first and second interview to go ahead with plans for a tubal ligation. She had an obstetrical history of two traumatic birth experiences and two miscarriages. Her husband is 48, and all things considered, SEVENTEEN decided it was time to make a permanent decision about Trying Again. SEVENTEEN stated:

SEVENTEEN: I think due to age factors and many things, taking everything into account, I'm leaning more towards just being really happy that I've got two beautiful children...kind of maybe thinking about enjoying life with my husband after the kids are grown. And there's always a little bit of sad or kind of wondering what it would have been like...I think I'm at ease with the way things have turned out.

## Summary of the Experience Categories

Six processes/categories have been described as meaningful for understanding the human experience of miscarriage. These categories were developed based upon the teachings of 20 women who had lived through an early pregnancy loss. The six experience processes which were presented in the first part of this chapter are: Coming to Know, Losing and Gaining, Going Public, Sharing the Loss, Getting Through It and Trying Again.

### The Caring Categories

The history behind the development of the caring categories (which are depicted in Figure 4) was briefly mentioned in Chapter III. To reiterate, my original "road block" in seeing these caring processes was my actual dissertation question which reads: "What are the caring behaviors of others that are identified as helpful by the woman who miscarried?"

I was nearing the end of my first round of interviews when two very crucial eye-openers occurred. The first one was: I asked SIXTEEN to tell me, "What are some of the things people said to you or did for you that made you feel cared for or cared about?" She responded:

- SIXTEEN: This is something I'm having trouble with because when you first told me what kinds of things we would be talking about, it occurred to me the last couple days that I don't know that I can remember them. And that's unfortunate 'cause I don't know exactly what people said.
- ME: Maybe if you can't remember exactly the words, can you tell me what was the message? I mean what did they convey to you in what they said?
  - SIXTEEN: That, that one is easier. What they said to me was that "God, it must really hurt; that really must be hard," and um, excuse me (crying), can I do this?
  - ME: That's O.K. (teary-eyed), I'm trying to keep from doing it myself.
- SIXTEEN: Um, you know the worst thing you can get is to not have somebody realize how much it hurts...

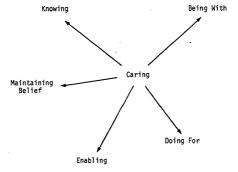


Figure 4. The Five Caring Categories which underlie the behaviors of others that are perceived as helpful by the women who miscarried.

The second major insight I received was from my chairperson, Dr. Jean Watson, who pointed out how concrete my preliminary caring categories were versus how rich the developing experience categories were. The preliminary caring categories were actually the codes which I had used to index the informant's transcripts (i.e., caring means, touching, giving time, listening, etc.). The caring codes listed behaviors. They failed to express the meanings.

Putting together the observations of SIXTEEN and Dr. Watson, I suddenly realized the folly was in the original research question. Instead of asking informants to list caring behaviors, I should have simply been asking them, "What are the caring needs of a woman who miscarries?" This would more likely have helped me to understand the process which underly the behaviors.

Luckily, as it turns out, as I reviewed my transcripts, the information on caring is very much there. My informants in a variety of ways wove their caring needs into their telling of their experience. Once I realized the need to readjust my lens to look for meanings or processes, the Caring Categories were quite obvious. The processes which underlie behaviors which were perceived as caring are: Knowing, Being With, Enabling, Doing For, and Maintaining Belief. In the following sections, these categories will be expanded upon.

#### Knowing

Knowing identifies the woman's desire to be understood for her experience. The women wished to be appreciated for the particular meaning the pregnancy loss had in their lives. By way of

an analogy, in <u>Analyzing Social Settings</u>, John Lofland (1966) distinguishes between two levels of human understanding. His levels are helpful to the explanation of Knowing as a category. Lofland states:

A significant feature of being a modern person-of living in what we call the modern world-is to know about a wide variety of other human beings but not to know them. To know about a category of human beings is to have it represented by second parties that such a category exists. We can know about Hottentots, Russians, presidents, delinquents, hippies or whatever through newspaper, television, face-to-face reports and other mediated means. But we can also know people through our own direct, face-to-face association with them, extending over some significant period of time (Lofland, 1966, p. 1).

In terms of professional caring (i.e., on the part of a nurse or physician) the "mediated" means may be to assign the woman who miscarries to the status of patient (to place "roles" between the nurse and woman). She is then one who has the condition we know about: miscarriage or spontaneous abortion. However, if the health care provider chooses to transcend that "mediated" intellectual gobetween and get to know the woman and her personal loss, then we have an instance of personal knowing, a knowing that means caring.

In terms of non-professional caring (i.e., on the part of spouse, friends, etc.) the analogy to Lofland's levels of knowing still holds. We can assume that what we know about miscarriage (i.e., You can always try again!) is meaningful for dealing with someone who miscarries. Or, we can choose to know how a woman perceived her particular loss.

It must be noted that twice the word "chooses" has crept into this discussion of Knowing. It becomes obvious that my perception of Knowing as an instance of caring is that Knowing is a willful act. Understanding of a woman's loss in her life is something that must be sought after. It involves a willingness to abandon one's preconceived notions of what miscarriage entails.

As stated in my second assumption in Chapter I, Meyerhoff (1971), Watson (1979), and Brown (1981) have all noted the importance of knowing in caring. Meyerhoff (1971) emphasized the importance of knowing another in order to care. Likewise, Watson focuses on the Interpersonal aspects of caring (interpersonal versus nurse to patient, doer to object). Finally, Brown (1981) stated, "This kind of knowledge requires of the knower the ability to experience and be with the other as a separate, independent being rather than an extension of the self." As I see it, "extension of the self" has two relevant meanings. They are: "I see you as I understand miscarriage" (i.e., according to my preconceived notions) or as an extension of my professional role (in order for me to "nurse," you have to "patient").

Moving away from the literature and to the informants: The following excerpts refer to caring as Knowing. In the first example, an instance of "not Knowing" is provided by EIGHTEEN who had just finished telling me that her obstetrician, in trying to emphasize the positive, had invited her to focus in on the fact that at least she had been able to get pregnant.

ME: Yeah.

EIGHTEEN: Yes, there are plenty of women out there that would die for the chance of getting pregnant in

the first place.

ME: Yes, uh-huh, uh-huh.

FIGHTEEN: But that didn't mean anything.

ME: Yeah.

EIGHTEEN: It didn't mean anything:

ME: Well, that's not what you were losing right then.

EIGHTEEN: Right. And getting pregnant later, if I could, was not...

ME: The issue?

EIGHTEEN: Right, it had nothing to do with what was

happening. It was irrelevant.

To continue with EIGHTEEN and another incidence of not Knowing:

EIGHTEEN: I got to the hospital and I was supposed to report to outpatient. That was fine. I got my paper work; they told me to follow the colored stripe to the lab area. And I'm walking up to where they draw the blood, and there were two younger females...standing at the desk. And they looked at me, and they go, "Boy, you musn't be having a good day. What's so glum about?" As I'm handing them--they said, "It's not going to be that

terrible"---as I'm handing them my paper work. I didn't even say anything.

ME: These are the gals that work there?

EIGHTEEN: Yes. And then they look at my paperwork, and one of them goes, "Oh, you're just having a D and C. That's not so bad. I had one of those." I didn't open my mouth. I knew if I opened my mouth, you know, I felt very-on the edge of control—so I just kept my mouth shut. I sat down, she drew the blood, I held it, put the bandaid on, and just walked out.

On a more positive note, FIFTEEN described how deeply she felt her two obstetricians cared for her:

FIFTEEN: He just wanted to talk with me about what had happened, and, I think more to be support than anything. To say that he was really upset that it happened again. That he was concerned. That he suggested having chromosome tests done. He said frequently they don't like to do this until you've had three miscarriages, but he said, "You know, I feel like it would be something that would be important for you to go in and have done."

I had umpteen people tell me you need to go find another doctor. You need to get another opinion...And, I probably would do it if I had the doctor back home, but there's something about these two. They're just so human and down to earth. They don't have this doctor facade. That makes it easier to talk with them and work with them. And it really makes me feel good that they're both just as interested.

ME: It sounds like they treat you like a person, not just a patient.

FIFTEEN: Yea, very much so.

ME: Do you think they realized your pain?

FIFTEEN: Oh, I know they did. For example, in my post-op visit...He didn't even come in and say...I guess I was thinking well he's a doctor so he'll come in and examine me and then he'll say if you have any questions, let me know. He just came in and I thought he was going to cry. He put his arms around me and, oh, of course with that I just burst into tears and sat there and cried for forty-five minutes.

ELEVEN described her secretary as caring:

ELEVEN: Well, she just basically understood how I felt and always wanted to know if I was O.K., if there was anything she could do for me, and she's very supportive of me anyway, because she---in just my

whole life---if there's anything I ever need, she's right there. I don't know---she was real supportive in the miscarriage.

SEVEN described her relationship with her obstetrician and the nurse practitioner at the obstetrician's office.

SEVEN:

I never felt like I'd just been processed through. They made me feel like they knew this was a unique thing happening to me, that it was my own little special problem, and that they handled it that way. They didn't make me feel at all like, you know, one out of however many patients they have that lose a baby and that's no big deal.

Finally, THREE shared this example of a time in which she felt that a co-worker understood her loss:

THREE:

Like just recently, I talked to a man at work whose wife is pregnant and he right after my miscarriage, he made some comment to me about, "Well, you sure seem down in the dumps lately." And it was recently that I just said to him, "Do you remember telling me that I seemed sad?" And I told him why, and I said, "I was sad, and partly I was even sadder because you have a wife who seems to be having a real normal pregnancy, and it hurt me." And he told me, "My wife had a miscarriage before she had this pregnancy. It was a real hard thing for both of us because there was nothing I could do. We both found out that there are a lot of people who do have miscarriages." And he's not usually a real sensitive person, but for him to be able to just say that to me, I thought was a real fine thing.

Relationship of Knowing to the experience categories. If one looks at THIRTEEN's Sharing the Loss, it is quite obvious that no one Knew the meaning of her loss. Obviously, a fundamental part of

sharing the loss is Knowing on some level the meaning of that loss in the woman's life. Likewise, the comments received in Going Public will be tempered by the amount of knowledge the public has about the meaning of miscarriage in a woman's life. In the case of Trying Again, Knowing the woman's loss and ongoing fears should certainly result in obstetrical care that recognizes the woman's need to deal with her anxieties. The relationship between Knowing and Coming to Know is that a caring Knower should recognize the angst which accompanies the mounting evidence of impending loss.

# Being With

Being With is the category that illustrates the woman's need to have others feel with her; not necessarily <u>as</u> her, but <u>with</u> her. This category goes one step beyond the Knowing. It involves not only Knowing the meaning of the woman's loss, but also feeling some of her sense of loss. Obviously, most cases of willful Knowing will involve some feeling. It is hard to imagine that one could truly Know the meaning of another's loss without feeling some "emotional tugs." If one rereads the Knowing excerpts above, indeed, quite a bit of Being With is evident.

Similar terms for "Being With" that have been cited in the caring literature are compassion; empathy; presence; love, tenderness and comfort (Leininger, 1981). Each of these terms involve a relationship between two human beings that moves beyond a mere cognitive knowing and surpasses the bonds of assigned clinical or social roles. Travelbee (1969) captured the essence of Being With in what she called "Emotional Involvement." Travelbee states:

Emotional involvement is necessary if the nurse is to establish a relationship with a patient or any other human being. Emotional involvement is both cognitive and affective. It is the ability to transcend self and to care for, and about, another human being—and to do this in such a way that one is not incapacitated by one's caring and concern (Travelbee, 1969, p. 48).

In order to Be With another human being, physical proximity is not necessarily essential. Human relationships that involve caring can communicate compassion and involvement even from a distance. For example, TWO's husband was described as Being With her through her entire loss even though he was physically away as part of his job most of the time.

TWO: His comments really helped. I mean, when he'd tell me that it was just a lot better, that maybe there was something wrong with the baby. And if I was having a hard time, then he'd just--he was real with me through all of this. 'Cause you know a lot of husbands could have just said, "Well, I'm getting sick of this." Because for a long time I did cry...he'd understand, you know. He said, "I know you've been through a lot." And he'd send me over to my mom's [400 miles away] while he was

gone...I don't know, just because he was always there, and he just seemed to understand.

Being With obviously occurs on differing levels depending on the relationship between the carer and the cared for. The caring between two people who live a loss as a married couple will usually involve a much deeper sense of overall Being With, or sharing the pain than say, the Being With between a nurse and a client. On the other hand, in some aspects of the woman's loss experience, a professional caregiver may play the most important empathetic role. For example, in the emergency room or during the D and C, the

presence of a compassionate caregiver may make all the difference in terms of the woman's perception of having been treated as person versus object. For example:

TEN: The people at [the hospital] were so special. They were so understanding and they were women. They were really tuned in. I went to check into day surgery...and a woman says, "Well, what seems to be your problem?" I said, "I'm having a miscarriage." Bam---upstairs. There wasn't a second. I mean you could see the look on their faces. They felt so bad...they felt with me. And they just felt so bad about it, and I felt bad, but I knew they knew I had to deal with it.

FIVE described how much her husband's compassionate presence meant to her:

FIVE: He was right in there with me the whole time. I don't know if I can think of anything he said.

ME: So it sounds like it was more just the being there with you?

FIVE: Yeah, I mean it was like we both went through it together. It wasn't just me going through this. It was definitely him going through this too. He was just, I don't know, I can't imagine going through something like that by myself if he hadn't been there...He felt sad because, I mean it was so hard on both of us emotionally dealing with it, and he felt like he wished he could have taken some of the physical part of it onto himself too.

SIX described how much her co-workers' caring mattered:

SIX: I had the women at work that all really helped me.
My friend, Helen, the one that was so happy when I
got pregnant...she told me, "I didn't ask because
I knew it hurt so much for you." She says, "It

just broke my heart." I told her, "I know." I says, "I know." And then I told her, "But at least I can try again." She says, "We sure can, can't we?" She's great, she helped me through it.

SIX conveyed one other story about a woman who was with her in her pain. The woman described here was SIX's hospital roommate.

SIX: Even her family...her sister and her son...would come in and they would talk to me. She just cared. And then when I started to really get sick on Friday, she came over to the bed, and I was crying, and she just hugged me, and she said, "I'm so sorry, and I care." She didn't even know me, but she cared.

THIRTEEN had the sad experience in the hospital of no one responding when she cried out she was losing her baby. When I asked her what a doctor or nurse should do to make a woman feel cared for, she responded:

THIRTEEN: Don't gloss over it or just pretend by not mentioning it that something else is going on in your body....To me it would be more helpful if they would let you know what's going on, what to expect...and to even if they don't mean it, they can pretend, can't they...that they care or that they're a little bit sorry....That joy that's felt in the delivery room when you, there's a normal live birth. Can't they just kind of turn it around the other end. That's just about the other extreme of the way you feel, just really.

THIRTEEN went on to theorize why nurses and doctors can't or won't Be With people in pain. It is interesting to note that she was

more willing to accept the caregiver's lack of involvement than she was willing to accept the caregiver's lack of Knowing.

THIRTEEN: Well I just assume that they can't get involved. I don't know personally, I just figure that they have to put up this protective barrier not to get involved with every case that comes their way. But maybe that makes me feel better about the fact that they don't give a crap.

To end this section on a more optimistic note, EIGHT offered two examples of professional caring that conveyed a sense of Being With:

EIGHT: (Re: The Hospital Staff.)

It was just the fact, O.K., what you're going through, and they seemed...they had compassion, not that I'm saying I'll feel sorry for me...But I don't know, maybe it's my visions of hospitals. You know, that they can be sterile and they do their job. (EIGHT made noises of a working hospital)...cause they do this all the time. But it was like they really cared. All of them.

EIGHT: (Re: Her obstetrician.) He was very concerned. It was almost like he was sitting there holding your hand. You could just see it in his eyes that he was really concerned about how I felt as a person. Not, I'm a doctor, you're a patient.

Relationship of Being With to the Experience Categories.

Like Knowing, Being With obviously had very close ties to Sharing the
Loss. In essence, Being With might be the caring that made the loss
feel shared. As was shown in the Getting Through It category, the
sharing or Being With was very closely tied to the recovery process.

Being With would also help to facilitate the Going Public process in

that a compassionate public is much more receptive of the woman in her pain. Finally, as for Trying Again, a caregiver who can Be With a woman no matter what form her "Trying Again" might take, is a caregiver whose compassionate presence will ease that Trying Again process.

## **Enabling**

Caring that is Enabling is caring that facilitates the woman's capacity to grieve. To Enable grieving is to provide support of the woman's Getting Through her loss. Frequently, Enabling involves preparing the woman for the grieving process, conveying to the woman a willingness to be available to her, and allowing or validating her right to hurt. To Enable is to let her "lean on" the carer. Enabling is blocked when the caregiver (or non-caregiver as the case may be) is rushed, abrupt, judgemental, or conveying of an inability to handle the woman's needs.

As Watson states, "A caring environment is one that offers the development of potential while allowing the person to choose the best action for himself or herself at a given point in time" (1979, p. 9). Likewise, Meyerhoff has stressed the importance of patience on the part of the caregiver in order to allow the "cared for" to grow and move within her own time frame. This need was obviously recognized by the nurse who cared for EIGHT.

EIGHT: She'd say, "How are you doing? How are you feeling?" It wasn't just come in and, "Are you

awake?"

ME: Did she discuss with you your miscarriage at all?

No. She just said, "How are you doing and how are you feeling," and I guess that would be my time to say, "I feel like shit." FIGHT:

MF . So she left you a wide opening?

EIGHT: Yea. I think so.

And didn't push when you weren't ready for it? MF:

FIGHT: Well. I didn't feel. I... I never even to this day sit around saying woe is me. I mean nature is

going to do what nature is going to do.

The nurse's not pushing EIGHT allowed EIGHT to cope in her own manner. Yet the opening conveyed, "It's O.K. to talk if you're ready." EIGHT's nurse enabled her to grieve in her own private way. Privacy and "There's no need to dwell: there's nothing you can do about it so accept it" were demonstrated throughout EIGHT's transcript to be her way of dealing with death. (It is interesting to note EIGHT's father is a mortician and EIGHT's outlook was. "Where there is life, there is death.")

FOUR offered advice on what would make a woman feel cared for. As it turns out, what she has suggested is a form of Enabling:

FOUR: They should give information on things that most women go through, similar like to if they tell you that you might go through post partum depression after a child. That you might feel the same symptoms, that you might be depressed, or you might be confused or just that type of thing. I think the thing that might have helped too, is to tell the spouses, like they do with the pregnancy, that the woman might feel the same type of emotional tearings or things like she does when she's pregnant.

EIGHTEEN's obstetrician did exactly as FOUR suggested. The following took place at the obstetrician's office before EIGHTEEN Had her D and  $\mathbb{C}$ :

EIGHTEEN: He opened up a lot of feelings that I was feeling and didn't even know I was feeling at the time. He also talked to Rick a lot which I thought was real good then, and I do now. And he also gave me a booklet on We Care to read.

ME: Tell me about some of the feelings he opened up for you.

EIGHTEEN: Well he was...if I remember...he was addressing Rick, really, when he was saying this, because he said, "At this particular time, the woman usually is feeling very much a failure," which I was. "And is very emotionally involved and will show her emotions very readily," which I was. "And the man, the husband, is not"...the way he worded it was, "The husband's concern is for the wife." Where my concern was for the baby.

Related to Enabling the woman's grieving is keeping her informed, being honest, and explaining. Those women who were not given a reason for their loss immediately put the blame on themselves. ONE in particular blamed her tendency to get depressed as the rationale for her loss. SIX, ONE, TWELVE and THIRTEEN were never told that there was nothing they could have done that would have caused or prevented their loss; consequently, guilt due to lack of knowledge served to enhance the pain for all of these women. A failure to provide information is a failure to "Enable."

On a personal level, FIFTEEN described an incident where her needs to grieve were blocked by her mother:

FIFTEEN:

And so my mother came out and she stayed here for three weeks. I knew that she could sense what was happening with me, what I was going through and that I needed the support. That she wanted to give that support. And yet, things somehow got mixed up where I was being supportive of all the things that were going on in her life when she got here. By the time she left, I was exhausted. And I guess out of my own unselfishness, never would have, never will and never did bother to tell her, "You know this is really a strain on me. You know I need for you to just let me be the one to sit around and boo-hoo. or whatever, you know."

THREE's parents were more supportive. In the following example, THREE expains how both her parents and a book she had read on pregnancy loss Enabled her to grieve.

THREE:

See my parents really know that this is real important to me, so I guess what they did was just express an understanding of how I was grieving and they didn't try to make it better.

ME:

It sounds like you're saying that both your parents and the book let you know that somebody else knew what your pain was.

THREE:

They didn't know what the pain was...my parents don't know; the book did. But what my parents did was let me say that it was O.K. to feel the pain. And that's what the book did real well for me too.

FIVE spoke about how helpful other women who have miscarried were in Enabling her grieving:

FIVE:

I feel pretty good emotionally. It seems I talk to a lot of people or run into a lot of people who've had miscarriages, and it's easier to talk about. It's nice to have somebody who wants to listen to you talk and won't...and is sincere and not judging or tossing it aside or stuff like that.

THREE had a similar experience with a close friend who had miscarried in the past.

THREE:

Even though we've shared a lot about how we feel. it wasn't until it happened to me that I called her up and I said. "I feel crazy." She said. "Yeah, you do." normal." And (Short laugh.) "And that's real said, "Don't And she inside...let it out." In fact, maybe she's the one who kind of helped me to figure out how to do that....Somehow she made me realize I was feeling crazy because I wasn't expressing my feelings.

Relationship of Enabling to the Experience Categories. The link between Enabling and Getting Through It is most obvious. Acceptance of and preparation for the woman's need to grieve in her own manner was shown to be integral to the recovery from loss. In one of the assumptions for this study, the link between caring and loss was said to be that the woman's caring needs would be individually defined based on her perceptions of loss. Thus far the caring categories Knowing, Being With and Enabling have been shown to be "universals" which get uniquely "expressed" in any one instance. The "unique-expression-in-any-one-instance" is another way of saving that carring is custom-fitted to the woman in her particular loss. Enabling which recognizes a woman's preferred coping strategies is, as Watson (1979) states "healthogenic." Enabling is 1) promotive of recovery-or-Getting Through It; 2) sensitive to the ongoing fears in subsequent pregnancies (Trying Again): and 3) supportive in decisions to not-try-again (i.e., tubal ligation or practicing birth control).

### Doing For

Doing For is the caring category that answers the woman's need to have others do-for-her in her time of duress. It is a rather simplistic notion that is best translated as the caregiver acting as understudy to the cared for. The caregiver does for the woman what she would do for herself if she had the knowledge or emotional and physical strength to do so.

In Leininger's transcultural studies, she captured doing-for in the words: cumfort, health maintenance acts, helping behaviors, protective behaviors, restorative behaviors, and succorance (Leininger, 1981). Doing For conveys caring in competent helping acts whether these acts be neighborly (i.e., sending over a casserole), protective (i.e., checking her I.V. fluids), life restorative (i.e., doing the actual D and C), anticipatory (i.e., "This is how to call me if you need help to the bathroom"), or security promotive/maintaining vigilance (i.e., "They came in and checked on me all night long.")

NINETEEN felt cared for when her obstetrician came into the emergency room and acted like he knew what he was doing:

NINETEEN: It was like everybody was on the phone, everybody was back and forth, so they didn't know what to do with me. They didn't know if I was still pregnant or not. I'm bleeding and I'm thinking, they're acting like, "Well, maybe you're still pregnant." They didn't know. That's what I didn't like.

It's that...the not really knowing. And that's when...finally, when Dr. Jones finally came over to the hospital...He came in right away, he wanted to see what they told us to bring in, which was just a little bit of stuff. Everybody else was saying, "Well, that's not very much." You

know, and I thought it was a lot. Jones looked at it and said, "This is probably what they saw on ultrasound, today, right here." And then he examined me and said, "In fact, you're miscarrying right now." And he just said...you know it was like he took over. And there was no more question, finally, I have to say that. It was over. I mean....

He said that you can still show positive three months later after you've had an abortion. So that made me kind of mad. I mean that should be common knowledge...I thought why did they put me through all that?

In NINETEEN's example, it is obvious that there is a certain level of competence that is expected of the caregiver. The "taking-over" wiped away the "not knowing." Being cared for by someone who "knew what he was doing" was comforting to NINETEEN. She stated:

NINETEEN: "This is how it is. You are this way. And that's going to be it. I'm sorry." But he was real good. It was great. If he hadn't been so good, it would have been a lot worse.

ONE was very disappointed at the insensitivity she encountered. ONE had begun to cramp in the ultrasound room. The ultrasonographer told ONE to "Tell her doctor," and then sent ONE up to her room.

ME: Was your husband with you at that point?

ONE: Yes.

ME: How did he act?

ONE: Oh, he was upset. I don't think I should have been walking around when I was bleeding and stuff,

but I walked up to my room...

ME: Oh, they had you walk up to your room?

ONE: Yes.

Goodness: MF: Did the doctor know you walked up to

your room?

I don't know. He wasn't with me at the time. So ONE:

I don't think so.

MF: Did you tell him afterwards?

ONE: No.

ME: That seems kind of hard on a woman when she's in

the middle of miscarrying.

Yes 'cause I was really bleeding bad, and I kept ONE: telling my husband that's when I got cramps really

bad. I was telling him I can't walk any more. And he was holding on to me. And the nurse just was standing beside me. You know, she didn't help me at all.

ME: That's amazing. How did you feel at that point?

ONE: Very mad 'cause they acted like that was what was supposed to happen...because the doctor asked me, he said, "Tell me when you're bleeding heavy." So I did...he just told me that I should take it

easy, 'cause that's why you have a miscarriage is when you're upset and stuff. But he should have knew that I already had it 'cause I told him what

had happened.

For ONE, the failure of everyone to Know, Be With, or Do For was a source of considerable anger in our first interview. She continuously told me she felt "so alone, like I was a nobody." This vignette serves as a tragic way to emphasize 1) the need for caring in the midst of all the technology; and 2) the fact that professional caregivers can "make or break" an already tough situation. It should be noted ONE told me later in her second interview that in her next pregnancy she was going "to try not to get upset."

apparently heeded the physician's comment that being upset led to her loss.

Likewise, SIX perceived that she was getting less-thancompetent care when the obstetrician on duty (not her regular doctor) balked at the idea of a D and C. (SIX was bleeding and cramping quite heavily.)

SIX: He said you can go home tomorrow. I said, "Aren't you going to clean me? Aren't you going to do "Well, I don't like to do that because I think miscarriages take care of themselves." I said, "That's the first I've heard of that! I thought you do one of those." He said, "A D and C." I said, "Yes." He says, "Well, some doctors like to do it. Myself, I don't." My husband looked at me and was telling me in Spanish, "You tell him that I want---we want you to get well and for them to do a D and C on you and clean you, and...I want you well..." I couldn't believe it. I kept saying, "Here I am---half something---and this guy doesn't want to do what he should do, and I know that's what they need to do. This cramping has got to stop. I can't stand the cramping no more. I can't stand the bleeding no more."

SIX had been bleeding and cramping for about five days as an inpatient. Her request was finally granted. SIX's assertiveness got her her D and C. (N.B. It must be noted both ONE and SIX are Hispanics. It seems more than coincidental that the only two Hispanics in this study were treated in such a way that they both perceived they were being glossed over.)

In order to switch the focus to more positive instances of Doing For, SEVEN's experience with her nurse practitioner and obstetrician involved quite a bit of caring. SEVEN:

And I have to give that office a lot of credit. They were very helpful during the whole thing. The nurse called me after a week just to make sure I was all right. Little things like that they did that they didn't have to do. The doctor made the effort, coming to the hospital, where obviously that could have been done by whoever was on staff. That was very important to me. Um, during the whole wekend I was home here, they called once, and they always made me feel like...never hesitate to call.

EIGHT described how caring in the form of Doing For was conveyed to her:

EIGHT:

They had me on whatever all night long and the night nurse she was, I just loved her to death,

she was great.

ME:

Tell me about what she did for you?

EIGHT:

She'd come in, she'd come in like every hour and take my temperature and pulse and the whole thing and check the little bag. They kept me on something all night long. And she told me, sine said, first I, when I really woke up, I asked if I could have some water. And she said, "Well, let me get you tap water because this ice water might be a shock." And it went down fine, no problem. And she said, "Oh, you're O.K." And she said, "If you have to go to the bathroom, let me know and I'll help you there..." But she was just, it was like your mom. And she was just...it wasn't just, "You can do it." It was, I don't know, she was just a real person.

Doing For on the part of friends and family involved such things as making phone calls to notify others that a miscarriage had taken place:

EIGHTEEN: I asked Rick in the days to come, also that weekend, to make as many phone calls as he could.

That I didn't want to have to tell people. I felt that I could deal better with people already knowing.

and babysitting...

SIXTEEN:

So she had made the offer if there's anything I can do, let me know. So the next morning I called and told her what had happened and I said I could use some help with Kay today....So anyway she came over that afternoon and took Kay to her house for four or five hours. And I just slept most of the day. I kind of read, and slept and hung around in hed.

and cooking...

FOURTEEN: Friends who just had a baby wanted to bring dinner down.

and being tender...

TEN:

And I was so preoccuppied with things that I was losing things. I did my bids for that month and I misbid, and I bid all weekends. I mean everything....I'd lost my camera, I'd lost a pair of bows to put on my black patent leather shoes. I missed bid. I'd gotten, I'd lost the baby, and I called Chuck at work and I said, "This is my life, I'm flying horrible three day trips Saturday, Sunday and Monday." I said, "I've lost the baby. I've lost the camera. I've lost June and I've lost the bows." He said, "I can give you everything else back but June." (Laughing) That was so cute 'cause for my birthday, I got bows, a camera...It really helps, those little things.

Relationship of Doing For to the Experience Categories.

Doing For usually conveyed a certain level of Knowing and Being With.

It also served to Enable grieving. In NINETEEN's case, the doctor's

"Doing For" resulted in confirmation for her Coming to Know. For ONE
and SIX the less-than-adequate Doing For served to block their

"Getting Through It;" in essence the non-caring added to their grief.

The husband who made phone calls for EIGHTEEN aided her Going Public.

The casseroles, babysitting, and birthday gifts all conveyed a form of Sharing the Loss.

#### Maintaining Belief

Maintaining Belief focuses on the woman's need to have others not lose sight of her capacity to get through the loss and to ultimately give birth. The women needed others to continue to believe in their capacity to get past the tough times and to eventually successfully Try Again. In the case of the women who chose not to have another try at pregnancy, Maintaining Belief took the form of believing in/or supporting the woman in her decision.

In the assumptions which underly this study, Watson was quoted as saying, "Caring responses accept a person not only as he or she is, but as what he or she may become" (Watson, 1979, p. 9). Maintaining Belief involves, as Meyerhoff points out, a basic sense of trust and hope. Trust involves the appreciation of the uniqueness of the other and the other's ability to make wise judgements. Hope is "an expression of a present alive with possibilities and plenitude... it implies that there is or could be something that is

worthy of commitment and that mitigates against despair" (Carper, 1979. p. 15).

The major dilemma I faced in understanding Maintaining Belief is that one informant after another kept telling me that caregivers should tell a woman she can eventually have another baby. Yet I knew, "You can always try again" was often perceived as uncaring. I could not understand how this could be perceived as caring until I saw this distinction: if the comment was made based on Knowing and Being With, than it was received as caring or hope producing; whereas, if the comment was made based on non-Knowing and non-Being With, then it was perceived as uncaring. For example, EIGHTEEEN who had the misfortune of having her D an C done in the delivery suite, told me about a nurse in the delivery room who conveyed a belief in her. The nurse told EIGHTEEN, "The next time I see you in here, it will be to deliver your baby. I know you don't believe that now, but I will." EIGHTEEN said for weeks after, she had to lean on that comment to get her through the more difficult times.

SIX who had a long history of infertility was reassured by her midwife that she could Try Again.

SIX: I did get pregnant. So I told Mindy that and she said..."We know you can get pregnant on Pergonal, and it works for you. So there's no reason why he should not give you a referral." So I've got a referral waiting for me whenever I want to go.

NINETEEN who also had a long infertility history discussed how important Maintaining Belief is:

NINETEEN: But just sort of being understanding, giving you hope...that helps a lot. That helped me. See, if they hadn't given me hope, if they had said, I can't have kids, it would have totally destroyed me. They gave me a little bit of hope, that helped.

At our first interview, even TWENTY who had had at least seven miscarriages told me how important it was to tell a woman to Try Again. On the second interview, I asked her:

ME: You said the doctor should tell her, "You can always try again." And it intrigued me that you said that because you did try again a lot of times and had miscarriages. How come that was comforting for you? That confuse

TWENTY: Well, I don't know, because I guess with me, myself, if I was younger, I would say, "Yeah, you can always try again." And I mean it is a hurting thing when you say, "Well, just forget it. Don't try to get pregnant again because you'll go through the same thing." But I don't know, it just seemed like comforting when you say, "Well, you can always try again. It's not the end of the world." You know what I'm saying?

ME: Oh, O.K. So you're saying, it's comforting when they offer you some hope still?

TWENTY: Yes, I couldn't put it into words, but yeah, you know, he even..he could be lying...I'm not saying they're lying...but at least if there's a little tiny bit of hope there to give you something to live...to look toward or whatever, you know.

Husbands were very important Belief Maintainers:

SEVEN: This sounds silly, but I can---one of the first things he said was, "Oh, well, that's all right honey. This just means we get to practice some more. That's the best part anyway." He says, "Me'll just practice, and we'll get it right next

time." He never said...I had a few guilt feelings about, "What's wrong with me, why can't I have a baby?" And he never questioned that...And there was no doubt in his mind that we would be able to have another baby and that everything would be fine.

ONE's spouse was not so confident which may also have contributed to ONE's feeling so alone:

ONE: Well, right now you know I want to get pregnant, so, so I'm really scared because I'm afraid something will happen. And Kurt said, one time we were fighting and he said, if and when I get pregnant nothing had better happen to it or else he's going to be really upset. So that really scares me.

ME: Um, how did he adjust to the last miscarriage, your husband?

Oh, he was sort of upset because he wants to have his family and get it over with, you know. He

didn't want to wait another six months.

ME: So you get the feeling he's not too patient this

time if you would have another miscarriage?

ONE: I hope that nothing happens this time.

ONE:

Another aspect of Maintaining Belief was captured by EIGHTEEN. She told me how important it was for the people who were around the woman who was grieving to believe in her capacity to get back to "her old self." EIGHTEEN felt that when she was "unable to see the light at the end of the tunnel," it was important for others to reassure her she would heal. Likewise, a friend of TEN's who had had a miscarriage helped her to believe she would get through it.

TEN:

I came home, called another friend of mine who's had two miscarriages, and she said time will heal it. It will be O.K. And after it seemed like it was going to be alright...She was very comforting. And after having gone through two, I couldn't understand how she would be so unhysterical. And I was really on the verge of, you know, jumping off a cliff when I only had one.

ME:

She was able to tell you time would heal?

TEN:

That time would be O.K. and to be real positive about the outcome of the whole thing, and that it was just a random selection and...so I, that kind of helped me.

Finally, Maintaining Belief in the case of women who opt for tubal ligation manifests itself as belief in the woman's capacity to make the right decision. SEVENTEEN's physician suggested she take time to make her decision.

SEVENTEEN: And he wanted me to wait 90 days before coming to a permanent decision.

ME:

How did that piece of advice sit with you?

SEVENTEEN: Fine, I felt that 90 days wasn't an unreasonable amount of time.

ME: Right. And what are you leaning towards now?

SEVENTEEN: I think due to age factors and many things....I'm leaning more towards being really happy I've got two beautiful children...

The physician's belief in SEVENTEEN's capacity to make a

Relationship of Maintaining Belief to the Experience Categories. People who Maintained Belief helped the woman to not only Get Through It, but to Try Again. Given the ongoing fears of Trying Again, Maintaining Belief will probably be crucial for the woman's capacity to enjoy her subsequent pregnancy. In the case of a woman who opts for a tubal ligation, the Maintenance of Belief in the "goodness" of her decision and her right to make that decision will prove integral to her finding peace in her decision.

# Relationship of the Caring Categories to Watson's Carative Factors

In Watson's book, <u>Nursing: The Philosophy and Science of Caring</u> (1979), ten carative factors were postulated. These factors were said to "form a structure for studying and understanding nursing as the science of caring" (Watson, 1979, p. 9). The caring categories developed in this study appear to "fit well" with Watson's factors. In the following paragraphs, an attempt will be made to equate Watson's factors with the caring categories described in this study. It must be kept in mind that just as there is, admittedly, quite a bit of overlap between the caring categories, so is there quite a bit of overlap between which factors relate to which categories.

The first, third and tenth factors: "the formation of humanistic-altruistic system of values;" "the cultivation of sensitivity to others;" and "the allowance for existential-phenomenological forces" are akin to the values which were said to underlie the willful desire to understand in the Knowing and Being With categories. The presence of a caregiver who desires to

understand the woman's personal meaning of her loss and the willingness to Be With her in her loss suggests a caregiver who is willing to on some level existentially live the other's loss.

The category Enabling is akin to factors four, five and seven: "the development of a helping-trust relationship;" "the promotion and acceptance of the expression of positive and negative feelings;" and "the promotion of interpersonal teaching-learning." Each of these factors captures part of the process which was said to Enable the grieving of the informants. It was suggested that successful facilitation of the grieving process involves a trust in the woman's capacity to heal in her own good time, an acceptance of the need to ventilate her feelings, and an effort to prepare her for the difficult times to come.

The category Doing For is captured in the carative factors six, eight and nine: "the systematic use of the scientific problemsolving method for decision-making;" "the provision for supportive, protective, and (or) corrective mental, physical, sociocultural, and spiritual environment;" and "assistance with the gratification of human needs." Doing For, as described in this study, involved a perceptive assessment of the woman's needs and the competent, comforting meeting of those needs.

Finally, carative factor two, "the instillation of faith-hope" seems to most closely capture the essence of Maintaining Belief. It was suggested in this study that many of the women felt that one of the most caring acts anyone could do for them was to convey a genuine belief in their capacity to eventually give birth.

The belief of others served to instill a much desired and needed sense of hope.

## Summary of the Caring Categories

In this section of the paper, five caring categories were described. These categories are Knowing, Being With, Enabling, Doing For, and Maintaining Belief. The caring categories are the processes which underlay the behaviors of others which were perceived as helpful by the women who miscarried. Finally, within this section an attempt was made to relate the caring categories back to: 1) the assumptions which underlie this study; 2) the categories which described the human experience of miscarriage; and 3) the carative factors described by Watson in Nursing: The Philosophy and Science of Caring (1979).

### Additional Findings

Additional findings of this study are significant findings which bear mentioning, but which did not fit totally into the categories which were described here. These findings are intriguing observations which I've made and may indeed be the roots of possible other categories which should be explored in future studies. These findings will be presented in a brief manner.

 Location of D and C. As pointed out by Friedman and Gradstein (1982), placing the woman who is in the midst of spontaneously aborting in the maternity sections of a hospital shows very little sensitivity. Both EIGHTEEN and THIRTEEN described the extreme pain of passing by the nursery, leaving their husbands in the father's waiting room, and in the case of THIRTEEN, being rolled into the room in which she delivered her last child. Equally insensitive was doing the D and C in a doctor's office that was known to be a place where women went to have therapeutic abortions (TAB).

2. Abortion. Abortions (therapeutic) were addressed in this study in two ways. First, women who had a history of a TAB discussed their previous loss with me. Every one of them admitted that they certainly gave it some thought at the time of their present loss, but did not get too fixated on regrets or guilt. They basically felt that what they had done was right for them when they did it, and they were surprised to realize how much difference the situation they were in (i.e., happily married, wanting a baby) could make in terms of the grief they felt.

The second way in which abortion was addressed was in terms of the anger women felt towards those who would elect to do what they were being forced into doing. Many of the women asked, "Why me, why not someone who doesn't want their baby?" The women expressed extreme anger at the unfairness of it all and occassionally at women themselves who electively aborted. None of the women who had had a TAB voiced that same anger at women who abort, but some did question why they couldn't have their desired child.

3. Relationship of Previous Pregnancy Losses to Most Recent Loss. Contrary to the findings of Benfield (1978), this study seemed to point to a more difficult Getting Through It for those women who experienced previous pregnancy losses. The three women who had lost children at birth (TEN to adoption and SIXTEEN and THIRTEEN to

stillbirth) tended to be much more confused, upset and dwelling on their past loss than the women who had had TABs. The three women who had had traumatic births (ONE, SEVENTEEN and SIXTEEN) all seemed to experience alterations in relationships with their spouse after this miscarriage. SEVENTEEN and her spouse actually had their conflict after her first miscarriage when she felt he had been more supportive of the doctors than her; at the second miscarriage, his support went to her and they had no conflict. ONE's husband warned that he would not be able to deal with another miscarriage and ONE said she was upset because her husband was never around. SIXTEEN and her spouse had not resumed sexual relations seven weeks after her loss and they were having problems discussing their abstinence.

The women who had long standing histories of infertility tended to focus initially on the unfairness of it all. They felt, as NINETEEN said, "tricked as if someone were dangling it in front of me and then snatching it away." These women as a group tended to eventually focus on "The at-least-now-I-know-I-can-get-pregnant" aspect of it as they began to recover.

Finally, women who had previous miscarriages seemed to fall into two groups. Those who had two in a row (FIFTEEN, TWENTY and SEVENTEEN) entertained very strong doubts of whether they would ever be able to, in FIFTEEN's and TWENTY's case have children, and in SEVENTEEN's case have more children. (N.B. SEVENTEEN and TWENTY opted for tubal ligation, FIFTEEN was actively Trying Again.) Those two women who had at least one live birth between losses seemed a little bit less afraid of never being able to have more children than

those women who had two miscarriages in a row; but considerably more afraid than those who had had only their one miscarriage.

- 4. The Physical Aspects. The D and C, bleeding, cramping and pain received more attention in the pilot for this study than in the final study. With the larger group of women, it was my finding that whereas the physical aspects of the loss certainly were stressful as they occurred, they seldom were a source of ongoing concern. Physical recovery occurred much sooner than emotional recovery. The D and C itself was certainly addressed in each interview, yet with the exception of a few minor incidents that the women recalled in our discussions, it seemed to not rate much attention (i.e., a category in itself). The meanings attributed to the physical symptoms in terms of Coming to Know were addressed in that category. The need for physical care was addressed in Doing For, and the problems of weight loss and hormonal induced post-partum depression were addressed in the Going Public and Enabling categories respectively.
- 5. <u>Guilt</u>. Unlike the findings of Borg and Lasker (1981), Stack (1980) and Peppers and Knapp (1980), guilt did not seem to be an overwhelming problem for this group as a whole. This may well be due to my observation that with a few exceptions, this group had been given considerable support with the fact that miscarriage is a purely chance, genetic induced, process of nature.

The women <u>usually</u> admitted transient self doubts that were rapidly diminished by supportive spouses and health care providers. Part of the discrepancy in findings between this and other studies may be due to the fact that this study's "sample" had all experienced

recent loss. Unlike the women in other studies who had their loss up to 20 years ago, the health care providers in this study were all quite aware that the woman could not have caused her own body to spontaneously abort. With a few exceptions, the group of physicians who cared for the informants in this study were said to have communicated this information effectively to the women. Indeed, ONE, TWELVE and THIRTEEN who had not had cause discussed with them, were probably the most convinced that their actions had led to their loss.

6. <u>Ultrasound</u>. With the exception of FOURTEEN, every woman had an ultrasound performed at some point. It would appear that the ultrasound had two basic meanings in this study. First, whether it be through the ultrasound screen or the Doppler (which uses ultrasound waves to detect heartbeat in early gestation), this piece of technology was described as incrementally increasing the maternal attachment process in early pregnancy. It is my suspicion that the ubiquitous use of ultrasound may even offer challenge to the psychology of early pregnancy literature which describes the task of incorporation as being the predominant psychological theme prior to fetal movement. In fact, I postulate hearing the heartbeat via doppler or visualizing the fetus via ultrasound may well institute the stage of differentiation considerably earlier than that which has been traditionally theorized.

The second meaning of ultrasound in this study has been alluded to in the Coming to Know process. In many instances, the ultrasound itself was the point of confirmation for the informants. Whether the woman read her fate on the screen or in the

ultrasonagrapher's expression, this evidence provided by ultrasound was quite pivotal in the woman's realization of her loss.

- Cultural Variability. The predominant cultural background in this study was White Anglo-Saxon, middle class American. There were only three women of minority ethnic background: ONE and SIX were Hispanic, TWENTY was Black. There are perhaps three observations that I can tentatively offer about this subgroup. First, the interviews with ONE and TWENTY did not flow as smoothly or last as long as the interviews with the remainder of the informants. In reviewing the transcripts, I have noted that both of these informants were much more quarded or cautious in choosing their responses (i.e., they seemed more intent on using the right words); their answers did not always address my questions; and I seemed considerably less responsive to their cues. On the other hand, SIX's interview was comfortable. lengthy, and flowed smoothly. The second cultural observation was addressed in Doing For, that is the tendency for ONE and SIX's health care providers to gloss over their needs. My final observation was that the consistent use of religion (It's God's will) as a coping strategy was more strongly expressed by this subgroup (two out of three) than the remainder of the informants (two out of 17).
- 8. Strengths and Gains. Although this finding was addressed in Losing and Gaining, it bears repeating that, with few exceptions, the women in this study were able to identify some "good" in their pain. As stated in the assumptions for this study, Marris (1974) suggested that part of successful grieving is being able to find some positive meaning in the loss. This search for meaning and

identification of "good" suggests a strength of the human spirit to survive through even the roughest of times.

There were a number of gains identified in this study. The most frequently mentioned positive outcome was a deepening of the informants' marital relationships. Also identified frequently was a "gained sensitivity." Some even referred to their miscarriage as a growth experience. Lastly, if nothing else, many informants felt things could have been worse; and thus not having to bear "the worst" was seen as a more positive than negative outcome.

### Summary of Chapter IV

In this chapter, the findings of this study were presented. Six experience and five caring categories were hypothesized as being meaningful to the understanding of the human experience of miscarriage and the caring needs of the woman who miscarried. In addition, a few incidental findings of this study were offered. Finally, findings were compared and contrasted with the pilot study, the perinatal loss and caring literature, and the five assumptions which underlie this study.

#### CHAPTER V

#### **NEW DIRECTIONS**

This research offers new directions for study in two basic domains. Nethodologically, it addresses some issues which are meaningful to the scientific study of the diagnosis and treatment of human responses to actual and potential health problems. Substantively, it addresses issues which are meaningful to the understanding of maternal perceptions of loss in early pregnancy. Chapter V briefly addresses the issues raised by this study and suggests some new directions for nursing research related to humans in situations of loss.

## Methodological Issues and Directions

- How useful is this methodology for addressing the concerns of nursing?
- 2. Is it possible (or ethical) to leave the nurse out of nursing research?
- 3. What are the implications of <u>The Ethnograph</u> (Seidel and Clark, 1983) as an adjunct to qualitative research?

#### Usefulness of the Method

In discussing the usefulness of this methodology for nursing, four things must be kept in mind: 1) it is lengthy, tedious, and in two words--NOT EASY; 2) it is difficult to describe the exact methodology employed; 3) it requires a venturesome spirit that is comfortable with taking on faith that things will fall into place; and 4) it is tremendously rewarding.

First, I will attempt to address the "not easy" aspect. The amount of time and energy it takes to do justice to the experience of 20 women in a critical life event defies explanation. The price for gathering rich data from 20 warm, open, sharing human beings is that the researcher feels an overwhelming responsibility to give that information back to society in such a way that no one informant's contribution is slighted. Thus, the length of time it takes to make sense of the data and the length of space it takes to present that data can both become quite unwieldy. The tediousness of this research comes into being in terms of the discipline it takes to keep oneself fully abreast of each informant's experience and the relevance of that experience to the emerging categories. The constant need to listen, read, reflect, reread, breakdown, synthesize, reflect and reread results in the usurping of a considerable amount of time and energy.

For those who like to work within prescribed guidelines, the qualitative route is highly discouraged. I have come to discover that the reason there are few step-by-step guidelines for qualitative research is that in many aspects, the actual analysis is akin to the thought process of the researcher. Trying to put a formula on how to

force the actual category out of the data into the researcher's mind is like trying to describe the workings of intuition.

It takes considerable faith on the part of the researcher that if the data is consulted frequently and thought about constantly, somewhere, somehow an underlying process will be identified. The researcher is not the only one who's faith is taxed, so must the consumer be willing to sit comfortably with the fact that intuiting and empirical observation are creditable ways to go about "doing science." Both the researcher and the consumer must be willing to place faith in the researcher's rigorous attempt to stay close to her data as she seeks out new understandings of common human experiences.

Finally, the rewards of this research process far outweigh the price. The chance to listen to the same story told from 20 different well-informed angles is an opportunity afforded few. When the constant reflection and questioning brings forth a new idea, it is quite exciting to return to the data and see if indeed that idea holds up. Even more exciting is "going public" with the findings and having the population to whom the findings apply tell you how meaningful the evolved categories are for capturing their experience.

Bearing the above four comments in mind, the methodology described in this study has a lot to offer nursing. First of all, it involved little more than a curious disciplined nurse going to a person in her own environment and asking that person to teach the student researcher about her responses to her health problem. Second, the findings are all of potential usefulness for nursing care. The experience categories provide new insights for nursing

assessment and evaluation. The caring categories suggest guidelines for psychosocial treatment modalities for human responses to actual and potential health problems.

In terms of building future nursing knowledge (i.e., theories), the fact that these data come directly from persons in need of caring makes this quite a useful way to define where caring is needed and what "kinds of caring" are wanted. This methodology lends itself to the birth of insights which provide as many questions as answers. The questions lead to more research and ultimately more nursing knowledge about the phenomena of concern to nurses.

#### The Nurse as Researcher

The outside reviewer of my research style made two comments that led to this discussion of the issue of nurse as qualitative researcher. First, she commented that the questions I asked may have restricted my chances of getting at "other ideas," i.e., the spiritual meaning of miscarriage. Her second comment was that at times I made-like-a-nurse instead of a pure ethnographer and that may have changed the informants' and my relationship.

After much thought, I have decided to accept the two comments as positive, not negative criticisms. As a nurse, I seek out nursing knowledge: knowledge of persons, environments, health and nursing. While those guidelines are quite broad, they do suggest that some of what I evolve should be ultimately somehow ammenable to nursing practice. Also, the questions asked were so broad and open-ended that in those cases where "spiritual" coping strategies were preferred, they certainly seemed to have been communicated. Now, if

I were a theology student, the remainder of my interview would probably have explored the woman's relationship with her God, church, bible, etc. Since I am a nurse, I pursued the knowledge that religion is a support to this informant, and I bear in mind that there may be others like her. Henceforth, when and if I should come in contact with this preferred strategy in practice, my role would be to facilitate the client's capacity to tap that resource.

The second comment about my moving into my role as nurse is really an important issue for nurses doing research. As I see it, the comment should have been broader than just the fact that I "made-like-a-nurse" at times. Truth be told, I also made-like-a-mother, and made-like-a-woman as it seemed appropriate. My informants were told that a nurse would be asking them about their miscarriage; they, therefore, had some expectations even before they ever met me. It is my suspicion that hearing that it was a <u>nurse</u>-researcher is what got "my foot in the door," perhaps, even as far back as getting physicians to agree to refer women to me.

As for me moving into a nursing (mother, woman) role, to me it seemed like the comfortable thing to do as my relationship with the informants unfolded. If, indeed, qualitative research shuns the subject/object distinction between researcher and informant, then it seems wrong to expect the researcher to be nothing but scientificethnographer in her relationship with informants. The fact of the matter is that the reviewer also stated, "Your informants seemed relaxed-certainly a clue to your own state. I was absolutely shuddering as each told their story. If I hadn't listened, I would have doubted you could have gotten such rich descriptions." Why the

rich data? As I see it, it was all in the give and take of my relationship with the informants. I moved in and out of whatever role seemed right for the moment. My role as nurse was just one of them.

Finally, there is one other issue that bears discussion. How ethical is it to not-nurse where nursing is obviously needed? For example, when an informant would share with me her anxieties over what she did to cause her miscarriage, I'd have my tape recorder on and get the woman to tell her guilt, fears, worries, etc., and how much she had shared this with her spouse and physician. Do I then, ethically, move on to the next question or do I stop and explain the accident of nature, genetic, no way she could have caused it theory? Or, when a nineteen-year old informant tells me how much she wants to get pregnant and how confused she is about the "right time of the month," do I leave her befuddled and get on with my agenda? Truth is, in both instances, I shared my knowledge. It was the least I could give back for all they were giving me.

As I see it, it is so false to think the informant is ever going to see me as non-nurse. Furthermore, my being a nurse is probably a great deal of the reason why the women thought it was O.K. to discuss some topics (i.e., sex, physical symptoms, their marital relationship). Nurses as qualitative researchers need to question how meaningful it is to accept the critique that we make-like-nurses in research. Perhaps we should just accept it as true that we <u>are</u> nurses and are <u>perceived</u> as nurses, and then figure out how to <u>capitalize</u> on our role as nurses in research.

### The Ethnograph

This dissertation was the first fairly large study to put <u>The Ethnograph</u> (Seidel and Clark, 1983) to the test. Consequently, as the study progressed, "bugs" in the fledging program were encountered. If it were not for the fact that John Seidel was never more than a few feet away and ever ready to trouble-shoot, my temptation would have been to abandon the program quite early on. An additional dilemma in the use of <u>The Ethnograph</u> is that it can be quite expensive in terms of time and money when used on a main frame computer. It is my understanding that future versions of <u>The Ethnograph</u> which are being written for personal computers will solve this problem.

The Ethnograph did, nonetheless, produce what it said it would: a copy of all informants' statements sorted by codes. As I went to write, it was delightful having a separate manila file for each code. For example, in the file entitled "Othermis," I had a copy of every statement made by every informant that referred to their contact with other women who have miscarried. In writing about the category Getting Through It, when I wished to support my argument that other women who miscarried played a meaningful role, all I had to do was to read through the "Othermis" file until I could find the statements I chose to quote.

The usefulness of this software package for qualitative research looks promising. However, at present there remains some problems that need to be worked out (i.e., expense). It is my hope that these dilemmas will be overcome in future versions of the program.

### Substantive Issues and Directions

The categories which emerged from this study are innovative ways to view both miscarriage and the caring needs of women who miscarry. Having questions asked by a nurse has resulted in answers that are meaningful for nursing. The information generated may provide new insights for nurses in practice as well as research.

Practicing nurses could conceivably use the knowledge along with other necessary strategies for collecting data in order to assess women who miscarry. Collecting clinical assessment data via the experience categories will lend additional data to aid identification of the woman's responses to her actual health problem as well as outline her potential health problems (i.e., failure to Get Through It due to lack of others to Share the Loss, or difficulties in subsequent pregnancies due to unresolved earlier loss or ongoing fears). The caring categories may also be of potential clinical use in not only treatment (i.e., Enabling, Doing For), but also in evaluation of self as a caring person (i.e., did I know her loss, was I able to share, did I convey a maintenance of belief in her?). Finally, having knowledge of both experience and caring needs of women who miscarry should lead to a greater sensitivity in the care of women who experience early pregnancy loss.

The use of the findings of this study for research and the building of nursing knowledge are twofold: 1) it lays the foundation for additional study of loss in early pregnancy (experience and caring needs); and 2) it may conceivably be of use in providing

insight into other conditions of human loss. The remainder of this chapter will focus on these two ideas.

### Future Directions for Understanding Early Pregnancy Loss

The categories developed in this study need to be tested on both similar and different groups of women in order to validate their usefulness beyond the 20 women on which they are based. These categories are at the level of a naive substantive theory (Glaser and Strauss, 1967). They pertain to one human loss condition and as of right now, they are probably best described as not too generalizable beyond 20 women and one researcher.

Future research directions are multiple:

- Another researcher could take the 40 hours worth of interview transcripts and replicate the analysis of this study to see if they come up with similar categories.
- Another researcher could take my categories and see if they could find evidence of the categories in the transcripts.
- 3. Using the same questions and methods developed in this study, the study could be replicated with another group of women (hopefully a group quite different from this group, i.e., more ethnic minorities, single women, more habitual aborters, clinic patients, etc.).

- 4. I, or another researcher, could take my categories, develop questions that directly address the categories and see if the categories hold up in another group of women. This group of women could be similar to the group studied or different (i.e., teenagers). Using a similar group would help to clarify or strengthen understanding of the categories. Using a dissimilar group would serve to not only strengthen categories, but test their usefulness on populations beyond the group they were developed on.
- 5. A content analysis of the findings section (Chapter IV) of this study could be done to help identify more specific indicators of the categories. Hopefully a content analysis of the findings chapter may help to isolate words that were frequently used by the informants in each of the categories. These indicators could be used to develop a more quantitative tool which would allow the study to be expanded to include a larger number of women at one time.
- 6. The husbands of the women who miscarry could be included in future studies to see: 1) if the categories are meaningful with this group; and/or 2) if there are other categories necessary to understanding the husband/father's experience and caring needs.

7. Finally, in terms of a secondary analysis of the data, there are probably a number of correlational questions that could be asked of the data (i.e., Is there a relationship betwen history of pregnancy loss and length of time from loss to turning point? Is there a relationship between number of "Sharing the Loss" strategies identified and Getting Through It, etc.).

#### Future Directions for Understanding Human Loss

The potential for the findings of this study to provide insight into other conditions of human loss seems promising. If nothing else, the categories should conceivably be fruitful for the other circumstances of maternal understanding of loss. Anecdotically, I have been told by a number of people that these categories have potentially a broader range of applicability. For example: 1) a woman who is infertile shared with me how meaningful the categories were for describing her experience: 2) two social workers who work with couples who experience perinatal loss (including neonatal loss) have suggested that the categories are quite meaningful in these maternal loss situations; 3) finally, a colleague, working with older people who have experienced recent death of spouse due to cancer has suggested that with some reworking, the categories would also be meaningful within this group (i.e., Trying Again might be translated into getting back into life without the spouse).

Glaser and Strauss (1967) refer to the taking of categories developed under one human condition and testing them under differing

human conditions, as the process of raising a theory to the level of a formal theory. A formal theory is defined as having been developed for a formal or conceptual area of inquiry. It differs from a substantive theory mainly in scope. A substantive theory tends to stick close to a specific human situation (i.e., early pregnancy loss); whereas a formal theory addresses a broader conceptual area (i.e., human loss).

Testing the categories developed in this study first with similar groups with similar conditions; next, differing groups with like conditions; then similar groups with differing conditions; and finally differing groups with differing conditions will all serve to broaden the usefulness of the categories. This broadening of usefulness is akin to Glaser and Strauss' formalizing of a theory. In terms of differing conditions with which to try these caregories, it would be fascinating to test their usefulness with such human conditions as stillbirth, elective abortion, infertility, cesarean birth, neonatal loss, birth defects, sudden infant death syndrome (S.I.D.S.), loss of older child, loss of spouse, cancer, and many more human loss experiences across the life span.

# A Word of Caution

While these categories are insightful, one must be cautious in how they are used. A basic premise which underlies this study was that all women would uniquely express themselves in their loss. There may be common processes that all have to go through; however, there are any number of ways that any one woman might express herself in that process. The categories are to be used as insights, not

formulas; they should only serve as partial guidelines in diagnosing and treating human responses to the actual and potential health problem of miscarriage. The caregiver in any one situation should draw upon the knowledge provided here as well as other available clinical knowledge for evaluating clients.

Just as we need to <u>avoid</u> the conceptual leaps that attachment takes place at the point of quickening, or that replacement child problems automatically apply to couples who miscarry, or that marital demise is a foregone conclusion to pregnancy loss, so must we cautiously use these categories as prescriptions for practice. These categories are descriptions/interpretations, not prescriptions. They should be used accordingly.

## Summary of the Study

This dissertation has focused on the human experience of miscarriage and the caring needs of the woman who miscarried. Assumptions which underlie the study were shared and literature which seemed relevant to the purposes of the study were reviewed and critiqued. Findings of the pilot were also shared. The methods employed to develop the categories were reviewed prior to the presentation of findings. The findings were supported by the statements of the informants, and when relevant, by the original assumptions, the pilot study, and the literature reviewed. Finally, directions for future use of the categories in practice and research were suggested.

#### Night Dreams

At night my child comes to me in a special way.

He comes to me in sweet memories and dreams along the way.

I sing to him special songs I know and melodies of love.

He smiles and he coos at me in fondest ways of love.

But when morning comes, my babe must go,

For he died inside my womb.

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### Appendix A

### Preliminary Investigation of the Emotional Impact of Spontaneous Abortion A Pilot Study

### Protocol for the Open-Ended Interview

These questions will be asked of the respondent in an interview format. The conversation will be taped. The purpose of these questions is to attempt to understand the emotional impact of the spontaneous abortion as described by the woman who has experienced such an event in the last three months.

### Questions:

- Would you describe your lifestyle? Occupation? Age? Educational level? Socio-economic level? Self-image as mother. career woman?
- Would you please tell me about the other members of your family? (Elaborate as above.)
- 3. Was this your first pregnancy? Was there anything remarkable about your previous pregnancies?
- 4. Please tell me how you felt when you first realized that you were pregnant this time. What was the meaning of this pregnancy to you? How do you think your spouse felt about the pregnancy?
- 5. How public were you about your pregnancy?
- 6. How did you feel during the pregnancy physically? Emotionally?
- Would you please describe the miscarriage for me (sequence of events, physical, emotional feelings, care received).
- 8. What was the meaning of this miscarriage for you? Family members?
- 9. Did you see the fetus? How did you react?
- 10. Did you fantasize about this child? What were your dreams for the child? Had you chosen a name for the child?
- Had you ever thought before that you might miscarry? Why? Before this miscarriage, what was your idea of what a miscarriage entailed? How have those ideas changed?

- 12. If you have ever miscarried before, how did that (those) miscarriage(s) compare to this one?
- 13. How did you let others know of your miscarriage? How did they react? What comments were helpful? Harmful?
- 14. Why do you think this miscarriage occurred?
- 15. What do you see as your usual ways to cope with stressful situations? How well did these usual strategies work in this instance? What specifically did you do to get you through this whole event?
- 16. What role does religion play in your life? What was the role of religion in dealing with the miscarriage?
- 17. What are your plans for the future? What are your plans for future pregnancies?
- 18. Are there any questions that you think I should be asking you about your miscarriage that I have not already asked? How well do you feel we have explored the emotional impact of your miscarriage? Is there anything you wish to tell me that you think will help me to better understand your miscarriage?
- 19. Have you any questions for me about this study?

D.O.M
#1
<b>#</b> 2
Gestational Age
APPENDIX B
<u>Data Sheet</u>
1 I.D. Number
2 Referral Source
Wife Partner
3 Age 6 Age 9 Married to father
4 Occupation 7 Occupation 10 Living with father
5 Education 8 Education 11 Length of time living together or married
12 Family income level
13 Number of previous pregnancies
14 Number of previous pregnancy losses
Types:
15 Stillbirth
16 Neonatal/death
17 Miscarriage: Early (Before 15 Weeks)
Late
18 Therapeutic abortion
19 Ectopic pregnancy
20 Number of children
21 Male
22 Female
23 Other people living in household
24 Religion 25 Culture

### Appendix C

# The Human Experience of Miscarriage

### Protocol for the First Open-Ended Interview

These questions will be asked of the respondent in an interview format. The conversation will be taped. The purpose of these questions is to attempt to understand the human experience of miscarriage as described by the woman who has spontaneously aborted in the last three months.

### Questions:

- 1. Self-image as mother, career woman? Cultural background?
- Would you please tell me about the other members of your family? (Elaborate as above.)
- Was this your first pregnancy? Was there anything remarkable about your previous pregnancies? How close to your last pregnancy was this one?
- 4. Please tell me how you felt when you first realized that you were pregnant this time. Was this a planned pregnancy? What was the meaning of this pregnancy to you? How do you think your spouse felt about the pregnancy? Did you ever suspect this pregnancy would end? Why?
- 5. How public were you about your pregnancy?
- 6. How did you feel during the pregnancy physically? Emotionally?
- 7. When did you first suspect you were miscarrying? How did you feel? What did you do?
- 8. When did you know you were miscarrying? How did that confirmation make you feel?
- Would you please describe the miscarriage for me. (Sequence of events, physical, emotional feelings, care received.)
- 10. What was the meaning of this miscarriage for you? Family members?
- 11. Did you ever see your fetus on ultrasound? Did you see the fetus when you miscarried? How did you react? Did you show the fetus to others?
- 12. Did you fantasize about this child? What were your dreams for the child? Had you chosen a name for the child?

- Had you ever thought before that you might miscarry? Why? Before this miscarriage, what was your idea of what a miscarriage entailed? How have those ideas changed?
- 14. If you have ever miscarried before, how did that (those) miscarriage(s) compare to this one?
- 15. How did you let others know of your miscarriage? How did they react? What comments were helpful? Harmful?
- 16. Why do you think this miscarriage occurred?
- 17. When a woman miscarries, what does she lose? Does she gain anything? Can you find any "good" in this whole event?
- 18. Was there anyone/or anything that really "touched" you throughout this whole event? Was there anything/or anyone that gave meaning to all of this?
- 19. How has your health been since the miscarriage? How is your appetite? Your sleep?
- 20. Have you recently experienced any other losses in your life? Tell me about them. Do you think this influenced your miscarriage experience?
- 21. What do you see as your usual ways to cope with a stressful situation? How well did these usual strategies work in this instance? What specifically did you do to get you through this whole event?
- 22. What role does religion play in your life? What was the role of religion in dealing with the miscarriage?
- 23. What are your plans for the future? What are your plans for future pregnancies? Did you doctor/midwife discuss this with you?
- 24. Were there any things that people said or did that made you feel cared for or cared about during your miscarriage? Who were they? What did they do? Why do you call what they did caring?
- 25. Is there anything that you wish had been done for you that would have made you feel cared for? How would you like to be cared for by a doctor, nurse, minister, neighbor, relative, etc.?
- 26. If you had to describe this whole experience in one word, what would that word be? Why do you choose that word?

- 27. Are there any questions that you think I should be asking you about your miscarriage that I have not already asked? How well do you feel we have explored the emotional impact of your miscarriage? Is there anything you wish to tell me that you think will help me to better understand your miscarriage?
- 28. Have you any questions for me about this study?

### Appendix D

### The Human Experience of Miscarriage

## Protocol for the Second Open-Ended Interview

- How are you feeling now? Physically? Emotionally?
- 2. Tell me how you feel about the miscarriage now.
  - a. Are your feelings as intense as they were right after the loss?
  - b. When did you find yourself starting to get over it? Can you give me a turning point?
  - c. Will you ever be totally over it?
- 3. Have you been back to see the doctor since we last spoke? How were you feeling at the time of that visit?
- Can you tell me if there was ever a time after your miscarriage that you found you had to remind yourself that you were no longer pregnant?
- 5. Are your plans for future pregnancies the same now as when we last spoke?
- 6. When you were pregnant, did you think you were "attached" to the fetus? Was there a "bond" between you? Can you tell me why you say that?
- 7. Would you say you lost a child, a fetus, a pregnancy, a part of yourself, or something else? Why did you choose your answer?
- 8. Is there anything else that happened since we last spoke that had an impact on your dealing with your miscarriage?

### Appendix E

### Subject Consent Form

for Participation in Clinical Investigation Project University of Colorado Health Sciences Center

The Human Experience of Miscarriage

Participants: Women who have experienced a spontaneous abortion within the last fifteen weeks and who had not yet felt

fetal movement.

Date: June through September, 1983.

Dear Participant:

You are being asked to participate in a study to investigate the impact of miscarriage/spontaneous abortion. This study is being done so that we in the health care system might better understand the experience of a woman who miscarries.

You were selected to participate in this study due to your recent experience with a spontaneous abortion. Your agreement to participate in this study will in no way affect the treatment you have been or will be receiving from your health care providers.

If you agree to participate, you will be asked to respond to a set of open-ended questions which will be posed by the investigator. There will be two interviews which will be taped. Each will take approximately one hour of your time. The anonymity of your response will be guaranteed. This study will be of no benefit to you. The only risk might be discomfort resulting from talking about your miscarriage experience. You are encouraged to ask any questions that may occur to you. The investigator, Kristen Swanson-Kauffman may be reached at the orthodox of the control of the

Authorization: I have read the above and understand the discomforts, inconveniences and risks of this study. I agree to the participation of (name) in this study. I understand that if I refuse to participate or withdraw at any time, my treatment will not be affected in any way.

Signed:	
Witnessed:	 
Date:	

### Appendix F

### Steps in Computer Coding and Sorting of Transcripts

A. An example of a "raw" transcript.

zME: Oh, before you even became pregnant, did you ever think of yourself as the type of person who might miscarry? Old you ever dive that any thought?

\*TWO: Yeah, I did.

#ME: Tell me how come.

aTWO: Well, because, I'il tell you my mom drilled this into my head because i've never been a real healthy ester. And she would always tell me, "You're going to not be able to have any kids because you don't eat healthy." You know. And so that had been drilled in my head all the time, and in fact, when I did miscarry, the town that I'm from is a real small town, and that gossips very bad, real bad. And when I did miscarry, the town that the state of the st

An example of a numbered, formatted transcript.

2248 ME: I see. O.k., um, thisis a question 2249 that I don't know if it's soins to 2250 make any sense and we misht have 2351 aready adressed it, was there anyone 2552 or anything that really touched you 2553 through the whole event. That really 2554 sot you in a very sensative spot.

2355 TN: I think we probably hit on 2356 everybody, except for the people at 2357 Sweedish (?) were so special.

2358 ME: Tell me about them.

2359 TN: They were just a special. They were 2360 so understnading and they were women, 2361 and even the anaesthesiolosist was a 2362 woman. They were really tuned in. I 2363 went in to check into day surgery 2364 which you so downstairs through the 2365 E.R. and you check in, and a woman 2366 says well what seems to be your 2367 I said problem. I'm: having 2368 miscarriase. Bam..upstairs. 2369 wasn't a second. I mean you could 2370 just see the looks on their faces, 2371 they felt so bad.

# C. An example of a hand-coded segment.

```
644 TN:Oh yea, it's just aufull. That to
645
      me was really the toughest...it was
      almost, I'll tell you it was a
646
647
      relief to set to the doctor and,
                                               CONFIRM
648
      lost the placenta there, you know,
                                                644-659
649
      all that stuff came blasting out in
450
      his office. Thank God I made it that
651
      far, cause it was not, not a pleasant
652
             Put, um, I was almost
653
      relieved when he confirmed it.
654
      mean I felt horrible about that, the
455
      fact that I was miscarrying, but I was
     so releived that it was indeed a
656
     miscarriage and that I hadn't lost my
657
     head. It was wierd.
458
```

# D. An example of a computer-printed coded segment.

```
644 TN:Oh yea, it's just awfull. That to #GUSH *CONFIRM
645
     me was really the toughest...it was
646
     almost,
               I'll tell you it was
647
     relief to set to the doctor and,
      lost the placenta there, you know,
     all that stuff came blasting out in
649
650
     his office. Thank God I made it that
651
     far, cause it was not, not a pleasant
652
     sight. But, um, I was almost
653
     relieved when he confirmed it.
6.54
     mean I felt horrible about that, the
655
     fact that I was miscarrying, but I was
     so releived that it was indeed a
454
     miscarriage and that I hadn't lost my
657
     head. It was wierd.
653
```

### E. An example of a sort page (sorted by the code "parents").

#PARENTS SIX: 139 SIX: Yes, because he comes from a #PARENTS family that believes that you should-141 -once you set married, you should 142 have children right away. 143 ME: Ub-hub. 144 SIX: And his sisters have sotten 145 married, and they've had children sotten #OTHMOTH right away, and us--we're still here. 147 ME and SIX: And no children. #PARENTS SIX: 910 SIX: Saturday morning, I woke up and #PARENTS 911 they checked me, and he said, "We'll 912 just have to wait and see what 913 harrens." So, my mom, everybody came--my sister, my friend Susan 914

915 came. I didn't see Susan or my mom. 916 My mom came in the morning, and my 917 sister and Bev, my cousin, and Timmy's sirlfriend--they came. And 918 919 Mom brought me some nightsowns, and she said I looked really pale, and I 920 921 didn't look sood at all. And she said, "What did the doctor say?" 922 I said, "Just to wait and see." She 923 924 said, "I can't believe this is all 925 they're doing. They're just waiting. 926 What are they waiting for?" I said, 927 "I don't know." So then my sister-

# Appendix G

# The Human Experience of Miscarriage

# Inter-Rater Reliability

Α.	Coming to Know
	1. Is this category present in this transcript?
	If present:
	2. How did the woman come to know she was miscarrying?

3. What was her first sign?

4. Was there a point of confirmation? If so, what was it?

 What were her emotions throughout her "coming to know"? Please support your response with (an) example(s) from the text.

## B. Going Public

1. Is this category present in the transcript?

If present:

 How public was this woman with her pregnancy? Please give (an) example(s) to support your response.

 How public was she with her miscarriage? Please give (an) example(s) to support your response.  Please describe the interaction between how public she was with her pregnancy and how public she was with her miscarriage.

 In your opinion, how was going public with the miscarriage for this woman (i.e., was it emotionally trying or "no big deal")? Please support your response with (an) example(s) from the transcript.

# C. Losing and Gaining

1. Is this category present in this transcript?

### If present:

What did this woman lose with her miscarriage? (Give more than one answer if it is applicable.)

 What was this woman's "emotional assessment" of the meaning of this loss? (i.e., sad, relief, anger, etc.) Please give (an) example(s) from the transcript to support your response.

What did this woman gain as a result of her loss? Please give (an) example(s) from the transcript to support your response.

# D. Sharing the Loss

1. Is this category present in this transcript?

### If present:

 In your opinion was this woman's loss shared with others? Please support your response with (an) example(s) from the transcript.

3. Did it appear to you as though others understood her feelings? Why did you respond as you did?

# E. Getting Through It

1. Is this category present in this transcript?

### If present:

 Please describe (briefly) this woman's experience with "getting through it." (i.e., How long did it take her to get past the "acute" stage if she did at all. Was there a turning point? How was she at the time of the second interview?)

3. Was this woman "over it"? Please support your response with (an) example(s) from the transcript.

In your opinion was her grieving "normal" or "healthy"? Why did you respond as you did?

# F. Trying Again

1. Is this category present in this transcript?

# If present:

What were this woman's plans for the future?

3. Were there any "ongoing fears" that were left over from the miscarriage? If present, how did these "ongoing fears" impact on her "trying again"?

### II. Caring Categories

N.B. "Caregivers" refers to both professional (nurse, doctor) and personal (family, friends) providers of care.

# A. Knowing

1. Is this category present in this transcript?

### If present:

- Were there any "caregivers" who knew (on some level) or understood the meaning this woman's loss held for her? Please support your responses with examples from the transcript.
  - a. Professional?

- How did the "caregivers" express their knowing? What were the behaviors (words, actions) that manifested their "knowing" or "not knowing" as the case may be?
  - a. Professional?
  - b. Personal?

В.	Being	With

Is this category present in this transcript?

### If present:

- Were there any "caregivers" who were able to "be with" the woman through her loss? (Did anyone "feel" her loss? This does not necessarily mean to the same depth of feeling the woman did.)
  - a. Professional?

b. Personal?

- 3. How did those caregivers express their "being with" the woman or "not being with" as the case may be?
  - a. Professional?

	ıab'	
c.		

. Is this category present in this transcript?

If present:

- Who enabled this woman to express her grief? Who blocked the expression of her grief?
  - a. Professional?
  - b. Personal?
- 3. How did those caregivers express their "enabling" or "non-enabling" as the case may be?
  - a. Professional?
  - b. Personal?

- D. Doing For
  - 1. Is this category present in this transcript?

# If present:

- 2. Who "did for" this woman? What did they "do for" her?
  - a. Professional?

# E. Maintaining Belief

1. Is this category present in this transcript?

# If present:

- Who "maintained belief" in her? How did they express their belief?
  - a. Professional?