

A PHENOMENOLOGICAL STUDY OF PARENTS' EXPERIENCE  
FOLLOWING STILLBIRTH OR EARLY INFANT DEATH

By

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## ABSTRACT

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This study was designed to discover parents' experience following a stillbirth or early infant death. The conceptualization of the research problem was based on Kleinman's (1978) cultural system model which directed the researcher to elicit directly from clients their explanatory models, or their way of viewing the experience.

The specific research questions were (1) How do couples perceive and interpret their experience following stillbirth or early infant death? and (2) How do couples view the social support they have received at the time of their infant's death?

Six couples, who were recruited primarily from bereavement support groups, participated in the study. Each couple had experienced a stillbirth or early infant death between four months and four years prior to the study. Data were collected from the subjects with the use of unstructured interviews, allowing the experiences to unfold as they were perceived by the participants.

Four main themes that evolved from the data were (1) anticipation of parenthood and the shattering of hopes with the death or knowledge of impending death of the infant; (2) a multidimensional personal grief experience; (3) an

interpersonal grief experience influenced by the social support of health care professionals, of friends and family and of the spouse; and (4) reflection and search for meaning in the experience.

The discovery of couples' perceptions of their bereavement experience and their view of the support received will assist in enhancing the ability to provide more effective nursing care to bereaved families. Implications for nursing practice, research and education are delineated.

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## CHAPTER ONE

### Introduction

#### Background and Conceptualization of the Problem

Birth is usually seen as a joyful time of new life and hope; however, when death occurs before or shortly after birth there is a sense of an "overturning of the natural order of things" (Lewis & Liston, 1981, p. 147). Perinatal death occurs approximately once in every one hundred births with the 1983 rate of stillbirths past 28 weeks gestation at 4.9 per 1000 live births and the rate of neonatal deaths under 28 days of age at 5.5 per 1000 live births (Statistics Canada, 1983). Perinatal death is thus an atypical, often unexpected event for parents.

Pregnancy and parenthood are major transitions in life involving change and adjustment. Bereavement is also viewed as one of life's major transitions (Hayes, 1976; Holmes & Raye, 1967; Moos, 1977), a change that people are least prepared for and find hardest to accept (Marris, 1974). Perinatal bereavement is especially difficult for parents because it is a maturational crisis of failure of parenthood as well as a situational crisis of death (Quirk, 1979; Johnson, 1979). Furman (1978) suggests that death leads to a process of detachment from the loved one as well as an identification process where the bereaved take into



themselves aspects of the dead person or relationship. In perinatal death, the baby has often not lived long enough as a separate person for identification to occur. Although there is a sense of loss, there is little sense of having lost a person with whom experiences have been shared (E. Lewis, 1976).

The literature presents perinatal loss as a crisis for parents that, if not resolved, can lead to problems in the future. Depression was found by Clarke and Williams (1979), Clyman, Green, Rowe, Mikkelsen and Ataide (1980) and E. Lewis (1976). Wolff, Nielson and Schiller (1970) however, found that it was not debilitating depression. Disturbance in communication, marital and sexual problems, as well as difficulties with other children are family concerns or problems in some cases (Clyman et al., 1980; Giles, 1970; Helmrath & Steinitz, 1978).

The social support received from others influences the ability to cope with crisis and adapt to change (Cobb, 1976; Schlossberg, 1981). The spouse, family, friends, and health care professionals are potential sources of support for people experiencing perinatal death. Stringham, Riley and Ross (1982) and E. Lewis (1976) state that few health care professionals are able to talk directly to grieving parents about their stillborn babies. This reticence may be due to a lack of understanding of the experience and needs of bereaved parents. The researcher's personal experience as a

community health nurse involved feelings of inadequacy and limited understanding of the experience of perinatally bereaved families.

Community health nurses are in a position to provide support to bereaved parents thus assisting them in coping with the death of their child. Such intervention may prevent long-term psychosocial problems arising from unresolved grief. Support can take the form of maintaining and strengthening the support system of the family, and particularly of the couple (Norbeck, 1981; Wright & Bell, 1981).

In spite of rapidly expanding knowledge and technology in health care, there is evidence of dissatisfaction with the quality of care received from health care professionals (Kleinman, Eisenberg & Good, 1978). This dissatisfaction has been expressed by parents following perinatal death (Wolff, et al. 1970). E. Lewis (1976), Davidson (1977), and Helmrich and Steinitz (1978) have identified a "conspiracy of silence" from health care professionals when parents indicated the need to talk about their experiences. Discrepancies between parents' needs and health care professionals' behavior are apparent in the different ways professionals and clients view their illnesses and need for health care.

Kleinman has developed a cultural system model to explain the interactions between different sectors of society in relation to health care. Sickness is experienced and responded to in three arenas (1) the popular sector, which includes the individual and the family as well as social network and community activities, (2) the professional sector, and (3) the folk sector, which includes nonprofessional healing specialists. Because of differing roles, relationships, beliefs, and transaction settings, these three groups construct reality in different ways, called explanatory models by Kleinman. When explanatory models conflict, health care may be impeded (Kleinman, 1978).

Kleinman's cultural system model gives direction to the researcher to elicit the experience directly from those who have experienced it; in other words, to find out from parents how their infant's death affected them. Discovering the clients' construction of reality will assist the professional sector, which includes nursing, to (1) provide more appropriate care to clients and (2) to foster the popular sector sources of support, particularly the family, as most illnesses and decisions to seek help are managed solely within the popular sector (Kleinman, 1978). The focus of this study will be the explanatory models of the couples experiencing the loss, i.e. the popular sector. The professional sector model as seen by the couples will be

addressed. The folk sector will not be considered in this study.

### Problem Statement

Death of an infant before or shortly after birth is, for parents, a major loss that has the potential to cause personal and family problems if the grief is not resolved (Clark & Williams, 1979; Clyman et al., 1980; E. Lewis, 1976). An understanding, therefore, of the grieving experience of the parents will help nurses provide better care and foster support systems for the family. To promote an understanding of the experience of couples following the death of their infants, this study will address the following questions: (1) How do couples perceive and interpret their experience following stillbirth or early infant death? (2) How do couples view the social support they received at the time of their infants' death?

### Purpose of the Study

The purpose of this study is to gain an understanding of the experience of parents following stillbirth or early infant death in order to provide more effective nursing care. The study attempts to discover how couples perceive their bereavement experience and how they view the social support they receive in a belief that a better understanding of the experience and identification of the characteristics

of effective support will enhance the ability to give and foster this support.

### Assumptions

This study is based on the following assumptions:

1. Stillbirth and early infant death are meaningful experiences for parents.
2. Meaning can be communicated by people who have had the experience.
3. The construction of the experience is a valid representation of the experience and can promote further understanding of the topic.

### Limitations

This study is limited by the subjects' willingness and ability to express their true feelings and perceptions of the experience. Schwartz and Jacobs (1979) note the possibility of "a discrepancy between what people say and what they mean" (p. 41). This limitation was reduced through clarification and validation of subjects' accounts during data collection.

Because the sample was obtained primarily from bereavement support groups, the findings may be limited to couples who have utilized resources similar to those used by the couples in the study.

### Definition of Terms

Perinatal death: Dorland's Medical Dictionary (1981) defines perinatal as "pertaining to or occurring in the period shortly before and after birth; variously defined as beginning with completion of the twentieth to the twenty-eighth week of gestation and ending seven to twenty-eight days after birth" (p. 990). When used in reference to the study population, perinatal death will include the entire sample of deaths which ranged from 31 weeks gestation to seven weeks of age. Subsumed under this definition is the phrase "stillbirth and early infant death," used interchangeably with perinatal death.

Parents: natural mother and father who had intended to raise the child together.

Experience following perinatal death: emotional, psychological, physical and social response to the loss of fetus or infant.

Social support: Information leading one to believe that he or she is cared for and loved, esteemed and a member of a network of mutual obligations (Cobb, 1976).

### Organization of the Thesis

This chapter has presented a framework for conceptualizing the problem, a statement of the problem and

the purpose of investigating the problem of parents' experience following stillbirth or early infant death.

Chapter two discusses phenomenology as the methodological perspective used in this study. The methodology used in designing the study, gaining access to subjects, collecting data and analyzing the data is also covered.

Chapter three describes the application of the phenomenological approach in analyzing the data from this study.

Chapter four is a descriptive analysis of the data obtained from parents who have experienced the death of an infant. Reference to the literature is made throughout the discussion in chapter four.

Chapter five summarizes the findings, draws conclusions and states implications for nursing practice, education and research.

## Chapter Two

### Methodology

#### Theoretical and Methodological Perspectives

The qualitative research design of phenomenology is an appropriate methodology for this study in which the researcher is seeking to understand the experience of a particular group of people, namely parents who have suffered a stillbirth or early infant death. "Phenomenology is the study of human experience from the actor's particular perspective. The purpose of phenomenology is to more fully understand the structure and meaning of human experience" (Knaack, 1984, p.107).

Two broad complementary approaches used in nursing research are the quantitative and the qualitative approaches (Oiler, 1982). The quantitative method seeks to study nature in terms of small measurable units (Omery, 1983) whereas the qualitative approach tends toward a more holistic approach (Oiler, 1982). Quantitative research uses experimentation with the objectives of causal analysis and control whereas qualitative research uses description with the objectives of identification and understanding of phenomena (Giorgi, 1975a; Omery, 1983).

Phenomenology is a type of qualitative research that attempts to "describe human experience as it is lived"



(Oiler, 1982, p. 178). In phenomenology all phenomena, including human experience, are investigated and described as they appear to the individual. All data obtained from the subject are deemed relevant. Data include the individual's subjective perception of the experience under study as well as the effects of that experience and perception on him or herself (Omery, 1983).

Because the researcher is attempting to understand the experience from the perspective of the individual, the researcher must recognize his or her own preconceived ideas, attempt to set them aside, and focus on the participant's perspective (Oiler, 1982; Omery, 1983; Schwartz & Jacobs, 1979).

Phenomenological research is congruent with the conceptualization of the problem that is based on Kleinman's cultural system model. The cultural system model gives direction to find out how participants in health care interactions construct reality. In obtaining perceptions of parents who have experienced the loss of an infant and attempting to find common themes in these experiences, the researcher hopes to better understand the reality of the experience for others going through a similar experience.

### Research Design

Study participants were recruited primarily from two bereavement support groups in the Greater Vancouver area.

Leaders of these groups were contacted for assistance in informing potential subjects of the study. Introductory letters (see Appendix A) explaining the study and inviting participation were given to the leaders for distribution to those eligible. Interested couples contacted the researcher or consented to have the researcher contact them to provide more information about the study. Six couples in total participated in the study. Four of these couples agreed to participate following contact through a bereavement support group; one couple heard about the study through other participants; and another couple heard about it through a friend of the researcher. An explanation of the purpose of the study and the role of the participants was given to the prospective subjects. A consent form explaining the study and the rights and protection of the subjects was signed prior to commencement (see Appendix B).

Eligible subjects were those who had experienced a stillbirth or an early infant death. Because the grief experience occurs over a span of time, the researcher chose a minimum of six months after the death, to give the parents time to reflect on their experiences and construct them in meaningful ways for themselves. In this sample the maximum length of time since the death was four years. Problems in gaining access to subjects led the researcher to adjust the minimum time span in the case of one couple who indicated interest in the study four months after their child's death.

A "theoretical sampling" procedure as outlined by Glaser and Strauss (1967) was utilized. The sample consisted of subjects who were competent to speak to the experience on the basis of having lived it. With the theoretical sampling method the researcher collected data and immediately began coding and analyzing it. The initial coding and analysis gave direction for continued data collection to develop the concepts that were emerging. "Theoretical saturation" (Glaser & Strauss, 1967) occurs when no new concepts are being found in the data. In this study, the sample size was limited to six couples due to the comprehensiveness of the data obtained. No new concepts arose from the data in the interviews with the sixth couple, indicating theoretical saturation.

#### Data Collection

Data were collected from the subjects during unstructured audio-tape recorded interviews. Following an explanation of the study, the researcher elicited a description of the experience allowing it to unfold as perceived by the couple (Giorgi, 1975a,b). Clarification and elaboration was occasionally sought by the researcher; for example, if the father did not spontaneously add his comments to those of the mother on a specific point, he was invited by the researcher to do so.

The first interview covered the events leading up to the child's death; the reaction of the parents to the death; the reactions of others to the death and to the parents following the death; the interaction with health care professionals and the effects of the death on the couple. The audio-taped interviews were transcribed and analyzed.

In the second interview the researcher sought to clarify aspects of the first interview. The emerging conceptual themes were validated by sharing with parents the researcher's interpretation of the data from the initial interviews.

Timing of the first interview ranged from four months following the death to four years. Second interviews were planned for one month after the first, but due to personal constraints for the researcher, were conducted about six months after the first.

### Description of Subjects

The couples participating in this study had all suffered the loss of at least one child during pregnancy or in early infancy. The actual experiences of these couples covered a wide range in terms of time of the death, expectation of the death, other children in the family, time since the death and previous experience with loss and grief.

Two of the couples had experienced the stillbirth of their child between seven and eight months gestation. In

both cases, the mothers had become concerned due to decreased or lack of movement, and fetal death was confirmed shortly after this concern was expressed to their doctors. One woman was unsuccessfully induced but still carried the fetus for two weeks prior to spontaneous delivery. The other woman was expected to abort the fetus spontaneously but carried it a further five weeks.

The infants of three of the couples died within hours of birth. One couple had known since five months gestation that there were problems and that the baby could die before birth. The baby was delivered at term and lived for three hours. Another couple delivered twins with one surviving minutes and the other surviving for several hours. Although medically no problems had been anticipated and the twin pregnancy had not been identified, the parents felt they had known subconsciously that survival of their twins was unlikely. One couple's baby died of a genetic condition one hour after birth. This couple was unprepared for the possible loss of their baby as results from an amniocentesis were normal. Their next child, who had the same genetic problem, survived for three weeks. Although they did not know the second baby's state of health until birth, they were aware of the increased probability of a recurrence of the genetic disorder.

One of the couples had had three fetal losses at the five-month to six-month period and had recently experienced

the loss of their seven week old baby through sudden infant death syndrome.

Three of the couples had at least one other child prior to the infant death. One couple had subsequently adopted a child and another couple had given birth to a healthy child since the death. One couple had had an early miscarriage following their infant's death.

### Data Analysis

Data analysis was based on Giorgi's steps in phenomenological methodology (1975a,b). The steps are outlined here with a full description of the analysis procedure in Chapter Three. (1) The researcher read through the description to get a sense of the whole. (2) The researcher reread the description looking for units of meaning. (3) The researcher combined similar units of meaning into categories that were clarified and elaborated on by relating them to each other and to the whole. (4) The researcher reflected on the categories and transformed them from everyday language into more abstract concepts. (5) The researcher synthesized and integrated these insights into a written description.

### Ethical Considerations

The researcher ensured that subjects were informed about the study prior to their giving consent. She

explained the nature of the study, its purpose and intended use as well as the expected role of participants and confidentiality of the data given. Participants were assured that consent was voluntary, that they were free to withdraw or refuse to answer any questions at any time, and that refusal to participate would not jeopardize further medical and nursing care.

Confidentiality was ensured by the use of coding to identify the transcripts. The transcripts were read by the researcher and her thesis committee only. Subjects' names and other identifying information were not used in any presentation of the data.

Subjects were given access to the results of the study.

### Summary

This chapter has described the theoretical and methodological approach of phenomenology in studying the experience of parents following perinatal death. The next chapter will more fully describe the process of data analysis within the phenomenological paradigm.

## CHAPTER THREE

### Application of Phenomenological Analysis

The purpose of phenomenology is to describe phenomena as they are lived (Oiler, 1982). The qualitative study of people in their natural environments is a process of discovery and learning what is happening. Lofland (1971) elaborates on this in the following way:

Since a major part of what is happening is provided by people in their own terms, one must find out about those terms rather than impose upon them a preconceived or outsider's scheme of what they are about. It is the observer's task to find out what is fundamental or central to the people or world under observation.  
(p. 4)

Phenomenology, as a way of discovering what people are experiencing in their own terms, is consistent with Kleinman's (1978) explanatory model framework for viewing sectors of the health care system.

Having gathered the data through interviewing couples following perinatal loss, the researcher must analyze and organize the interview data in a meaningful way. "The qualitative analyst seeks to provide an explicit rendering of the structure, order, and patterns found among a set of participants" (Lofland, 1971, p.7). To develop such a



description of the participants' experiences, the researcher based her analysis on the method Giorgi described in his work on the application of the phenomenological method in psychology (1975a,b).

### Viewing the Whole

The first step was to read through the transcripts to get a sense of the whole. In this study the researcher personally conducted the interviews and transcribed most of the tapes. This involvement along with reading through the interviews allowed the researcher to grasp the essence of the descriptions.

### Identifying Units of Meaning

The second step of the analysis was a slow, methodical reread to identify changes in topic or meaning. Each resulting unit of meaning was then summarized with a brief statement using terms similar to those used by the subjects.

### Creating Categories

In the third step similar meaning units from all of the interviews were categorized. The categories ranged from very concrete, such as a description of the child's condition and timing of events, to more abstract such as hope, isolation and sadness. Approximately 40 categories were identified during this process. Some categories were

subsequently broken down further, while others were combined. The ideas that evolved through this categorization were compared with each other and related back to the whole.

### Developing Themes

The researcher pondered the data and rearranged the 40 categories to develop four main themes from the data. The themes that evolved were (1) anticipation of parenthood and the shattering of hopes with the death or knowledge of impending death of the infant; (2) a multidimensional personal grief experience; (3) an interpersonal grief experience influenced by the social support of health care professionals, of friends and family and of the spouse; and (4) reflection and search for meaning in the experience.

Although the steps in the analysis are outlined in a sequential order, the researcher moved back and forth between the intact description, the meaning units, the categories and the themes to ensure that the themes reflected the actual content and to promote an accurate and complete description.

### Synthesizing a Written Description

The themes that evolved from the descriptions directed the researcher to search out literature beyond that specifically related to perinatal death, in areas such as

loss and grief, social support, developmental and situational crises, and health care provision. This literature was integrated with the description of the couples' experience within the framework of the four themes that arose from the study data.

Chapter Four is a descriptive analysis of the data provided by six couples who had stillbirths or early infant deaths.

## CHAPTER FOUR

### A Descriptive Analysis of the Data

In each case, the parents' description of the death of their infant and their experiences surrounding the death indicated to the researcher that this was a significant event in their lives, that the loss was enormous and that the grief was overwhelming at times. The joy they had anticipated in being parents and in sharing life with their infant had turned into extreme sadness and pain. Two major aspects of the experience were evident: that it was a personal experience with an individual response of grief and that it was a shared experience with grief influenced by interaction with others.

This chapter will describe the following aspects of the parents' experience: (1) anticipation of parenthood and the shattering of hopes with the death or knowledge of impending death of the infant; (2) a multidimensional personal experience of grief at the death of the infant; (3) an interpersonal grief experience influenced by the social support of health care professionals, of friends and family and of the spouse; and (4) reflection and search for meaning in the experience. Relevant literature will be used throughout the discussion to compare the experience of the study parents with the findings and theories of other researchers.

### Parenthood Anticipated and Hopes Shattered

Many factors influence peoples' motivation to become parents, their expectations of the experience and of the child, and their contributions to the experience. Because of the complexity of the psychology of parenthood, there is an even greater complexity in the curtailment of parenthood.

An individual's ideas of parenthood begin long before pregnancy or the birth of a child. Smoyak (1982) has identified socialization as a family function in which children are imbued with the idea of continuity. She believes that "the most important work of parents as socializing agents is to get each succeeding generation to want to go on" (p. 25). One's concept of parenthood thus begins to form in early childhood.

Along with the individual's concept of parenthood, society has attached a variety of symbolic meanings to pregnancy and childbirth. Pregnancy may be seen as the ultimate creative act, as a rite of passage into adulthood, as a proof of womanhood or manhood and as a symbol of sexuality (Colman, 1983). Miles (1984) goes on to say that children are in some ways extensions of their parents into the future, representing continuity of life and immortality.

The process of becoming parents is considered a major transition in life (Bibring, 1959; Murray, Luetje, & Zentner, 1985). Pregnancy is a developmental crisis that

involves physical changes in the woman, growth of the fetus and emotional changes in both parents (Klaus & Kennell, 1982). These changes normally produce stress and anxiety.

The changes and the resulting stress and anxiety are the focus of various psychological tasks of pregnancy that serve as a preparation for parenthood. Rubin's (1975) maternal tasks of pregnancy are expressed as (1) seeking safe passage for herself and her child through pregnancy, labor and delivery; (2) ensuring the acceptance of the child she bears by significant persons in her family; (3) binding in to her unknown child; and (4) learning to give of herself. Ensuring safe passage and binding in to the child were particularly relevant to the parents in this study.

Five of the six couples had specifically planned their pregnancies, therefore there was high anticipation of sharing their lives with their infants from early in the pregnancy. Three of the couples had experienced previous fetal loss which may have increased each couple's emotional investment in the survival of this child.

Considerable energy was put into a safe passage for the child both by parents who suspected a problem and by those who had no reason to believe that problems would arise. A mother who knew during pregnancy that her baby's survival was doubtful felt that she had to do all she could for her baby's sake:

Mother: All the time I had to keep drinking milk and taking vitamins and being healthy and doing all those things because maybe the baby was going to be all right.

In considering diagnostic tests one couple stated that the child's safety took precedence over the value of knowing the condition of the child.

Father: They were prepared to go to the extent of inserting a probe and snipping a piece of the baby's skin and then studying that under a microscope to see if it had the same thing that [the first baby] had. So there was a certain amount of experimentation that was going to take place. And each experiment of course added to the risk and we had to determine whether we would go as far as we had to, or could go, to help any future babies, ours or others, but we weren't prepared to increase the risk to our current baby in any way, shape or form.

The process of parent-infant bonding that occurs at birth has been emphasized by Klaus and Kennell (1982) but as Peppers and Knapp (1980) and Kirk (1984) point out, there is direct evidence of affectional ties developing early in pregnancy. The binding in process was described by one mother in the following way:

Mother: I think that people don't. . . realize that almost from the time of conception, or a little bit later when we saw the first ultrasound picture at twelve weeks, that baby became very real to us, and that you kind of became parents from that point. . . I think the moment of delivery is a confirmation that yes, that's right! But you advocate far before that. And I think your own maternal care, you're saying "You're not born yet, but I still care about you" type of thing.

One mother realized the importance of binding in to her unborn child and expressed an awareness that this was not happening for either herself or her husband.

Mother: I remember saying to [husband] right at the beginning, I can't get in touch with this baby, I don't know what it is, but I can't get in touch with this baby. . . . And when I was trying to get the baby to turn head down, I kept hearing in the back of my mind, no, it's not safe for this baby to be born. It was sort of, I just knew. I wasn't scared of it, I just knew. [Husband] couldn't get into the pregnancy at all.

Binding in occurred for the couple who had not wanted another child and had therefore not planned this pregnancy.



Mother: By the time one has got to the third or fourth month, you know, you're very resigned to [having another baby] and in fact we had a complete turn around and were really looking forward to it. . . .

Father: We had actually, you know, sort of equipped ourselves mentally and physically for this new baby.

In each case, the bonding that had occurred during pregnancy and up to the time the child had died was between the parents and this particular child. They saw the child as an individual in his or her own right and not someone who could be replaced by a future child or by a child they presently had.

Because of the physical and emotional preparation and the high anticipation of parenthood, the realization that the baby had died or was very likely to die came as a severe shock to the parents. One mother described the contrast of expecting the child and then losing the expectations:

Mother: Anticipating parenthood is not just seeing the child in front of you that you are going to hold, it's all kinds of dreams. And they are all just . . . shattered.

Another mother described dramatically the impact of her child's impending death:

Mother: It landed as a bombshell and our lives went on hold.

According to Davidson (1984), pregnancy is normally a time when both the mother and father organize their lives around the expectation of a child. The couples in this study showed evidence of concern for safe passage of the child and took measures to ensure safe passage during pregnancy. A concern about binding in to the unborn child was also evident as a preparation for parenthood. The infant's death brought to an end the hopes of a future with the child.

### The Personal Experience of Grief

What happens when the hopes are shattered, when preparation is no longer required, when the whole process of physiological, emotional and physical preparation is curtailed by the death of the baby? One mother described the experience in the following way:

Mother: The word shattered . . . describes it beautifully because it's something that happens like bang, like that, something that you had taken the time to spend thinking lovely thoughts about. The word shattered also makes me think of something being broken in thousands of pieces and that's what you feel like.

Although the death of an infant before or shortly after birth has similarities to other major losses, perinatal loss may be more complex. Factors that exacerbate the grief in this case include emotional attachment that parents have prior to birth, the hopes, expectations and dreams for a future tied up with the child that are dependent on the child's survival and the idea that the loss is of a part of oneself as well as the loss of a separate person (Furman, 1978). Several parents compared the death of a child with the death of a parent.

Mother: [My father] died over Christmas. . . . It's a different loss than your children. It's still very much a deep loss but it's something you don't plan like you do with your child. Dreams, hopes. . .

Another mother stated the comparison in a more general way:

Mother: They say, "The death of a parent is the death of your past but the death of your child is the death of your future."

Saunders (1980) in a comparative study of adult bereavement in the death of a spouse, child and parent found that higher intensities of grief were present following the death of a child than following the death of a spouse or parent. Death of one's child may not be given as much

significance by society as the death of a person in other close relationships.

Grief, as defined by Carlson, is "a complex combination of numerous emotions felt at the time of loss" (1978, p.87). Attempts to understand, explain and predict grief patterns have led to the identification of stages of grieving by Bowlby and Parkes (1970), Kubler-Ross (1969) and Lindeman (1944). Although these theorists acknowledge that grieving is individual and that not all people go through all stages or go through the stages in the order outlined, there is a tendency in the application of the theory to expect all of the stages and expect them in the order described. For example, Jensen, Benson and Bobak in their 1981 maternity nursing text state, "In the face of a loss or the threat of a loss, the person's reactions follow a predictable pattern" (p. 23). Lindeman's three phases and Kubler-Ross's five stages are then outlined. Callahan, Brasted and Granados state that individual variation in grief response is "probably more the rule than the exception" (1983, p. 156).

Murphy (1983) addresses the complexity of the bereavement process and from her extensive review of the literature concludes that bereavement is a multivariate phenomenon. The poignant nature of parental grief is captured by Arnold and Gemma (1983):

The nature of grief on the death of a child cannot be adequately described; no schema can contain it. Its breadth and depth defy description. Grieving is a continuous process, with peaks, valleys, and plateaus. It is a complex process that is bound to the individual who grieves uniquely like none other. . . . How can we describe something so profound that clouds our minds and numbs our senses? (p. 34)

### Dimensions of grief

The parents in the study discussed feelings of shock, numbness, disbelief, anger, guilt and a great deal of sadness and pain in reaction to the loss or threatened loss of their child. There was no evidence of a particular progression or of all couples experiencing all of the identified emotions. Reactions to the loss of an infant will therefore be discussed as dimensions of grief rather than stages or phases of grief.

### Shock, numbness, disbelief.

Although literature indicates that most expectant parents have fears about the health of their unborn infants (Klaus and Kennell, 1982), this fear does not appear to prepare them for the actual event of death or impending death. The parents in the study expressed shock at the death of their infant or at the knowledge that their infant

was not expected to live. One mother talked about the initial reaction:

Mother: I was just desperately upset and I think [to husband] you were in shock actually, weren't you? I mean it was just such a shock, you know, at seven months pregnancy to suddenly discover that the baby has died.

A father indicated a lack of feeling at the time of his twins' death:

Father: [I was] pretty much numb and in shock. Not too many sensations of any kind.

The parents who had already lost one child as a result of a genetic disorder were aware of the possibility of the second child having the same problem but were still shocked by the reality of the second child's death:

Mother: Somehow you go around and you don't expect that it will happen twice in a row.

The couple who knew of the baby's critical condition during pregnancy talked of the grieving prior to the baby's death and discussed the absence of the reaction of shock at the time of death.

Mother: For the last basic four months of the pregnancy we knew. We knew that things probably weren't going to work out. So after she died, the nurses couldn't understand why we weren't falling apart, but we had already,

Father: We had already fallen apart,

Mother: We had fallen apart and grieved and everything, and it almost seemed like this was the conclusion, this was it, you know. We grieved after that too, but it was a different kind of grieving, but it wasn't shock.

Feelings of numbness, disbelief and denial were a part of the initial reaction of shock. These feelings have similarities in that they all are mechanisms to delay a full realization of the impact of the loss. Disbelief was expressed by one mother:

When this started happening it took us a while to believe. It took me a while to believe this was really happening. You just don't, the idea of a baby dying is far from you anyway.

Numbness and denial are captured in this woman's reflections on her feelings following knowledge of the death of her baby in utero:

Mother: So I went for five weeks with the baby dead, and it was pretty tough, I mean for four weeks I walked around like a zombie, not feeling anything. The only thing I felt was things in my head. The rest of me was kind of not there. . . . The day after I'd been to the hospital and found the baby was dead I was just so beyond myself I didn't know what to do. . . . I couldn't even look at myself in the mirror. I'd look at my face, the rest of me I didn't want to know it was there, I just wanted to try to forget it.

The initial reaction of shock allows for a gradual realization of the meaning of the loss and how it will affect the life of the bereaved. It allows for the incorporation of grief in tolerable amounts. The period of shock has been described as a cushion or a protection from the intense pain of the loss that allows time for reality to penetrate awareness (Miles, 1984). This was evident in one woman's statement, "It felt like a dream at that point, knowing it was going to hit me later but it really hadn't yet."

#### Guilt.

In attempting to make sense of the death or impending death of their babies, most parents found they had to deal with feelings of guilt. Causation guilt described by Miles



(1984) and by Callahan et al. (1983) occurs as parents are trying to understand the cause of the death. "They often think about ways in which they may have caused or contributed to the death by sins of omission or commission" (Miles, 1984, p.228). One mother talked of the guilt following sudden infant death syndrome:

Mother: We found it extremely hard. My whole thing was that I had done something wrong. . . . But you know, we were both just totally shocked. . . .

Another mother who had pressed for a vaginal delivery rather than a caesarean section described the overwhelming feeling of guilt:

Mother: The guilt around that place was enormous for everybody because we thought it was the birth that had done it. . . . And I'm going oh, my gosh, here we've made the wrong decision, and the guilt, oh, God, it was awful, wasn't it? It's like here I put so much effort into this pregnancy and this birth and then something like this happens.

The mother in the couple who had not planned this pregnancy described her feelings of guilt and the sadness that accompanied it:

Mother: You do sort of go through this thing of did I have a drink too many, did I. . . . I remember feeling guilty and sad that the baby had died and we had sort of wished it not to be there in the first place initially. . . . But after the baby was born, I guess I still had a little bit of that. I was so sad about it.

The basis of the guilt felt by the parents in this study appeared to be related to the possibility of an unwitting part in the child's death. Guilt is an emotion turned inward whereas anger is often directed toward others.

#### Anger.

Anger is an emotion that is commonly expressed in bereavement (Kubler-Ross, 1969, Lindeman, 1944). The anger may be directed at health care professionals, at people in the social support system, or at the person who has died (Miles, 1984). Feelings of anger toward their infants were not expressed by the parents in this study. One couple talked of the anger they felt about having to go through the experience:

Mother: I found it very hard to deal with and I cried a lot. . . I was very angry, I was, what did I do that this should be happening?

The anger that most of the subjects talked about was directed toward health care professionals or toward people in their support system. An awareness of the possibility of overreacting in anger was discussed by one father:

Father: We have to be careful that we don't sometimes take out our frustration that our children didn't live on the medical facilities. They probably, if there is an objective point of view which I don't think we can have, the conclusion would be that they did everything quite proper and maybe a little more sensitivity could have been shown at certain times. But there is a danger of taking out our own frustrations and that's the only place to take it.

Although anger has been identified as part of grieving there may be a tendency to discount the content of the anger when the parents have a valid reason to be angry about the treatment they have received.

In contrast to the anger felt by most couples, one couple indicated they had not experienced feelings of anger. This couple felt adequately supported by health care professionals, by friends and by each other. They reflected that "in that it was an awful situation, we had a good time of it."

Sadness and pain.

The intense grief which parents experience following the death of a child includes deep sadness and pain (Miles, 1984). One couple discussed planning the pregnancy in relation to the pain felt:

Father: It was something we had been planning for. I guess it hurts even more if you plan for it.

Mother: It hurts, it just hurts. It doesn't matter, planned, unplanned, it hurts.

The pain and stress of the labor and delivery was not relieved by the presence of a baby as it is for most parents. The physical and emotional suffering was expressed by the following mother:

Mother: It took a lot out of me, especially having nothing to show for it. . . . It was a tough time. Physically I was tortured, I was really tortured.

Bowlby and Parkes (1970) have described yearning and searching as a phase of the grieving process. The purpose of this yearning and searching behavior may be an attempt to fill the void caused by the loss and thereby ease the sadness and pain the parents are feeling.

One mother attempted to ease her severe pain by calling the child's name:

Mother: I remember I sat at the kitchen table and I just screamed and I hollered and I cried and I screamed [child's name]. I just screamed his name.

Another mother expressed a quiet yearning for her child when seeing the intimacy of which she was deprived.

Mother: You'll be walking down the mall or something and you see a father with a brand new baby or a mother just cuddling or nursing her baby and it's not an envy, it's when I see that happening, they're consumed by each other, the baby and the parent, it's like they're in another world. It is a real sadness to be missing your own. It brings home what you've desired.

The desire to have tangible evidence of the child's life and death was apparent in the parents' experiences. Creating memories was a way to show that there is a reason for the sadness and pain, that the child lived, was important and that the intense grief was valid.

Mother: You have to get your memories together when you've lost a newborn. You get as much together as you can. That's why I took pictures of absolutely everything.

The personal experience of loss and grief for parents varied from person to person but was characterized by deep,

painful emotions. The personal experience was influenced by the social support received through interpersonal interactions occurring at the time of death and subsequent to the death of the child.

### The Interpersonal Experience of Grief

The reactions to the death of a child described in the previous section did not occur in isolation but were affected by the interactions parents had with others and with each other. The meaning of situations and events, and the ability to cope with stressful events is developed through interaction within the social context (Charmaz, 1980).

According to Dimond and Jones (1983) and Cobb (1976), social support directly affects health, provides a buffer against the effects of high stress, mediates the development of coping strategies and softens the impact of stressful life events.

The need to talk about the death or impending death of the infant and receive support through the experience was evident in the experiences of all of the couples. Arnold and Gemma have noted that families grieving the loss of a child "receive inadequate recognition for the intensity and significance of their loss" (1983, p.42). This may be because others have not known the child, whereas the parents

have been intimately connected with the child throughout pregnancy.

Interactions occurred on three fronts: with health care professionals, with friends and family of the couple and within the couple itself. Health care professionals and the health care system represent the professional sector in Kleinman's cultural system model (1978), while the friends, family and spouse are a part of the popular sector. The folk sector in Kleinman's model was not identified as part of the parents' experience.

#### Interactions with Health Care Professionals

In Canada the health care system has become intimately involved in pregnancy, labor and delivery. Due to the critical circumstances surrounding the deaths or impending deaths of the infants, interactions with health care professionals were a significant part of the study parents' experience.

Despite the advance of technology related to perinatal care, the interpersonal aspect rather than the technological aspect was the focus of the parents' comments. Chapman and Chapman (1983) take the stand that the interpersonal actions and reactions occurring during the utilization of technology determine whether helping has occurred. They go on to state that "effective helping is ultimately defined by the patients" (p. 50). This viewpoint is consistent with

Kleinman's cultural system model which directs health care professionals to elicit the perceptions of illness and care from the patients themselves (1978).

For all the study couples, the interactions with health care professionals had both positive and negative aspects. Three issues addressed by parents were (1) information sharing, (2) decision making, and (3) sensitivity to the parents' needs, feelings and experience.

#### Information sharing.

Social support has been defined by Cobb as information leading one to believe that he or she is cared for and loved, esteemed and a member of a network of mutual obligations (1976). In interactions with health care professionals, sharing of information in an appropriately sensitive manner helped parents feel they were a part of the mutual obligations, and that they were esteemed and valued enough to be a part of the health care process.

The parents needed information to help them understand and make sense of the situation. Knowing the condition of their infant and knowing the causes of death helped them to grasp and accept the reality of the death. An example follows of one couple who experienced the unwillingness of ultrasound technicians and doctors to share information:



Father: I could see that they couldn't find what they were looking for and when we asked them some questions, they wouldn't give us direct answers. . . . When we tried to get the information out of the doctors themselves, those that had the responsibility and were able, were actually in the position to give more information than the technicians, they didn't, they would clam up. It turned a good experience to a really bad one.

Another couple, whose child was a victim of sudden infant death syndrome had difficulty obtaining an autopsy report. Having this information was particularly important for these parents to ease their guilt about the death.

Mother: We got the first autopsy report back. What happened was the doctor went on holidays. We went and asked for the autopsy report and they said, "Oh, sure." They made a photocopy of it and we got it. The second final autopsy report was to come later on, so I phoned back to the doctor's office about a month later and asked them to send a photocopy of [child's] autopsy report. And the person said, "Oh no," and I said "Why not?" and she said, "Because you're not entitled to see it." And I said, "I beg your pardon, why not?". . . And she said, "Well, you should never have gotten the first one, that's our property." I was really upset,

so I phoned the coroner's office, and the coroner, she said, "He was your son, you're entitled to see whatever you want to see." To this day I can't see why they refused. But it bothered me, it bothered me terribly.

Parents felt a need to understand the condition of their child and the possibility of a recurrence in another child. As most of the deaths in this study were the result of relatively unknown and uncommon syndromes, information was not readily available to the parents. Parents therefore needed information from professionals about the conditions and about the particular manifestation in their child. One father described his frustration at the delay in receiving information:

Father: We were trying to make a decision whether to have another child and the decision required input from genetics. And we couldn't make that decision if we didn't have that information and it was very frustrating. A very difficult time. It was as if this child has died, we have lab work and we have this to do for the living, when we get around to it, we'll do that.

In commenting generally about the availability of information to parents, one couple felt they had an advantage but were concerned about others who did not have a

background in health or were not as aggressive about getting information. Leavitt (1982) also expresses this concern in her observation that "lack of orientation to even the simplest routines and surroundings keeps the patient and family from asserting even a modicum of independence" (p. 38).

Father: A lot of people don't even know what to ask, a lot of things are new to them. They don't have a medical background like [wife] does, and they knew that I required answers and I let them know that, they gave it. But it's not an automatic system. They don't automatically help you out. You have to establish that and a lot of people don't know how.

Mother: I think you sometimes feel, and even more so people who don't know what to ask, feel at the mercy of the system, because I know we did and we were getting answers. I can well imagine what people would feel like that just had to take one day at a time depending on whether the doctor felt like telling them that, or thought he should, or whatever.

Some of the parents had not experienced a loss of this magnitude before and were amazed at the intensity and duration of their feelings. Callahan et al. (1983) note that infant death often occurs at a time in parents' lives when death has not yet become a frequent event. As well as

information desired about the conditions of the infants, these parents indicated a need for information about the grieving process.

Father: Most people want to have you carry on the grief rather than show you how to get over it, show you how to help yourself. The people in the medical profession want to be able to see you grieving right in front of them rather than giving you hints and giving you aids to get over it.

The following couple identified one person in the health care system who had given them valuable information about grief, but indicated that earlier access to the information would have been helpful:

Mother: The genetic specialist tried to help us realize the grieving process, what was involved in the grieving process, which nobody else had discussed before.

Father: But that wasn't until some months after, two, three months.

Parents did not indicate that they were given too much information or that information given was overwhelming in their emotional state. Health care personnel may withhold information because they perceive that clients cannot tolerate it. Callahan et al. (1983) see withholding of

information as a function of the health care professional's own denial rather than the parents' needs. One couple who desired open, honest communication with health care professionals was able to initially set the stage for this:

Father: [Wife] was pretty knowledgeable so maybe we had an unfair advantage. We let them know right off the bat that we would not tolerate any withholding of information or coloring it in a fashion that was [perceived to be] more tolerable for us.

One mother viewed her doctor's complete sharing positively despite the critical state of her infant's health:

Mother: My doctor always let me read all the reports that came in. She believed in 100% sharing and she included [husband].

Adequate information was essential for parental decision making to occur in conjunction with the health care personnel involved.

#### Decision making.

Parents saw the time of their infant's death as a time when many difficult decisions had to be made. They accepted this decision making role as both their right and their responsibility and wanted to be involved in the decisions

made by the health care team. The Fetus and Newborn Committee of the Canadian Pediatric Society states that "involvement of the parents in the decision-making process is essential and may assist them in their subsequent grieving" (1983, p. 337).

The way information was given to the parents was a factor in the decisions made. Lovell, in her 1983 study of identities of mothers and babies in perinatal loss, observes that women "took cues from the experts who also played a crucial part in defining the situation" (p. 756). Going along with what seemed to be expected was evident in this father's account:

Father: They asked me what we wanted done, but to that point nobody had even warned me of the possibilities. There was no time to sort of decide between us what we wanted done or even ask the advice of our families or friends or anything. It's suddenly, there at the hospital, just delivered a stillborn, do you want a private burial or do you want us to dispose of the body? And I'm standing there and I'm in a complete [sic], feeling sick and, God, what's happening to me, and I just say well dispose of the body, get this out and finished with as soon as possible. . . . But my idea is that I was asked to make a decision [when] I didn't really know the consequences of what I was into.

Decision making throughout the experience of the loss of a child was done either by professionals only or in conjunction with the parents. The decision making done by professionals often involved conflicting opinions that led to frustration and decreased confidence on the part of the parents.

Mother: That little glimmer of hope is the killer, because our doctor, and all the obstetricians she talked to said, "Hold off, don't induce labor. The longer that your patient is to term, the better it is." The ultrasound people at the end of December said, "This baby is going to die, induce labor, it's a 'fait accompli.'" But I guess obstetricians have a slightly different bent.

The study parents expected to be involved in the decision making process. Health care professionals may, however, feel that protecting and shielding parents from having to make difficult decisions is helpful. Davidson (1977) has called this protective tendency the "surrogate suffering syndrome," a defense mechanism used by onlookers to decrease their own feelings of helplessness. Taking decisions away from mourners adds to their suffering by increasing their feelings of helplessness and vulnerability. Howard and Strauss see shared decision making as a part of humanized health care in which patients "regardless of their

education, have a right and perhaps a duty to participate as much as possible in decisions about their care" (1972, p. 81). One father expressed his alarm at the life and death decision made without parental input:

Father: It was a bit scary to find that there are two definite positions in the hospital. One says the baby doesn't have a hope and if it does it's going to have a terrible life anyway so just let it die. The other says do what you can and don't take that decision into your own hands. There was a time when they had stopped feeding, they had stopped intravenous and they were just letting her die. And that period was only about eighteen hours when I realized what was going on and we immediately took very definite steps and made it known that we wanted her supported with at least oxygen and fluids, otherwise you're not even leaving room for a miracle. . . . They were medical meetings, granted, but they were discussing the life of our child! And I couldn't see anything that they could discuss that was secret from us. What possible thing could they be discussing that we shouldn't be involved in?

The following mother planned to be completely involved in the decisions about her child's treatment. Although her mind was whirling with all the things going on, she still expected to make decisions regarding her child.



Mother: He said, "Hopefully this is just a temporary condition, you know, his lungs could just be immature or whatever. And he needs to go on the ventilator for awhile." And what was going through my mind was how much was I going to allow them to do with him. My mind was just whirling, trying to figure out what was going on and get everything sorted out.

Throughout the experience of information sharing and decision making, parents were aware of how sensitive health care professionals were to them and to their child. The degree of sensitivity was significant to how positively or negatively parents viewed the experience.

Sensitivity to parents' needs, feelings and experience.

Sensitivity to the parents arises from an attitude of respect for both the parents and the child. Respectful treatment is a right that patients should be able to expect (Storch, 1982). According to Storch, this right is a moral one in which the principles of beneficence and fidelity are adhered to. Beneficence means "that one acts to benefit others in a way that will contribute to their health and well-being" (Storch, p. 71). Fidelity "is a voluntary commitment of one person to another. . . predicated on a genuine care and concern and a deep respect for humanity" (Storch, p. 73). This idea of care, concern and respect for

humanity is supported by Howard and Strauss, who emphasize the value of empathy in humanized health care:

If practitioners contain their sympathy and avoid seeing the world from the vantage point of their patients, they cannot as readily understand the needs of those patients and appropriately respond to them as unique human beings. (1972, p.83)

The sensitivity of health care professionals was commented upon at length by parents. They addressed both positive and negative aspects of which all parents had both in their experience. The key aspect in the interactions was respect for both the parents and the child, even if the child had already died.

Respect for parents and child included acknowledgement and recognition of each member of the family. Seeing the family as a unit and understanding that the child is a significant part of that family, even after he or she has died, helped in the empathic understanding of the family's experience. Most of the couples found that there was interaction with and concern for the mother but often the father was ignored or disregarded.

Father: The doctor would come in and address her. I'd ask a question and they'd answer the question to her. The nurses, some were good, others, I was just an

add-on, I really didn't have anything to do with this situation. Even when I asked medical questions about her health, they sort of treated me as though, what right have you to ask these questions.

In one couple's interaction with health care professionals the mother was ignored:

Mother: I first noticed that they wouldn't talk to me but they would answer [husband's] questions. I was just this hysterical pregnant lady, right? They would never tell us the truth.

Respect for the child was considered important by the parents. Parents saw their child as a significant person and they wished others to do the same. One father talked of the rapidity with which health care personnel wanted to remove the evidence of his child's life:

Father: When I went away for a couple hours sleep, after [child] had died, [wife] was all doped and not capable of making any decisions, they had her sign a whole lot of documents concerning death certificates, just hours after. They wanted to get their books straight. The death certificate was signed and [child] didn't have a name. His death certificate came with no name on it, just [surname]. . . . They also suggested that they simply put him through the hospital

incinerator where, they call it cremation but they said, "Don't worry, he would be burned with other human parts". . . . That's the way they wanted to treat our baby! And that was shocking! That was denying the existence of this child. They just wanted to whisk it away. It didn't happen. It did happen! It did happen! It's real!

Another father indicated the casualness with which the child's memory was treated by the doctor and shared his own perceptions of the child's place in the lives of himself and his wife.

Father: Our family physician, he came by and it was almost as if we had lost a golf ball, you know, reach into your bag and find another one, forget the one you lost. Well, we weren't going to let that go by so we stopped him right there. No we don't forget, no we don't put this behind us, this has a special place in our lives, this baby was alive for three hours and we lived with her from the time she was conceived until the time she died, and this is not something you can put out of your mind.

Respect for the family was shown in health care professionals' openness and willingness to talk in a caring supportive manner as well as in their ability to sense when

parents needed to be alone. One woman identified helpful characteristics as caring, willingness to answer questions, and future availability:

Mother: My gynecologist was excellent. He had been with me through all of my pregnancies. I was really impressed. I went into his office just for a checkup. He took the time to call [husband] and he sat us both down and talked to us, and to me that was a professional. He cared, he really cared. And if we had any questions or if we needed anything as far as reassurance or whatever, he was there and he still is there.

The following comment indicates that a supportive attitude on the part of nurses may be more important than their knowing what to say. This woman and her husband singled out one nurse in particular for her ability to sense the parents' need for quiet respectful support:

Mother: Everybody was so supportive, they were kind, they were empathetic, I'm thinking particularly of the nurse who was with Dr. K. during the inductions and the delivery. She was fantastic. She did not talk much, but just her very presence was supportive, her silence was supportive. It was amazing. . . . you just felt her empathy. There wasn't much interaction [with the

nurses] and I welcomed that. They probably realized that. I really wanted to be alone.

As indicated in the section on decision making, parents wanted to be seen as active participants in the child's care, with the staff open to their opinions, feelings and knowledge of the situation. An example follows where this was not the case:

Father: So nobody listened to us and that's so hard when they don't listen and they don't do you the courtesy of reading your chart, you know, those types of things mean a lot when you're going through this. And they don't understand that you're upset.

Parents also wanted those involved in their care to be aware of the information available for their case.

Mother: [The public health nurse] came in and just sort of sat there and I told her about the birth. I said, "Do you know why they died?" because she sort of, she started saying something about intrauterine growth retardation, and that bugged me! That they would tell her that, because to me at that point [it] was like saying that I hadn't taken care of myself for my baby. I know that's not the only reason, but it's one of the good ones, smoking or whatever, so that bugged me that she didn't know. It's not her fault.

Some of the parents indicated they were recipients of paternalistic actions, as described by Storch (1982), in which health care professionals acted for the person's good without consulting the person. One mother was upset by a nurse's attempt to protect her from the experience when her desire was to be totally involved.

Mother: So while [child] was dying, one of the nurses came over, bustled around my bed and started to take me out and, "Excuse me, what are you doing?" "Well, I was just going to take you out in the hall." And I said, "Oh, no you're not!". . . She was trying to protect me, you know, take me away while he was dying. That was not what I wanted.

The three main aspects in the interactions with health care professionals were information sharing, decision making and sensitivity to the parents. These areas are not mutually exclusive but overlap in the provision of appropriate health care. Providing information and encouraging involvement in decision making must be done in a sensitive, humanistic, empathic manner, viewing the client as an active person in the process.

Bereavement support groups are a potential source of support for parents although only two couples discussed their involvement with such groups. The other couples either did not address this source of support or had chosen

not to be involved. One couple indicated that the bereavement support group they attended was significant in their understanding their own grief and that of their spouse. This occurred through listening to others share their experiences and realizing they were not alone in feeling as they did. One couple attended two groups but did not find them helpful or supportive.

Most of the interactions with health care professionals occurred at or near the time of death. Parents' grief over their infant's death and their need for support extended far beyond the time of death. As Kleinman (1978) has noted, much of health care occurs within the popular sector of family, friends and community.

#### Interactions with Friends and Family

Norbeck (1981) has observed that the maturational crises of pregnancy and parenthood evoke spontaneous support from friends, relatives and even strangers but the support for the crisis of death is much more difficult for members of the support network to provide. Two areas that were significant in the interactions with friends and family following the awareness of the death or impending death of their child were the actual response to the parents and the acknowledgement of the child as a significant person.



Response of friends and family to parents.

The study parents indicated that the response of their friends and family was an important part of the experience and influenced how they were able to cope with their grief. They wished friends and family to realize the significance and immensity of the loss, to be aware of the time it takes to deal with the grief and to be available to talk with them and listen to them when they felt they needed it.

Some of the study parents found that initially support was readily available and freely offered. They also found that there was a withdrawal of support and an expectation that grief should be over sooner than parents were ready. Kirk (1984) has pointed out that the process of grief takes much longer than most people realize or families are willing to allow. One mother talked of having support and attention initially then of having it withdrawn:

Mother: It's like you're in shock the first two weeks. And that first month, well, it was actually the first two or three weeks, we got lots of cards, lots of phone calls, lots of people coming around and bringing flowers and things. That's always nice to have that. And then it kind of stops and you're on your own. . . . Everybody has their own lives to live.

The couple who had suffered two infant deaths compared the support received after each death:

Father: [First child] was born, and then he died in an hour, and then two or three days later [wife] was home from the hospital and people tend to think that she's home, she's fine. Whereas with [second child] there was a twenty day period where we were really struggling and suffering ourselves. People brought food, our church supported us an awful lot through prayer and just being there, our fridge was full of food, we didn't have to cook anything.

In attempting to understand her friends' lack of support, one woman attributed it to fear:

Mother: People are afraid, they don't know what to say, consequently they don't say anything. Their lives are back together and yours should be too.

Two couples indicated very little support even at the beginning of the experience:

Father: I find that even when I try to bring up the subject, most people change the subject. So I gave up trying to bring it up.

Mother: As far as family and friends were concerned, none of them knew what to say, what to do for us. They

all just wanted to hush it up, didn't want to talk about it, which you know, from our support group we thought that's not what we need, that's the opposite of what we need.

In contrast to couples who felt isolated by their friends and family, one mother indicated a need to be alone and saw her friends' reticence to call as an indication of their sensitivity:

Mother: I didn't want to talk to people, I didn't want people for a while, I just needed to go through this grief on my own, but I felt an enormous amount of support. I knew people were phoning, I knew my family all knew and you know, were grieving for the baby. . . . I knew there was a great deal of, a network of sort of empathy, you know, and even if it wasn't spoken, which it wasn't often and a number of people have said to me since, "We didn't know what to say," or, "We thought maybe you should be left alone, or "We thought you really wouldn't need outsiders," I did feel the warmth, the support, the empathy.

Even though parents were grieving and wanted the support of friends and family, they still wanted to be treated as normal vibrant people. The following comments by three mothers show this desire to be seen as normal, the

appreciation when they were seen as normal, and the frustration when they were not:

Mother: In December my parents treated me as if I was dying. I would go visit them and they would just sit there as if I was passing on to my great reward. . . . So really it was like people doted , I mean, they were meaning well, but it was always an intensity. My sister was the only one who treated us like we were still normal.

Mother: I was very lucky that a friend of mine who had had her baby and friends of mine who were pregnant had enough. . . I think it took a lot on their part to include us in. I think it meant a lot to us that they still saw us as vibrant human beings.

Mother: The worst thing to do when a child dies is to not bring the subject up. What people really need when they lose a child is to sit down and talk. People are hurting, they don't know what to say. Our first comment when our child died was "I know there's nothing you can say, but just be with us, stand by us." I had to phone people because they never phoned us and say "Hey, we're okay."

Parents noted that in social interactions with the father, there was often an implication that he was not

grieving to the same degree as his wife. Mandell, McAnulty and Reece (1980) found a devaluation of the father's role at the time of the death of an infant and a lack of awareness of the affectional bonds between infants and fathers. H. Lewis (1980) also noted that mothers are allowed more time to grieve than are fathers and that men are expected to be strong and not show their emotions. Several fathers talked of the negation of their feelings by others and then by themselves, which may have prolonged or complicated their grieving process.

Father: People were caring and concerned, and the comments were always something like, "So how's the baby, you know it must be really tough for your wife." I got to the point where I believed I wasn't supposed to be feeling the way I was feeling and so I tended to feel it was abnormal so I buried those feelings. . . . Sometimes I felt like saying, "Well, what about me?"

Another father similarly expressed how others' failure to acknowledge his pain affected him:

Father: Everybody, from the moment it happened, kept re-emphasizing the point that [wife], how is [wife] feeling, how is she handling it? You've got to be awfully strong to keep [wife] going. . . . Because everybody tells you that you can't possibly be feeling

as much as the woman, it's almost very hard to feel that, or show as much emotion, so it kind of forces you to hold back.

Five of the six couples commented on the reaction and support of their parents. Some found their parents very supportive and understanding, others felt a withdrawal and an inability to talk about the death of the infant. Miles (1984) has discussed the grief of grandparents which is for the lost grandchild as well as for the pain that their children are feeling at the loss of their child. Grandparents are a potential resource for grieving parents and may need to have their grief acknowledged to enable them to be more effective in their support. Two parents' comments follow:

Father: My family in particular didn't understand that grief at all, well, I shouldn't say, at all. It was like, it's over with now, why aren't you better? They couldn't possibly, or didn't somehow understand it at all. I don't think there was a great deal, I shouldn't say there wasn't a great deal of sympathy, just a real lack of understanding.

Father: The one thing that really makes me very sad and still bothers me terribly, even now, is that I didn't get very much support from my side of the

family. Friends at work and [wife's] side of the family were ultimately the best support system that I received.

The study parents attempted to understand the reactions of their friends and family and in some cases to shield and protect them from the discomfort of the loss. E. Lewis (1976) suggests that this attempt to protect others from the distress may deprive themselves of the talk that ultimately aids mourning.

Mother: Now I realize that the reason [friends] didn't allow me to talk about it and they still don't allow me to talk about it is basically they don't, they still don't know what to say. It's a very hard situation and I think they are still very upset.

Some of the couples talked about the effects that the experience of losing their child and the subsequent interactions with others had on their friendships.

Mother: It's hard when people don't phone. It's very hard to remain close to them. You should be able to share the good times and bad times. Not that you want to cry on their shoulder constantly, you don't, but you have to share your experiences with them.

Another parent talked of the strengthened bond that he and his wife felt with some of their friends after the child's death:

Father: In the one case, if the friendship was to be described as them here, us here, with a thread in between, I think it is now them here, us here with a very strong cable in between. The friendship has grown to where they would do anything for us and we would do anything for them.

The support from friends and family was seen by parents in a positive light if sensitivity to their needs was demonstrated. Another aspect of support was the attitude shown toward the deceased child.

#### Acknowledgement of the child.

As well as responding supportively to parents, friends and family were expected to acknowledge the child in his or her own right. This may be difficult for them to do as they have not known the child and often have not even seen the child (Stringham, et. al., 1982). Lovell (1983), Clyman, et al. (1980) and Helmrath and Steinitz (1978) have found that the death of an infant is often considered a "non-event" and the significance of the child as a person is not acknowledged. The parents in this study had an attachment to the particular child they had lost and felt the need for



others to recognize this attachment as well as acknowledge the child. Acknowledging the child included allowing the parents to grieve for this particular child and not discount the grief by focusing on present or future children. One couple's recommendation arising from their experience was:

Mother: If we could tell people, when people have lost a child, never, ever say to them, well so-and-so lost a child and they have five healthy children. Don't give them the illusion they're going to have more kids. (a) You don't know if they ever want any more kids, (b) you don't know if they can ever have any more kids, and (c), which really should be (a), nothing in the world ever replaces that child.

Other inappropriate comments were quoted by the following mother:

Mother: I've had my friends say, "Oh you're lucky, at least you have another one," or "You're lucky it didn't happen to your other child," or "You're lucky you didn't have him long, you didn't have an attachment."

The study couples had not had their child long but they did have a strong attachment. Because of the short life of the baby, they had few tangible memories. Cards, pictures,

the funeral service and special burial site were helpful in creating memories of their child.

Health care professionals as well as friends and family were sources of support to the couple experiencing the loss but the source of the most support appeared to be the couple's relationship itself. This is not surprising as they had both had the expectations of having a child and had both been through the experience of having these expectations shattered.

#### Interactions within the Couple

The stress of the death of a child and the subsequent grief that parents go through puts severe pressure on the marriage relationship. This stress on the marriage and the potential for marriage break-up was noted by the couples in the study done by Helmrath and Steinitz (1978). A similar concern was expressed by a father in the current study.

Father: I cannot remember a time when we had ever had such a low point in our lives and it is that kind of stress that will break people apart.

The couples in this study however, all felt that the experience of losing their child had ultimately drawn them closer. This closeness had occurred as a result of or in spite of problems encountered during the experience.

Shared and individual grieving.

Couples talked of this experience as a shared experience as well as an individual experience. Although both were expecting to be parents and both had these hopes shattered, the experience was different due to the physiological aspect of the mother carrying and bearing the child. The following mother talked of her sense of isolation and loneliness and acknowledged her husband's loneliness as well:

Mother: I wouldn't talk with people, "Gee I felt some movement," you know, because I knew that maybe this was never going to happen, so those kinds of things, you know, I shared them with [husband] but I found that even [husband] after a while, I didn't even want to tell him. So I kept a lot of that to myself. I told him later on, but it was very hard. In the middle of the night, it's kind of you and the baby, and you know, it was lonely at times, and I think it was very lonely for [husband] at times.

The same mother concluded that, "The fact is, you grieve together and you grieve separately, and sometimes you're up and the other person is down."

Problems encountered.

Because the nature of the experience was both shared and individual, problems of misunderstanding between the parents occurred at times. Two problems evident in the study parents' accounts were the differences in their emotional response and the differences in time and duration of their response. Helmrich and Steinitz (1978) noted that the pace of resolution of grief was different for mothers and fathers leading to lack of communication. Clyman et al. (1980) also observed that parents expressed their grief in different ways and at different times. This is evident in the following couple's experience:

Father: After about a month or so I was ready to stop talking about the event and just carry on. I tend to internalize grief and things like that and [wife] of course, her make-up along those lines is exactly opposite. She works things out by talking about it, which is a much healthier way of doing it but it's not the way I do it. So that created a lot of friction for quite a while after that.

One father felt that bonding had not occurred for him as it had for his wife and therefore his grief was less than that of his wife.

Father: I think it was hard for [wife] to understand that it didn't affect me. In fact almost all of the anguish I experienced was for [wife].

Mother: No, I picked that up at the time, that your concern was almost totally for me, and that was all right. I somehow found that okay in that, in a way, it was helpful. It was helpful that there weren't two of us emotionally upset, you know. . . . I don't remember resenting it at all for the baby's sake.

The following couple saw in retrospect that the difficulty they had had in communication was a result of their different ways and times of feeling their grief.

Father: I could be quite happy at one moment and [wife] was really upset about something, and I'm going, "Well, what's the matter?" I'd be happy and I'd say something and [wife] would just need that little pinprick to burst her and oh, no, there we go again. Then I'd think I'd be over it and I'd be in a hole again. Not openly, I don't think I was open about it. . . .

Mother: Before going to the support group, I'd just get upset and we couldn't talk about it.

Coping with problems.

The study couples had come through a difficult time in their relationship because they were aware of the potential problems that a major crisis such as the death of a child could produce. This awareness seemed to give them the understanding and the patience to work through the difficulties.

Mother: One thing I was saying to him after the first day, we've got to be careful, marriages die after the death of a child, and we've got to be very careful. And that's one of the main things, is being aware that people grieve at different times and different stages, and it doesn't mean that they're not grieving. You have to allow the other person to do it. And that's hard, that's really hard. You know, we have a really solid marriage, but...

One father talked of the need to be supported by the partner and the difficulty when the partner's needs were also great. These parents dealt with this by allowing time for themselves as individuals.

Father: You're really aware of the need to be careful. You really need to be careful with each other, in our relationship, because when you get to that point, you

don't always have a lot to give and yet it's a time when you really need from the other person. So when the other person is hurting and you're hurting and you have nothing to give, you have to be careful that you don't defend yourselves, you really take time when you need it. Even a day here and a day there. Just to recharge your batteries.

The awareness of present and potential problems led these parents to an acceptance and understanding of their partner's experience and needs as shown in the following quotation:

Mother: I think that men feel that they have to be strong, and I think that it's real important that both of you, you don't even have to be strong for each other, and it takes a lot to learn that. I mean, you lean on each other, but one of you does not have to walk through your days thinking, I should be the strong one. There were times when I was strong for [husband] and times when [husband was strong for me] and times when we were both whimpering fools. It was okay. But I think the death of a baby either draws you together or throws you apart. I don't think you're ever the same again.

Most of the study couples had experienced tension and strain in their marriage relationship due to their differences in expressing grief and in their varying needs for support at different times. Their awareness of the harmful effects such an experience could have on their relationship helped them endure the difficult times.

In the interpersonal experience of grief, social support was an important component that helped parents to cope with the loss of their infant and influenced their personal experiences of grief. Schneider (1981) has given possible reasons why an ongoing source of support is important in grief. The experience of one loss creates a fear of loss of all important attachments. "The presence of even one reliable source of support, whether it be family, religious faith, minister, nurse or counsellor, which endures can challenge these fears" (Schneider, 1981, p. 37). Supportive relationships permit the bereaved to share the experience of their loss. "For growth to occur from loss, there needs to be some public acknowledgement that what happened really happened" (Schneider, 1981, p. 38). Finally, supportive relationships assist the bereaved in getting a perspective, of seeing that life can go on and of seeing that although the loss will always be a part of one's life, the intense grief and pain will diminish with time.



The final section of this chapter deals with parents' reflections on the experience and their search for meaning in the face of this shattering loss of their infant.

Reflections on the Experience:

Search for Meaning

The death of their infant was not an event from which parents recovered but they learned to live with it and look beyond their pain for positive things in the experience. One woman stated, "We wouldn't want [child's] death to be in vain."

"Grieving is a lifelong process of learning to manage and negotiate in life without this vital part of oneself, which cannot be replaced" (Arnold and Gemma, 1983, p. 102). This lifelong process of grieving for the child was evident in some of the couples descriptions of the clarity of the memories of the child and the events surrounding the death.

Father: This experience was so intense, so much a part of every second of our lives, that I don't think I'll ever forget any portion of it.

Several parents talked of the recurrence of the memories and the feelings of grief over the child's death:

Father: For the rest of your life it's still there in the back of your mind and it comes to the surface every now and then.

An effort to make sense of the death included a search for meaning in the experience and for positive aspects of a negative experience. There was evidence of a re-evaluation of beliefs and life philosophy. The following couple talked of how the experience had changed their attitudes and priorities:

Father: There's also a change of attitude towards your daily activities. You sort of take the attitude that nothing is really that important anymore. . .

Mother: Things take on a different perspective. And material things, they just don't mean what they used to and as long as you have each other and your support system, who cares about anything else. It's always with you and it takes on a different perspective, but it's always with you.

The following parents found that their first child's death opened them up to a religious experience and commitment that helped them through the grief of their second child's death:

Father: With [first child] we hadn't had much thought about religion but as a result of his dying it brought

us much closer together and really made us search. . . we both made a commitment to Jesus and our lives just changed. . . . We made the funeral a statement of hope. It doesn't take away all the sorrow and pain here but it certainly is a different kind of pain and a different kind of sorrow.

Callahan et al. (1983) have observed parents' increased sensitivity to others and ability to relate more empathetically rather than avoiding others. Most parents talked of their increased sensitivity to others who were suffering and particularly to those who had lost a child. Several mothers also became involved as community resource people, in providing bereavement support to other parents. The ability to relate to other bereaved persons was seen as a positive outcome of the experience.

Mother: If I hear of a person who has had a family member die, I can go up to that person and tell them that I'm saddened by what has happened to you and if there's anything I can do, let me know. Which I wouldn't have done before. I would have turned away from them. I couldn't have faced them.

Callahan et al. (1983) also see helping others as a socially acceptable way of trying to deal with one's own distress.

Parents indicated a broadened appreciation and knowledge of life. One woman was convinced that there was no growth apart from suffering. The statements of the following two mothers are examples of the positive attitude they had toward the difficult experience of knowing grief.

Mother: I feel I've gained from the experience. In that I know what it feels like now to lose a baby, and I know what grief feels like. . . . One who has had this experience is going to be able to relate more to other people who go through the experience. It's a new, perhaps, understanding of what it's about and how you really feel.

Mother: It has expanded our knowledge of life and death an awful lot compared to some people. Some people probably are born and grow up and die and they never know any sort of grieving like that.

Schneider (1981) stated that "growth from bereavement is indeed possible. . . [and] loss can be a tragic opportunity for growth" (p. 35). One woman summarized her feelings about the experience in the following way:

Mother: It is a growing experience, but you really wish you could be allowed to grow in other ways. It's not something you would volunteer for, you know.

The parents in this study saw the death of their infants as a major loss that had changed their lives and would always be a part of their lives. These particular couples had attempted to make sense of their losses by finding meaning in them.

This descriptive analysis of six couples' experience following stillbirth or early infant death has presented and elaborated on the four themes that arose from the interview data: (1) anticipation of parenthood and the shattering of hopes with the death or knowledge of impending death of the infant; (2) a multidimensional personal grief experience; (3) an interpersonal grief experience influenced by the social support of health care professionals, of friends and family and of the spouse; and (4) reflection and search for meaning in the experience of stillbirth or early infant death.

Kleinman's (1978) cultural system model, the conceptual framework for this study, gave direction to elicit directly from clients their explanatory models or their way of viewing their experience. An increased understanding of the experience as described by those who have lived it provides a basis for more appropriate care and support to clients with similar experiences.

The study is summarized, conclusions are drawn and implications for nursing are made and presented in the final chapter.

## CHAPTER FIVE

### Summary, Conclusions and Implications for Nursing

#### Summary

Birth is usually a time of joy and hope for parents but when death occurs close to the time of birth, parents are faced with a major transition or crisis. This crisis may lead to personal and family problems such as depression and marital tension. The ability of parents to handle such a crisis is influenced by the social support received.

Kleinman (1978) has developed a cultural system model to explain the interaction between different sectors of society in relation to health care. He has identified three social arenas in which sickness is experienced which are the popular sector, including the individual, the family, and the social network; the professional sector; and the folk sector. Each of these sectors constructs the reality of situations in different ways called explanatory models by Kleinman. In order to provide appropriate care and support to clients the professional sector must understand the experience as seen by those who live it.

Kleinman's cultural system model has been used as a way of conceptualizing the problem of the experience of perinatal bereavement. This model has given direction to the nurse researcher, as part of the professional sector, to

elicit the experience directly from parents who have experienced a perinatal death.

The questions this study sought to address were (1) How do couples perceive and interpret their experience following stillbirth or early infant death? and (2) How do couples view the social support they have received at the time of their infant's death?

By discovering how couples perceived their bereavement experience and the social support received, nurses are able to gain a better understanding of the experience thereby enabling them to provide more effective nursing care and foster social support for bereaved families.

This study used the qualitative research design of phenomenology to address the questions regarding parents' experience following stillbirth or early infant death. Phenomenology, an inductive descriptive type of research attempts to "describe human experience as it is lived" (Oiler, 1981, p. 178), therefore phenomena are investigated and described as they appear to the individual.

Six couples, who were recruited primarily from bereavement support groups participated in this study. Each couple had experienced a stillbirth or early infant death between four months and four years prior to the study. Data were collected from the subjects through unstructured, audio-taped interviews, that allowed the experiences to unfold as they were perceived by the subjects. Second



interviews were conducted for clarification and validation of the themes that emerged.

Analysis of the data was based on Giorgi's (1975,a,b) steps in phenomenological methodology. These entail reading the transcript to get a sense of the whole, identifying units of meaning throughout each transcript, creating categories of these meaning units and developing the main themes from the data. The four themes that evolved from the data provided by the six couples were (1) anticipation of parenthood and the shattering of hopes with the death or knowledge of impending death of the infant; (2) a multidimensional personal grief experience; (3) an interpersonal grief experience influenced by the social support of health care professionals, of friends and family and of their spouse; and (4) reflection and search for meaning in the experience.

The data indicated that prior to the infant's death, parents had emotionally and physically prepared for parenthood. Ensuring a safe passage and binding in to this particular child were aspects of this preparation. The high anticipation and the specific preparations were brought to an end with the death of the infant.

The shattering of hopes and dreams precipitated a personal reaction of grief in the parents. Their descriptions of grief indicated a complex, varying combination of emotions that did not appear to follow a

particular sequence of stages common to all. Grief included feelings of shock, numbness, disbelief, guilt, anger, sadness and pain. Shock, numbness and disbelief appeared to serve as a protective mechanism against the full impact of the loss, giving parents time to accept the loss more slowly.

Guilt arose for some of the parents as they attempted to make sense of the experience with questions such as "Could we have prevented the death?" and "Why did this happen to us?" Some of the parents felt anger at the loss of their infant and at the lack of support or the type of support received at the time of their bereavement. No anger was directed toward the infant who had died.

Parents experienced overwhelming feelings of sadness and both physical and emotional pain. Yearning and searching behavior appeared to be attempts to fill the void caused by the loss of the infant. The few memories the parents had of the child were cherished and shared, to reinforce that the child had been a part of the parents' lives and to give validity to their extreme sadness and pain.

The personal experience of grief was influenced by the social support received through interactions with others. This interpersonal experience of grief involved health care professionals, friends and family, and the spouse.

In the interactions with health care professionals, parents felt they needed information about the condition of their infants to understand and make sense of the situation, to decrease their guilt and to plan for the future. They observed that they often had to aggressively seek information, that it was not automatically given to them. Some parents also felt they needed information about grief and the grieving process.

Adequate information led to appropriate decision making which parents wanted to be involved in. They saw the decisions regarding their infant as their right and their responsibility.

Parents talked of the sensitivity of health care professionals to their needs, feelings and experiences. Valuing the infants and including the father were important in interactions. Positive characteristics of health care professionals were openness, willingness to talk in a supportive, caring manner, consulting the parents about their needs and desires and acknowledging the parents' contributions to the situation.

The friends and families of the couples were seen as a significant part of the social support network. Parents wanted their friends and families to realize the immensity of their losses; to understand that the infants were significant persons in their own right; to give them time to grieve; to support them through talking and listening; and

to view them as normal, vibrant people. Some of the parents found that support was present initially but was withdrawn too soon. Some also observed that fathers were expected to be strong and therefore received less support than mothers.

Interaction within each couple was important as parents relied on their partners as a major source of support. As the experience was both a shared experience and an individual one, some problems arose in the different timing and intensity of grief reactions. Another problem was in both partners' need for a great deal of support. Parents felt that awareness and understanding of the potential problems had drawn them closer together.

As parents reflected on the experience and looked for meaning, most indicated they had vivid memories of their infant and of the events surrounding his or her life and death. Gains from the experience included a re-evaluation of their philosophies of life, an increased sensitivity to others and a broader appreciation and knowledge of life.

### Conclusions

Three conclusions that are drawn from this study are

1. Stillbirth or early infant death is a major loss for parents that remains a significant part of their life experience.

2. The grief of bereaved parents does not always follow a particular pattern or sequence but has many dimensions that may be experienced in various ways.

3. The grief experience of parents is influenced by the support received from health care professionals, from friends and family and from the spouse. Effective support may be inhibited by the failure to see perinatal death as a significant event and by the lack of knowledge of how to react and behave in the event of a stillbirth or early infant death.

The findings and conclusions from this study have implications for nursing research, practice and education.

### Implications for Nursing

#### Implications for Nursing Practice

This study has implications for nursing practice in relation to direct client care and more broadly as it seeks to influence health care delivery and societal attitudes toward death.

Because of the multidimensional nature of grief and the extensive variation of the experience and of the expression of grief, it is essential that health care professionals view grieving parents as individuals. More personalized service to perinatally bereaved parents could result from eliciting the parents' construction of the experience

throughout contact with them rather than making assumptions about their feelings, needs and their progression through the grieving process.

Providing adequate information in a sensitive caring manner will assist parents in understanding and making sense of their experience of stillbirth or early infant death. As grieving parents are made aware of aspects of their child's condition, of procedures surrounding the birth and death, and of the expected course of events, they will be more equipped for involvement in decision making regarding their child.

The physiological nature of pregnancy and birth leads to a health care focus on the mother. In the event of infant death, support also is directed primarily toward the mother. There is a need to view both parents as active participants in birth and a need to realize that bonding occurs between both the mother and the child and between the father and the child. Support is therefore a need of both parents.

Parents showed an attachment to the particular child who had died. Nurses can support parents by acknowledging the loss of the infant as a significant person and assisting parents in procedures that will affirm the reality of the child.

This study has implications for community health nursing follow-up to bereaved families. Parents

specifically suggested that the community health nurse visit as soon as possible, make the visit when the father can be present, and provide information about resources such as literature and bereavement support groups. Community health nurses can also assist parents to understand their own reactions, their differences in grieving, the possible effects on the immediate family and the difficulties that friends and family may have in providing support.

More comprehensive care can be provided to bereaved parents when nurses function as client advocates, assisting parents to obtain the information they need from other health professionals and promoting parental involvement in decision making. Nurses can influence health care delivery by promoting adequate communication between hospital and community services, thus ensuring appropriate follow-up of parents experiencing perinatal death.

Nurses can work at a societal level by sensitizing and educating the public regarding the experiences of parents following perinatal death. One way to increase public awareness is through the popular literature. Expanding the focus of care to include relatives and friends of the parents would spread information about the intensity of grief, the length of grief and parents' need for acknowledgement of the child as a reality, and acceptance of their grief as it is expressed. This could be done through

providing appropriate literature for those supporting bereaved families.

### Implications for Nursing Research

This study has focused on the experience of the parents, those most directly affected by perinatal death. As social support is a significant factor in the parents' experience, further research on groups providing social support would be appropriate. Nursing is one such group; the close family and friends constitute another support group that could be investigated to further understand and expand the support network of bereaved parents.

One area of research could be nurses' perceptions of perinatal death and the factors, such as the gestational or infant age and the condition of the infant, that may influence nurses' views and hence their responses to perinatal death. The response to perinatal death could be assessed in terms of nurses' perceived roles and the actual interactions in providing support to parents following perinatal death. The question of how nurses deal with their own grief at the death of an infant in their area of work is also an area for further investigation.

Research pertaining to the role of family and close friends in the support system could address their perceptions of stillbirth or early infant death and look at



the questions, fears, concerns and difficulties they have in relating to bereaved parents.

### Implications for Nursing Education

In educating nurses about the grieving experience, it is essential that theories of grieving and stages and phases that have been identified be viewed in the light of the individual experience of the bereaved person.

Nursing education could encourage a clarification of students' own values and attitudes toward the beginning of life, infant death, the bereaved and an exploration of how these values influence nursing care to bereaved families.

This study has indicated the importance of sensitive, humanistic interactions between health care professionals and clients. As technology is increasing, nursing education must ensure that the teaching and learning of technological skills does not replace the interpersonal skills that are critical to nursing.

In conclusion, this study has attempted to discover and describe the experience of parents who have had a stillbirth or an early infant death. The results indicate that perinatal death is a major loss for parents and that their grief reaction is influenced by the social support received.

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Appendix A  
Participant Information Letter

School of Nursing  
University of British Columbia  
Vancouver, B. C.

Dear Parents,

My name is Janice Thiessen. I am presently doing graduate studies in nursing at the University of British Columbia. For my master's thesis I am interested in studying the experience of parents following the stillbirth of their child or the death of their child in the first week of life.

My past experience has mainly been in community health nursing in which it was usual to visit parents following the birth of a child. If the child had died, the postnatal visit became a more difficult one. I had many questions about the particular concerns and needs of the parents. In order to provide appropriate care to families, health professionals have to find out from parents what their needs are.

I believe that the people who are best able to talk about an experience, particularly the emotional aspects of the experience are those who have actually been through it. I therefore hope to interview parents who have suffered the death of their child during the time before or after birth to gain a better understanding of the experience from their perspective. I will interview parents who have experienced the loss at least six months ago. Such a study will contribute to more sensitive, understanding and supportive care available to parents.

If you are interested and agree to participate, the study will include (1) my visiting you in your home two or three times to interview you about your experience, and (2) tape recording our conversation which may last about one and one half hours per interview.

Your name and any identifying information will not be used in the study or revealed in any printing or publication of findings.

Parents' Reply

We are interested in the study described in Janice Thiessen's letter and give permission for her to contact us to discuss the study further. Our reply does not indicate that we have decided to participate in the study. This decision will be made after further discussion with Janice Thiessen.

Name:

Address:

Phone Number:

Signature:

## Appendix B

## Participant Consent Form

A Phenomenological Study of Parents' Experience  
following Perinatal Death

I understand that the purpose of this study is to find out what our experience as a couple was like following the stillbirth or early infant death of our child.

I understand that this study will involve the following:

1. The interviewer will visit us in our home two or three times.
2. Each interview will be about one and one half hours in length and will be tape recorded.

I understand that my name and any identifying information will not be used in the study or revealed. Confidentiality will be ensured by the interviewer using a code to identify transcripts of the recorded material, with the code known only to her.

I UNDERSTAND THAT I AM UNDER NO OBLIGATION TO PARTICIPATE IN THIS STUDY AND THAT REFUSAL TO PARTICIPATE WILL NOT AFFECT FUTURE MEDICAL OR NURSING CARE. I UNDERSTAND THAT IF I PARTICIPATE, I CAN WITHDRAW AT ANY TIME OR REFUSE TO ANSWER ANY QUESTIONS WITH NO EFFECT ON MY FUTURE MEDICAL OR NURSING CARE.

I understand that if I have further questions I can contact the nurse researcher.

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I understand the nature of this study and give my consent to participate. I acknowledge receipt of a copy of this consent form.

Date:

Signature: