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UNIVERSITY OF ALBERTA

COPING WITH FETAL GENETIC RISK: THE PARENTS' PROCESSES

BY

GWEN ANDERSON ©

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF NURSING

FACULTY OF NURSING
EDMONTON, ALBERTA
SPRING 1990

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SUBMITTED BY GWEN ANDERSON

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF NURSING

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DATE April 18, 1990

DEDICATION

This work is dedicated to all nursing students who strive to understand the holistic nature of human experience in health and illness.

> "Only as nurses discover and create
> their own practices and identities
> as nurse, and only as they understand
> the roles that these play in the
> viability of nursing will they discover,
> add to, and create their own profession"
>
> Leah Curtin and
> Josephine Flaherty
> 1982, p.129.

ABSTRACT

The purpose of conducting this study was to examine the social psychological experience of prenatal genetic diagnosis (PNGD) and counseling from the view point of expectant parents. The primary source of data were semi-structured interviews conducted with three expectant women and their husbands. Informants were recruited from an obstetrician who referred women to the Genetics Center for the sole purpose of investigating fetal genetic risk due to advanced maternal age.

Three interviews were carried out with each spouse at 12, 18, and 22 weeks of pregnancy. Data were analyzed for recurrent themes and emergent concepts using a constant comparative analytic technique. The process of data collection and analysis occurred simultaneously.

The informants described their experiences as four distinct yet overlapping processes: the chronological process of prenatal genetic diagnosis and counseling, the process of coping with fetal genetic risk, the process of deciding, and the process of parental fetal attaching. The process of coping with fetal genetic risk emerged as the core variable because expectant parents consistently attempted to regain personal control over the chronological events, while considering each decision path, and while experiencing the presence of the developing fetus, whose health condition was uncertain. Both male and female informants employed the same six coping strategies: waiting, hoping, seeking, deciding, protecting, and worrying with the

exception that the men denied that there was ever anything to worry about.

Another important finding was that the experience affected patterns of parental fetal attaching. Women delayed attaching to the baby until after the results of the amniocentesis was known, as a way of protecting themselves from the emotional pain of perhaps becoming involved with a child that may be aborted. In contrast, the men attached to the baby earlier in gestation than has been reported previously.

Further examination of the pregnancy experience during PNGD and counseling using a larger more diverse group of expectant parents would determine the validity and usefulness of the theoretical framework that emerged. The findings in this study may hold implications for the provision of genetic counseling services and subsequent follow up care of expectant parents who decide to terminate an abnormal fetus.

ACKNOWLEDGEMENTS

This work is the collective reflection of the collaboration of many loved ones who supported me and helped me to grow in mind, spirit, and strength throughout every stage of this academic/research process.

I revere the late Dr. Peter Bowen for his mentorship, inspiration and virtuous grace. I wish to thank Mikang Choi for her supportive clinical supervision and for role modeling joint expertise in both nursing and prenatal genetic counseling. Her insights about people, and her willingness to question and suggest hypotheses were instrumental in the grounding of the research findings to the empirical world of lived experiences in a prenatal genetics clinical setting.

I thank my friend Sharon Laskiwski, with whom I have shared laughter, tears, abstract ideas, creative "ahas", and spiritual kinship. Although we will continue to strive toward new achievements, this milestone is not ephemeral, but rather a foundation for the actualization of a holistic reawakening in our personal and professional selves.

I am indebted to my brother Nick, my sister Susan, her husband Wayne, and John and Irene for their eternal love and support. I thank them for their long-distance faith in me even during the deepest and darkest moments. I express gratitude to my parents for their quiet encouragement and to my friend Kim for his willingness and ability to actively listen.

I owe many thanks to my colleagues in the Faculty of Nursing:

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With great pride I wish to express my appreciation for the supportive contributions of my thesis committee members: Dr. Marilynn Wood, Dr. Peggy Anne Field, and Dr. Connie Varnhagen for their mentorship throughout this research endeavor with an attitude of academic, professional and personal excellence.

I behold with warm gratitude memories of the interviews with the informants. I was a stranger, yet they accepted me, and shared their inner most thoughts, feels and intimate secrets. I am grateful to them for their self disclosure.

Finally, I wish to acknowledge the financial support of The Alberta Foundation for Nursing Research which I was proud and honored to receive.

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CHAPTER I

Introduction

Prenatal diagnosis (PNGD) of genetically inherited disorders has been routinely available, for about fifteen years, to a select group of women in many countries around the world (Boue, Brambati, Ting-Yuan, Mikkelsin, Modell, Pergament, Schull, 1984; Wertz & Fletcher, 1988). Recent advances in molecular biology and genetic research have made it theoretically possible to diagnose any of the 3,000 inherited diseases that afflict humans (Lappe, 1984; Pines,1984). PNGD is a relatively new medical technology that is offered to expectant parents who are known to be at risk of having a child with a genetic disorder. PNGD is available for a rapidly growing list of genetic disorders (Weatherall, 1985).

Most commonly, women who seek prenatal genetic counseling do so because of advanced maternal age. The risk of having a baby with a genetic disorder increases substantially when women approach their late 30's and 40's. At age 20 there is a 1 in 1,550 chance of a "...significant chromosomal anomaly at birth..." (including Down's Syndrome), at age 38 years the rate increases to 1 in 103, at age 40 years it is 1 in 65 and at age 43 years it is 1 in 50 births (March of Dimes Birth Defects Foundation, 1987; Hunter, Thompson & Speevak, 1987; Naber, Huether & Goodwin, 1987; Dawe, 1986; Blumberg, 1984; Davies & Doran, 1982; Marion, Kassam, Fernhoff, Brantley, Carroll, Zacharias, Klein, Preist & Elsas, 1980; Shapiro, Comings, Jones, & Rimoin, 1986).

In recent years a new health care professional role, the genetic associate (counselor), has opened the field of clinical genetics to nurses. Nurses are employed in hospitals and community settings as genetic counselors; their major goal is to facilitate understanding of birth defects and modes of transmitting genetic disorders. Five essential aspects of the genetic counselor role have been documented: family counseling (Beck Black, 1979), provision of emotional support and anticipatory guidance; co-ordination of an interdisciplinary team of professionals and services (Field, 1988); translation of biotechnical information into meaningful terminology; and teaching relevant information (Fitzsimmons, 1985; Zander, 1985; Mertens, Hendrix, Kenkel, 1986; Rapp, 1988).

The earliest nursing article written on human genetics by Hillsman, (1966) documented descriptive case studies of what it was like for mothers to have a child with a phenlyketonuria (PKU) disorder. Social stigma, self concept, loss, loneliness, denial and the coping process were identified as common client problems, from which standards of prudent nursing practice were prescribed.

Clinical genetics has been a topic of interest to nurses in public health (Fitzsimmons, 1985), occupational health (Thomson, 1983; Williams, 1983), pediatrics (Williams, 1986), prenatal testing (Dawe, 1986; Cox, Sullivan & Roghmann, 1984; Davies & Boniface, 1979) and education (Zander, 1985; Forsman, 1983). The majority of nurse authors have attempted to understand how parents of genetically disabled children cope with chronic stress.

Many of these articles were based on anecdotal case studies and were written from the view of applying the nursing process to care of individuals and families with a genetic problem (Gibson, 1986; Leifson, 1987; Hymovich, 1987;1979; Mealey, 1984). Nurse educators and nurse researchers have unintentionally ignored the steady movement of nurses into the practice of clinical genetics. Nurses have only recently become interested in course work and clinical practice in the area of human genetics as demonstrated by the fact that only two authors have written text books on the topics of nursing and human genetics (Cohen, 1984; Muir, 1983). Only four masters of nursing programs exist in North America with a clinical focus on human genetics: the University of Iowa, (Mertens et al., 1986), the University of Florida, the University Cincinnati, and Boston College (Challela, 1990).

Statement of the problem

Researchers, to date have discovered valuable information about expectant parents' experience of PNGD and counseling. A multitude of factors that appear to influence the decision to undergo amniocentesis for PNGD and the psychological reactions that occur as a result of testing have been identified. However, the way that expectant parents describe their overall perceptions and feelings related to PNGD and counseling, still needs to be documented.

Another facet of the problem is that much of the research literature with the exception of a few large scale surveys, has excluded detailed examination and documentation of the thoughts, feelings, and attitudes of prospective fathers in relation to childbearing and prenatal fetal genetic testing (Rice & Doherty, 1982; Finley, Varner, Vinson & Finley, 1977). To get at the issues most significant to expectant parents, researchers must design studies aimed at elucidating the individual perceptions of both prospective mothers and fathers.

Following a review of the literature, it was still unclear how parents-to-be interpret or derive meaning from their experience of prenatal genetic services; nor is it understood how they integrate the new genetic knowledge into the context of everyday life, personal sociocultural values, spiritual beliefs and family/life goals. Consequently, little is known about how people are impacted by prenatal genetic health care services (Beck Black, 1980;1982).

Selection of a grounded theory approach to this problem allowed the researcher to discover a theoretical framework based on the informants' emic perspective rather than force-fitting their perceptions into an extant theoretical framework like decision making (Beeson & Golbus, 1985; Wertz, Sorenson & Heeren, 1984; Lubs, 1979) or information processing (Ekwo, Seals, Williamson & Hanson, 1985; Sorenson, Kavanagh & Mucatel, 1981).

The purpose of the study and the research questions

The purpose of this study was to discover whether there was a basic social process that explained expectant parents' feelings and perceptions of PNGD and counseling and to identify whether these experiences influenced prenatal involvement between the developing fetus and the parents-to-be. This study served as an initial attempt to expand awareness and understanding of the clients' perspective of the overall impact of this "routine" medical procedure on their high risk pregnancy (Sandelowski, 1988).

The following questions served to guide the research process; systematic collection of interview data, documentation of the researcher's field notes, data analysis and the writing of the thesis.

1. How do expectant mothers and fathers describe their experience of PNGD and counseling?
2. What similarities and differences exist between mothers' and fathers' perceptions of the PNGD experience?
3. How do expectant mothers and fathers describe their experience of the first and second trimesters of pregnancy?
4. What similarities and differences exist between mothers' and fathers' experiences of attaching to the fetus during the first and second trimesters of pregnancy?

The significance of this study for nurses

Nursing research and theory development related to human genetics has not kept pace with the movement of nurses into the practice of clinical genetics. In view of this fact, it is timely and appropriate for nurse researchers to investigate phenomenon integral to human genetics that has implications for nursing practice (Sandelowski, 1988). Nurses need to understand counselees' view point of PNGD and counseling so that they can provide holistic health care to those people who seek this specialized health care service.

Definition of terms

Prenatal genetic counseling session - means a session offered by the Genetics Center, conducted by a prenatal genetic counselor (nurse) and available to all expectant parents who were referred to the center by a physician and who meet the eligibility criteria for PNGD and counseling.

Advanced maternal age (AMA) - means an expectant mother is age 35 years or more at the expected date of confinement.

Prenatal genetic diagnosis (PNGD) - means one of two technical procedures: amniocentesis or chorionic villi sampling (CVS) used to obtain fetal cells for laboratory analysis in order to diagnose the genetic status of the fetus.

Amniocentesis - is the insertion of a hollow needle through a woman's abdomen into the amniotic sac to remove a sample of the fluid that surrounds the fetus. The procedure is usually preceded by an ultrasound examination to document the age of the fetus and it's location so that an appropriate site for insertion of the amniocentesis needle can be chosen (Simpson, Dallaire, Miller, Siminovich, Hamerton, Miller & McKeen, 1976).

Chorionic villi sampling (CVS) - is the surgical procedure whereby villi are removed via a catheter for the purpose of fetal diagnosis of a chromosomal or biochemical disorder. (Hamerton, 1989).

CHAPTER II

Literature Review

Background information

Gregor Mendel is known as the grandfather of genetics. In 1865 he founded the laws of mendelian modes of inheritance while conducting hybridization experiments with pea plants. In 1948 Dr. Barr discovered the sex chromatin or "barr body" enabling differentiation of male and female karyotypes which won him the Nobel Prize (Burgess, 1988/89). Until as recently as 1956 human beings were thought to have 48 chromosomes; we now know that the human body has only 46 chromosomes. In the past, the most common method of laboratory analysis used to diagnose genetic disorders was a biochemical (enzyme) assay. Genetic screening programs in health care were initiated in the 1960's. Detection of phenlyketonuria (PKU) in newborn babies, a mentally debilitating digestive disorder was the first of such programs. Routine prenatal testing of maternal blood for neural tube defects (NTD) in the fetus was first reported in the literature by 1973 (Fry, 1987).

Chromosomal karyotyping and DNA probes are now available for prenatal diagnosis of a wide variety of genetic disorders and may be used in the diagnosis of many inheritable diseases associated with: X-linked recessive, autosomal dominant, or autosomal recessive modes of inheritance (Boehm, Werle & Drahovsky, 1987; Asmussen & Clegg, 1982; Shapiro et al., 1986).

Genetic counseling has been defined as "...a communication process which deals with the human problems associated with the occurrence or risk of a genetic disorder in a family..." (Muir, 1983, p.354). The aim is to "...provide accurate information in a manner enabling individuals or families to make decisions that optimize their sense of well-being in relation to the occurrence or potential occurrence of an inherited disorder..." (Heading, 1975, p.297). The most eminent principle that guides genetic counselors is that the counselor must not convey information in such a way as to bias the person's interpretation of information or interfere with their human right to make autonomous decisions (Rapp, 1988; Fletcher & Wertz, 1987; Fletcher, Berg & Trandy, 1985; Fletcher, 1984).

Amniocentesis

Amniocentesis, the first prenatal diagnostic medical procedure was successfully initiated in 1966 (Brambati, Simoni, & Fabro, 1986). Amniocentesis is done at 16 weeks gestation and it takes approximately three to four weeks for the test results to be known. The risk of fetal demise as a result of the amniocentesis procedure has been investigated internationally and is generally accepted to be 1:200 procedures. Less commonly there are other complications such as maternal infection, vaginal bleeding, ruptured membranes or fetal puncture.

Chorionic villi sampling (CVS)

Most recently, Canadian researchers reported the results of a clinical trial for a second prenatal diagnostic procedure (CVS) which commenced in 1984 and concluded in 1989 (Hamerton, 1989; Fahy & Lippman, 1988). The optimal time to conduct (CVS) is at 9 to 12 weeks gestation and the test result is known within one to two weeks.

The overall risk of miscarriage is three to five percent. This rate is imprecise because the baseline fetal loss rate is normally about 10 to 15 percent during the first trimester, when a miscarriage occurs following a procedure it is not known whether it was a result of the procedure itself or whether it represents a natural spontaneous event. Vaginal spotting is a common side effect of (CVS) and maternal vaginal infection occurs rarely (Brucker & MacMullen, 1987).

Accuracy of the diagnosis

Both PNGD procedures are subject to measurement error; false positives or negatives do occur. With amniocentesis the accuracy rate is 99.5 percent (Temple, 1983) and with the (CVS) it is 95 percent (Hamerton, 1989).

In an effort to better understand existing knowledge about expectant parents' experience of PNGD and its impact on parental/fetal attaching behaviors, the researcher reviewed literature under the topics: factors that influence womens' decision to accept amniocentesis for the purpose of PNGD; the social psychological effects of undergoing the amniocentesis procedure; the social psychological effects associated with the possibility of having to make a decision regarding termination of an affected fetus; and the tasks of normal pregnancy. Because the subjects in this study were faced with advanced maternal age as the only genetic risk factor, the literature review was limited, as much as possible, to focus on this target population.

Factors that influence womens' decision to undergo amniocentesis

Biographical characteristics

Women who undergo PNGD and counseling

Researchers have documented a variety of social, cultural, religious and economic factors that effect a woman's decision to undergo amniocentesis for prenatal diagnosis. Most researchers employed a survey design to collect data from only women. The factors found to be associated with utilization rates of this service in the United States and Canada were: advanced maternal age, parity, religious affiliation, ethnic background, maternal education, family income, perception of the risk and accessibility of genetic services in the community (Naber et al., 1987; Hook & Schreinemachers, 1983; Roghmann & Doherty, 1983; Roghmann, Doherty, Robinson, Nitzkin & Sell, 1983 ; Davies & Doran, 1982; Volodkevich & Huether, 1981; Marion et al., 1980; Shinno & Kellogg, 1977; Forster & Davison, 1977).

The majority of women who accepted prenatal testing were described as Caucasian, well-educated, middle class (Davies & Boniface, 1979; Davies & Doran, 1982; Simpson et al., 1976), they lived in urban centers (Hook & Schreinemachers, 1983), and all concurred that they themselves should be the ones to make their own reproductive decisions following PNGD and counseling (Cox et al., 1984; Roghmann et al., 1983). These women utilized this service because the test was available, readily accessible to them and they could afford the financial and travel costs associated with accepting the service.

Women who choose not to undergo PNGD and counseling

On the other hand, women who lived in rural communities were often not aware of PNGD and if informed, the costs of travel, time or money prohibited them from attending a Genetics Center. Furthermore, they resided in rural communities; they usually had less than a high school education; they attended the first antenatal obstetrical visit too late in gestation for the testing procedure to be done (Volodkevich & Huether, 1981; Marion et al., 1980; Shinno & Kellogg, 1977; Naber et al., 1987; Hunter et al., 1987; Davies & Doran, 1982), which has been associated with immigrant women and women with high parity (Forster & Davison, 1977; Davies & Doran, 1982; Dawe, 1986; Cox et al., 1984).

Utilization rates of PNGD vary around the world. In Denmark 85 percent of women over 35 years are tested; in Sweden 98 percent of eligible women utilize PNGD and counseling services (Sjogren & Uddenberg, 1988). In comparison the American and Canadian [illegible]lization rates of amniocentesis for all eligible women range [illegible] to 35 percent (Dawe, 1986; Boue et al., 1984; Rudd, 1983). [illegible]ent utilization of PNGD is the idealized goal, then the Canad[illegible] and American statistics indicate that this health care service is vastly under utilized in North America.

Social psychological factors

Women who accepted amniocentesis for PNGD

Although most women have a strong desire to have a child they still sought PNGD to alleviate their fears of having an abnormal child (Roghmann & Doherty, 1983; Davies & Doran, 1982; Dixson

Richards, Reinsch, Edrich, Matson & Jones, 1981; Sorenson & Wertz, 1986; Hsia & Silverberg, 1973; Ekow et al., 1985). Career-minded primaparas in particular were willing to avail themselves to any medical procedure required in order to prevent the burden of having to care for a handicapped child. Beeson and Golbus (1985), the only researchers to report the husbands' opinion regarding the decision found that men were even less willing than their wives to take the risk of having an abnormal child.

Some women indicated that they felt an obligation to use the service simply because it was available and they felt it difficult to refuse the test when offered by the doctor (Rothman, 1987; Sandelowski, 1988; Roghmann & Doherty, 1983; Volodkevich & Huether, 1981; Dixson et al., 1981; Cox et al., 1984). In a study of Swiss women, Sjogren and Uddenberg (1988) found that many women thought it was their personal duty to protect the baby and release society from the burden of caring for a handicapped child. Advanced maternal age (AMA) women generally perceived PNGD as a means of preventing the birth of an abnormal child. They requested the test as a way of reassuring themselves that an undesirable pregnancy outcome would not occur (Winslow, 1987; Roghmann et al., 1983; Mealey, 1984; Dixson et al., 1981).

Women who refused the amniocentesis for PNGD

Women have reported a number of fears that adversely influenced their decision of whether or not to accept PNGD: the fear of spontaneous abortion as a consequence of the testing procedure (Hamerton, 1989; Dixson et al., 1981); the fear of fetal injury at the time of testing with permanent damage to the child's growth and development (Shinno & Kellogg, 1977; Roghmann et al, 1983); and the fear that the husband would be opposed to the test (Marion et al., 1980) or may force her to abort the fetus (Robinson, Tennes & Robinson, 1975).

Although the research evidence is inconsistent as to whether or not maternal religiousity influences this decision, the most commonly reported reason for refusing testing was a strong moral belief that life should be preserved at all costs (Davies & Doran, 1982; Ekow et al., 1985; Marion et al., 1980; Volodkevich & Huether, 1981; Shinno & Kellogg, 1977; Dawe, 1986; Roghmann & Doherty, 1983). The notion that acceptance of PNGD automatically meant that the woman would consent to a termination procedure drove some women away from testing altogether (Marion et al., 1980; Ekow et al., 1985; Davies & Doran, 1982). Some women were inhibited to accept PNGD because they were concerned that the "eugenic effect" (Thurmon, 1974) of PNGD would produce a world with little or no tolerance for handicapped people (Sjogren & Uddenberg, 1988).

Two other factors that were important to both women who accepted PNGD and those who did not were: the likelihood of having a successful amniocentesis puncture on the first attempt to obtain a fetal fluid sample (Hamerton, 1989); and skepticism about the accuracy of the test result (Hamerton, 1989; Dixson et al., 1981).

Perceived fetal genetic risk

Previous investigators have explored womens' perception of the fetal genetic risk to see how it influences their decision regarding whether or not to undergo PNGD. Teaching knowledge about modes of genetic inheritance of disorders and the risks associated with fetal testing was compared with subjects' ability to recall the same knowledge later in gestational time. It was presumed that the most influential factor in counselees' decision making process was acquisition of knowledge (Ekow et al., 1985; Lubs, 1979; Sorenson et al., 1981; Chase, Faden, Holtzman, Chwalow, Leonard, Lopes & Quaid, 1986). This hypothesis was based on the premise that people make decisions using a rational approach, weighing the benefits of procreation as compared with the personal loss of not bearing a child (Beach, Townes, Campbell & Keating, 1976; Beach, Campbell & Townes, 1979; Paulker & Paulker, 1987).

The major criticism of this analytic decision model is that it failed to account for counselees' perception of their social and personal factors that were intimately interwoven into the matrix of their decision making process. These investigators overlooked the fact that peoples' perception of risk incorporated a holistic perspective of their personal values, beliefs, attitudes and social network (Ekow et al., 1985; Tversky & Kahneman, 1974; Kahneman & Tversky, 1982; Cox et al, 1984). The finding that counselees tended not to accurately remember numerical risk probabilities further refutes the proposition that knowledge is the single most important factor affecting counselees' decision about PNGD testing (Lubs, 1979; Sorenson et al., 1981). Hence, the notion that attitudes, values, beliefs and a person's social context intermediate between opposing choices has been identified but what remains unexplored in detail is the meaning or significance of these variables in the decision making process.

Spousal disagreement in perception of fetal genetic risk has been documented by a number of researchers. Rice and Doherty (1982) purported that 80 percent of spouses differed in their perception of the risk. This same finding was supported by Sorenson and Wertz (1986) who concluded that spousal differences were unaffected by the intervention of genetic counseling. Partners disagreed about perceptions of: the burden of caring for a handicapped child, the seriousness of the problem, and the financial costs associated with having a handicapped child. These researchers did not offer an explanation to account for disparate spousal perceptions, but they did suggest that these differences adversely affected the marital relationship and the couple's ability to decide on future reproduction.

In summary, much is known about the static biographical characteristics of AMA women who chose either to accept or refuse PNGD. Many social psychological factors such as: fear of the impact of having an abnormal child on a woman's career and family life, moral beliefs, perceived obligation to protect society, whether or not the doctor recommended PNGD and their perception of fetal genetic risk have been implicated as motivators that make a woman choose one option over another. Much of the research regarding these factors has been conducted using a retrospective research design with heterogeneous populations of women who had varying degrees of fetal genetic risk.

Furthermore, the question of how much the husband's perceptions influence the wife's decision has not been addressed in detail by previous researchers. If spouses do differ in their perception of the fetal genetic risk then perhaps each partner interprets or attaches a different meaning to the consequences or possible outcomes.

A study designed to capture the meaning of the phrase, 'fetal genetic risk' may clarify and highlight differences and similarities between expectant mothers' and fathers' perceptions. Presumably, a better understanding of the meaning of fetal genetic risk would identify new factors or subtle differences between factors already suspected to influence spousal perceptions and decision making regarding acceptance or refusal of PNGD.

The psychological effects of undergoing amniocentesis for PNGD

Uncertainty

Advancements in human prenatal genetics have created numerous areas of uncertainty that require considerable deliberation and decision making on the part of expectant parents. When prospective parents are at risk of bearing a child with a genetic abnormality they are confronted with the burden of having to make several decisions: (a) whether or not to accept PNGD; (b) which testing procedure to undergo: amniocentesis or chorionic villi sampling; and (c) should the pregnancy be terminated if the test results indicate an abnormality in the fetus (Sjogren & Uddenberg, 1988; Beck Black, 1979;1980;1982)?

In it's broadest sense the concept of uncertainty is defined in the genetics literature as "...the time of most doubt..." (Robinson, Hibbard & Laurence, 1984, p.165). According to genetic researchers interested in exploring decision making, risk perception, and post counseling reproductive outcomes, uncertainty is perceived as a multidimensional phenomena. A taxonomy of four different kinds of uncertainty may be inferred from previous research studies: reproductive, pregnancy, diagnostic, and waiting.

Reproductive uncertainty

In a grounded theory study by Lippman-Hand and Fraser (1979a;1979b;1979c) the concept of uncertainty was discovered and described. Uncertainty emerged as a core variable when counselees described factors that influenced their process of decision making. Uncertainty was vaguely defined as the "...parents perception of the problem as uncertain..." (1979a, p.330). To the expectant parents, uncertainty meant that, the genetic information was ambiguous and the possibility of having an affected child was unpredictable. These investigators suggested that uncertainty was the most influential factor in postcounseling reproductive behavior. When reproductive uncertainty remained unresolved following counseling, counselees tended to play "reproductive roulette", not because they made a conscious decision to procreate, rather they simply did not practice a safe and reliable method of contraception.

Expectant parents in that study identified three concerns relating to uncertainty and decision making. First, expectant parents were uncertain about how family and friends would evaluate the rationality of their reproductive decisions. Second, uncertainty was manifested as fear regarding their ability to normalize the pregnancy experience (ie.) if they knew the baby was abnormal would they feel normal prenatal attachment towards the fetus and would they be able to carry on with the normal tasks of parenthood once the child was born. Third, they were uncertain about how to make a decision regarding the fetus, if an abnormality was found.

For the purpose of evaluating the effectiveness of genetic counseling Wertz, Sorenson and Heeren (1984) tested the proposition as posited by Lippman-Hand and Fraser. They operationally defined reproductive uncertainty as "...unsureness about undertaking a pregnancy in the next two years..." (p.80). These researchers were unable to substantiate the hypothesis that effective prenatal genetic counseling decreased counselees' perception of reproductive uncertainty.

The findings from these two studies indicated that teaching counselees about genetic risk, fetal genetic disorders and the prognosis of a child diagnosed with an abnormality did not alter their perception of post-counseling uncertainty. Those persons who were uncertain about reproduction prior to genetic counseling remained uncertain following counseling. Likewise those who were certain about reproduction in the precounseling period were equally certain in the postcounseling period. Although the giving of direct advice by the genetic counselor was correlated with uncertainty it served only to reinforce counselees' precounseling reproductive uncertainty.

Waiting uncertainty

Rice and Doherty (1982) described waiting uncertainty as the feeling of tension and anxiety associated with waiting for the fetal diagnosis following the amniocentesis test (Robinson, Tennes & Robinson, 1975; Robinson et al., 1984). Furthermore, they noted that this period is marked by "hiding" the pregnancy from others and indecision about parenthood until after the results are known. However, "waiting' would seem not to be a type of uncertainty so much as a factor influencing the experience of uncertainty.

Diagnostic uncertainty

Diagnostic uncertainty was defined by Blumberg (1984) as "...diagnostic imprecision..." or ambiguity leading to ambivalence about deciding on a course of reproductive action (p.210). Ambiguity and unpredictability were identified as two attributes of diagnostic uncertainty by both Beck Black (1979) and Zuskar (1987). These researchers observed that prenatal counselees were uncertain about the long term consequences of deciding to terminate a defective fetus or choosing to bear an abnormal child. Like the subjects in the study by Wertz et al., (1984) and Lippman-Hand and Fraser (1979a) these subjects were also uncertain about how other people may react to their reproductive choice.

Expectant parents desired as much information about PNGD as possible, and they wanted as high a degree of fetal certainty as possible. When the genetic risk was presented to subjects from a purely statistical stand-point, counselees could not interpret a clear yes-or-no answer about the diagnosis or the prognosis of their child (Kelly, 1977). Compounding the problem of diagnostic uncertainty, are the limitations of cytogenetic technology. For example, there is always a chance of error in the genetic diagnosis. Given the nature of biological function and the mechanics of chromosomal disjunction, there is much room for variation in the phenotypic expression of a particular genetic aberration. This means that a specific genetic diagnosis symbolizes a wide range in the degree of possible disability. A newborn could be born with any form of a genetic disorder varying from a mild to a very severe deformity. It is impossible to predict in advance the degree of disability that would be manifested in a particular child.

Current usage of the term uncertainty in the genetics literature implies three similar, yet different concepts. Sometimes the word refers to the fact that counselees can not predict the outcome of their pregnancy; whether or not the child would be healthy. At other times the term connotes counselees' indecision about whether or not they have decided to reproduce. Additionally, it refers to counselees' skepticism about the accuracy of the diagnostic test result (ie.) whether or not it would actually predict the unborn child's health status. Therefore, in future research it is necessary to discover and describe what uncertainty means from the expectant parents' vantage point in order to plan counseling interventions aimed at altering their perceptions. Further exploration of this concept may assist counselors to identify factors that influence counselees' perception of uncertainty. Exploration of expectant parents' experience of prenatal testing may reveal whether uncertainty as a construct is static or whether it changes with the passage of gestational time or the events of PNGD.

Anxiety

Research in the field of prenatal genetics concerning anxiety has exclusively focused on womens' psychological reaction to undergoing amniocentesis or chorionic villi sampling. Previous researchers have used the words: stress, impatience, worry and acute concern synonymously with anxiety. However, differences between how researchers define anxiety and how counselees define the term has yet to be systematically documented. Investigators have tended to skip over this initial level of inquiry, therefore anxiety has been understood predominantly from the analysis of data from survey questionnaires designed from the etic perspective. It would be interesting to find out if expectant AMA parents' perception of anxiety is the same as or different than the findings documented in these studies.

Reportedly, anxiety is a consequence of uncertainty (Beeson & Golbus, 1985; Evers-Kiebooms, Swertz, & van den Berghe, 1988; Giovanni, Trombini, Michelacci, Linder, Pathak & Bovicelli, 1983). A sense of doubt about the outcome of the pregnancy sustains womens' feelings of anxiety which remains high until after the fetal diagnosis is known and the uncertainty is resolved (Robinson et al., 1975; Robinson et al., 1984; Beeson & Golbus, 1985; Rice & Doherty, 1982). Women identified anxiety, fear, and uncertainty as the predominant feelings associated with thoughts about the possibility of fetal injury during the amniocentesis procedure and the possibility of fetal abnormality (Evers-Kiebooms et al., 1988; Robinson et al., 1975;1984; Blumberg, 1984; Leonardi & Esrig, 1982; Dixson et al, 1981; Beeson & Golbus, 1979; Finley et al., 1977; Golbus, Conte, Schneider & Epstein, 1974).

Factors that influenced counselees' perception of anxiety were identified as: maternal age (Sjogren & Uddenberg, 1988); fear of possible fetal abnormality (Robinson et al., 1975), the possibility of having to make a decision about termination (Beck Black, 1979; Antley, 1976; Sjogren & Uddenberg, 1988; Evers-Kiebooms et al., 1988; Finley et al., 1977), fear of loss of the desired child (Beeson & Golbus, 1985), fear of pain associated with the amniocentesis procedure, and fear of possible harm to the fetus during the procedure (Rice & Doherty, 1982; Beeson & Golbus, 1985; Hunter et al., 1987; Leonardi & Esrig, 1982; Finley et al., 1977). In consideration of these fears a question arises: Does the perception of anxiety resulting from undergoing PNGD and counseling influence expectant parents' involvement with the developing fetus?

Researchers have purported that high levels of anxiety are positively correlated with high levels of uncertainty (Evers-Kiebooms et al., 1988; Finley et al., 1977; Robinson et al., 1984). Proponents of this view posit that expectant parents experience their highest levels of anxiety and uncertainty during the period of waiting for the results of the amniocentesis procedure to be reported. The peak period of intense uncertainty and anxiety occurred at the time when the fetal diagnosis was expected (Evers-Kiebooms et al., 1988; Sjogren & Uddenberg, 1988; Brewster, 1984;

Blumberg, 1984; Rice & Doherty, 1982; Dixson et al, 1981 ; Beeson & Golbus, 1979; Godmilow, Milano & Hirschhorn, 1978; Finley et al., 1977; Robinson et al., 1975;1984). The relationship between anxiety and uncertainty, albeit anecdotal in nature, has consistently been reported. Comparability of the findings of these studies has been complicated by the fact that most investigators developed their own survey questionnaires to measure anxiety and neither theoretical or operational definitions of uncertainty were reported.

Beeson and Golbus (1985) described a four stage trajectory of anxiety during the course of PNGD and counseling. Anxiety was defined as "impatience." The women in that study reported the highest levels of anxiety and uncertainty just prior to the amniocentesis procedure, and these decreased dramatically after the threat of miscarriage had passed. Again, womens' levels of anxiety and uncertainty rose sharply just prior to the reporting of the fetal diagnosis, while the lowest levels were reported after expectant parents were informed that their baby was normal (1979).

Comparing three groups of women who had varying degrees of fetal genetic risk, Evers-Kiebooms et al. (1988) found that AMA women who had the lowest numeric probability of risk also had the lowest levels of anxiety, whereas women who previously had an affected child reported the highest level of anxiety. The group that reported the lowest level of anxiety were women who had one or more healthy children at home, had planned the present pregnancy, had no history of miscarriage, perceived their social network to be supportive, and had decided in advance of the amniocentesis procedure that they would terminate an abnormal fetus (Beeson & Golbus, 1979).

Differences between spouses' perception of anxiety during the process of PNGD were documented by four researchers. Silvestre and Fresco (1980), reported that the men in their study did not feel anxious during PNGD and counseling. When comparing gender differences from interview transcripts they found that men tended to medicalize the pregnancy by glamorizing the medical technology associated with testing. In a qualitative study comprising husbands and wives, Rice and Doherty (1982) found little agreement between spouses on the degree of worry that each felt while waiting for the PNGD result to be reported. Beeson and Golbus (1985) found that men who sought PNGD for AMA or previous birth of an affected child consistently had lower anxiety scores as compared to their wives. Similarly, Evers-Kiebooms et al. (1988) reported that expectant mothers showed a higher degree of anxiety than expectant fathers.

Reflection on the contributions of past researchers draws attention to the question of, how expectant parents define anxiety in relation to their unique experience of PNGD and counseling. In order to verify that expectant womens' perception of anxiety does change over the course of PNGD and counseling, it would be necessary to incorporate a repeat measures research design in a future study. What also needs to be discovered and described, is whether in fact, spouses differ in their experience of anxiety during PNGD and if so, what factors are attributed to these differences.

Reassurance

Feeling reassured following the reporting of the fetal diagnosis has been described by the majority of women who underwent PNGD process (Roghmann & Doherty, 1983; Vinson, Finley, Davis, Huggins, Rigdon & Finley, 1980; Finley et al., 1977).

Psychological effects of possibly having to decide about abortion

Recent developments in reproductive genetics have raised many new issues regarding the medicalization of pregnancy. Application of laboratory techniques to diagnose genetic abnormality in the fetus prenatally has stimulated moral/ethical questions regarding the fit between procreation and biomedical-technology (Hanmer, 1987). Investigation into the psychosocial consequence of this technology has slipped far behind the rapid integration of this medical science into antenatal care (Sandelowski, 1988).

One of the most complex social psychological issues to come out of PNGD is the dilemma of whether or not to terminate a fetus that is not perfect (Antley, 1976; Lebel, 1978; Fletcher, 1984;1983; Fletcher & Wertz, 1987; Fletcher et al., 1985; Temple, 1983). The non-directive approach to prenatal genetic counseling places the full moral responsibility of such a decision upon the counselees who use this service (Moreno, 1987; Roghmann et al., 1983). Despite the fear of possibly having to make a decision regarding termination, the majority of women who accepted PNGD stated that they would undergo the procedure again, if pregnant again (Evers-Kiebooms et al., 1988; Dixson et al., 1981; Godmilow et al., 1978; Finley et al., 1977; Sjogren & Uddenberg, 1988; Robinson et al., 1975). Although the majority of women who accepted PNGD decided prior to testing, that women remained uncertain even post counseling (Sjogren & Uddenberg, 1988; Beck Black, 1979;1980; Wertz et al., 1984; Dixson et al., 1981).

Women described the psychological effects of this dilemma as: fear, anxiety, uncertainty and ambivalence. Their distress was not limited to the possibility of a fetal loss, but awareness of a fetal genetic risk also, meant that the parent(s) were somehow inadequate or defective (Tishler, 1981; Antley, 1976). Expectant parents' self-concept suffered because this ominous possibility was internalized as self-blame or guilt (Antley, 1976; Kelly, 1977). As well, women who perceived that their husbands were not particularly supportive were concerned because they anticipated, that they alone would have to decide about abortion (Sjogren & Uddenberg, 1988).

In sum, the meaning of this moral dilemma for each prospective parent needs further investigation. Exploration of this issue may offer genetic counselors a clearer understanding of the overall social psychological impact of PNGD.

Prenatal attachment

Researchers have discovered that parental prenatal attaching behaviors occur as a process (May, 1982; Weaver & Cranley, 1983; Tilden, 1980; Lumley, 1980; Rubin, 1975; Stainton, 1985). In order to understand whether prenatal attaching behaviors of expectant parents in this study were deviant from traditionally accepted prenatal behaviors in a normal pregnancy, the literature related to both maternal and paternal prenatal attachment was reviewed.

Maternal role

1. The first trimester of pregnancy is described as a period of adjustment or adaptation to the conception. This period is marked by shock, initial rejection of the pregnancy and ambivalence. The only overt sign of the developing fetus are unpleasant physiological changes such as: fatigue, nausea and breast tenderness. By the end of this trimester, women have been reported to have resolved their ambivalence toward the pregnancy and the baby. They begin to dream or fantasize about the baby and engage the husband in conversations about possible names for the child and discuss the future (Gaffney, 1988; Pines, 1972; Schroeder-Zwelling, 1988; Rubin, 1975).

2. During the second trimester the fetus is imagined as a developing human being (Lumley, 1980). The mother-to-be may have begun prenatal classes; she engages in imaginary conversations with the child or may call it by a pet name. In an attempt to protect the baby, the woman may read about normal fetal development and avoid tasks that may cause personal strain or jeopardize the baby's well-being (Gaffney, 1988; Schroeder-Zwelling, 1988; Rubin, 1975).

3. By the third trimester the expectant mother has prepared for the birth of the child. This time period is marked by strong emotional investment in the child. Nesting behaviors and the practical aspects of motherhood are the mainstay of this phase as the woman becomes interested in labor and the impending birth (Gaffney, 1988; Schroeder-Zwelling, 1988).

Paternal role

1. The announcement phase implies the period from when the

conception was first suspected to when the pregnancy is actually confirmed; the timing of this phase may extend into the twelfth week of gestation. The prospective father notices the obvious signs of pregnancy in his partner. The initial shock of the news may leave him feeling quite upset, stressed, uncomfortable or ambivalent about the conception (May, 1982; Campbell & Field, 1989).

2. The moratorium phase occurs around week twelve and lasts until the twenty-fifth week of pregnancy. Men describe it as an adjustment period or a state of limbo. They tend to withdraw emotionally and distance themselves, as there are no visible signs of the baby, yet. This phase ends when the woman begins to look pregnant. The impact of the baby on the man's present lifestyle is imagined from a global perspective rather than a detailed analysis (May,1982; Campbell & Field, 1989).

3. The focusing phase extends from the twenty-fifth week of gestation to the time of delivery. The man's attitudes and feelings began to change as the baby is perceived as real and fetal life takes on new meaning. The pregnancy and the baby become very important to his personal life. The expectant father finds himself attracted to other fathers in his social network who assist him to work out the role expectations of fatherhood (May, 1982).

Factors that potentially interfere with normal prenatal attaching

Prenatal attachment was defined by Gaffney (1988) as "...the extent to which women engage in behaviors that represent an affiliation and interaction with their unborn child..." [<u>sic</u>] (p.107). Research regarding prenatal fetal attaching has generated two hypotheses. First, the belief that prenatal attachment directly affects the magnitude and the quality of postnatal attaching to the newborn. Second, prenatal attaching to the fetus progressively increases over the gestational period. Presently, more information is known about the factors that decrease prenatal attaching than is known about what variables enhance prenatal attaching.

<u>Factors suspected to enhance prenatal attaching</u>

A woman's perception of her social network as supportive has been found to increase her sense of personal control and mastery over the tasks of pregnancy, thereby enhancing prenatal fetal attachment. This support is generally provided in the form of a female role model, a positive relationship with the woman's own mother or a supportive male partner (Cranley, 1981a;1981b; Tilden, 1980).

Research evidence to confirm that prenatal ultrasonography alters parental/fetal attachment remains somewhat ambiguous (Rothman, 1987; Sandelowski,1988; Grace, 1984; Heidrich & Cranley, 1989), but there are a number of investigators who echo this hypothesis (Fletcher, 1983; Silvestre & Fresco, 1980; Dixson et al., 1981; Winslow, 1987; Schroeder-Zwelling, 1988). Winslow (1987) reported that an AMA group of women felt reassured following ultrasound visualization of the fetus. Dixson et al. (1981) purported that a group of AMA women experienced enhanced fetal attaching after the ultrasound procedure, even while they waited for the PNGD result.

Factors suspected to decrease prenatal fetal attaching

An exaggerated sense of ambivalence may occur if the first trimester of pregnancy is prolonged or compounded by severe morning sickness. This adds to the stress of adjusting to normal pregnancy and may theoretically, inhibit parental/fetal attaching (Campbell & Field, 1989; Lumley, 1980; Rubin, 1970).

An inverse relationship between high levels of state anxiety and maternal/fetal attaching has been hypothesized by a number of researchers (Gaffney,1988; Tilden, 1980; Robinson et al., 1975; Heidrich & Cranley, 1989). Mercer, Ferketich, May, DeJoseph & Sollid (1988b) suggested that high levels of maternal anxiety lead to premature birth. These researchers speculated that men rather than women were better able to control the adverse effects of stress. Perhaps this is because men do not have to carry the child to full term. Raphael-Leff (1982) posited the notion that concurrent life stressors such as bereavement, divorce or relocation of one's residence significantly interrupts the natural process of maternal psychological adjustment to pregnancy and the fetus.

Kemp and Page (1987) found no significant differences in prenatal attaching behaviors when comparing expectant parents who had either high or low risk pregnancies. In complete contradiction to this finding Penticuff (1982), reported that "uncertainty" about pregnancy outcome adversely affected prenatal attachment behaviors in a group of "high-risk" women. Uncertainty about the outcome of pregnancy was identified as a stressor, especially for women who had had a previous miscarriage or were labelled by the obstetrician as having a high obstetrical risk (Rubin, 1970; Pines, 1972). It has been proposed that a high degree of uncertainty has a negative effect on maternal self-esteem and health-status, which in turn lowers expectant mothers' sense of role mastery while they attempt to adapt to pregnancy and motherhood role (Mercer, Ferketich, DeJoseph, May & Sollid, 1988a).

Perinatal uncertainty has been acknowledged as a clinical problem affecting parents who delivered a high risk newborn in the past. In retrospect the question of whether uncertainty affects prenatal/fetal attaching as initially conceptualized by Galloway (1976) has re-surfaced in the minds of nurse clinicians who work in high risk labor and delivery. Presently, the concept of uncertainty for expectant parents undergoing PNGD and counseling remains unexplored, vaguely defined, and inadequately conceptualized (Stainton, 1989).

The effect of PNGD on parental prenatal attaching

The assumption that expectant parents who perceive their pregnancy to be at high risk alter their attaching behaviors toward the fetus may appear logical, however, there is a lack of evidence to support this idea. Researchers studying the affect of reproductive technology on parental/fetal attaching patterns have raised several questions that warrant exploration: (a) Does the process of PNGD affect the magnitude of parental/fetal attaching? (b) Does PNGD alter the gestational time period at which expectant parents attach to their unborn child? (c) Does prenatal knowledge of the baby's gender alter parental/fetal attaching behaviors (Fletcher, 1983; Reading, Cox, Sledmere & Campbell, 1984)? (d) Do expectant parents become so overwhelmed by the fear of possibly loosing the chance of having a perfect child that they are pulled simultaneously toward opposite poles: protective detachment and early attachment (Heidrich & Cranley, 1989; Sandelowski, 1988; Grace, 1984).

In summary, previous researchers have contributed a great deal to understanding the process of normal parental/fetal attaching. Now that amniocentesis/ultrasonography for the purpose of PNGD has been integrated as standard medical practice for high risk pregnancies, the question of whether or not this reproductive technology impacts on parental/fetal attachment is becoming of paramount concern to clinicians, researchers and ethicists.

Conclusions

Few authors have examined the impact of PNGD and counseling from the point of view of the expectant parents who utilize this service. A number of researchers have employed a repeat measures design to investigate the experience of PNGD and counseling but, no one has captured a prospective overview of the process which expectant parents go through during the first and second trimesters of pregnancy. Furthermore, differences in how each partner derives meaning from the events that take place during this experience or the significance of these events in relation to each spouses' social context requires further exploration and demarcation. To date, most of the empirical studies regarding both PNGD and prenatal/fetal attachment have focused on womens' perceptions while the husbands' point of view remains virtually ignored. In view of the fact that pregnancy and the process of PNGD are considered a family experience, it is imperative that health care professionals understand expectant fathers' perceptions of undergoing prenatal genetic services in order to discover what his point of view is and if his perspective affects his wife's experience.

Previous authors have documented the social, economic and demographic characteristics that differentiate women who choose to accept PNGD and those women who refuse the service. Uncertainty, fear, anxiety and conversely, reassurance have been reported as the natural sequelae of choosing to undergo this prenatal procedure. Fear of possibly having to make a moral/ethical decision regarding abortion, and fear of the burden of having to care for an abnormal child tend to strongly influence the process of decision making. What is not known is, whether there are spousal differences in the perception of these factors, the significance of these factors for each partner or how these factors influence an expectant parent's ability to cope with PNGD and counseling. Equally as important is the question of whether any of these factors affect prenatal parental/fetal attachment? In the next chapter the research design will be outlined, the method of obtaining subjects described and the methods of data collection and analysis will be presented.

CHAPTER III

The Research Design and Methods

Development of the process-orientation

The purpose of conducting this study was to examine the perceptions and experiences of expectant parent who face a genetic risk as it naturally exits in the social setting. Thus, an exploratory descriptive study was conducted using interview dialogue as the data. The premise underlying this study was that all phenomena should first be explored at the qualitative level (Diers, 1979), and substantive nursing theories should be developed from clinically derived data (Knafl & Marion, 1984). The emic perspective was presumed fundamental to the advancement of knowledge about the social and psychological effects of PNGD on its recipients and to the development of standards for nursing practice in the clinical area of prenatal genetics.

Despite the enormous volume of research into prenatal genetic counseling there is a surprising lack of research that examines expectant parents' overall perceptions of PNGD and counseling. It was apparent that an inductive examination of this experience should be undertaken.

"Most exploratory studies focus on process in an attempt to explain the phenomena under study...Process studies examine how people adjust or adapt to change" (Brink & Wood, 1989, p.16). A basic social process (BSP) accounts for change in human behavior over time. Further, a (BSP) remains constant regardless of variation in the population, changes in social conditions or the chronology of events (Chenitz & Swanson, 1986).

The Research Design

The study was conducted in a Western Canadian city and employed a generic exploratory model. The researcher personally interviewed a sample of 6 expectant parents in three marital dyads. Unstructured and semi-structured interviews and field notes were the primary methods of data collection. Paired interviews, one with each spouse in the marital dyad were conducted during the same home visit. All informants were interviewed at the same three time periods: 12, 18, and 22 weeks gestation. These specific periods were chosen because they marked the times when expectant parents directly engaged with a health care professional for the purpose of PNGD and counseling. In keeping with the three pre-determined time periods, marital dyads were interviewed alternately. Each pair of interviews were analyzed before the next pair of interviews were conducted. New interview questions were formulated after each pair of interviews to verify previous data, explore theoretical insights or fill in missing information. Data collection and data analysis occurred simultaneously. Data were analyzed using a constant comparative technique (Hutchinson, 1986; Field & Morse, 1985; Stern, 1980; Brink & Wood, 1989; Chenitz & Swanson, 1986; Glaser, 1978; Glaser & Strauss, 1967;1966).

Grounded Theory

An assumption that underlies grounded theory methods "...is that there are unidentified concepts or constructs that, if identified, will enable understanding and problem solving" (Munhall, 1989, p.172). By definition, grounded theory is a method of discovering what is reality in a given social setting (Stern & Pyles, 1985). It allows the researcher to gain a new perspective in a familiar setting (Stern, 1980).

Only one research study was found in the research literature pertaining to the field of prenatal genetics that employed grounded theory methods. Lippman-Hand and Fraser (1979a;1979b;1979c) explored the process of rational decision making using a population of 7 couples, 45 women and 1 man who sought prenatal genetic counseling for a variety of reasons. This was considered a hallmark study because the process of decision making had never been investigated before and nor had the dialogue from expectant parents, been routinely utilized as the primary source of genetic research data.

The chronological events that naturally occur as part of the PNGD and counseling process led the researcher to suspect that human phenomenon aligned with this health care service would also be process-orientated. Additionally, because there was a dearth of research from the emic point of view, grounded theory methods of data collection and analysis were selected for the design of this study.

The Sample

The majority of women who undergo prenatal genetic counseling are referred because of advanced maternal age (Naber et al., 1987; Blumberg, 1984). Therefore, the researcher selected expectant parents from this population. A description of the biographical characteristics of the informants is represented in Table 1.

Less frequently, women and/or couples seek PNGD and counseling for other reasons:

1. a known genetic disorder exists in the family of either parent-to-be.
2. the woman or the partner has had a previous child affected with a known genetic disorder.
3. the woman has had three or more spontaneous abortions.
4. either partner has a known or suspected genetically inherited disorder
5. previous stillbirth with a trisomy or other chromosomal anomaly.
6. a known family history of X-linked disorders.
7. maternal insulin dependent diabetes. (Rudd, 1983; Simpson et al., 1976; Hamerton & Doran, 1974).

For the purpose of this study a homogeneous sample of subjects was selected to facilitate ease of data analysis for recurrent themes and patterns of behavior that would be common to all informants. Potential subjects who had a risk factor other than advanced maternal age were excluded from participating in the study.

<u>Criteria for selection</u>

Available subjects were included in the study if they met the following criteria.

1. the informant was able to understand and read English.
2. the informant lived within a two-hundred kilometer radius of the Genetic Center where the genetic counseling session was conducted.
3. the informant was willing to participate in three

interviews over a five to seven week period.

4. the wife and the husband were willing to be interviewed separately.
5. the woman and/or the male partner attended an appointment with a prenatal genetic counselor at the Genetics Center and accepted an amniocentesis procedure for the purpose of PNGD.
6. any children at home were over the age of five years.
7. the informants would be attending a prenatal genetic counseling session for the first time.

The names of potential informants were supplied by one "high-risk" obstetrician who performed amniocentesis procedures for the purpose of PNGD. If the woman met the subject selection criteria, the couple were contacted by telephone at home by the researcher to elicit their willingness to participate in the study. The letter of introduction as set forth in appendix I was read over the telephone, to one partner in each dyad who was asked to discuss the study with the other partner. The researcher then arranged to contact the couple in two or three days to inquire about whether they had decided to decline or to volunteer for the study.

The researcher obtained both a verbal and a written, informed consent (see appendix II) from each informant prior to the first interview. Subjects were informed that they had a right to refuse to participate in the study or withdraw from the study at any time. When arrangements were made for succeeding interviews, informants were reminded of their right to researcher, if they chose to do so. All informants remained in the study for the duration of the data collection period and for a return visit after data analysis (from 1 to 9 months post the PNGD report) to verify the theoretical framework that emerged.

Method of Sampling Subjects

Ideally, the rationale for selecting study subjects depends on the direction of the evolving theory. In order to saturate the core categories that emerge following data analysis, a full range or wide variation in the subject population and/or the social setting is generally required so that complete variability of the categories can be achieved under different conditions. Theoretical sampling was not employed in this study. Instead, the researcher selected all available subjects, over a nine month period, who met the selection criteria and consented to participate. The researcher deliberately selected informants who were receptive to the researcher and open to disclose their inner-most thoughts and feelings (Field & Morse, 1985). The researcher chose informants who were knowledgeable about the phenomenon of interest and were able to articulate their personal experience.

A limitation of this study was that not all possible subject populations were sampled. Figure 1 illustrates a model that theoretically represents all subjects who face the four possible outcomes of PNGD and counseling: (a) those expectant parents who are informed that the fetus is normal, and they decide to continue the pregnancy; (b) those expectant parents who are informed that the

(c) those expectant parents who are informed that the fetus is normal but they decide to terminate the pregnancy; (d) those expectant parents who are informed that the fetus is abnormal, and they decide to terminate the pregnancy. This model was created inductively by integrating knowledge from past clinical experiences, analysis of data from these six informants and deductively by reviewing the literature for extant knowledge.

The investigator interviewed only two of these subject groups, (a) and (d). There were no expectant parents available during the time of data collection who fit into group (b). Forehand knowledge about which informants would have a positive fetal diagnosis was impossible, so the option of asking a woman and her partner to participate in this study after being told that their fetus had a genetic defect posed an ethical limitation. In the same light, it proved impossible to access the self-select group of subjects who theoretically, seek PNGD to justify termination of a normal fetus.

Method of Data Collection

The Setting

Informants were interviewed in their own homes where the environment was private, comfortable and conducive to the establishment of an open and informal rapport between researcher and informant. Informants became more relaxed and uninhibited about disclosing the intimate details of their thoughts, feelings, beliefs and needs with each subsequent interview. Children who were at home during the interviews imposed infrequent and very brief interruptions. The women were consistently interviewed first, then their husbands. While one informant of the dyad was being interviewed the other informant respected the spouse's need for privacy by occupying him or herself else where in the home or by vacating the premises.

<u>Interviews</u>

With a view to exploring differences and similarities in spousal perceptions and experiences, the wives and husbands were interviewed separately to facilitate candid disclosure of each informant's own perspective so that their independent comments could be compared (Beck Black, 1979). In total, 18 interviews lasting one and a quarter hours each were conducted with six primary informants at approximately 12, 18, and 22 weeks of pregnancy which generated approximately 400, single spaced pages of interview data. Three interviews were conducted with two primary informant dyads and one secondary informant dyad to clarify and verify the theoretical framework that evolved.

The first interview took place approximately one week after the wife or the wife and the husband attended a prenatal genetic counseling session at the Genetics Center. The questions on the biographical information sheet were asked of each informant at the completion of the first interview session. The second interview occurred one to two weeks after the women had undergone the amniocentesis/ultrasound procedures. The third interview was carried out about two weeks after the diagnosis of the prenatal test was reported. Validation interviews were carried out approximately one to nine months after the PNGD was reported to informants.

A list of semi-structured questions was devised for each of the three interviews which corresponded to the chronological events that occurred at specific time periods during the PNGD and counseling process (see appendix III). These same questions or a modified version of these were used as prompts to assist informants describe their perceptions and feelings associated with PNGD and the pregnancy. New interview questions were formulated as each interview was analyzed in an effort to clarify key concepts, verify conceptual categories and to fill in gaps in the information. During some interviews the informant was able to direct the interview session with minimal questioning.

The investigator emphasized an open-ended, non-directive style of interviewing and played the role of an active listener which encouraged informants to express what was important to them at that particular time.

Fieldnotes or Participant Observations

During each interview the researcher made notes or jotted down ideas needing further exploration. These notes comprised the researchers' hunches about how concepts were linked together or about a concept that needed further clarification. Observations related to informants' non-verbal behavior, and verbal interactions with other family members or observations related to the home environment were written as fieldnotes immediately following the interview. These fieldnotes were re-read again and again to develop new insights and ideas which led to the formulation of new questions prior to the next pair of interviews.

Method of Data Analysis

Inductive analysis of the data

Each of the audio tapes was reviewed following the interview so that the researcher could understand the informant's story and to write memos about what was happening in the data. These memos were reviewed and compared to previous memos. The tapes were transcribed, then reviewed to check for accuracy in transcribing. After corrections were made, each transcript was reproduced to make five copies.

Two copies of each transcript were coded with substantive key words which were written in the left hand margin. First level substantive coding was a process of reading and re-reading the data, line by line, to identify key words that symbolized the true meaning in the informant's dialogue (Stern & Pyles, 1985). Once coded, each transcript was cut into data strips that demarcated the informant's separate ideas. Each data strip was identified with a date, an informant number, an interview number and a gender in the right hand margin. Each data strip was then glued to a separate piece of paper, color coded for gender. Each strip of data was re-read so the researcher could capture and document, on the same page, any initial analytical thoughts or impression about the substantive content.

Each piece of data was compared with every other piece of data on an ongoing basis. Quotations that obviously clustered together were sorted into piles and classified into separate file folders or categories (Stern, 1980; Melia, 1982). Each descriptive quotation within each category was closely examined for similar properties and co-variations, those that matched or fitted together were sorted into categories that represented a different theme. Each category was labelled with a substantive phrase such as "preconceived notions about handicapped children." Data collection and analysis occurred simultaneously, meaning, [illegible] previously coded interview quotations were re-examined and compared to the new interview data, for each and every interview. This constant comparative technique provided the researcher with the insight necessary to expand new lines of inquiry and to identify data that needed to be verified during subsequent interviews with the same or new informants. As each interview was analyzed the category labels either remained the same or were modified accordingly to reflect the true meaning or message implied by informants' comments.

During first level coding, 32 substantive categories emerged. The researcher did not censor the number of categories as it was important at the onset of data collection and analysis to facilitate the emergence of as full a range as possible of substantive codes. This number of categories assisted the researcher to discover how variable and diverse informants' perceptions and feelings were. Later, as the research process evolved, some categories collapsed into high order categories, thereby reducing the data into four parent processes. Data strips within each category, were compared with all the other strips for similarities and differences, on an ongoing basis, to ensure that the content within each category was mutually exclusive (Melia, 1982).

The research process evolved as a dynamic, non-linear, interwoven web of simultaneous tasks: interviewing, jotting fieldnotes, transcribing, and analysis of the data which consisted of coding, sorting, categorizing, conceptualizing, memoing, diagramming and abstract theorizing.

From each individual piece of interview data, the overall themes and patterns of human response were abstracted to formulate a generalization of what was common to all informants. As new interview data were collected and previous data were re-examined; the core categories of the theoretical framework were continually tested for fit to see if the interlinkages were logical. Metaphorically, the data formed an ever evolving matrix of interconnected categories and overlapping processes. As pieces of data were shifted or perceived from a different perspective, a slightly clearer picture of the common, overall experience came into view. Continual repetition of the constant comparative process eventually resulted in mutually exclusive categories that remained intact and stable for all interviews. Finally, the categories were mapped into four parent processes that reflected the experiences common to all informants.

A category was labelled a core category if it demonstrated complete variability of the phenomenon under different conditions and over time. Not all core categories identified were basic social processes (BSP) but, each process did emerge as a core category. In other words, what differentiated one core category as the (BSP) was that the coping category emerged as the integrated process that best explained changes in human response patterns in all the other categories (Chenitz & Swanson, 1986).

The concept of coping emerged as a core category because expectant parents consistently attempted to regain personal control during all processes throughout the entire data collection period. The category of coping was deemed the core variable as it provided a meaningful explanation that interconnected all the categories together. Coping with fetal genetic risk was central to the theoretical framework as it "...accounted for most of the variation in the behavior about the problem..." (Chenitz & Swanson, 1986). In an attempt to further understand how the core variables were related; which ones were antecedents, which variables caused a particular response or how the conditions of a variable changed, propositional statements were formulated following completion of data collection and analysis (Stern & Pyles, 1985).

Use of grounded theory techniques assumes that the researcher would continue to interview and collect new data until no new information is obtained and the core categories are saturated (Simms, 1981; Atwood & Hinds, 1986; Hutchinson, 1986; Morse, 1986; Glaser & Strauss, 1966; Melia, 1982). With recognition of pre-set limits on the investigator's time and resources, it was concluded in consultation with the thesis supervisor, that the researcher had generated enough repetitious data to formulate a beginning theoretical framework that attempted to explain what was happening in the social setting for groups (a) and (d) of the theoretical model of all possible subject groups who seek PNGD and counseling (see figure 1).

Deductive theory building

Grounded theory methods involve both inductive and deductive processes of theory development (Stern, 1980). An inductive process of analysis was used to code and categorize the data strips. Deductively, the researcher re-examined the memos, diagrams and fieldnotes to see if there was an emergent fit of the data with an extant label as previously identified in past research studies, such as "coping." Conceptual maps were drawn in an effort to piece together a tentative diagram of possible interlinkages among the emergent categories. These maps were analyzed in an attempt to make sense of the data and to discover the common patterns or themes that were recurring for all informants. The diagrams were visual representations of the overall analytic scheme. The analytic diagrams and emergent theory were continually re-examined to compare "...similarities and convergences..." (Glaser & Strauss, 1967, p.37), of the emergent theory with existing models.

In the mode of deductive analysis the researcher conceptualized how all the categories fit together as a whole. The strategies of memoing and diagramming allowed the researcher to abstract the overall themes and patterns common to all informants.

Further validation of the theoretical framework was accomplished by returning to four of the primary informants and two new secondary informants, after data analysis, to ask whether the proposed four parent processes that emerged were truly representative of their experiences (Miles & Huberman, 1984). Informants tended to reiterate clarifying statements to verify how a previously described experience fit the models proposed.

Reliability and validity

The notion of scientific rigor as applied to qualitative research is somewhat confusing because the authors who discuss the criteria for evaluating qualitative research tend to use different titles to delineate and label the evaluation criteria. Equally frustrating was the discovery that these criteria were not mutually exclusive to a particular label. To evaluate the reliability and validity of this study, the concept of trustworthiness as set forth by Lincoln and Guba (1986) was employed. Trustworthiness involves the integration of four concepts: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1986).

Credibility

Two strategies: reflexivity and bracketing were integrated into every stage of the research process to make the researcher more aware of her own unsubstantiated presuppositions and preconceived ideas about the research topic. Reflexivity was practiced by writing a research diary, and by talking to as many professional and lay people as possible about the research project. Re-reading the diary and hearing myself or someone else express an opinion about what was going on in the data, brought to light the importance of bracketing, or putting aside my etic point of view. These strategies alerted the investigator to continually monitor and inhibit blatant biasing of the research process by asking limiting questions, or using a directive style of interviewing or attempting to force the interview data to fit into a preconceived theoretical framework. Repetitiously raising the question, What is the data telling me? encouraged the investigator to actively listen to the informants and discover what they were saying.

The third strategy for checking the "truth value" (Sandelowski, 1986, p.30), or representativeness of the emergent theoretical framework, was verification of the findings by four primary and two secondary informants and a nurse prenatal genetic counselor. All of these people offered suggestions for clarification of the analytic framework.

Transferability

Another word for this criteria is applicability. Transferability addresses the questions of whether the theoretical framework applicable to any other social setting and whether the psychosocial process of coping with fetal genetic risk apply to any other human condition? The only way of knowing if the theoretical framework is transferable to another social setting, is to interview subjects in an alternate social context to see if the framework "fits" or explains human response patterns in a new social context. The researcher interviewed two secondary informants who underwent PNGD because they had a 1:400 chance of having a child with a neural tube defect. These informants verified the applicability of the four emergent parent processes and further clarified gender differences in perception of the PNGD and counseling experience and prenatal attachment.

Dependability

In qualitative research it is generally understood that no two persons synthesize or theorize interview data in exactly the same way (Chenitz & Swanson, 1986). Hence, the concept of replicability to a qualitative researcher means that the investigator "...leave[s] an audit trail..." (Guba, 1981, p.87). A detailed description of the steps and decisions made by the researcher throughout the research process would allow an external evaluator to comment on the degree to which the researcher followed generally accepted qualitative research practices. To achieve this the researcher described the personal characteristics of study informants, outlined the research design, described the methods of data collection, explicated the rational for sample selection and codified the inductive and deductive modes of inquiry (LeCompte & Goetz, 1982).

Confirmability

Evaluation of the internal consistency of this qualitative study means making a judgement about whether the theoretical framework actually emerged from informants' shared experiences. The issue raised here is whether the data bits were homogeneous or whether the core categories were mutually exclusive (Atwood & Hinds, 1986). Do all of the data bits fit their respective categories? In an effort to enhance the reliability of the category scheme, the researcher continually re-examined categories and sub-categories for discrepancies between each piece of data. Eventually, a time came when the data strips in each category all fitted together; review of the data within categories indicated no further need for reclassification and the categories were deemed mutually exclusive.

Ethical considerations

Protection of informants' privacy, anonymity and confidentiality were prerequisites for commencing this study. Subjects were treated respectfully, fairly and protectively (Burns & Grove, 1987). Ethical clearance to undertake this study was obtained from the University of Alberta, Faculty of Nursing Ethics Review Committee and the ethics review committee in the health care agency with which informants were affiliated. Before commencing the study the researcher established an agreement with the nurse prenatal genetic counselor at the Genetics Center for referral and follow-up of any informants who verbally stated a desire for any type of further counseling.

Informants' confidentiality was protected by using code numbers on the audiotapes and the transcriptions. Audiotapes and interview transcripts were stored in a locked file cabinet during the study, then were placed in a safety deposit box where they will remain for a period of three years. After this time the audiotapes will be erased and the transcripts shredded. Anonymity of informants' verbatim statements was assured and protected by using pseudonyms in the thesis and other written reports.

In the future, before erasure or shredding of the transcripts, if the researcher wishes to re-analyze the data from this study in relation to another research proposal, ethical clearance will be sought, as appropriate from all six study informants and the affiliate agencies.

To some degree all informants discussed personal benefits as a "objective" listener role of the researcher; they felt free to openly and honestly express [illegible]es in their thoughts and feelings without fear of judgment or r[illegible]ule. Informants were touched by and commented upon the importance of the researcher's interest in their personal reproductive situation. They appreciated the opportunity to interact privately with a nurse researcher. The extra attention they received, reinforced their own positive self regard. Informants were enthusiastic to think that their self-disclosure could perhaps assist others who were also faced with a fetal genetic risk. Generally, the informants indicated that the opportunity to express themselves openly was in some way helpful.

This feedback was also reported by Norris (1986), who described how relieved the participants in her study felt when given the opportunity to release some of their thoughts and emotions in private. Norris suggested that informants obtained personal secondary gain in trade for their participation in the research project.

This study was designed to initiate a first step in the development of nursing knowledge dealing with clinical prenatal genetics. It is a descriptive, exploratory study that followed informants over three time periods during the process of PNGD and counseling. The study was designed to produce "gender sensitive" knowledge (Chinn, 1987, p.21) and the researcher aimed to incorporate the view points of both women and their husbands in order to broaden overall understanding of the impact of this health care service on

CHAPTER IV

Findings

The Informants

Selected biographical characteristics of the informants are presented in Table 1. There were six primary informants in this study; three females and three males comprising three marital dyads. Two of the women described their relationships as second marriages without children from this union. Two couples lived in an urban setting and the other couple lived in a rural township located approximately one hour away from a major city. All women were referred for PNGD and counseling because they were of advanced maternal age. All pregnancies were unplanned and unexpected. Two women had experienced a miscarriage within the last eighteen months, yet both had successfully delivered one or more live children. One informant dyad had adopted a child because they had a 13 year history of infertility; for them conception was perceived as "close to impossible." One couple had one child aged 6 years; another couple had one child aged 11 years. The third couple had two children aged 10 and 11 years. All three male informants were first time biological fathers.

The educational and cultural backgrounds of informants were reasonable similar; five-out-of-six informants held a university degree. Five of the informants were Caucasian, one was a Japanese person who had immigrated to Canada about three years ago.

worked part-time as a hairdresser. Two of the women were employed outside the home during the pregnancy; one full-time and the other part-time. Two men were employed in the business sector and the third male was self-employed.

The mean age for women was 37 years and their ages ranged from 36 to 38 years. There was a wider variation in the ages of male informants. The mean age for the men was 36.5 years and their ages ranged from 30 to 43 years.

For two informant dyads, both husband and wife attended the prenatal genetic counseling session at the Genetics Center, as well as the amniocentesis/ultrasound procedure. The husband of the third dyad did not attend the counseling session because his wife indicated to him that his presence was unnecessary, a "waste of time." One wife was unaccompanied during the ultrasound and amniocentesis procedure because her husband stayed at home to provide child care.

Throughout this chapter verbatim quotations were included to represent the content and the context of the data from each informant, as accurately as possible. As a way of maintaining confidentiality and anonymity, pseudonyms were created to prevent readers from correlating the biographical characteristics of individual informants with their personal statements, and to disguise which informants were in the same marital dyad. Data sources were identified in the text by a name and a number. For example Keith indicated that the informant was male and the statement was made during interview number one.

Overview of Four Parent Processes

In this research study the purpose was to elucidate a better understanding of how expectant parents experience prenatal genetic diagnosis (PNGD) and counseling services and to discover whether the PNGD experience impacted on expectant parents' perception of the pregnancy. Informants' described their experiences as a "process", a "current in the river of life", a pre-determined "path" of events occurring in a series of "steps." Glaser (1978) defined a process as "...something which occurs over time and involves change over time..." (p.97). Expectant mothers thought of this process as an unavoidable obligation, a responsibility that they had to comply with in order to protect the baby, themselves, their family and society in general. They wanted to "find out for certain" whether or not the fetus was genetically (ab)normal. Expectant fathers surrendered much of their power and decision making responsibility to their wives because they believed that the woman was ultimately in control of her own body and moreover, she would have to live with the consequences of her decision for the rest of her life. The men verbally accepted and supported their wives' decision to seek and undergo PNGD and counseling.

These six study informants experienced four processes simultaneously during the first and second trimester of pregnancy: the chronological process of prenatal genetic diagnosis, the process of coping with fetal genetic risk, the process of deciding, and the process of parental fetal attaching (see figure 2). The process of coping with fetal genetic risk (see figure 5) emerged as the core variable or the overall basic social process (BSP). This process consisted of three phases: confirmation of the pregnancy, perception of the threat, and coping strategies. These three phases were composed of six sub-processes: worrying, seeking, deciding, protecting, waiting and hoping. For clarity each sub-process was integrated into the findings chapter and described at the time of best "fit" in relation to the parents' chronological process of prenatal genetic diagnosis (PNGD). The six sub-processes of coping were actually nested inside all phases of the other three parent processes (see figure 2); all informants expressed variation in the degree and intensity of specific coping strategies in association to particular events in the process of PNGD and counseling. Coping with fetal genetic risk emerged as a parallel, yet, paradoxically divergent process for each gender, as were the processes of deciding, and parental fetal attaching.

The chronological process of prenatal genetic diagnosis

The emergent model of the process of PNGD, as identified and labelled by study informants served as the framework by which the findings in this study were organized and presented. This model, depicted in figure 3, represents the informants' perspective of the chronological events of PNGD and counseling. This theoretical model was mapped out following analysis of dialogue from the six study informants. How each event was perceived, the meaning attached to each event, and the expected outcome of each event were different for each gender. The process of PNGD was composed of three phases:

1. Recognizing the threat

2. Protecting self
3. Resolving the threat

Phase One: Recognizing the threat

During the early phase of pregnancy the conception was confirmed and the informants became aware of the genetic threat to the fetus. Women reacted to the news of pregnancy by being uncertain, fearful and worried, whereas the men responded with a sense of confidence and optimism. Each chronological event was described from the informants' emic perspective.

Pregnancy was confirmed

The women in the study were cognizant of the conception even before the pregnancy was confirmed by a pregnancy test. The absence of menstruation was interpreted as an obvious sign of pregnancy although it seemed "impossible." "I knew my dates ... so even a couple of days after I knew something was up and it was probably the most obvious." Emotional swings, a decreased level of energy and a general lack of well-being were symptoms that symbolized pregnancy and "there was nothing that would make this feeling go away." All the informants were shocked by the news that conception had taken place. The women lacked confidence to decide whether the pregnancy would produce a perfectly healthy child. They felt powerless in their situation because they had lost control over pre-plans already set for the future and they could not predict what the future might bring.

Shock and disbelief

The initial reaction was shock and disbelief for all informants;

Joan expressed "oh rats--oh no", "it can't be happening"; and Pam agreed "it really caught us off guard... we were very, very shocked." The conception was perceived as an event that "never should of happened" [sic]. All the pregnancies were unplanned; none of the informants had made a conscious decision to have a baby. Two informants in separate dyads, Joan and Nick had decided before this conception that they would not have any more children. One male informant had planned to have a vasectomy within a couple of months.

Pregnancy was a crisis

Two women described the impact of the crisis as so intense that they had to decide right away whether or not to terminate the pregnancy before it progressed any further. One of the women hoped for a miscarriage as a "way out" of "a bad situation." The unplanned pregnancy invoked a sense of crisis and powerlessness because the informants found out they did not have as much personal control over their own lives as they thought they had.

The notion that pregnancy is a developmental/situational crisis for many women is not new in the prenatal attachment literature (Tilden, 1980; Valentine, 1982; Campbell & Field, 1989). It has been hypothesized that precipitating stressors such as unexpected events and a known obstetrical risk, trigger the perception of uncertainty about the outcome of the pregnancy which may adversely affect family functioning during pregnancy. A stressor was defined as any undesirable event that challenged the family's coping resources (Mercer, Ferketich, DeJoseph, May & Sollid, 1988b).

Feeling ambivalent

Ambivalence has been documented as a normal component of all pregnancies in the first trimester (Campbell & Field, 1989; Penticuff, 1982; Raphael-Leff, 1982; Rubin, 1970). The informants in this study all experienced some degree of ambivalence. Ambivalence was perceived as emotional upheaval. Informants used the term "emotional rollercoaster" as an analogy to articulate the pattern of their thoughts and emotions. The women were ambivalent about the whole idea of having a baby and the inevitable changes in personal and family lifestyle which would place an extra demand on their coping abilities.

The women oscillated between not wanting to be pregnant and fantasizing about how much they would love to have a baby. Joan felt guilty about "hating the situation", not wanting to "get fat", and she also resented having to put her career on hold. Pam, who had been infertile for thirteen years and strongly desired a pregnancy felt guilty because she was not as happy as she "should of been" [sic] about the conception.

Raphael-Leff (1982) suggested that an "over-valued" or an "ambivalent" pregnancy could potentially be psychologically maladaptive for some women because they experienced extremely paradoxical feelings: "hope/distrust", "elation/detachment", "supreme emotional investment/dread and conviction of failure" (p.9). Pam and Joan projected such strong feelings of ambivalence toward the pregnancy and the fetus, that it seemed appropriate to question in a subsequent study whether their degree of ambivalence fell within the bounds of a normal reaction to pregnancy or was it an example of an over exaggerated state of ambivalence? The answer to this question would require a research study with a larger sample where the purpose was to compare the ambivalent experience in women who had a normal verses an at risk pregnancy.

Generally, the degree of ambivalence was much greater for the female informants than it was for the men. All male informants perceived the confirmation of pregnancy as their last chance to become biological fathers. The crisis for them was that the pregnancy suddenly occurred in concurrence with other stressful life events: marital conflict, bereavement and/or major financial decisions which made the pregnancy that much more difficult to "adjust to." Brad was "really excited" about having a baby, yet he feared the unknown and the unpredictability of life changes that would undoubtedly ensue with a new baby. Likewise, Keith "really wanted" a baby, his experience of ambivalence was broad in scope and quite generalized. He considered the added responsibilities of having another child and imagined how the baby would affect his long-term plans for retirement. His perception of the crisis was in relation to acquisition of the father role, in contrast he perceived his wife's reaction, riding an "emotional rollercoaster", was more traumatic than his own. By virtue of the fact that the human fetus grows and develops within the woman's body the man does not experience: "all day morning sickness", fatigue and the breast tenderness that marks the physical presence of the fetus. Awareness of the baby, for the men, was an intellectual, vicarious experience.

For them the pregnancy meant a change in family functions, additional responsibility and long-term commitment to the marriage and the family.

Facing the possibility of abnormality

For the six informants in this study there was a socially derived assumption that child bearing at an older age involved some degree of risk for the mother and the baby. The term risk was defined by Nick as "the opportunity of something not turning out the way you want it to." Advanced maternal age was cited by all informants as the principle factor that transformed an everyday life event into a risky situation. Both Nick and [illegible] remarked that all pregnancies were "fraught with risk" and since their wives were over the age of 35 years the "certainty" that something would go wrong was higher for them compared to other pregnant women.

Advanced maternal age was known to be the most important factor that increased a couple's risk of having a handicapped child. The term "Down's Syndrome" was used by all informants; it was quoted most often as the example of a "deformed" or a "mentally retarded" child. Although, none of the informants explained why or how this phenomenon occurred they were all aware of this ominous possibility.

Being an older parent

Both men and women expressed concerns about being an older parent. The main theme of these concerns was different for each gender.

The women questioned their ability to "cope", to be "flexible", to be able to "keep up" with the everyday demands of career and family relationships. The possibility of bearing a handicapped child was very "real" for the women. Past experience with handicapped children, as an elementary school teacher or the friend of a mother with a handicapped child stimulated the women to imagine "what if that was my child." The women extended their concerns about coping beyond themselves to include the baby, their career and the social/family network.

In contrast, the husbands were more internally centered. Brad and Keith, first time biological fathers, expressed fears regarding their ability to father "will I do all the right things?" The fact that both men already were step-parents appeared contradictory to the realization of becoming a father. With the confirmation of the pregnancy the men were striving to understand what changes would be required of them. Apparently this pregnancy meant a transition from the parent role to the father role, because biological fatherhood was perceived as "a whole new situation."

Perceiving the risk

All female informants were aware of the availability of amniocentesis for testing the genetic status of the baby prenatally. Pre-exposure to the "test" originated from a variety of sources: hearing about it from colleagues at work, talking with a friend who had personal experience, reading about it in library books, or hearing the story of how something similar had happened to a relative.

When the women initially accessed the health care system to confirm the pregnancy, they were labelled by the family practitioner/gynecologist as a "high-risk pregnancy." This label served to affirm the woman's self-realization that she was at risk. The self-realization that conception at a late maternal age increased a woman's chance of having a Down's Syndrome baby was passed intergenerationally as folklore. Naturally, the women requested access and referral to another doctor who was qualified to conduct prenatal genetic testing on the fetus. One well-informed woman knew that both procedures, namely amniocentesis and CVS, were available. The other two informants had heard only about the amniocentesis procedure. They perceived the amniocentesis test to be a "routine procedure" that should be "automatically" accepted, after all the technology was available and "other people are doing it."

Since the wife's age was known to be a major risk factor when she informed the husband that she planned to access prenatal health care services, the husband automatically accepted his wife's decision to seek more information regarding PNGD. One male informant stated that he was well-informed about prenatal genetic testing because he had recently read an article in the newspaper that described the concept of genetic risk and differentiated the two procedures of fetal testing, amniocentesis/CVS, and explained how a sample of fetal material was analyzed in the laboratory to detect genetic disorders in the baby.

Keith described his reaction to his wife's decision to undergo testing:

> You just sort of accept, like these are the things that you do when you get pregnant and you go to classes, and you do

> this and you do that... it was just another one of those things that you go to... that you do.

He expressed a sense of comfort in knowing that his wife had accessed the health care system. He, like the other two men in the study thought it was important that the wife seek health care regarding the pregnancy as a way to reduce her overall fear and uncertainty about the possibility of something going wrong.

<u>Reacting to the threat</u>

Traditionally, expectant parents anticipate a normal pregnancy when at the end of nine months a beautiful, healthy infant would be delivered. It is customary for parents-to-be to envision a perfectly, healthy child who will fulfill all their dreams and aspirations of being a good parent (Phipps, 1981).

In a normal pregnancy where the woman is at "low risk" her natural sense of doubt or uncertainty about the normalcy of the fetus is counterbalanced by a feeling of joyful excitement and anticipation for the baby (Bergum, 1989; Lumley, 1980; Rubin, 1970). But in a high risk pregnancy, the concept of risk denotes an unknown and immeasurable degree of threat or danger (Rothman, 1987). All the informants experienced a heightened sense of uncertainty which was coped with by hoping "for the best" but fearing that "the worst may happen."

In this study where the women were labeled as having a "high risk" pregnancy they feared that the "perfect child" they had hoped for might be lost. As a consequence of being in a state of uncertainty about the health of the pregnancy and the normal fetus the women were encumbered with worry. In a state of uncertainty the usual process of adaptation to the pregnancy and attaching to the fetus were put "on hold"; the women entered into a state of waiting or limbo. Each wondered whether she would even become a mother at all.

Uncertainty

Uncertainty was identified and described to some degree by all informants. The most frequent descriptor was "just not knowing." Other phrases facilitated an understanding of their perception:

Brad:

> It's like walking in the dark.

Joan:

> A person always feels a little kind of skeptical about the unknown, not really knowing what was ahead...a sense of, "what if."

Pam:

> I was really doubtful in the beginning...As soon as I found out that I was pregnant...just why I felt that way there is no explanation, I just did. Scared maybe, but then why should I be scared?

Although the informants had a sense of what it felt like to be uncertain, they found it difficult to put that state of being into words. At times informants described this state as like a pendulum that swung back and forth between deciding for certain that the baby would be normal and at other times they were unable to confidently decided for certain that the baby would be abnormal. Another conceptualization of uncertainty was a cognitive/affective state of being that changed in intensity, frequency and importance depending on the internal and external environment of the informant.

The feelings associated with the perception of uncertainty were similar, yet different, for male and female informants. The women talked about being worried, fearful, apprehensive, powerless, pessimistic, frustrated and lacking confidence regarding the pregnancy and the fetus. The males also described these same feelings but to a lesser degree. Males' perception of uncertainty was described similarly at all three interviews. The expressed their uncertainty in terms of having a global sense of "constant curiosity" about the baby.

Brad:

> It's a thrill or excitement like leaping into the unknown.

Keith:

> It will be interesting to see what the baby would be like.

Brad:

> There's an element of curiosity.

Analysis of the data indicated that there were six interrelated attributes of uncertainty:

Attributes of uncertainty

1 Lack of knowledge was

situation. They felt powerless and incapable of making any reproductive decisions with out more information about the genetic risks involved.

Joan:

> In deciding whether or not to continue or terminate the pregnancy, that's when we...I decided that to continue I would want to have more information.

Brad:

> Fear is born out of a lack of knowledge...not knowing what is going to happen in my life, I mean there is enough uncertainty and other factors...influencing my life. So the more I know about more things, the more I can decide what I will do based on the knowledge.

2. Lack of comprehension of the knowledge prevented informants from grasping the profound significance or essential meaning of the genetic and biological information. It also indicated that new information meant something different to every person who received it.

Nick:

> Maybe that process is too big a pain in the neck for people involved in the delivery of medical services to consider keeping every patient fully informed all the time but in this area I think because of the importance of the decision that you're making, the impact it's having on the

> ...Give me relevant information...Don't tell me 10 or 11 of 21 if it doesn't mean anything.

Brad:

> People may hear what you said but they don't know what you're talking about, they may look at things entirely differently.

The fact that the science of human genetics was "in the realm of...like the theory of relativity, I mean you know it's there but you really can't explain it" exemplified the complexity and incomprehensibility of genetic information. The information had very little meaning until the informants integrated it into the context of their every day life experiences.

3. Lack of personal control over their reproductive circumstances was a consequence of the unpredictable "surprise" conception at an age when the risk of fetal abnormality was perceived to be high. All informants felt some degree of powerlessness, yet the antecedent conditions of this state were different for men than for women.

Joan:

> I was disturbed because I thought I had control of my life and found out I really did not.

Pam:

> This whole process, I mean I don't really have a lot of control over it of course, you know it's nine months and I think that's kind of a hard thing to adjust to...I find that kind of frustrating.

From a slightly different perspective, two male informants, Keith and Nick felt uncertain about whether the pregnancy would continue or be terminated as they knew that if the genetic test did indicate an abnormality ultimately the wife held the power and control over reproduction.

Nick:

> Ultimately the decision is hers, I wouldn't make her see the pregnancy through to the end if she didn't want to.

Nick also described a sense of powerlessness that occurred as a side effect of accepting prenatal genetic services.

Nick:

> There's really nothing that you can do about it. You feel like you are caught in the current and just being swept along. You just don't know and to some extent that's exactly what it is, just being swept along. You don't know where you are going to land. You really don't.

4. Ambiguity or not being sure about the significance of knowledge or events resulted in feelings of confusion and frustration for the informants. Frustration was expressed by all male informants as they did not know how to make sense out of the new information. This frustration was perpetuated by just "not knowing" precisely what information was more true or more relevant than another piece of information. Informants were fearful about making a decision because they were unable to decipher which information was most relevant to their situation.

Brad:

> If you just overloaded me with information, and I would have to make a decision...I could go home and agonize for weeks...because there's a chance of this, and there's a chance of that...this is definitely true and that is definitely true and it goes on and on, and you can't make a decision anymore.

5. Lack of confidence about some future outcome overlapped with the concepts of lacking personal control and subsequent powerlessness. The female informants lacked confidence in their ability to successfully deliver a healthy child. They suffered from a lowered self-esteem as a result of being uncertain or doubtful about their reproductive ability .

Joan:

> I take phenobarb for epilepsy...my question was how is this going to affect the pregnancy...my first pregnancy...she had a hole in her heart...would this happen again...I lack confidence as far as the outcome of nine months...I'd like to feel more confident.

(and at the next interview):

> She actually had a heart defect and I really felt, boy I can't do anything right.

In contrast, the male informants felt overly confident about the pregnancy and the normalcy of the baby right from the beginning. During the second round of interviews, about two weeks after the amniocentesis procedure, all three male informants again expressed an intuitive confidence that the baby "would be okay."

Brad:

> Confidence implies that you already know what will be happening ...that everything will work out fine...But in fact by that time I felt extremely confident that everything was going fine. But I don't know why, I mean it wasn't as though we had been given a tip-off or anything like that. We were waiting for the results...everything just seemed fine.

Nick admitted to "over playing" his sense of confidence in an effort to give reassurance to his wife as he knew that she was experiencing a high level of anxiety and doubt about the pregnancy and the normalcy of the baby.

6. Unpredictability of the outcome of the pregnancy was a concern to all the female informants and to one male informant. However, the gender of the baby and it's normalcy are always questioned in any pregnancy (Bergum, 1989). For these advanced maternal age women the uncertainty about the normalcy of the fetus became of paramount concern.

Joan:

> Will it be okay...will it be healthy...will it be physically fine...I would feel much better if it wasn't so unpredictable.

Unpredictability brought on feelings of powerlessness and frustration. Because it was impossible to predict, it was impossible to plan out how the future might change the informant's life style. One strategy used by all informants to cope with uncertainty was "let's wait and see." Their state of uncertainty was generally accepted as something that had to be endured until after the result of the amniocentesis was known.

Nick:

> It's a high level, a high degree of uncertainty that you just have to go through.

Joan:

> I would like my child to have the route of least resistance and unfortunately that's not predictable.

An operational definition of uncertainty emerged following theoretical analysis of the verbatim statements and substantive codes. Uncertainty was a cognitive/affective experience that felt like a state of limbo. Informants were unable to make a decision about whether or not they would become parents because they were unable to assign definite meaning or value to the statistical risk of occurrence and/or the biological information related to genetics. This prevented them from feeling confident to predict the outcome of their pregnancy.

During the first phase of this process, recognizing the threat, informants described four types of uncertainty: life event, pregnancy, fetal and abortion. Each type of uncertainty was described from the emic perspective to clarify its essential attributes and distinguishing features.

<u>Type of uncertainty</u>

1. Life event uncertainty was perceived as just a part of the human condition of life. There are some things in life that you have

no control over and you can't know ahead of time what the outcome will be. "For some things in life you just take a chance just like every one else because some things only God knows for sure." The essential message underlying this type of uncertainty was a sense of helplessness because the decision makers lacked power and control to change their reproductive situation. The decision maker perceived an inability to change predestined fate.

One female and all the male informants suggested that the best way of maintaining personal control in daily life was to avoid worrying about the uncertainties because "you can't change them" anyway. Pregnancy was perceived as a life event where the outcome was as uncertain as buying a lottery ticket or being killed while flying in an aircraft or while driving in a car. There was always some degree of risk involved in everything in life.

Sue:

> If we don't have a normal baby, it's not my fault, not my husband's fault. God give it-God give it to us.

2. <u>Pregnancy uncertainty</u> was a concern for five of the informants during the first trimester of pregnancy. They were fearful, worried and apprehensive about the possibility of a miscarriage.

This fear, for one female informant evolved from skepticism that she could successfully deliver a child after being infertile for so many years. Four of the informants who had experienced a previous miscarriage identified a specific "critical time period", after which the conception was considered "safe." This critical time period was self-determined based on informants' recall of when the last baby was spontaneously aborted.

A commonly used strategy for coping with pregnancy uncertainty was to "wait and see" if the pregnancy survived past the critical time period then, to "wait and see" if the genetic status of the fetus justified continuation of the pregnancy.

3. <u>Fetal uncertainty</u> was perceived differently for women as compared to the men. The question of whether or not the fetus was normal or abnormal was crucial for these three women. As a way of protecting themselves they held "back the positive emotions of anticipation and excitement" about the fetus:

Sue:

> If we don't know if baby is having some problem [<u>sic</u>], I have to worry about ten months, but if I know it before...like four months and the baby is very normal, I can enjoy my pregnancy and relax for six months.

Joan was most concerned about:

> That fear that I would like to know, or be more sure, that my unborn child is...not going to have an abnormality.

Brad and Nick experienced only a slight degree of uncertainty about the baby, but for Keith his sense of doubt and indecision about fetal normalcy forced him to focus on differences in perception and beliefs that he and his wife had about abortion. Brad and Nick were confident that the baby was going to be "fine." Fetal uncertainty for them was more of a "curiosity" about the baby's gender, it's physical and personality characteristics.

Brad:

> Like is it going to be one gender or the other, unless you go through some of the testing, you won't know until it's actually born.

4. Abortion uncertainty revolved around the possibility that the baby would be diagnosed with a genetic abnormality. Clearly there was a message that the informants were not able to make a decision about whether they were going to have the baby until they received more information about the baby's genetic "health." Two female informants wondered how they would cope with the consequences of a decision to terminate or to continue the pregnancy, if an abnormal diagnosis was reported.

Pam:

> You really don't know, you really haven't made your mind up [about abortion]...not at all, and I still haven't...well it's uncertainty I guess.

In a subtle and non-intrusive way, the three women voiced their sense of ambiguity about abortion specific to their reproductive circumstance; once perceived as an immoral act, their own pregnancy crisis forced them to re-evaluate previously held values and beliefs about abortion. Two of the women avoided open expression of their thoughts and feelings about a possible abortion as they attempted to protect themselves and their family from the pain and despair associated with such thoughts. Instead the women tended to deal with their sense of unpredictability, lack of control, lack of ability to make a decision, lack of total comprehension of the risk by worrying.

In contrast men protected themselves by not thinking about the issue of abortion. They put off making a decision until after they received more information or until such a time that the decision would become "absolutely necessary."

Worrying

Worrying was defined by the women as a constant state of being that occurred as a consequence of the unpredictability of the fetal genetic risk and self doubt about being able to deliver a healthy child. Since the women lacked confidence in knowing that their pregnancy would end with a healthy baby they could not decide confidently or with any degree of certainty that in fact they would become mothers.

An interesting observation was that worrying and anxiety were used interchangeably by the informants, but they never substituted the word stress to describe their worry. Joan defined worry as:

> a concern that...it's like a presence inside of you...whether you share that worry with somebody by verbalizing it, or keeping it to yourself, it's still there-it's still inside of you.

Worry, to some degree, was thought to be a natural reaction for all expectant parents. All three women and one male informant identified worrying as their "major coping mechanism" regardless of the fact that it doesn't change anything and it "doesn't help." The women described themselves as "real worriers" and depreciated their need for worry:

Pam:

> Ninety percent of the time I have not really justifiable worries...if I can't find something to worry about I make stuff up.

They worried about a variety of issues, but two overall themes categorized their worry: concerns regarding self and the possibility of fetal abnormality. Joan experienced guilt because she felt ambivalent about the pregnancy and having a baby. She was fearful that this "negative" attitude would prevent her from developing a warm and loving relationship with the expected child pre and postnatally.

Pam made a conscious effort to protect the developing fetus from environmental chemicals that she thought would affect it's normalcy. She questioned whether her diet was appropriate; she tried to avoid cigarette smoke, hair spray and the noxious fumes from felt pens. Her behavior was indicative of a "hypervigilant" (Folkman, Schaefer & Lazarus, 1979) desire to protect the baby.

When Sue recalled memories of past deliveries she was very anxious about "lots of bleeding after delivery." This fear of the unknown enhanced her sense of powerlessness and helplessness about the pregnancy.

All male informants denied that they ever worried about the normalcy of the baby. They felt "fairly confident" that there was nothing to worry about.

Keith:

> Nine months is an awful long time to be sitting on the edge of your chair...life goes on, you gotta [sic] do other

things...You can worry but you can't change it.

All the men acknowledged that to some degree they worried about the safety of mother and child particularity at the time of the amniocentesis procedure. The quality of their worrying was described as analogous to the term "caring"; it seemed natural to worry if they cared. Men also reported a generalized or global nature to their worry; they believed that worry was a natural part of the waiting process. The men denied that their own worry was a coping mechanism, instead two male informants labelled their wives as "overly worried" "more so than other pregnant women." The men assumed that their partners were worried about normal physiological changes related to pregnancy like: weight gain, stomach upset, fatigue and increased heart rate. Rather than explore their wives' sense of worry, instead the men chose to project a sense of confidence in an attempt to reassure their wives that there was nothing to worry about.

Subconsciously, these men not only denied their own worry they also, grossly underestimated the significance of worrying as a coping strategy for their wives.

Seeking support

1. The pattern of telling significant others about the conception and their motivation for telling was not the same for these informants as one would expect from "normal" expectant parents. Normally, parents-to-be announce the news of their pregnancy to everyone in their social network. Expectant parents normally feel ambivalent about having a baby, but there is usually very little indecision about whether the pregnancy would end with a child.

Similar to normal expectant parents these informants felt a need to tell family and close friends about their pregnancy. The difference for these informants was that they were cautious about who they selected to tell their news. They told people who were "closest to them" and those they thought would "support" them. The most predominant reason for telling others was to elicit support. The notion of social support was important for the women as a means of "reaffirming" the social acceptance and value of undergoing PNGD. The womens' social network was perceived as a safety net, into which they could fall in case the result of the genetic test indicated an abnormality in the fetus. Joan said:

> I think it is really important to have other people there so that you may not fall flat on your face, but if you stumble, you know that you've got support near by.

Both Joan and Pam concurred that friends rather than family offered the most empathetic support since they communicated understanding of their ambivalent feelings. Close friends tended to understand their fears related to the inevitable adjustments in life style and family relationships that a new baby would demand.

Conversely, the family members were "ecstatic" and insensitive to the womens' need to avoid and withdraw from the reality of the conception. Pam's sense of guilt was reinforced by her mother:

> I'm really disappointed, I thought you would be a lot happier about it than you are. Your sisters are more happier than you are. "Well that's right, they are." Don't say such a thing.

Brad was so confident that the pregnancy and the baby would be fine he wanted to "let the whole world know." He commented that if his wife tried to keep the pregnancy a secret until after the amniocentesis results came back at 20 weeks gestation that it would be impossible to "conceal the pregnancy" for that long. In contrast, both Keith and Nick were content to tell as few people as possible. Nick:

> The people who need to know, know and the people who don't need to know I prefer not to tell.

The findings in this sub-category were difficult to summarize for male informants because individually and as a group they made contradictory statements. At times they denied the need to protect themselves because they had already made up their minds that the pregnancy and the baby were going to be fine, while other statements indicated a need for sympathy and support from others for being an older parent. They equated this event with other life events that were not shared with others because it was "none of anyone else's business." In not seeking support they used defensive avoidance, withdrawal from others and "keeping busy" as ways of protecting themselves and attaining a sense of personal control over a confusing situation. Perhaps the males sought support from their wives and the home environment rather than placing themselves in the vulnerable position of having to tell others what they were really thinking and feeling.

2. Reasons for not telling others about the pregnancy were born

out of fear, worry and a perceived need to protect others in case the pregnancy was miscarried or terminated. There was a social stigma associated with having a baby at an advanced age thus, fear of judgment and ridicule from others. This fear was expressed by Nick:

> I know what's going to happen. There is going to be a lot of ribbing and kidding, you're really an old guy.

Joan also felt vulnerable to criticism from others:

> There will be people within my family who think I'm far too old...they may even express their feeling that I've made the wrong decision as far as continuing this pregnancy.

The topic of timing, when would it be safe to tell others, was openly discussed between partners in only one couple. They did not want to be "congratulated" by a lot of people then perhaps later be faced with "oh no-isn't that terrible." This same reaction was also voiced by other informants but it was not clear that the topic was ever discussed between spouses within the other two marital dyads. Perhaps a lack of open communication between partners may precipitate some degree of marital conflict, in the form of either acute reaction or exacerbation of chronic disharmony.

Uncertainty and worry about the possibility of miscarriage or fetal abnormality inhibited these six informants from sharing the news about the pregnancy until after the test results were known. Informants subconsciously tried to protect themselves on a cognitive, emotional, spiritual level from the possibility of having to publicly explain a fetal loss, if that occurred in the future.

Phase Two: Protecting self

The same six sub-processes of the process of coping with fetal genetic risk: worrying, hoping, seeking, deciding, protecting, and waiting that occurred during phase one of the chronological process of PNGD and counseling recurred in phase two.

Attempting to regain personal control

All informants had preconceived expectations about genetic counseling. The women were more directive than the men in taking steps toward seeking genetic counseling and prenatal diagnosis. Two concepts appeared most pertinent to informants as motivating factors to seek professional health care service, a sense of powerlessness regarding their reproduction and a need for self protection. They expected "to find out to a great degree of certainty" the genetic normalcy of the fetus.

Preconceived expectations of genetic counseling

One preconceived expectation was common to all informants. They expected information about the availability of PNGD and whether it would tell them the "likelihood" of threat to either mother or fetus. Brad made a comment that summarized what he wanted to know:

> I want to know more about...tests and test results,..just sitting around discussing the possibilities and the percentages.

All informants were clear about wanting to be told "all of the information" and to exercise autonomy by making their own informed decisions.

The process of PNGD and counseling was evaluated positively by four informants, two of each gender. Their positive attitude was expressed as "the whole concept is a good idea and it shouldn't be restricted to people who are perceived to be in the high risk group."

Motivation to seek genetic counseling

Seeking knowledge was an attempt adapt to the pregnancy; a way of regaining personal control. Any new knowledge was perceived as a "good thing." Knowledge offered informants power to predict beforehand the outcome of their pregnancy and gave them credibility and personal authority to make their own informed decisions. Brad indicated how important it was that new information be relevant and meaningful to him:

> The ability to understand the information and that sort of thing...may be quite variable among different people, but in the end these people are still seeking more information.

Brad expressed the supposition that all informants filter knowledge through a "personal screen." He believed that the receptivity of counselees to new knowledge was influenced by their personal beliefs regarding their own biological, psychological, spiritual and social environment.

Sue sensed a moral, social, and spiritual obligation to seek prenatal testing in order to protect herself and the baby. She sought "certainty" or evidence that the child would not have to endure or inflict any pain and suffering.

The male informants consistently talked about "taking advantage of the available knowledge." The husbands were relieved to know that their wives had sought medical care. They expected confirmation that the baby was normal would reduce their wives sense of uncertainty and worry. They were optimistic that their wives would be reassured by knowing that the baby was normal, thus allowing them to relax, feel comfortable and enjoy the remainder of pregnancy. Keith described the function of PNGD as "sort of a measuring stick...something reassuring."

Expected outcome following PNGD and counseling

1. Seeking certainty was important to all the informants. Both male and female informants were seeking a high degree of certainty about the "health" status of the baby. They expected that the ultrasound would reveal information about the physical growth and development, and the amniocentesis would inform them about the genetic normalcy of the baby. The trajectory for seeking certainty was parallel in events for men and women but the expected outcomes were divergent for each gender. The category, seeking certainty was very clearly labelled by all informants within the context of their dialogue. Knowing for certain was described as:

Keith:

> Knowing with certainty whether you're gonna [sic] have a normal child or an abnormal child...we're gonna find out for sure what's happening...You can hope for the best or you go through the test and you just find out for sure what's going on.

Nick:

> Certainty is where you do all the tests and you say, those tests are right here. Those two things can still happen whether you've got a two percent chance or a 98 percent chance...knowing that you have a 98 percent chance puts you closer to certainty...I'll call 98 percent likelihood of an outcome, certainty...once you've passed a certain number, you better start planning on it happening...this is what's going to happen.

To the men, the test meant preparing for the anticipated baby. They sought confirmation that the baby was normal.

2. <u>Seeking justification</u> to either terminate or continue the pregnancy was described by female informants only. If the fetus was diagnosed as normal that information would be used to rationalize why it was a blessing to have a baby at an advanced maternal age. Conversely if the baby was diagnosed as "severely abnormal" that knowledge would be used to justify "killing a baby." Women viewed the test as a means to predict the future; would they have a baby to mother?

Joan:

> I would like to know, or be more sure, that my unborn child is not going to have an abnormality...I'm really concerned about having a Down's Syndrome child.

When Joan and Pam compared the CVS and the amniocentesis procedures for PNGD they decided that the amniocentesis would give them a greater degree of certainty about the status of their child. They recognized that the procedure would apprise them only about the genetic status of the child "there's a lot of other things it can't tell, so I think it takes that one part of it away, but certainly not all of it."

3. Seeking confirmation that the baby was normal was a commonly held expectation of PNGD for the male informants. Because the men were overly confident that they would have a perfectly normal, healthy child, they welcomed the opportunity to find out the gender of the baby. The test meant preparing for the baby beforehand.

Male informants perceived that the wife was so "concerned" about the risk of abnormality that she would "require a fair degree of reassurance that everything is okay." They also indicated that they wanted to remove any little bit of doubt or uncertainty about the normalcy of the fetus. Brad's comment best exemplified the male point of view:

> Make me more certain that is in fact what we are going to have, a normal child.

Although informants recognized that nothing was for certain and nothing could be guaranteed they still desired as high a degree of certainty as possible.

Finding meaning in the information obtained at the genetic counseling session

To create meaning from the genetic information conveyed at the counseling session informants were required to integrate the new genetic information into the context of their lives. Comments that described how informants made sense out of the information were sorted into three categories: psychological reaction to the knowledge, perception of the risk, and consequences of acquiring new genetic information.

Reacting to the knowledge obtained

Unanimously, the informants commented that the genetic counseling session was a positive experience that was well-worth repeating given another pregnancy. Joan's statement was indicative of how three informants felt:

> Very meaningful...very helpful in sort of helping me move onto the next step...positive...I felt good...I felt impressed. I was impressed with this lady, and the information she gave us, and how she handled it...all very positive reactions.

The psychological benefits of genetic counseling were consistently stated by all informants. Joan found the experience to be "very reassuring, comforting" and it gave her "twice as much confidence about taking the test than before going in."

The word "counseling" was perceived to be a misnomer by all of the informants. Joan said:

> I couldn't really call it counseling, it was more an information session.

When recalling what they had learned during the genetic counseling session the words, "percentages and probabilities", "chromosomes" "genetic defects" and "explaining the process" were remembered. They commented on how much they appreciated the counselor for making the information more meaningful by talking in terminology that they could understand.

The video was deemed valuable as it showed the differences between the two diagnostic procedures, amniocentesis and chorionic villi sampling (CVS). Equally as important, it prepared them for the actual procedure. Interestingly, the methods for terminating the fetus as discussed in the video were consistently unobserved or not remembered by any informants.

All female informants suggested that they needed even more information. By virtue of their years of work experience with handicapped children in the education system, two of the women knew a variety of congenital "problems" by medical names. As a result of past experiences with handicapped school children their sense of fear was heightened about their own developing child. These two women did not know what caused the abnormalities, and they were curious to know more detailed information. They wanted to know which abnormalities belonged in which category: "genetic defects", "chemical" hazards, or "birth injuries." In an effort to further mitigate their fear the women wanted to clarify which abnormalities could be identified by the ultrasound and which ones by the amniocentesis procedure. They wanted to know the degree of certainty or safety they could expect from the results of the genetic test. They definitely wanted to protect themselves from "burden" and they wanted to protect the fetus from unjustifiable pain or suffering.

Pam was hypervigilant in her drive to seek concrete facts. She used knowledge seeking as a tactic to alleviate some of the discomfort associated with feeling out of control over her reproductive condition. Pam desired a high level of comprehension of the prenatal genetic information compared to all the other informants. Pam wanted very specific information about the difference between a genetic disorder and an inherited disorder. It was important for her to differentiate the characteristics of different disorders such as: "Turner's", "Williams", "Down's", and "Edwards" Syndromes from the perspective of what type of handicap could be expected and how difficult would it be to cope with a child diagnosed with one disorder compared to another.

Feelings of powerlessness were manifest in a few pejorative comments that implied that the genetic information conveyed was inadequate. Pam expressed hostility regarding the genetic counseling session "I did not learn a lot of information, except for the video, it was absolutely useless."

Like the other women, yet to a greater degree, Pam attempted to regain personal control by intellectualizing about and sorting out which intervening variables were more relevant than another. Knowledge acquisition symbolized a means of self protection from the worst possible outcome.

Procedural information was not enough for these women. They desired experiential evidence of how they might be able to cope with a child diagnosed with a "mild" handicap in case their fetus was genetically affected, but not so severely as to justify termination. All the women articulated a need to share their fears and preconceived values about handicapped children with an objective listener, someone who would not judge their moral or spiritual character.

Powerlessness or lack of control inherent in the state of being uncertain about the possibility of abortion was of obvious concern to one male informant. He criticized the merit of prenatal genetic counseling because the differences between his and his wife's views on the issue of abortion were not discussed. He described what he thought should have been addressed during the genetic counseling session regarding the psychological impact of PNGD.

Keith:

> The psychology...or the emotional part of it doesn't really come out...they don't deal with that...it was more factual...perhaps they're not there to handle that part of it...maybe there are groups that they could refer you to. There's social workers in the hospital that, you know deal with grieving and death...how to take care of your new child...all kinds of different situations, psychologically... there's nothing saying, have you thought about that. She never went over...what the choices were if you had an abnormal baby, they were made clear, but it was never asked, are you...can..are you psychologically prepared to make that decision or have you thought about it...do you think you could make that decision?

Perhaps Keith wanted to openly discuss the fact that he and his wife disagreed about whether termination of the pregnancy was a viable alternative if the test result indicated an abnormality in the fetus. Arnold and Winsor (1984), suggested that the use of imagined scenarios during genetic counseling sessions would facilitate exploration of how couples make decisions which would uncover and potentially lead to the resolution of disequilibrium between spouses regarding differences in perceptions or psychological reactions to genetic testing. Keith was disappointed that the psychological aspect was not discussed.

Differences in perception of the risk

The comments made by informants in this study support previous research that the subjective recall of risk probabilities post-counseling is often inaccurate (Hsia & Silverberg, 1973; Lubs, 1979; Sorenson et al, 1981; Ekow et al, 1985). Only one male informant correctly recalled the numeric probability of fetal genetic risk. The informants translated the word risk into a dichotomous measure; there was either a high or a low probability of a favorable fetal outcome. Furthermore, the risk was thought of as binary in terms of whether the expectant parents would or would not be required to make a decision regarding abortion.

Female informants did not remember the numerical percentages or probabilities of risk. To them the overriding message underlying the statistics was "what if" that happened to them. The women "reacted to the threat of abnormality." Joan's comment illustrated the females' perspective of risk:

> I'm just trying to think of the numbers that she gave me...us, and they don't come to me...I thought, my goodness-that's a high--high number when you get into my age bracket.

Pam, like the other two women in the study perceived risk as "fear." All the women feared two possible outcomes: they feared that the hoped for perfect child would be lost or that they would have to bear the burden of caring for a handicapped child for the rest of their lives. When the women heard the medical view point on fetal genetic risk they were forced to weigh the desire to have a perfect child against the burden of having to terminate a defective child.

In contrast, the men attempted to deny the risk of fetal abnormality or the possibility of "termination." When they did admit having a slight degree of fetal uncertainty, the risk was perceived as "pretty, pretty small", "insignificant" and just as unlikely as "winning the lottery." This preconceived mind-set strongly influenced Brad's interpretation of the risk:

> I was a little more confident that all the news was going to be good news before we went...than my wife was...I went in there with the feeling that all news is going to be good news. More so I was delighted when that's how I perceived it to be...three percent seems to me to be high, unless you look at it the other way around and say, well ninety-seven out of a hundred are born perfectly normal.

Keith also confirmed this view point of the genetic risk:

> One out of a hundred and seventy women her age, they have a Down's baby, or something like that. That's fairly insignificant, although some people would dwell on the one out of one hundred and seventy...I don't think too much about the statistics...they have a bearing on it...what it means to me is, small enough...it's a very, very small percentage.

The males used the statistical probability of risk as though it was scientific proof to support their "intuitive optimism" about having a normal baby. The women interpreted their husbands' "logical" approach to PNGD as dialectically superior to their own emotional response. Comments made by male informants implied, for the most part, they were able to effectively block out or deny the possibility of fetal abnormality, to them it was unthinkable.

Intellectually, they knew that it could happen, but on an emotional/spiritual level "you hope that you are one of the ones where it doesn't happen." This raised the question, why did these men deny the possibility of abnormality? Perhaps the men refused to accept the notion that they could contribute to the creation of a "deformed" baby. Defensive avoidance of the reality of a possible fetal abnormality was perhaps founded on the males' perception that fetal anomalies were caused only by a reproductive problem in the woman. This misconception may be especially prevalent among first time biological fathers faced with a last chance conception as they may need to defend their virility.

Conceivably, an intolerance to ambiguous situations may explain some of the difference in perception of the risk for men and women. The men processed information using a concrete or "black and white" style of thinking. An intolerance of ambiguity about whether or not they should make the transition to fatherhood may have forced them to regain personal control by perceiving an uncertain life event as certain. Congruent with the axiom that a positive or negative attitude is self-fulfilled, male informants purposefully chose to believe in the certainty of a favorable outcome because the ambiguity inherent in the feeling of uncertainty was too difficult to cope with on a daily basis. Brad believed that "if you think things aren't going to work out then they probably won't." The men were unwilling to worry about the possibility of fetal abnormality or abortion.

These three men believed that the women held ultimate power and legitimate authority regarding any reproductive decisions. Perhaps the male informants dealt with their sense of powerlessness over reproductive decision making by rationalizing that everything would be okay hence no further decisions about the pregnancy would have to be made.

Consequences of acquiring genetic information

The purpose of seeking new knowledge was to make "informed decisions." Informants perceived that the process of decision making was greatly influenced by the amount and complexity of the knowledge. They "hoped" to use the new information to help them make a decision which reflected "the best possible outcome." The best possible outcome was stated as "what ever consequences the individual can live with." Informants wanted more information to improve their understanding of the situation. Brad thought it should be the role of the genetic counselor to ask the counselee "do you really understand what I've said?" as a method of judging whether or not people had the "raw materials" needed to make a decision.

Making decisions

The process of deciding

One informant defined a decision as "an event that takes place with consequences later." Two conditions antecedent to making a decision were: "the ability to recognize an actual or a potential problem" and the "awareness of the passage of time." The ability to make a decision connoted, to all informants, that they had control over their lives. Making an informed-decision with consideration of the consequences meant something different to each gender. The women imagined what the outcome of a decision might "mean to you in the future." They visualized scenarios to assist themselves to come to terms with what it would be like to care for an abnormal child. The men talked about decision making in relation to future role adjustments, financial security and plans for retirement.

The process of deciding in this situation was described as a series of decisions where the previous decision enabled the decision maker to move on to a subsequent decision. During each stage, of the chronological process of PNGD and the process of coping with fetal genetic risk, informants were required to face a new decision. The process of deciding also influenced the process of parental-fetal attaching.

The process of decision making was influenced by informants' individual moral beliefs; the pre-existing pattern of decision making within the marital relationship; their perception of the consequences of each decision alternative; and their state of uncertainty about whether an abortion would be necessary once the PNGD was known. Informants perceived that the purpose of PNGD and counseling was to make informed decisions, hence they were highly motivated to seek new knowledge, integrate the new knowledge into their personal belief system, then decide on a course of action that would best suite their individual cultural backgrounds, concurrent life stressors, previous patterns of coping with threatening circumstances and idealized life/family goals. The interrelationships among the factors that influenced informants' process of deciding are illustrated in figure 4. The sub-coping process of deciding was most important to informants during the first two phases of the chronological process of PNGD and counseling.

1. Recognizing the threat automatically meant making decisions. An unplanned or surprise conception meant that the first decision "do we want to have a baby?" was no longer within the informant's control. Confirmation of the pregnancy precipitated the women to ask "do we just terminate now or do we go on?" The third question that required a decision was "do we go for testing or do we just wait and see what happens?" In recognition of the genetic threat, the women in particular stated that, in order to carry on with the pregnancy, they needed more information.

2. Protecting one's self from a "surprise" at the time of labor and delivery motivated the female informants to pursue PNGD. The men tended to stand in the side-lines and allowed their wives to be consumers of technology. PNGD and counseling offered informants the opportunity to regain a sense of personal control over their reproductive destiny.

Previous generations of women had no choice about whether or not they were willing to parent a handicapped child; advances in medical technology now offered them a choice. They could choose to protect themselves from what they perceived as the inevitable burden of bearing a handicapped child or they could choose to commit themselves to loving and caring for a handicapped child. These women viewed PNGD as an opportunity to exercise authority and autonomy over their own bodies. In other words, these women could make an informed choice about whether they would even have a baby.

Male informants viewed the process of decision making as an opportunity to foresee the outcome of their procreative intention, which allowed them to imagine future changes in lifestyle and personal responsibilities. Having personal control over reproduction had a positive effect on their self-esteem which in turn gave them the personal strength to ameliorate fears about having a newborn and helped them to make the transition toward fatherhood.

A logical approach to decision making was very important to all informants, yet Brad recognized that factors other than obtaining knowledge influenced the decision making process.

> I don't think most human beings are computers, in that you just feed them a lot of information and they spit back the most logical answer...the more I know about the situation, the more informed my decision may be, the more complex, the more difficult my decision may be, but in the end, what constitutes my idea of what's good and bad is really independent of that information.

In this instance, the preceding statement demonstrated the inapplicability of a purely logical or rational model of decision making. One male informant stated that in order for the genetic counselor to understand counselees' receptivity to new information, their ability to make decisions and their judgment of what was the "right" decision, the health care professional should take into consideration, a person's character, cultural background, moral/ religious beliefs and personal life circumstances.

How moral beliefs affected decision making

Informants recognized the burden of decision making was conjoined with PNGD. The burden for them was having to face two issues: morality and eugenics. In an attempt to make sense on an emotional/spiritual level, informants re-examined their own moral and religious probity to bring into focus possible individual and social consequences of a decision to terminate.

The ultimate purpose of genetic counseling was perceived as moral decision making: "whether or not to abort." Two prospective fathers viewed abandonment of a handicapped child, immoral and inconceivable. If the female informants considered this option they did not discuss it with the researcher.

All informants agreed that any moral decisions that resulted from the prenatal test should be made by the expectant parents. While, there are experts in the fields of medicine, theology and philosophy, who are knowledgeable, these experts should not be allowed to "build the moral houses" in society.

Some informants struggled on a philosophical level to determine the eugenic effect of PNGD. There was a concern that modern-day reproductive technology would alter the composition of the human race forever as expressed by Pam:

> I don't feel right about it...I mean what's going to happen eventually, we're going to have this whole race of perfect little beings, being born because all the others will be terminated before they even get there...I figure well, it's an option that's available and a lot of other people are doing it...it's something that's widespread now, so I might as well.

Resolution of the eugenic dilemma, for Nick was predicated on the premise that the purpose of prenatal genetic testing was to mitigate "as much pain and suffering in the world as possible" not to "recreate the human race."

How abortion uncertainty affected decision making

The possibility of a fetal abnormality was very real for these women, yet for the men it was an extreme, theoretical abstraction. To a great extent, two of the male informants were able to completely deny the threat of abortion, henceforth they avoided discussing it with their partner or making any decision about what the couple might decide to do if the test indicated a fetal anomaly. The rational for this kind of reaction was best explained by Nick:

> If I'm uncertain about something, I try to put off making a decision as long as I can. Hoping that I will get more information, that I will learn more about the consequences, that I'd know more certainly what the consequences would be.

Two male informants rationalized their lack of open discussion about abortion by suggesting that even if the couple did make a decision about abortion before knowing the test result it would be a waste of time since the couple would probably have to ré-evaluate the decision if they were actually confronted with a "genetic problem." These two informants expected the prenatal test to provide probative evidence that the baby was normal, thereby negating any perception of abortion uncertainty.

The other male informant, who was aware that his wife would abort an abnormal baby, did experience a state of abortion uncertainty because he realized that the pregnancy could end in an abortion. Two male informants had already decided, perhaps erroneously that abortion would be unnecessary whereas, the other male, who was more realistic in his perception of the risk, remained undecided.

The women attempted to regain personal control over their situation by defensively avoiding open discussion about the possibility of abortion. Sue was the only informant who admitted to her partner that she was certain she would abort an abnormal fetus:

> I know killing a baby is not good, worse is having an abnormal baby...I must defend and protect.

While in a state of fetal uncertainty the women could hold off making a decision about abortion. All the women "put things on the back burner until...confronted with them" and kept "busy." They protected themselves from feeling the "guilt" or "sadness" associated with thoughts of "having to kill a baby." As long as there was some degree of fetal uncertainty there was hope that an abortion would not be necessary. All the informants concurred that they could not make a decision regarding abortion until after the test results were known. A commonly made statement was "everything hangs on the results."

How the marital relationship affected decision making

Two styles of decision making were revealed by the three marital dyads in this study. One couple exemplified a mutual style of decision making where "there would be a lot of discussion" about alternative choices before the spouses conjointly agreed upon any decision. Joan stated that she would consider the difference between how she and her spouse would cope with the consequences of a decision before making a choice. This style of decision making reflected a supportive and harmonious marital relationship that remained relatively stable even though the pregnancy was perceived as a stressful life crisis. This husband felt like an active participant in the decision making process.

The peremptory style of decision making was dogmatic in nature. The other two couples illustrated the use of coercive power by one partner. The potential for either acute or exacerbation of chronic marital disharmony was exemplified in a comment made by one male informant "sure there is a potential for it [marital conflict]...you know you are basically choosing a child or a wife--and putting your wife in a very difficult situation." This man felt "a lot of frustration" and dealt with the situation by trying to "channel the [negative] emotions into something else." His wife's style of leadership was an impetus for avoidance of open discussion about abortion and the postponement of making a decision about possible termination unless it became obvious that such a decision was absolutely necessary.

Deciding to have PNGD and counseling

The decision

Two styles of decision making were reflected in informants' comments, mutual and peremptory. With a mutual style of decision making, the husband had equal input and power of opinion in the process of decision making. The two men who engaged in a peremptory pattern of decision making felt some degree of helplessness and powerlessness. Their willingness to accept a peremptory style of decision making was motivated by the perception that "ultimately" the woman had the final say about the baby as it was "housed" in her body. The women unanimously stated that they were the one who made the decision to seek prenatal genetic counseling and their husbands supportively agreed.

Nick:

> She made the decision and basically told me what she was going to do it and how she's going to do it which I think is all right. That's the way it should be.

As well, the male informants relinquished some of their personal control over the situation to health professionals in exchange for predictive information about the baby. Keith and Nick made comments that exemplified this perspective.

Keith:

> They recommended it to anybody over thirty-five, and we just, Dr. S. said, oh well, I'm going to set this up for you...they called us we didn't call them...and we said okay. I think we both realized that it is something that we should go through. I don't know-there wasn't very much discussion about it. Maybe...I didn't think it needed discussion, and she never brought it up.

Weighing the risks

Female informants expressed the explicit message that "it was better to be safe than sorry"; and that the amniocentesis procedure "maybe uncomfortable a little bit, but it's worth it." One female informant who had a choice between testing procedures, chose to have the amniocentesis because she perceived that the risk of miscarriage associated with the chorionic villi sampling (CVS) procedure was "a little too high." This same informant erroneously recalled, from the prenatal genetic counseling session, that the rate of miscarriage following amniocentesis was a higher risk than the risk of having a fetus with a genetic disorder. Even though these statistics indicated that it was "illogical" to have the test, she decided it was worth the risk in order to protect herself from the possibility of having a child with a genetic problem. It became clear that the women were so fearful of having a child with a genetic disorder that they eagerly welcomed medical intervention.

Male informants generally perceived the risks associated with the amniocentesis procedure as "insignificant." Minimization of the risk allowed the men to accept the womens' autocratic decision to have the test done and prevented them from worrying about possible harm occurring to either the wife or the baby. The men were so confident that the baby was normal they believed that the test "could do no harm" and in fact it would alleviate the wife's uncertainty and worry about the baby.

Women

Preventing attachment

The possibility of fetal abnormality and/or abortion was uncertain for these women which lead to feelings of anxiety, fear, and a lack of confidence about the future. They chose to protect themselves emotionally from investing in the fetus for two reasons: a sense of ambivalence "do I really want this baby" and a heightened sense of uncertainty "will I actually have a baby to mother." The most frequently cited factor affecting maternal/fetal attaching was exemplified by Pam's comment:

> Well in case there is something wrong, if we do decide to abort...I haven't made that attachment too strong at this point because there's doubt...well uncertainty I guess...There was always that kind of "if" in the back of my mind.

The women experienced attitudinal and emotional flips from a state of uncertainty to certainty like "waking up in the middle of the night" convinced that "the worst was going to happen" then at another time thinking "how nice it will be to have a baby sister or brother" for the present child.

Attaching was defined by Pam as "just kind of that feeling of there's something there, that's really...really a part of me, that's a baby" She disclosed: "I've never really felt that yet." The women employed three defense mechanisms to maintain a sense of protective detachment from the fetus: denial, defensive avoidance and intellectualization.

In an effort to depersonalize the presence of the baby the woman talked about the fetus from an intellectual/rational perspective. They avoided displaying the emotional "exhilaration" of being pregnant and the social symbols normally associated with preparing for a baby. By protecting herself from the pain of the worst possible outcome, a fetal loss, the women used the coping strategy of worrying to fortify their strength and courage in case the genetic test indicated that an abortion would be necessary.

All women in the study exhibited three or more of the following depersonalizing behaviors in response to the pregnancy/fetus.

(a) concealment of the pregnancy by not telling others and not wearing maternity clothes until after fetal normalcy was "certain."

(b) denial of having any dreams or fantasies about the baby.

(c) holding back the anticipation and excitement about having a baby.

(d) distancing herself from others who may "plant a seed of doubt" about having a baby at an advanced age.

(e) perhaps delaying the cognitive awareness of fetal movement.

(f) referring to the baby as a fetus

As a consequence of fetal and abortion uncertainty these women felt the need to protect themselves from the possibility of three negative outcomes: (a) the emotional pain of personally investing in a genetically abnormal fetus, (b) the stigma of choosing to abort a fetus, (c) the stigma of parenting a handicapped child.

Although these women contended with feelings of ambivalence and a sense of uncertainty there was some evidence that they were "binding-in" (Grace, 1984), with the fetus. For example, Pam and her daughter would say "good night" to the fetus. Pam and Sue exercised discretion and caution regarding environmental hazards that would harm the fetus, such as: alcohol, cigarette smoke and over-the-counter medications. One male informant stated that he had been coerced by his wife to attend an early-bird prenatal class.

Men

Aborting the baby was inconceivable

Again, the female and male informants proceeded on divergent trajectories of understanding and coping with the genetic threat. While the women were deliberately preventing attaching to the fetus the men were perhaps overly conscious of facilitating parental and sibling bonds with the baby. The men repeatedly questioned their wives about the presence of fetal movement and they made attempts to listen to the baby's heart beat. Open discussion about abortion was unnecessary because consentiently the men believed that the prenatal genetic test would confirm the baby's normalcy. Brad's statement best illustrated this perception:

> Intuitively... I have always felt quite confident that

> there would not be a genetic problem in our case.

Nick agreed:

> I didn't think I would ever be put in this kind of position...[deciding on abortion] I really didn't.

On an intellectual level, Brad stated:

> There was always the possibility of...say an abortion, say terminating the pregnancy, if it turned out that this child was--would be seriously deformed...that's sort of like an extreme example...I felt that if the worst happened, we would deal with it then. But I never really felt that that's what's gonna happen [*sic*].

The men protected themselves emotionally by denying the possibility that the baby could be so severely affected with a genetic disorder that abortion would be deemed necessary.

Women

Parenting a handicapped child would be a burden

This category emerged exclusively out of data from female informants. The three most pertinent themes discussed were: abortion of an abnormal fetus was a moral/social responsibility; an abnormal baby would have an adverse impact on the family network; and caring for an abnormal child would become more of a burden as the parents and the baby aged.

The moral/social responsibility

The underlying assumption here was that an abnormal child was a burden to society. This supposition was tempered by the belief that the greatest responsibility parents had in life was to recreate perfect children who would inherit the earth. One women implied that religious and moral commitments to "pro-life" had to be sacrificed for the social and political good of all people. An abnormal child was perceived as a "waste" of time and money, thus a burden to society.

<u>The impact on the family network</u>

These women realistically acknowledged that in Canada the primary responsibility for child care lies within the domain of womens' work. Undoubtedly an abnormal child would greatly increase the woman's workload and add to the stress of juggling family relationships. There was a concern that the life long burden of a handicapped child would not only adversely affect the quality of life for the nuclear family, but the family of origin would also be burdened particularly, if one of the child's parents dies. There was a deep felt need to protect, and maintain "peace and happiness" for existing family members even if that meant, giving up this fetus. Pam perceived that a handicapped child would be a burden:

> With a child possibly Down's Syndrome for example, you're basically looking at that child living with you forever, ever and ever. I mean with our ages...there's always that possibility, that it would be living with us for the rest of it's life and then when we couldn't handle it anymore, then what does a person do with him. That would come sooner than a person would want...there's that worry.

In attempting to understand coping patterns in families with handicapped children Damrosch and Perry (1989) found that women reported feeling burdened, overwhelmed, embarrassed and fearful about having a handicapped child. The women in this study disclosed the same concerns.

<u>Parenting a handicapped child becomes more of a burden as the parent and child age</u>

These women were able to foresee into the future by imagining scenarios of what life would be like caring for a handicapped child. Sue and Pam speculated that their husbands were only thinking about having a newborn baby, not the long term consequences of having a handicapped child. Being old and parenting at the same time was worrisome because the informants could not predict their future health condition.

In summary, womens' ability to envision the future by imagining scenarios of what it would be like to care for a handicapped child, undoubtedly heighten their perception of risk and perhaps affected their willingness to take a reproductive chance. By seeking PNGD the women were attempting to regain personal control over their reproduction in order to protect themselves and their family from the perceived inevitable burden of a handicapped child.

When analyzing this data, it seemed logical to question whether in fact these women ever experienced uncertainty about aborting an abnormal fetus. It became clear that a distinguishing attribute of abortion uncertainty was not that the women were unable to decide whether or not to abort an abnormal fetus, but rather it was an inability to predict whether an abortion would be justifiable in their case. Consequently, all the women and one male informant stated that they were unable to decide beforehand whether they would chose to terminate without knowing the results of the PNGD test.

Men

Handicapped children are lovable too

This category was generated from interviews with male informants only. In their opinion, prenatal genetic testing was not solely for the purpose of deciding whether to abort or not to abort an abnormal baby. More importantly it was perceived as a process that helped parents-to-be prepare for the future regardless of whether the baby was normal or not. In preparing for the birth of a handicapped child, the men asked themselves if they were capable of parenting "a child with special needs." It was a question of "how handicapped is this child going to be and could I handle that?" If for some "unique" or "unusual" reason the test result indicated an abnormality in the baby, the men thought they could "cope" with a handicapped child; after all "that's my baby no matter what happens."

Nick:

> I just don't think that's right, to bring a child into the world and because they're not perfect, dump them somewhere.

These men genuinely expressed their belief that Down's Syndrome children were "loving, wonderful kids" who lead "useful and meaningful lives and bring a lot of joy to other people." The genetic test meant preparation for the future, parenting either a normal child or a child with special needs, not as a method to predict termination or continuation of the pregnancy. It was inconceivable that the baby would be so severely abnormal that an abortion would be necessary.

Reactions to having the amniocentesis and the ultrasound

For both prospective mothers and fathers the ultrasound procedure was considered more meaningful and auspicious than the amniocentesis. The supportive attitude and obvious expertise of the doctor and the ultrasound technologist instilled a sense of trust and faith in the medical procedure as well as belief in the accuracy of the test. Immediate feedback, such as "there's the heart and the baby's arms and legs", was generally accepted as reassurance that the baby was physically normal.

Seeking reassurance

During the ultrasound procedure the women sought reassurance about the baby "is everything okay?" and confirmation that the "baby's kicking" was normal. Informants made discrepant comments; Joan and Sue felt more reassured following the procedure whereas, Pam did not find the ultrasound "at all reassuring." She continued to be uncertain and at times feared the worst case scenario. She wondered which, if any, fetal anomalies could be detected by the ultrasound at such an early age in fetal development.

All of the male informants were very reassured and felt confident that the baby would be normal following the amniocentesis/ultrasound procedure. Brad and Nick were protective and worried about their wives regarding the amniocentesis procedure, as it appeared "riskier" than they had anticipated. They feared that the amniocentesis needle "would invade the baby's space or somehow cause harm." Also, they did not want their wives to experience any pain or become upset. One gender difference between male and female informants was their interpretation of the the meaning of the diagnostic procedure. The men were much more curious about the baby in general and they especially wanted to know the baby's gender. This indicated that the PNGD test meant certainty of a favorable fetal outcome.

Pregnancy certainty

As a result of seeing the "baby" much of the doubt that women previously had about the pregnancy was suddenly flipped from pregnancy uncertainty to pregnancy certainty. Joan described her reaction:

> To me it made it much more concrete...it sort of gave me a reason why none of my clothes fit...it sort of pulled it all together for me...I mean there was the source of the changes.

Coincidental to the ultrasound and amniocentesis procedure there were a number of physiological changes going on in the woman's body. She had gained weight, her clothes did not fit and her abdomen was bulging. All of these factors contributed the to mitigation of pregnancy uncertainty.

Fetal certainty

Similarly, the women experienced a shift from a high degree of fetal uncertainty to a high degree of certainty that the baby would be physically normal. They were told that physically the baby looked "fine." Female informants stated how important it was for them to receive "the baby's first picture" when the ultrasound procedure was completed.

Visualization of the baby on ultrasound symbolized an emotional shift from hoping and wishing for a normal baby toward a strong sense of confidence that the desired perfect child would be born. A particularly important example of this shift was obvious in that the women replaced the medical term fetus with the word baby.
Sue's sense of confidence about the baby was heightened:

> After test I am thinking baby is eighty percent normal and twenty percent is abnormal.

Joan had a repeat amniocentesis because it was impossible to obtain an amniotic fluid sample during the first procedure. The pain of uterine contractions brought on by that attempt were instrumental in helping her to accept the pregnancy and recognizing her desire to have a baby. Acceptance of the pregnancy and anticipation of the baby marked a resolution of earlier feelings of ambivalence.

Male informants all described the baby as being more "real" after ultrasound "it wasn't this abstract thing anymore"; "this wasn't just a blob." The ultrasound strengthened their sense of confidence and optimistic that the baby would be normal.

Fetal uncertainty

Paradoxically, Pam stated that she always felt uncertain about the baby's genetic status and Sue expressed contrary feelings of being certain then uncertain about the normalcy of the fetus. Both women were concerned that, because they could not see the baby on the screen, they were still "not sure", but "had to believe...the doctor knows everything." All women were fully conscious of the fact that the genetic normalcy of the baby remained unknown until after the results of the amniocentesis were reported.

Abortion uncertainty

Nick was not completely reassured. Knowing that abortion was still a probable outcome if the test showed an abnormality, he remained uncertain about whether the baby would be terminated. Like the female informants, he continued to protect himself by "holding in" the positive emotions of anticipation and excitement about the baby because there was still "a potential for disappointment."

The power of medical technology

Generally the men were impressed, more than the women, with the technological power of the amniocentesis/ultrasound procedures. They marvelled at the miraculousness of the genetic test. It was perceived as a powerful tool that could answer mysterious curiosities regarding the growth and development of the baby while in utero. Nick wondered if the test could predict "the likely weight of the child and hence the likelihood of having a difficult delivery." Sue viewed the technology in terms of it's potential to improve the quality of life for future generations. Nick was delighted with the fact that when he accompanied his wife to the amniocentesis procedure the experience emphasized "health" and not the "sickness" which he remembered from his last impression of hospitals.

One informant compared the personal value of information derived from prenatal testing with the idea that "ignorance is bliss." He concluded that once scientific advancements were in general practice it was "foolish" of people to decide to remain ignorant, although there was a realization that the availability of the technology "puts a great burden on us" as expectant parents were now faced with moral decisions which they would not ordinarily confront.

Considering the technological nature of PNGD, the experience of pregnancy was perceived to be highly medicalized; health professionals were deemed as having a lot of power and control over parents-to-be because of their expert knowledge. Nick expressed his sense of voluntarily powerlessness:

> First of all you're dealing with very important questions and answers here and so you're just happy that that's happening...You just don't question the process. If they tell you to be there at such and such a a time you go and you be there...I don't know that anybody else or anything else can tell you to do that and you would be as accepting as you are in this circumstance. I think that really tells you the kind of impact or power this has on the individuals involved. That they are so willing to accept someone having absolute and total control over them over a period of time.

The men exercised caution in relation to believing information conveyed by the "experts." For them the process of genetic testing was analogous to taking the car to a mechanic, where you were "taking a chance." The "mystique" of medical knowledge made most informants suspicious about what information would be conveyed to them. For example, there was a potential for health professionals to "withhold" information or perhaps they would use "loaded phrases" which would strongly influence how the information was interpreted, thus the decisions that would be made. When informants accepted genetic services they also accepted temporary powerlessness insofar as, they had no control over the testing procedure, the accuracy of the results or the type or extent of information they would be told about the fetal test results.

Informants feared the use of deferent power by experts who held this "amazing" medical knowledge. In the eyes of the informants there was a great potential for the experts to manipulate those people who undergo PNGD as laypersons were completely dependent on these expert professionals for their genetic services.

Attaching to the baby following the ultrasound

Awareness of the passage of gestation time, the sensorial experience of quickening and visualization of the baby on ultrasound all played an essential part "in a slowly evolving process of adapting to the baby." Following ultrasound, women were less afraid of having a baby and for male informants, the baby became real.

Maternal attaching

1. Phase one of the chronological process of PNGD, recognizing the threat was marked by feelings of "surprise", "shock" and "ambivalence." All of the women were concerned about their own physical well-being. The symptoms of morning sickness, fatigue and breast tenderness were emphasized. Perceiving themselves as "older" expectant parents with established career roles, two women were highly ambivalent about whether they wanted to be pregnant or have a baby. All the women went through the motions of seeking appropriate

professional advice to confirm the pregnancy and to undergo PNGD. They were in a state of ambivalence as well as a state of uncertainty about the pregnancy/fetal outcome. All the women denied having any fantasies about the developing fetus during the first interview. During this period the fetal outcome was unpredictable; all the women were fearful, worried, powerless and lacked confidence that they would deliver a healthy newborn.

2. Phase two of the PNGD process, protecting self was initially manifest as depersonalization, concealment, distancing and avoidance of the awareness of pregnancy and the fetus. The women attempted to prevent attachment to the fetus by distancing themselves; they concealed the pregnancy from others; they held back the emotional exhilaration that normally accompanies confirmation of a pregnancy.

Visualization of the fetus on the ultrasound screen at 16 weeks gestation was a reassuring experience for two women. This turning point was marked by the appearance of baby things in the home. One woman began to wear maternity clothes for the first time. Joan bought "the baby's first teddy bear." Seeing a "picture" of the fetus assisted the women to recognize the pregnancy as the cause of all of their physical changes. Admittance of the fact that the fetus was growing inside their bodies enhanced acceptance of the pregnancy and the baby. This realization dissipated previously held feelings of ambivalence.

An opposing dilemma was the reminder that the genetic status of the baby was unknown until after the results of the amniocentesis was reported, so although two of the women began to believe that everything would be fine paradoxically, they were motivated to continue protecting themselves emotionally in case of fetal abnormality and disappointment.

3. <u>During phase three of the PNGD process, resolving the threat</u> was achieved for the four informants who were told that their baby was normal. Two of the expectant women allowed themselves to resume normal tasks of pregnancy. One woman stated that upon receipt of the good news, the emotional, social, cognitive catching up associated with taking on the mother role hit her like a "tidal wave." Resolution of the fetal/abortion uncertainty sparked an interest in planning for child care at home while the woman would be hospitalized for the birth. Another concern that became evident at this time was fear of labor. The good news facilitated discussion about how to celebrate the birth.

<u>Paternal attaching</u>

Fathers' progressive involvement with the pregnancy and the growing fetus was perceived as a "slowly evolving, natural process."

1. <u>Phase one of the PNGD process, recognizing the threat</u> was metaphorically described as a "rollercoaster" during which the men attempted to adjust to the news of pregnancy. Confirmation of the unexpected pregnancy initiated feeling of "shock", ambivalence and a sense of crisis. The men questioned whether or not they could live up to the new responsibilities impending with expansion of the family. They did not look forward to "getting up at night", "changing diapers" or being "tied down." Their "intuitive" thoughts of optimism and "anticipation for the baby" provided comfort for

these three men, thereby countervailing any uncertain negative feelings about possible abnormality in the fetus. Despite knowing the fetal genetic risk and accompanying their wives' through the amniocentesis and ultrasound process, these men prepared to become a first time biological parent.

2. <u>During phase two of the PNGD process, protecting self</u>, the men began to attach to the growing and developing baby. All of the women concurred that their husbands were attached to the baby right from the beginning. They asked their wives if they could feel fetal movements on their abdomens and requested to listen to the baby's heartbeat. This behavior demonstrated that the men had vested interest in the baby regardless of whether or not it might be a handicapped child. Two husbands visualized on the ultrasound screen, the "flashing heartbeat" of their baby at 16 weeks gestation, even before their wives had reported feeling fetal movement. All the men talked about the impending baby as something real. "It was suddenly coming into a situation where, now this is real...the baby is coming and it's going to be real." Accepting the pregnancy meant "it just is...it's a real event coming up, there's so much evidence now that it is real. It's not a vague time off in the future." The men already perceived the fetus as a baby.

3. <u>Phase three of the PNGD process, resolving the threat began</u> at 20 to 21 weeks gestation, immediately upon receipt of the fetal diagnosis. When the women "started to balloon" and the baby "started to kick" at around 20 weeks gestation their husbands interpreted these changes as "exciting." One male informant resolved a personal

conflict by deciding that he would accompany his wife into the delivery room. This same informant disclosed that he planned to "enjoy" this baby during the first year of life much more than he had with the previous child. The intensity and magnitude of males' involvement with the baby during this time was reflected in Keith's comment:

> Probably at eight weeks it [deciding to terminate] would have been relatively easy...at 20 weeks it's a whole different thing.

With a sense of certainty the two men in the families where the baby was diagnosed as normal, became actively involved in preparing the home and making life decisions relevant to securing financial stability. These men were acknowledging and preparing for their fatherhood role by resuming the tasks of pregnancy and becoming involved with the pregnancy and the baby.

Family attaching

All six expectant parents openly discussed the baby with their children right from when the pregnancy was confirmed. The children were looking forward to having a baby sister or brother. During interview 2, after the amniocentesis and ultrasound, some family discussions occurred where they imagined and speculated about what physical and personality characteristics the baby would have. For example Nick wondered if "this baby was going to be another dancer" and Joan teasingly stated that she hoped the baby would not inherit the father's nose. The baby had become "a part of the family even before it was born."

Waiting

Waiting was a recurrent theme that threaded through every phase of the PNGD process. Waiting in this situation was defined as "impatience" and "a feeling of urgency for something" which implied associated anxiety. Initially, the women were waiting to become pregnant; they were not planning conception but at the same time none of them rigidly protected themselves with birth control. Two informant dyads had adopted a "let's wait and see" attitude about conception.

Waiting as a sub-process of coping

All informants experienced a sense of "waiting a long time" while they accessed the health care system to find out whether or not their baby was genetically normal. They waited to see the doctor to have the pregnancy confirmed, then they waited to see the high-risk obstetrician, then they waited to attend the prenatal genetic counseling session, then they waited for the amniocentesis procedure, and they waited for the results of the amniocentesis test. While they waited they were uncertain about what would happen next, each new event in the chronological process of PNGD seemed like a new turning point requiring another decision.

Unanimous for all informants, waiting was described as "it puts the joy of the pregnancy on hold for four to six weeks." The condition of waiting was disparate between women and men. During the first phase of the process: recognizing the threat, women described waiting as a state of numbness "I feel nothing" and powerlessness, "I can do nothing." Not only were they waiting, friends and family "felt like they're waiting" too. "Everybody is waiting for the results of the test." During the second phase of the process: protecting self, the momentum of waiting built as the time approached when the PNGD would be reported. Following the amniocentesis/ultrasound procedure women protected themselves from the possibility that "the worst could happen" by "keeping busy" and "holding back" the "anticipation and excitement" of having a baby. They distracted themselves by keeping busy at work or in the home. About a week before the doctor was expected to call to report the results of the amniocentesis the women became "jittery", "anxious", "worried" and "irritable." At that time, the women frequently asked their husbands whether the doctor had called and if he had not they wondered why the call had not come. They waited in a state of worry and uncertainty; "was this a sign of bad news" or could they still hope that "everything will work out for the best."

On the other hand, during phase one and two of the PNGD process, male informants generally denied ever feeling a sense of waiting. Although they were somewhat anxious to get the fetal diagnosis they chose to cope by underestimating the significance of waiting and the association between their anxiety and waiting. The males' coped by over exaggerating their sense of confidence and optimism about the normalcy of the baby which negated the need to wait for or worry about the results of the amniocentesis. Nick explained his way of thinking:

> She's pregnant and we're going to have a baby and that's it. That's really all there is to know...It's like there's really

> nothing that you can do that's going to change the circumstances that you've got, so don't worry about it.

Paradoxically, all three men admitted to being "a little bit anxious" towards the end of the four week waiting period. It seemed that as much as the men tried to deny the possibility of abnormality, to some degree, they were still uncertain about whether it would be necessary to terminate the pregnancy.

Abortion uncertainty

The importance of the search for knowledge about the fetus was to resolve the moral question of quality of life. While informants were waiting for the test results they attempted to sort out in their own minds the answer to their moral dilemma about abortion. They questioned, under what conditions of abnormality would it be justifiable to terminate the baby? All informants described some criteria to differentiate degrees of severity of handicap/abnormality. The two categories that emerged were: (a) "mild" and (b) "severe"; which in essence translated into (a) "what can I cope with" and (b) "what am I not capable of dealing with."

The criteria for a mildly handicapped child were as follows:

1. "a heart, a seeing or a hearing problem." (Pam)
2. "like William's syndrome...the physical features...they're not as instantly recognizable by the general populace...a very pixie-ish appearance to their faces." (Joan)
3. "having an I.Q. of 90." (Brad)
4. "a Down's child I think I could cope with that." (Pam, Keith, Nick)

The criteria for a severely handicapped child were described as:

1. "say mentally in particular...perhaps never going to talk or anything like that." (Brad)
2. "Too much trouble with baby...baby can't close their mouth...brain and mentality has some problem...and the back can't work" [sic]. (Sue)
3. "if the baby can't take care of it's self...baby is not happy...if they just lay in bed...can't walk, can't eat...if they are all the time in the bed." (Sue)
4. "if it is not like a human...it can't take care of it's self for it's whole life." (Sue)
5. "the only concern I would have is Down's Syndrome...I think a severely handicapped child would be a Down's Syndrome." (Joan)
6. "a child that was going to look forward to a very short life with a great deal of pain." (Nick)
7. "a non-treatable disease." (Nick)

A lack of social prescription about abortion for genetic reasons required informants to deal with the issue of abortion independently without the benefit of pre-established social norms. Because the fetal diagnosis and perhaps a decision about termination was expected within a short period of time, informants may have been motivated to examine in their own minds what degree of handicap in the baby they would be able to live with. On the other hand, this data may have been artificially generated in response to the researcher's line of inquiry. During interview number two or three the researcher asked the questions "what kind of thoughts or factors do people consider when they consider making a decision to terminate a pregnancy as a result of the fetal diagnosis?; and "could you describe what you mean when you say "severely abnormal"?; and "are there varying degrees of severity or abnormality?"

Hoping and wishing

The concept of hope was most crucial at this stage in the process because all informants experienced their greatest degree of anxiety just prior to when the test result was expected. All informants, but especially the women, felt a noticeable increase in their level of anxiety. The women were more "jittery" and began to "bite [their] fingernails." Two male informants described themselves as "a little anxious to get the results back." Friends and relatives were contacting the couple to ask whether the fetal diagnosis was known. Informants attempted to neutralize their anxiety by employing two coping strategies: hoping and protecting themselves by keeping busy.

Informants perceived the "last couple of days" as "the worst part." They felt a sense of unpredictability or "just not knowing" whether "we would have to make a decision on terminating the pregnancy." The absence of a telephone call to report the PNGD results was open to ambiguous interpretation, "had the laboratory made a mistake?"; "was there a problem with the sample?"; and "will we have to go through this all over again?" Even though the majority of informants felt reassured after seeing the baby on the ultrasound, four weeks earlier, their sense of "fear of the unknown" was heightened at this time. Informants lacked a sense of confidence about deciding whether they would have a normal baby and the last few days of waiting for the test results amplified their sense of powerlessness and dependence on medical technology to reveal their reproductive fate.

The terms "hoping" and "wishing" were usually stated as one phrase. The women sensed a subtle difference between the words but they could not articulate the separateness of one word from the other. Painstaking analysis of the verbatim quotes yielded the distinguishing characteristics of each concept. Recognition of the subtle difference between these words was verified by four primary informants when the conceptual model was presented to them at the completion of data analysis.

Hope is a spiritual concept and for these informants it was a sub-process of coping that evolved throughout all phases of the PNGD process. Hoping was a condition of the process of waiting, consequent to the conception. Conceptually, the coping strategy of hoping was modified by two factors namely, the passage of time and the occurrence of different steps or events that "kept cropping up."

Hope was manifest as statements of optimism and belief that ultimately only what was good would occur. Keith and Joan gave examples of hopeful strategies "making the best of a situation and having a positive attitude demonstrated "building-up hope."

On the other hand, wishing was a self-directed, cognitive/ emotional act that served to remind the informants that they had the power of rational choice to control the direction of their lives. By changing attitudes or personal behaviors they expected to willfully alter the outcome of some future or past event. Wishing implied that the informant was responsible for making decisions and selecting choices; these choices were dependent on and tempered by personal characteristics, human conditions and life goals. "Hindsight" was perceived as the essential characteristic of wishing. "Wishing this would all go away" was stated by two informants. After Pam found out the baby was genetically abnormal she wished she had taken better care of herself and had a better attitude about the pregnancy earlier on in the pregnancy.

In comparison hope was always future orientated. Hope was manifest as a statement of faith. Their faith was based on the premise that if human efforts failed to effect a desired change then some power greater than one's self would ensure that the very best possible outcome would occur. Sue symbolized hope as "crossing the fingers." Joan envisioned hope as looking for Interstate 101, on the highway of life. All informants hoped "for the best", but at the same time were "scared of the worst"; they hoped for a "healthy, happy baby."

Spiritually, hope was expressed as the desire to recreate a "perfect child" in the image of the divine being. In other words, hope represented the belief that a divine power was ultimately protecting the informant's destiny. This hope could not be washed away by tears, fear, worry or denial. In varying degrees of depth and intensity, all informants hoped for a normal child. Hoping as a sub-process of coping with fetal genetic risk was evidenced throughout every phase of the basic psychosocial process.

Phase One: Recognizing the threat

Prior to this conception, every month for thirteen years of marriage, Pam hoped to become pregnant. Keith hoped for a strong and ever lasting mutual commitment to marriage which was symbolized as the birth of a child. The other informants began to hope after the conception was confirmed. In the early phase of the process when informants were highly ambivalent, they either verbally or to themselves wished that the pregnancy "would all go away", or that it "doesn't work out." They wished for life to re-stabilize, to return to a time when daily events were more or less controlled and predictable.

During phase one, the women experienced brief moments of temporary elation and exuberance about the pregnancy. These ideals were quickly shattered by an overwhelming fear of the possibility of fetal abnormality and/or abortion.

"Right from the start" the men chose to respond to this threat with over exaggerated confidence and "intuitive optimism." The men said that there was no need for them to be hopeful because, as a matter of natural course, they expected the pregnancy to end with the delivery of a beautiful, healthy child.

Phase Two: Protecting self

After the prenatal genetic counseling session, the women perceived the threat of fetal abnormality to be "high-high." As a result, their hopes for a normal baby were offset by feelings of despair which were born out of the fear that the worst possible scenario of abnormality could happen. As their abdomens began to grow, when they saw the baby on the ultrasound screen and when fetal movements were confirmed, the strength and depth of the womens' hope crystallized. The women could no longer "hold back" or defensively avoid the feelings of attachment for the baby. The baby became a human being, instead of an inanimate object. While they waited four long weeks for "the phone call" about the test result, hoping became the predominant mechanism for coping with the worry, fear and powerlessness associated with a heightened awareness of fetal and/or abortion uncertainty.

Joan perceived hoping as a coping strategy that "doesn't work", but in her state of powerlessness and helplessness she recognized hoping as a deep inspiration that "doesn't stop." Hope was used as a coping mechanism to help all the informants regain some sense of control over their unknown future.

During this phase of the process the men continued to defensively avoid thoughts about fetal abnormality or abortion. Their sense of confidence and feelings of optimism regarding the "health" of the baby were affirmed when they received positive feedback about the baby after it was visualized on the ultrasound screen. Although Nick expressed his belief that the test results would be "fine" he admitted to waiting, to some degree, in a state of uncertain limbo about the normalcy of the baby and the necessity of abortion. He stated:

> I just hope we don't get put in that position of having to make any decisions.

The depth and strength of Paul's hope was isometric to the hope experienced by the women. Like the women, he perceived the risk of abnormality as a threat, therefore he prepared himself emotionally for the possibility of "disappointment" and despair. Hope for the other two male informants was more superficial; they hoped that the remainder of the pregnancy and the delivery would be safe for both mother and baby.

Phase Three: Resolving the threat

With the reporting of the prenatal test result the informants either resolved the threat or in contrast the danger became paramount if the baby was diagnosed with a genetic disorder. Those four informants who "won the lottery" (Nick) went on to resume the normal tasks of pregnancy. Unfortunately, those informants who received bad news were suddenly thrown into "grief and despair."

Getting the phone call

Negative results: "winning the lottery"

1. Reacting to the news was displayed as excitement or elation, relief, relaxation and contentment. But laypeople who receive the news may initially be confused by the choice of words used by the health professional. The phrase "negative results" implies an undesirable or ominous outcome which is the opposite message intended by the professional. Although the phrase "negative results" means that the findings of the test are normal, when Sue received "the phone call" her first interpretation was "your baby is abnormal." Once this statement was clarified by the doctor she was "very happy." Joan's response to the news was:

> I felt quite happy when I got my phone call about the amniocentesis...I felt...it wasn't a jump-up-for-joy kind of feeling, it was a sit-back-and-smile and a feel-warm-all-over kind of feeling.

These two informants felt relieved, calmed and relaxed. The positive news meant that they would not have to worry for the next five months about the normalcy of the baby. They felt reassured to "find out for certain" that the baby was genetically normal. They believed that a successful delivery was still not certain because future life events could somehow alter the outcome of the pregnancy. However, the normal diagnosis facilitated a sense of comfort, security and confidence which is what the women had hoped for prior to undergoing PNGD and counseling. Joan described a modification in her strategy of hoping. Hoping for a normal baby suddenly shifted from a present focus to a future vision: the "child's wedding."

Brad and Keith concurred that the reporting of a negative test result made them feel even more reassured and confident. Their belief that the baby was normal had been confirmed which lead them to further believe that the pregnancy and the delivery would proceed normally.

All three male informants were curious about and anxiously waited to find out the sex of the baby. Gender differences in perception of the fetal genetic risk became evident when in contrast, the women were interested to find out the baby's gender only after they knew that it was normal. Joan explained that choosing to know the sex of the baby was an opportunity to further enhance fetal attachment prior to the birth. Now that she knew for certain that she was going to have a girl she was thinking of only girls' names and shopping for "frilly dresses."

2. Resuming the normal tasks of pregnancy was described by Joan as a "tidal wave", where once the results of the test were known, "all of a sudden you catch up on everything you have been holding back."

The intensity of waiting prior to finding out the test result fell drastically after the test results were known. For four informants their sense of waiting was transformed into a relaxed sense of preparation for the baby. Immediately the good news was shared with close relatives, peers at work, and friends. Brad planned to "baby proof the house" and Sue began to think about contacting her mother to make arrangements for care of the family while she was in hospital to deliver the child. As a couple, the expectant parents began to prepare the baby's room with a crib and other baby furnishings. Partners discussed baby names; knowing it's gender made it easier. Joan began to decorate the nursery and she found herself spending time just watching, observing female babies.

Positive results: taking a chance and losing

1. Reacting to the news was described as a sense of powerlessness and despair. Pam recalled a conversation that she had with her obstetrician two days prior to receiving "the telephone call."

Pam:

I saw Dr.S on Wednesday and he checked everything and he

> said to me at that point I can guarantee you everything is all right because if everything wasn't I would have heard by now.

Her reaction to this reassurance was:

> I guess this is going to work out...I was starting to feel a little optimistic about it. Still not totally certain or I guess feeling that it was for real, but starting to at least accept, I guess more positive.

Two days later when the doctor called, he told Pam:

> 'I'm sorry but it's trisomy 18 and we've got to abort right away and I've got a bed booked tonight.'

Pam was in a state of shock, intense crisis. She described herself as "devastated", "hysterical", "in a dream." Her intuition "right from the beginning" was that the worst would happen and in fact that is what had happened. Her hopes for the "perfect child" were shattered. She was embroiled with frustration because she had been "jipped, robbed" of a baby she desperately wanted. Pam attempted to regain personal control by withdrawing from others so that she could "digest" the information. It was Friday afternoon when she received the information. Since the health care services were closed over the weekend Pam was "really frustrated" because "we were left out in the cold." There was no one to turn to for more information or to respond to the questions she needed to have answered. With her husband as the only support person over the weekend, she endured her emotional, psychological, spiritual pain in isolation.

Nick felt shock, denial and frustration which were verbally expressed as anger at being so ill-informed. His anger was directed at the health care professional who made the phone call:

> First of all there should not have been a phone call from the doctor telling us the results of the amnio...someone should personally and physically deliver the information and they should arrive on the doorstep with a stack of books about two feet high and they should say here is what you are faced with, here are the kinds of decisions that you're going to have to make, here are the results of those decisions and here is the information that you can read that will describe to you what you are doing. And they should do it in person, not over the phone...They don't have to arrive on the doorstep, they can phone up and say look you got a problem here. Get your butt down here and we'll talk about it...it should not be done over the telephone...Absolutely no way.

In consideration of the fact that Nick was able to effectively deny the possibility of fetal abnormality and abortion, perhaps his perception of shock was more intense than for a person who had accepted the threat, and anticipated the impact of the worst possible outcome. Nick was utterly surprised by the diagnosis of a fetal abnormality:

> I mean I know that there's a higher incidence of this and a higher incidence of that and one out of so many and on and on...But I just didn't expect it to be us, that's all.

A major concern for him was that he perceived himself to be "very ill-informed." He still did not know what the diagnosis meant or whether the baby was affected and if so to what degree of severity.

2. <u>Diagnostic uncertainty</u> for Nick meant:

> No matter how much information you have, you still got to make the decision and in a case like this being better informed doesn't make it any better of a decision...but what it does is it makes it easier for you to be more comfortable that what you're doing is right for your baby. That what you're doing is at 75, or 85, or 95 percent chance that you're doing the right thing. Whereas right now, I simply could not tell you, no idea and I should have a better feel for it than that because the decision's so important that it requires a higher degree of certainty than what I had.

Pam described her sense of uncertainty in this excerpt:

> I mean one out of every 5000 births is trisomy 18 and then you put a mosaic in there too which gives you the more uncertainty...there was nothing concrete, there was nothing, it was so abstract and it was such an uncertainty in so much that it could have been anything from normal to totally abnormal...the whole range.

All of the attributes of uncertainty were present in the concept of diagnostic uncertainty: lack of knowledge, lack of comprehension, lack of personal control in the situation, lack of confidence in making a decision, and the unpredictability of a future outcome. Exemplary comments were included here to explicate the significance of these attributes for Pam and Nick.

(a) Lack of knowledge

Right from the beginning Pam was a hypervigilant knowledge seeker. The same pattern of behavior reoccurred in this phase of the process. In contrast, throughout the two previous phases of this process, Nick was content to take a more passive role. He received and accepted new information rather than taking an active part in the pursuance of knowledge. Now, acutely aware of the crisis situation, Nick suddenly perceived himself as ill-informed about genetic disorders in general and why they occurred. As a consequence his sense of self-esteem and personal confidence were demeaned which further intensified his sense of powerlessness and helplessness in the situation. These two informants wondered but did not ask whether there were any other testing procedures that could be done to either confirm or refute the fetal diagnosis.

(b) Lack of comprehension

Neither of these informants were able to understand or derive meaning from the clinical diagnosis. The genetic term mosaicism "meant absolutely nothing to" them. Pam's comment about the pamphlet on trisomy 18 demonstrated her inability to comprehend the written material given to them "that pamphlet, I cannot understand, not a word, nothing." She felt angered and frustrated that her self-directed efforts to acquire new knowledge had not improved her ability to understand or cope with this sudden crisis. The frustration of understanding "absolutely nothing about what this was all about" was compounded by the pressure of "having to make up our minds right away."

An inability to understand the principles of human genetics would have been acceptable to Pam "if everything had've been normal." This perspective was v[illegible] by three other informants, as well. But, since the baby had been diagnosed with a genetic disorder she blamed herself for not being better informed.

(c) Lack of personal control

Concomitant to finding out the problem with the baby the obstetrician suggested the solution to the problem. Both informants concurred that the information conveyed to them about the baby implied that there was "no hope" and that there were "no options." The fact that arrangements had already been made for immediate termination of the baby imposed an intense feeling of pressure to make a decision either immediately or very quickly. Power and control over the situation was no longer in the hands of the informants. They perceived that they were never given an opportunity, by any health professional, to work through a problem solving approach. They wondered how they would make a decision about the baby once notified of the genetic diagnosis and how would they come to terms with the baby's probable condition? They perceived that the non-directive approach to decision making as employed by the geneticist and the genetic counselor was in sharp contrast to the paternalistic approach employed by the "high-risk" obstetrician.

Sue suggested how she thought the situation should have been handled:

I think if somebody had of come out with an

> explanation...look, here is what this syndrome is called, here are the possible complications, here are the probabilities of such and such occurring and giving us more of an overview instead of like all of a sudden this is what now, I think you should do.

(d) Ambiguity

These informants expected that the test result would provide them with a high degree of "certainty" about the normalcy/abnormality of the baby. Instead, the information that they received was open to their own interpretation. They were expected to sort out relevant from irrelevant facts and assign their own values to the information conveyed to them and weigh out which facts should most influence their decision. The problem with the genetic diagnosis was that they perceived that it could be interpreted differently depending on the person hearing the information.

Nick:

> Maybe I expect too much from science, but very much you're left to not only draw your own conclusions but to determine which information is most important and that is very hard for someone who is not knowledgeable in that area.

(e) Lack of confidence

Given the ambiguity of the genetic diagnosis and the unknown prognosis for the baby, neither informant was able to assign a definite value or meaning to the risks involved for themselves as parents or for the baby if the pregnancy was allowed to continue. To them the risk was an extreme dilemma. They imagined that they were deciding to either: continue a pregnancy where the baby may be so severely affected it would die in utero or they may terminate a baby who's only abnormality was a cleft palate. A lack of confidence was expressed as a lack of "comfort" about making a decision in either direction.

(f) Unpredictability

Nick and Pam expected the results of the amniocentesis to be reported as a probability, as a percentage of chance, but it was not. Nick explained the importance of using analogous scenarios from everyday life to make the probability more meaningful "you should be able to assign degrees of probability to likely outcomes and those degrees of probability have no meaning unless you're talking about things you already know." Two weeks after the termination neither informant could accurately predict whether they had terminated a normal or an abnormal baby. "All it was was a flip of the dice" [sic].

Making the decision

These informants were faced with making two choices: either to continue or to terminate the pregnancy. When considering the decision to terminate, all study informants discussed how much more "traumatic" it became to make that decision as the baby grew and developed.

The most important criterion for making that decision was the absence of hope. Pam stated "the chances were that we really didn't stand much hope at all. So that kind of made up our minds that there was just no way that this could work out." Nick agreed "nobody would talk in terms of there being any hope for this baby."

Another criterion was that the only other option available was that the baby would experience "a hell of a lot of agony then death." Pam and Nick agreed, that given this alternative there was no choice.

Neither informant discussed feeling powerless in this situation, however intuitively it seemed that a sense of powerlessness would be a condition associated with such a dilemma. Contrary to this, both informants perceived that although they had complied with the obstetrician's suggestion for termination, they maintained personal power and control over the final decision. The professionals expected them to make a reproductive decision, however the informants felt uncomfortable and unprepared to make a decision because they perceived themselves as "not well enough informed." Pam recalled that she was in such a state of shock and confusion during the ordeal; she thought that she was in control over her own decision but, in retrospect she wondered whether she really was autonomous. Pam stated she had "the final say in what was going to happen...I think I did, if I wanted to."

Living with the consequences: termination of the baby's life

While these informants were in attendance at the Genetics Center on Monday morning, the obstetrician called the Center to request that Pam "come in right away." So Pam was hospitalized immediately in a private room on an antepartum unit. She had no experience with labor and delivery other than what she had read about over the course of this pregnancy. In describing the sixteen hours of labor, Pam focused on the emotional pain rather than the physical pain. She perceived that "nobody knew how to handle a situation like this." Her relatives were insensitive to her need for privacy,

Pam:

> When I was in the hospital and I was really in agony, in labor and whole family's there and I just kind of thought why and I told the nurses beforehand,...look I don't want any visitors and they put a note up on the door so my mom and dad walk in and the nurse says '...Oh, Pam doesn't want any visitors...' I had all these people around watching me, like I was just yeah it was terrible...it was really hard, really hard. Ron's trying to tell them to leave and I mean they're making small talk about the weather and here I'am sitting there thinking, 'why don't you guys leave', my sister's had two kids and saying breath through your nose and blow out through your mouth and I said 'get lost'. Yeah I was really glad when visiting hours ended and they finally left.

She remembered being in the room alone when the baby was delivered. The nurse was called into the room and "it was put in kind of like a tupperware container and taken away right away. That was it. There was nothing said, absolutely nothing. Nothing at all."

In an effort to protect her husband she sent him out of the room when the nurse arrived. "But it was pretty lonely." She wished in hindsight that she had looked at the baby, found out it's gender, and perhaps even held it in her arms. Pam perceived that the health care system viewed the termination of the baby as the end of the process but for her it was not the end. She still did not know for certain the genetic status of the baby and nor did she know its sex or anything about it's physical features.

Pam blamed herself for being helpless, not knowing what was happening; not knowing the signs of impending delivery. She was isolated by the nurse, her family and to some degree by her husband. Although he provided support from his vicarious stand point; she was the only person who really knew what it was like to labor for so long then deliver a "killed baby."

Nick stated "to separate out the emotions of the experience from the details...it's the emotions that I remember." The impact of those emotions were captured in this quote.

> So it's done. That's it. But you're unhappy about having to make the decision...it was no fun...that's one of the hardest things I've ever had to do in my life and maybe the one that hurt the most. It's true. It really is.

Nick felt so uncertain about whether or not they were doing the right thing by terminating the baby, he had to prevent himself from stopping the doctor when the saline solution was being injected into his wife's abdomen. He was overwhelmed by the lack of support or empathy from the staff; to him it appeared like the helping profession was "just a job." "Nobody had an understanding of just how hard it was on us to be there doing what we were doing."

Going public

Once the informants were at home, the telephone started to ring.

There were two types of people who called: those who were curious and it was none of their business and the people that they genuinely wanted to talk to. Nick was straight foreword in his explanation "we had to end the pregnancy because if we didn't the alternatives would be totally unacceptable for the baby." He did not "worry about what someone else might think" when he disclosed that the baby was terminated.

The stigma associated with choosing an abortion was of some concern for Pam. She told people at work that the pregnancy ended because she started to "bleed." Pam tended to respond to callers with a "pat answer" and stated "fine" when they asked how she was feeling. As Pam was experiencing overwhelming "grief", she protected herself by withdrawing from others, avoiding shopping malls where she might see babies, and she kept busy at work/home to defensively avoid open discussion of the details of what she had endured.

Loss and grieving

Pam like the other two women, tried to prevent attaching to the baby to protect themselves, but eventually it became impossible to deny her desire to have this baby. Although she courageously prepared herself to accept an abortion if it was necessary, once done, the impact of that decision was "devastating." Giving birth should have been equivalent to getting married. It should have been the happiest day in Pam's life, instead she was filled with deep emotional pain: grief and despair. In grieving the loss of the baby Pam wished she had been more cautious and protective of the baby in those first few weeks of conception. She hoped for another chance to conceive.

Pam stated she was still "obsessive" about this pregnancy. She was desperate for more information so she could understand just what had happened, to accept it, and to be better prepared for the next pregnancy. To resolve the experience by perceiving it as one of those life events that you have no control over was unacceptable. Pam wanted a concrete explanation for why this occurred to her. Perhaps a concrete answer would have provided the reassurance she needed to spark faith in and hope for her ability to successfully conceive and deliver a healthy child if given another chance by some divine intervention.

Pam needed to talk to someone who understood what it was like to lose a baby. She felt isolated and alone in her pain because family and friends belittled her experience of fetal loss by equating it with a miscarriage. She was unaware that psychological counseling following a genetic abortion was available through health care services. Pam was skeptical of the help that may be offered from health professionals because the ones she had been in contact with throughout the pregnancy were judged as "cold" and "clinical."

Nick thought that the best way to deal with his loss and grief was to accept it and get on with life. Though his perspective was "it was done and over with" some of his comments implied feelings of unresolved guilt for having decided to "kill the baby." His grief was manifest as anger, denial and hope. The anger stemmed from his perception that he was not well enough informed about the genetic diagnosis or the prognosis for the baby. He denied the need to explore and express his emotional pain. In an effort to support his wife he too hoped for another chance to conceive.

He suggested that his wife needed to resolve the loss and wondered if psychological counseling would be helpful to her. Pam immediately considered two strategies for replacing the lost baby.

Trying again or seeking adoption

Trying again

Two different connotations were derived from the phrase "try again"; one was the informants perspective and the other was the attitude of family and friends. Trying again was "an emotional response" used by the informants and other people as a means of dealing with the fetal loss. As a way to minimize the significance of the loss, family and friends equated this tragedy with a miscarriage; one of those life events, although disappointing, nonetheless an unforeseeable aspect of womanhood. Pam interpreted this "so what" attitude as an insensitive lack of understanding which further heightened her experience of isolation, alienation and loneliness.

Pam's initial reaction to the termination was "wanting to replace" the lost child "right away." She hoped for two things: another chance to conceive and that she would not feel so "uncertain" with the next pregnancy. Pam's fear of recurrence of a genetic problem with a subsequent pregnancy was outweighed by her misconception that because an abnormality had already happened once, there was only a "very slight...slim chance" of it ever occurring again (Tversky & Kahneman, 1974, p.1126). This fear of recurrence adversely affected Pam's ability to decide whether to try again or opt for adoption.

In the context of hoping for another chance Pam bargained with herself to better protect the next baby during the initial weeks of pregnancy and to have a "more positive attitude right from the beginning." Regret for not adequately protecting this baby raised the question of whether Pam understood that she was not responsible for the genetic aberration in the baby.

Nick did not explicate a desire to try again. He implied that he needed a resolution period to adjust and internalize his loss and grieve. His coping strategies were "keep going...put it aside" and to "catch up on life later."

Seeking adoption

Adoption was a viable alternative for these informants because their name had been on an adoption waiting list for five years. "It certainly is easier to adopt" and if the criteria for selecting the child is very specific, the chance of receiving a "perfect child" was very high. "One nice thing about adopting, you're just handed this perfect, perfect child." Ambivalent feelings of hope and uncertainty about the possibility of conception made it more difficult to make any decision about how to fulfill the desire for a perfect child.

How these informants perceived their pregnancy as they compared themselves to normal expectant parents

The pattern of divergent perceptions was again evident for women and men. Comments in this category were primarily from the female informants. Women perceived that PNGD contributed to their overall sense of "calmness" because they were able to approach the pregnancy from a logical perspective as opposed to reacting emotionally. Men tended to emphasize the discomfort of holding back the elation and anticipation of having a baby. Generally, the male informants thought that their wives were over reacting to the risk, "overly worried" or "just paranoid."

Unanimously, the women agreed that it was normal for all expectant mothers to worry about the health of the baby during the entire nine months of pregnancy. This was believed to cause stress not only for themselves but also for the baby and anyone else who knew about the pregnancy. All informants suggested an improvement to the provision of PNGD and counseling service would be to make the test available at an earlier period in gestation and to shorten the period of waiting for the diagnostic results.

The most commonly stated benefit of this genetic health care service was alleviation of uncertainty; the fear of the unknown. The fear of "what if" was dismissed. The women felt "safe", "relieved", "confident", "secure" that their dream of delivering a "perfect baby" would come true. Joan, who experienced a self-described higher than normal level of ambivalence about the baby, perceived the whole process of PNGD and counseling as a positive experience. She said it gave her the "courage to carry on" during the early stages of pregnancy when she felt ambivalent and unable to decide whether she would actually become a mother of a newborn.

Pam stated that given another pregnancy she "definitely" would not undergo PNGD as no one was ever able to tell her for certain whether the baby was genetically normal or not. She perceived that the uncertainty about the baby's condition would never be resolved.

Comparing themselves to expectant women ineligible for prenatal genetic diagnosis, two of the women suggested that as a result of PNGD they were now in a position to make concrete plans for the future. They no longer had to worry or wait; they already knew "for sure" about the normalcy of the baby and it's gender.

Validation interviews with primary and secondary informants

One, two hour interview was conducted with four primary informants in two marital dyads and two secondary informants. Both husband and wife were interviewed together. The four parent processes were validated when these informants immediately recognized the processes as representative of their personal experience. Interviewing spouses together was advantageous in that gender differences in perception of the risk, the degree of perceived uncertainty and patterns of prenatal/fetal attaching were verified and openly discussed between partners.

Summary

The purpose of this chapter was to document the experiences of six informants during the first and second trimesters of pregnancy while they underwent PNGD and counseling. The findings were derived from verbatim statements made by informants which were grounded theoretically by using a constant comparative technique of simultaneous data collection and analysis. The significance and meaning of recurrent themes, patterns and processes, from the "emic" perspective were described in relation to the chronological events of the genetic counseling process. The process of maternal, paternal/fetal attachment and the process of deciding were also documented. The six sub-processes incorporated in the process of coping to fetal genetic risk were integrated, as they fit, into the chronological process of prenatal genetic diagnosis (PNGD).

Confirmation of the pregnancy precipitated the experience of uncertainty which,in turn, triggered the process of coping. Throughout the process of coping with fetal genetic risk five types of uncertainty were delineated: pregnancy, fetal, life event, abortion and diagnostic. Waiting in a state of uncertain limbo to find out the diagnosis of fetal normalcy or abnormality had a significant social psychological impact on all the informants and influenced parental/fetal attaching while waiting for the test results. This effect was more obvious in the comments made by the women as compared to data from the men. Keith, represented a negative male case. His perceptions of the events and his style of coping were often similar to the womens' perspective but were less intense.

A significant finding was the discovery of two parallel but divergent coping trajectories for each gender in the study. All informants reacted similarly by employing the same coping strategies when confronted with the threat of fetal genetic risk: waiting, hoping, seeking, deciding and protecting, except for worrying. Both male and female informants employed worrying as a coping strategy but the men denied that there was ever anything to worry about.

The differences in how each gender coped with the process of PNGD and counseling were a result of disparate points of view about the fetal genetic risk, the expected fetal diagnosis and preconceived notions about having an abnormal child. These differences were not openly discussed between spouses during any phase of the PNGD and counseling process.

Another important finding was that the process of PNGD affected prenatal attaching behaviors for both expectant mothers and fathers. Women delayed attaching to the baby until after the amniocentesis result was known whereas the men tended to experience the "focusing" phase of involvement with the baby prior to the 25 to 30 weeks gestation as documented by May (1982).

It was not the objective of the researcher to generalize the findings from six informants to a target population of all expectant parents faced with a fetal genetic risk. Moreover, the researcher's aim was to follow prospectively, expectant parents through the process of PNGD and counseling to document each spouses' perception of the events involved with PNGD and their perception of the progress of the pregnancy. The fact that the data, regarding the outcome of a positive amniocentesis result was collected from only two informants, is a limitation of the study design, never-the-less, the data is richly descriptive and demonstrates a need for further investigation of this phenomenon.

The function of the next chapter is to explicate how the findings from this small sample of informants contributed to the depth and scope of extant knowledge regarding the processes of PNGD and counseling, prenatal attachment and coping with fetal genetic risk.

CHAPTER V

Discussion

In this study the purpose was to examine the perceptions of women and their spouses regarding prenatal genetic diagnosis (PNGD) and counseling. The expectant parents in this study described four processes that occurred simultaneously throughout the first and part of the second trimesters of pregnancy while they underwent prenatal genetic diagnosis (PNGD). The four parent processes were: the chronological process of prenatal genetic diagnosis (PNGD), the process of coping with fetal genetic risk, the process of deciding, and the process of parental-fetal attaching (see figure 2). The chronological process of PNGD (see figure 3) from the informants' point of view served as the model to present the findings of this study. The processes of deciding (see figure 4) and parental-fetal attaching were also described in chapter four. The theoretical model that emerged as the overall basic social process common to all informants was the process of coping with fetal genetic risk (see figure 5). This process is the focus of the discussion chapter.

In this chapter the findings from the current study were integrated with extant knowledge from previous investigation into the topics of prenatal genetic counseling, uncertainty, coping, and prenatal attachment. These topics were discussed in separate sections but in actuality the concepts were inseparable and intricately intertwined. Implications of the study findings on future research and its impact on nursing practice was also reviewed.

Coping with fetal genetic risk:

A basic social process (BSP)

The process of coping with fetal genetic risk (see figure 5) emerged as the core variable or the overall basic social process (BSP). This process consisted of three phases: confirmation of the pregnancy, perception of the threat, and coping strategies. These three phases were composed of six sub-processes: worrying, seeking, deciding, protecting, waiting and hoping. This single process impacted on and accounted for spousal and gender differences in response patterns during all three of the other parent processes.

A significant finding in this study was that both women and men experienced the same coping process, with the exception that the men did not admit to having employed worrying as a coping strategy. For the most part, each gender followed a parallel but divergent trajectory of coping. Spousal differences emerged regarding their perception and meaning of the genetic risk; their degree of uncertainty about the fetal outcome; and the magnitude and intensity with which each gender used the same coping strategies to modify their experience.

In order to understand how the results of this study fit with what is already known in the research literature about the process of coping with prenatal genetic diagnosis, the theoretical model "Coping with fetal genetic risk", as derived from the research data was elaborated upon in relation to: uncertainty, and parental/fetal attachment.

Uncertainty

The informants in this study described uncertainty as a state of "not knowing for sure" which implied cognitive awareness of an inability to decide or predict with any confidence what the future would bring. Uncertainty was perceived as just one of those situations in life that every one is saddled with; pregnancy was just another uncertain life circumstance. This uncertain philosophy about life was also discussed by Bercik, (1980). All pregnant women must deal with the uncertainties inherent with not knowing in advance what the outcome of the pregnancy will be (Bergum, 1989; Rothman, 1987). What was different for these three female informants as compared to normal mothers-to-be was that they expected that for the most part their uncertainty would be resolved when the fetal diagnosis was finally reported to them.

According to the taxonomy devised by Monat, Averill and Lazarus (1972) the nature of uncertainty reported in the current study was "event" uncertainty since "the time of occurrence is known, but where the probability of occurrence may vary." It was not "temporal uncertainty" (p.237) because the informants did not know if the fetal genetic risk would invariably result in harm.

Conceptually, informants' definitions of uncertainty were essentially the same as the definition coined by Mishel (1988). These study informants expressed words and phrases to describe their state of uncertainty: "limbo", "holding back", "nothingness" which were similar to the descriptors used by infertility patients interviewed by Sandelowski (1987). The characteristics or attributes of uncertainty as reported in this study were the same as those identified by Mishel (1981) and Norton (1975) except ambivalence. Informants' comments about ambivalence were inferred as a concept related to the pregnancy rather than an attribute of uncertainty.

Common to all the women, uncertainty was more important to them than their husbands because it represented the possibility of an unfavorable end to their reproductive intention. That meant that the had to protect and prepare themselves for the worst possible outcome. In opposition, the male informants thought of uncertainly as an "opportunity" (Mishel, 1988, p.230). They viewed uncertainty as an opportunity for success; they were completely preoccupied with the idea that a favorable outcome would occur rather than a negative one. This coping strategy strengthened their sense of hope. Because the men were able to defensively avoid the reality of a fetal genetic risk and its potential for harm, they said they did not admit to using worrying as a coping strategy. Instead they used an 'opportunity' interpretation of the risk information to collaborate their sense of "intuitive optimism." This finding supported the proposition that people who use escape-avoidance coping strategies to deal with highly uncertain situations use emotion-focused rather than problem-focused coping mechanisms (Hilton, 1989).

Similar perceptions have been documented by other investigators. The subjective experience of uncertainty has been perceived as a stressor and posited as having a negative influence on human behavior (Cohen, 1983; Parsons, 1980). Paradoxically, uncertainty has been identified as a state of mind that facilitates a person's sense of optimism and perception of hope, especially when the prognosis of a disorder remains uncertain (Davis, 1960; Jones Jessop & Stein, 1985; Mishel, Hostetter, King & Graham, 1984; Wiener, 1975; Hilton, 1989).

Mishel (1983) hypothesized that how well people coped with a given situation is dependent on their ability to resolve uncertainty. She purportes that women diagnosed with breast cancer who had a high degree of pessimism and uncertainty exhibited problems adjusting to ill-health and alterations in their personal relationships (Mishel et al., 1984). Many researchers accept the idea that uncertainty does have an effect on human behavior and that coping strategies such as vigilant information seeking, social support and client/health professional interactions decrease the negative impact of this state of being (Monat et al., 1972; Janis & Mann, 1977; Mishel, 1981; Mishel,1984b; Shalit, 1977; Wiener, 1975; Jones Jessop & Stein, 1985; Sandelowski, 1987; Boss & Greenberg, 1984). Unfortunately researchers in the area of prenatal genetics have paid insufficient attention to the concept of uncertainty as related to the process of coping with PNGD and counseling; therefore, little is known about how it influences the process of coping for this clinical population.

In this study, informants described their state of uncertainty as something that changed over time as a result of the sequence of events in the PNGD and counseling process. Informants' comments were categorized into five different classifications of uncertainty: pregnancy, fetal, abortion, life event and diagnostic. One or more types of uncertainty were experienced at any given time as the chronological events changed over time, so did the object and intensity of informants perceived uncertainty.

Anecdotal references to four types of uncertainty have been made by other researchers in the area of prenatal genetics: reproductive, decision making, waiting and diagnostic.

The extant label, diagnostic uncertainty, as reported by Beck Black (1979) and Zuskar (1987) was described by two informants in this study. Hilton (1989) and Sandelowski (1987) proposed that ambiguity, an attribute of uncertainty, intensified the subjective experience of an unknown risk because it was interpreted as a lack of personal control over the situation. The couple in this study who decided to terminate their fetus felt an intensification of their powerlessness when they were informed of the fetal diagnosis. Their sense of ambiguity was a result of an unknown perception of the degree to which the baby would be affected by a specific genetic abnormality; it was "a flip of the dice" [sic] thus the prognosis of their child remained diagnostically uncertain; as well they perceived that the information they were told by the geneticist, the obstetrician and the gynecologist was inconsistent and contradictory. This same couple talked about having doubt and skepticism regarding the accuracy of the laboratory test result, as well as a lack of "100% sureness" about the genetic expression of the diagnosed disorder. Their ambiguity was strongest when they reflected on the decision that they made regarding whether or not termination of the baby was justified in their circumstances. Therefore, it would be important to ensure that counselees have a clear understanding of the limitations of cytogenetic laboratory technology.

Reproductive uncertainty, coined by Wertz (1984; Wertz and Sorenson, 1986; Sorenson & Wertz, 1986) has received recognition from a number of authors (Sjogren & Uddenberg, 1988; Ekow et al., 1985; Beeson & Golbus, 1985; Sorenson et al, 1981; Beck Black, 1981; Lubs, 1979). In these studies the term was conceptually and operationally defined as "unsureness about undertaking a pregnancy in the next two years" (Wertz, 1984,p.79). Reproductive uncertainty in this current study was inferred as unsureness about whether or not the woman was biologically and physically capable of reproducing and delivering a normal, healthy child. Both definitions imply having to make a decision in the face of unknown future events; the latter conceptualization denotes unpredictability and powerlessness while the first definition presumes desire and preserves personal control.

Decision making was inferred as an attribute of all types of uncertainty rather than as a separate kind of uncertainty. The attribute of decision making marked the difference between ambivalence and uncertainty. Ambivalence, although relevant to the experience of uncertainty did not truly represent a model case of uncertainty, rather it was a borderline concept (Walker & Avant, 1983) because informants' descriptions of ambivalence emphasized mixed feelings but the element of decision making was missing.

Waiting uncertainty (Rice & Doherty, 1982; Robinson et al., 1979;1984) was not relevant to the informants in this study, nor did their comments verify its existence. The researcher interpreted the data within the waiting category as a coping strategy, not as a different type of uncertainty. Waiting for the fetal diagnosis was contingent upon the time frame over which the chronological events of PNGD occurred.

Pregnancy, fetal and abortion uncertainty as implied but not labelled or explicitly defined in previous research (Lippman-Hand & Fraser, 1979a;1979b;1979c; Beck Black, 1979;1980) were very significant concepts for these six informants. Surprisingly, these concepts have not been addressed by past researchers interested in the affects of PNGD and counseling.

Uncertainty was inferred as a mediating variable between the perception of hope which meant the baby would be normal and the perception of despair which meant the baby would be abnormal. Informants' changing perception of the situation, as more or less certain of a positive or a negative outcome, represented the continuum of certainty. Thoughts of hope invoked feelings of confidence, optimism, anticipation and excitement. In opposition, thoughts of despair triggered feelings of loss, grief, shame, isolation, alienation, loneliness, hopelessness, hostility, remorse, and self-blame. Two male informants tended to cope with uncertainty by maintaining hopeful, optimistic thoughts whereas the three women and one man 'tee-ter-tottered' between hope and despair while waiting for the genetic diagnosis of the fetus. Uncertainty which acted as the fulcrum that shifted towards either hope or despair was influenced by the individual's perception of the risk, the chronological events of PNGD, the pressure of gestational time and the person's perception of the world. In an effort to protect themselves, the women tended to think about the worst possible outcome, that the fetus would be abnormal. On the other hand, a combination of factors, namely knowledge of the physical presence of the fetus, enlargement of the abdomen, fetal movement, and the image of a physically normal child on the ultrasound screen, would not allow the women to totally disregard hopeful thoughts that the baby would be normal.

In summary, current usage of the term uncertainty in the genetics literature is similar but slightly different from the perceptions of uncertainty expressed by these six informants. Categorization of informants' comments into a taxonomy of five different types of uncertainty revealed that expectant parents do in fact perceive uncertainty in relation to their reproductive situation and attach personal and social meaning to the PNGD test. There were spousal differences in the perception of uncertainty and how each gender coped with the process of PNGD and counseling.

Coping

Many nurse authors have accepted the cognitive appraisal model of coping described by Janis and Mann (1977) and Folkman and Lazarus (1988), and Folkman, Schaefer and Lazarus, (1979). In this model, coping was defined as "...an attempt to gain mastery over conditions of threat..." (Clarke, 1987, p.670). For the purpose of this study the researcher did not differentiate between the terms coping and defense mechanisms.

Coping is thought to be an evolutionary process of managing and mastering the dynamic relationship between person and environment. This process is believed to be triggered by stressful stimuli (Graydon, 1984; Shalit, 1977; Folkman & Lazarus, 1988). Informants in the current study identified the fetal genetic risk as a threat because it meant that the pregnancy "may not work out" the way they anticipated. The term stress was never used by any of the informants.

Coping was defined by Joan as "day to day management" and it was perceived as something that went on for "forever." The perception of threat or danger regarding the fetal genetic risk was more significant for the women in comparison to the men. Perhaps the women perceived the pregnancy itself as an anomaly (Silvestre & Fresco, 1980) because they were physiologically "older" or conception seemed impossible after a history of infertility. The women interpreted the genetic threat as a potential harm that could happen to them. In contrast, the men intellectualized the threat; they perceived the occurrence of a fetal abnormality as very unlikely. Two male informants defined successful coping as making a decision that they felt "comfortable" with or one that they "could live with" because it fit into the context of their everyday lives. Coping also meant keeping a harmonious marital relationship.

Factors known to affect cognitive appraisal of a threat are: intelligence, personality, past experiences, social support and religious beliefs (Myers, 1983). Informants in this study identified two additional factors: concurrent life stressors and their sense of personal control or the perception of having their life pre-planned in another direction.

Coping related to a prenatal genetic threat was described by Lippman-Hand and Fraser (1979a), as knowing that the risk of genetic abnormality could be "dealt with." Parents in that study buffered their perception of the fetal genetic threat with a sense of confidence knowing that they bore a normal child in the past. This reassured them that "the worst" may not happen. The "families" in the Lippman-Hand and Fraser study imagined scenarios of "what would it be like if an affected child was born." The three female informants in the current study also used scenarios in an attempt to understand the reality of the potential risk and to assess their parental coping abilities. The imagined scenarios for the women helped them to rationalize their belief that having a handicapped child would be a burden. Similarly, the men questioned their own ability to cope with a handicapped child, "what can I cope with and what can I not cope with." All three men recalled childhood memories and past experiences with handicapped children to rationalize why they thought they could cope with parenting an abnormal child. Although, Arnold and Winsor (1984) utilized researcher-contrived scenarios as an intervention to deliver genetic counseling, descriptions of actual scenarios created by the people who undergo prenatal genetic services has never been documented.

A variety of coping models exist in the research literature the "cognitive appraisal" or problem solving model of coping as posited by Folkman, Schaefer and Lazarus (1979) has been most widely accepted by health-illness researchers and has been empirically tested (Jenkins & Pargament, 1988; Shalit, 1977; Clarke, 1987; Warner, 1981; Vingerhoets & Marcelissen, 1988). The cognitive appraisal model has also been employed in situations of health and illness to describe and interpret peoples' perceptions of uncertainty regarding the prognosis of their disease (Hilton, 1989; Mishel, 1981).

Within this model, the concept of coping comprises both problem and emotion focused behaviors. Emotion focused behaviors are described as a composite of defense mechanisms orientated toward managing or controlling one's emotional response in a situation such as: intellectualization, denial, reaction formation, avoidance, blaming and distancing (Folkman & Lazarus, 1988; Gurklis & Menke, 1988; Vingerhoets & Marcelissen, 1988; Clarke, 1987; Myers, 1983; Shalit, 1977). Problem focused behaviors are centered around seeking new information for the purpose of making informed decisions in order to attain a highly valued goal (Clarke, 1987).

Instead of just accepting and applying Lazarus's theory of coping, informant statements were analyzed to discover the essential components of coping that were described by these six informants. The respondents in this study described three types of coping behaviors: cognitive, intrapsychic, and spiritual. Each of these coping categories is discussed with a view to reveal similarities and differences between spouses and genders. Lazarus's cognitive appraisal model of coping was compared and contrasted with the theoretical model of coping as described by informants in the current study.

Cognitive coping strategies

Seeking knowledge and support, making decisions, waiting and wishing were cognitive coping strategies employed by all informants. Predominantly, women tended to take on the role as the seeker of knowledge and social support; they also asserted control over reproductive decision making to a much greater degree than their male counterparts.

Seeking

1. Knowledge symbolized a means of regaining personal control over their reproductive situation. The female informants were vigilant knowledge seekers, whereas the men were more passive about receiving information from professionals and vicariously from their wives. Womens' vigilant search for information has been described by Kessler, Kessler and Ward (1984) as an attempt to absolve themselves of the guilt naturally associated with not accepting PNGD, then having a child with a genetic disorder. In their anecdotal report, women sought the advice of an expert professional to collaborate with and to share their sense of responsibility regarding procreative decision making. The women in this study reported similar thoughts. Because they were such vigilant knowledge seekers this activity might have heightened their sense of helplessness/powerlessness because the genetic information tended to reinforce the plausibility of the threat or harm. The concept of vigilant and hypervigilant knowledge seeking has also been documented as a means of coping by Folkman & Lazarus (1988).

2.Seeking support was more important to the women than it was to their husbands. Women sought social support from family members and close friends about the social acceptance of having a child at an advanced age and the appropriateness of undergoing PNGD. They sought support from the medical profession about the normalcy of the fetus, and confirmation that the physical changes they experienced with pregnancy were normal. In contrast the men generally denied their need for social support, and they were reserved in telling others about the pregnancy or their wives' decision to seek prenatal genetic diagnosis (PNGD).

Deciding

The men and women in this study perceived decision making as a way of actualizing personal responsibility and control over an event that would drastically change their lives. Both Falek (1984) and Blumberg (1984) suggested that genetic counselees integrate a variety of social, psychological, economic and environmental factors during the process of deciding and that rational review of new information is not the single most important criterion for making a decision. The informants in this study identified factors that they considered important, as well as how these factors fit into the overall decision making process (see figure 4).

Two distinct styles of decision making, mutual and peremptory, were described by the informants. These styles may be associated with the quality and stability of the spousal relationship. A pattern of mutual decision making may be indicative of an open, trusting, communicative relationship while, the peremptory style may represent manifestation of either temporary or chronic marital discord.

With confirmation of the pregnancy the women adopted a leadership role in making their own reproductive decisions which placed the men in a subordinate position. Because the men acknowledged their wives as the ones who were pregnant and the ones who carried the growing fetus, they perceived their wives' leadership as natural; the "way it should be." Unanimously, all informants concurred that the couple were the persons best "qualified" to make a moral life or death decision about the fetus if such a decision became necessary.

Gender differences in the pursuance of prenatal genetic knowledge as reported by these informants supports the findings in a study by Sjogren and Uddenberg (1988). The great majority of the women in that study described the husband's role as "...that of a moderately or little committed advisor..." (p. 269). Similarly, the three female informants reported that the final say regarding acceptance of PNGD was their sole decision.

Hostile reactions by one male informant in this study and his adamant belief that he was "not well enough informed" to make the moral decision regarding termination may have been a consequence of his decision to accept a more passive role in seeking new information and decision making. Perhaps this reaction is exemplary of a defensive-avoidance style of coping (Kelly, 1977).

Waiting

Waiting represented a significant experience for expectant parents during the process of PNGD and counseling. Informants' perceptions and the meaning they attached to waiting changed over time, and the perception of waiting was different for each gender as was the object of what they waited for.

The concept of waiting was modified by individual beliefs, personal conditions antecedent to the waiting experience and changes in events over time. One female informant had waited 13 years for a pregnancy prior to this conception; she waited in the realm of the natural world placing trust in the "...power and process of nature..." (Fujita, 1985, p.111). Waiting four weeks for the amniocentesis results was described by one male informant as, the "wheels of medicine turn slowly" and two female informants as a "long, long time." One female interpreted waiting for the fetal diagnosis as a period of nothingness or limbo, devoid of thinking or doing anything because the forces of medical science and technology were in control. Waiting prior to receiving the test results symbolized informants' overt expression of powerlessness over their own reproduction and dependence on medical science. Once expectant parents received a diagnosis indicating that the baby was normal, the nature of their waiting transformed from hope and fearing despair to joyful anticipation and a period of preparation for the birth of the baby.

Documentation over time of the process of waiting revealed that waiting was important to informants not just during the four week period prior to receiving the fetal diagnosis (Evers-Kiebooms et al., 1988; Branson Ruiz-Bueno, 1987; Robinson et al., 1984; Brewster, 1984; Beeson & Golbus, 1979;1985; Dixson et al., 1981; Godmilow et al., 1978; Finley et al., 1977), but that waiting was an integral part of each phase of the PNGD and counseling process. To draw attention to the experience of waiting only during the period following amniocentesis is a gross underestimation of the informants' sense of waiting throughout the whole pregnancy and PNGD.

The subjective meaning of waiting for women was described as "impatience" yet it stimulated their sense of hope. They waited for evidence to justify either termination or continuation of the pregnancy. They described themselves as "having a real sense of waiting" especially just prior to receiving the fetal diagnosis. In contrast, waiting for the males meant "holding back" their exhilaration about and anticipation of having the baby; they waited for confirmation of the normalcy. Even though the men expected the PNGD test to indicate normalcy of the baby, they held back feelings of elation, excitement and expectation because their wives anxiously and impatiently waited for medical evidence to "make certain" that the baby would actually be born. Womens' view of waiting was characterized by powerlessness. Whereas waiting for the men had more of an experiential quality. It was perceived as a natural component of the process of becoming a father.

Wishing

Wishful thinking has been described as an "escape-avoidance" activity. It's function is to neutralize emotional distress but ironically only provides brief respite from an unpleasant situation. It has been associated with symptoms of depression and anxiety

(Folkman et al., 1979; Folkman & Lazarus, 1988). Perceived powerlessness was inherent in the strategy of wishing as was evidenced by the informants in this study. Because the act of wishing was generally contingent upon retrospective hindsight it was interpreted as a passive means of regaining personal control. Sometimes wishing was in response to feeling guilty for not having taken appropriate action in the past and at other times informants employed it as a bargaining strategy that helped them cope with their grieving process. Unfortunately wishing as a coping strategy has received little attention from other researchers, hence the answer to the question of whether wishing is used as a coping strategy in other health-illness circumstances remains unknown.

Intrapsychic coping strategies

This category is equivalent to the emotion-focused behaviors as described in the extant literature by Folkman et al.(1979;1988). The pattern of intrapsychic coping was the same for both female and male informants in this study. They used denial, defensive avoidance and intellectualization as strategies to protect themselves from feeling the full emotional brunt of the fetal genetic risk: the possibility of fetal abnormality or abortion. The rational for using these strategies, was based on the individual's expectation of the outcome of the PNGD, which was significantly different for each gender. The women were preparing themselves to accept the worst case scenario which meant that the baby would be abnormal and a decision regarding abortion would have to be made. The men expected that the PNGD would show that the baby was normal and that there was nothing for either expected parent to worry about.

Worrying

The perception of external or internal stimuli as a threat or a danger is generally accepted as a prerequisite for activation of coping responses on emotional, cognitive and behavioral levels. Individuals expect that activation of a coping response will restore intrapsychic equilibrium and facilitate a homeostatic balance (Myers, 1983). Worrying as a coping strategy had both adaptive and maladaptive effects for the women in the current study.

Worrying was described as an internal coping strategy and not just an emotional reaction to awareness of the fetal genetic risk. The three female informants described it as a pervasive obsessive thought pattern that protected them from externalizing their worst fears and preconceived notions about having a handicapped child. Worrying helped them to cope with the unknown by forcing them to think about and prepare for the possibility of fetal abnormality and/or abortion.

Worrying was triggered by a shift in their perception of uncertainty about the normalcy of the baby. Thinking about potential problems such as, maternal illness or the diagnosis of a fetal abnormality stimulated an emotional response of fear but ironically, this was considered positive because their worrying forced these women to prepare themselves for the possibility of disappointment or fetal loss.

As a coping strategy worrying activated problem-orientated behaviors such as vigilant seeking of knowledge, seeking social support, and unquestioned compliance with the amniocentesis/ ultrasound procedures. In contrast, the female informants' perception of powerlessness and unpredictability regarding the genetic status of the fetus threatened their self-esteem which resulted in feelings of shame and guilt which supports the work of other authors (Hilton, 1989; Folkman & Lazarus, 1988; Kessler et al., 1984; Kelly, 1977; Shalit, 1977). Fearing ridicule, judgement or precipitating conflict with their spouse, these women avoided open discussion with their husband about their concerns, worst fears and self-doubts. The women tended to accept sole responsibility for the couple's reproductive circumstance hence, they prepared themselves psychologically and socially to accept the personal stigma of having a fetus diagnosed as abnormal.

This avoidance/denial pattern of behavior, paradoxically supported the men's perspective that there was nothing to worry about. The coping mechanisms of denial and avoidance offered the men freedom from worrying. They did not perceive the risk of fetal abnormality as a reality, yet they waited for the diagnosis. This perspective was further fortified by an "opportunity evaluation" or optimistic perception of the fetal genetic risk. These three men denied that they used worrying as a coping strategy but in actuality they did worry about the health status of the baby. The male informants used denial and avoidance to circumvent open discussion about the possibility of fetal anomaly and/or abortion. Their ability to distort reality was paradoxical to the kind of support and open discussion the women needed to help them deal with their fear that the worst outcome just might happen.

Differentiation of the concepts of worrying and anxiety as documented by previous researchers is impossible with the descriptive data generated by this study. In order to really understand the relationships among the phenomenon of coping, worrying and uncertainty further research would be necessary using groups of expectant parents who had varying degrees of uncertainty regarding the genetic status of their unborn child and the woman's ability to successfully deliver a child (Monat et al., 1972).

Denial/defensive avoidance

Denial has been defined as "the refusal to accept or acknowledge" (Morehead & Morehead, 1981, p.148), an event or an emotional reaction. Unpleasant thoughts or feelings are selectively ignored (Clarke, 1987). Denial in the form of defensive avoidance was a maladaptive coping strategy that served to protect the informants from coming to terms with the reality and potential severity of the threat. The women attempted to deny the pregnancy and the presence of the fetus as a way to protect themselves from the possibility of emotional pain if they invested themselves in a baby that may be so severely abnormal that it would have to be terminated.

Consistent with the findings from a study by Folkman and Lazarus, (1988) the female informants employed detachment, a form of denial, to distance themselves physically and emotionally from the fetus. It has been hypothesized that women suspend the task of investment or binding-in with the fetus until after the PNGD result is known (Blumberg, 1984; Kessler et al., 1984; Brewster, 1984;

Beeson & Golbus, 1979). Female informants attempted to deny the pregnancy by not wearing maternity clothes, not telling family or friends about the pregnancy until they could no longer conceal it, not displaying any "baby things" in the home. Hiding the pregnancy from others has been suggested by Kessler et al. (1984) as a means for dealing with the anticipation of guilt, shame and humiliation that may accompany a termination procedure or the birth of a defective fetus. This finding supports the conclusions of Lever Hense (1989) who found that women who had a previous perinatal loss used "resisting attaching" and not telling others about the pregnancy to protect themselves from the possibility of recurrent fetal loss. The fear of social stigma was manifest by one female informant who explained the termination of her baby to others, by saying it was the result of "bleeding." She did not want to admit to others that the baby was severely abnormal hence she had decided to terminate it. Following the termination of her baby, this same informant protected herself from feeling despair, anger, and hopelessness by avoiding social settings where she might be in contact with mothers and their babies.

Another form of denial, reaction formation, as discussed by Folkman & Lazarus (1988), and Myers (1983) was commonly used by all male informants in this study. They turned the statistics of their genetic threat around and emphasized a high probability for a positive reproductive outcome, thus the men protected themselves from the discomfort of having to come to terms with the potential problems associated with a realistic perception of the risk. Considering that nothing would be known or decided upon until after the results of the amniocentesis test, this strategy served to bolster the moral strength of both husband and wife as their denial and avoidance allowed them to carry on as normally as possible in a myriad of daily social roles (Kelly, 1977; Folkman & Lazarus, 1988). Coping behaviors established by use of denial are thought to be quite fragile if the environmental stimuli should suddenly or unexpectedly change (Folkman & Lazarus, 1988). This perhaps explains, to some degree, the depth and intensity of depression, despair and hopelessness experienced by the couple who were suddenly confronted with the decision of whether or not to terminate their baby who had trisomy 18.

Intellectualization

The coping mechanism of intellectualization defined as "the exclusion of emotional reactions to situations" by Clarke, (1987, p.672) was demonstrated by study informants. In an effort to protect themselves from the potentially overwhelming feelings of anxiety, despair, helplessness, hopelessness, guilt or shame informants sought and firmly held onto the clinical facts conveyed by all health professionals they came in contact with during the process of PNGD. There was a cold sense of objectivity in informants' descriptions of how the testing procedure was done, their recall of the medical names and the symptoms of particular genetic disorders, and their interpretation of the statistical information. Intellectualization was equally important as a coping strategy for both genders in this study. It allowed informants to project a sense of personal control over their emotions in the situation. This coping mechanism became even more crucial for the female informant in the dyad who terminated their baby. She desperately needed to know the cause of the baby's abnormality. One possible explanation for this reaction is that she was attempting to regain personal control over her negative feelings (Phipps, 1981). She perceived that if she could understand what had happened to the baby, she would then be in a better position to accept the loss of her perfect child. For her, a vigilant search for knowledge may have been motivated by a sense of guilt about the fetal anomaly as well as a low self-esteem, both of which are often associated with perceived social stigma and personal shame (Kelly, 1977). The husband, equally as vigilant about seeking more information after the unfavorable fetal diagnosis, needed to feel assured that the decision they made, to terminate the baby, was the right one.

Spiritual coping strategies

Hoping and having faith in a power greater than one's self have been recognized as normal human responses under conditions of uncertainty in relation to illness (Fitzgerald-Miller, 1989; Hilton, 1989; Olshansky, 1988). Acknowledgement of spiritual needs and resources is inherent in many codes of nursing, but to date there has been little nursing research done in this area (Simsen, 1989). It is evident from the responses of these six informants that nurse genetic counselors need a sound knowledge base in ethics and philosophy if they are to provide quality care to the clients who undertake PNGD and counseling.

Hoping

In the dictionary hope was defined as "...confidence in a future event; expectation of something desired..." (Morehead & Morehead, 1981, p.262). Hoping for the informants in this study meant spiritual faith and belief. The strategy of hoping provided informants with a sense of spiritual inspiration that counterchecked thoughts of despair and fear of the worst. All informants hoped that God or some greater power would look upon them favorably and allow their perfect child to be born. Faith, prayer and belief in the power of God were identified as effective coping mechanisms that reduced dialysis patients' subjective experience of dependence, powerlessness and helplessness (Gurklis & Menke, 1988; Jenkins & Pargament, 1988; Janis & Mann, 1977). Spiritual faith was again found to be an important coping strategy for expectant women who had a previous perinatal loss (Lever Hense, 1989).

The informants in this study supported the proposition that individuals in a state of uncertainty tended to feel hopeful and optimistic that everything will work out for the best (Hilton, 1989; Mishel & Murdaugh, 1987; Mishel et al., 1984; Christman, McConnell, Pfeiffer, Webster, Schmitt, & Ries, 1988). Suspended in a state of uncertainty while the fetal diagnosis was unknown, the informants held onto the hope that the baby would be normal. In complete contradiction when it became known to one couple that their fetus was certain to be abnormal there was a sudden absence of hope. When the obstetrician suggested immediate termination the couple interpreted this information as "certainty" that "there was no hope" for a positive outcome to the pregnancy.

The male informants stated that their major coping strategy was to sustain a high level of hope or "intuitive optimism" which was classified by Fitzgerald-Miller (1989) as "a conviction that a positive outcome is possible" (p.25). They protected themselves from thoughts of despair by not allow themselves to consider an opposing view point.

Prenatal attaching behaviors

The social psychological impact of medical technology on the beneficiaries of antenatal health care has come to light as an important area of human behavior deserving much investigation (Heidrich & Cranley, 1989; Sandelowski, 1988; Harding, 1980; Grace, 1984; Fletcher, 1983). The moral, social, political and economic impact of reproductive technology on expectant parents and the power it holds over them during the process of PNGD should not be underestimated. Informants in this study perceived that the scientific power behind cytogenetic technology was in and of its self neutral, but the application of such techniques for the purpose of deciding whether a fetus should live or be terminated was value-laden. Evidence to support the notion that reproductive technology influences prenatal attachment is sparse and conflicting (Sjogren & Uddenberg, 1988; Sandelowski, 1988; Rothman, 1987; Grace, 1984; Dixson et al., 1981; Silvestre & Fresco, 1980).

Maternal attaching

The women in this study coped with fetal genetic risk by attempting to cognitively, socially and emotionally withhold attaching to the "fetus" until after they were "certain" that the "baby" was normal and they made a decision not to terminate the fetus. The women in this study denied having any fantasizes about the baby during the first two interviews which is in contrast to what other researchers have found (Lumley, 1980; Pines, 1972; Schroeder-Zwelling, 1988).

Data from the female informants in this study supported a previous speculation that expectant women do not fully accept the baby as real or anticipate the birth until after the amniocentesis result is reported (Sandelowski, 1988; Rothman, 1987; Silvestre & Fresco, 1980) This finding is contrary to the conclusions of Heidrich & Cranley (1989). They suggested that women who underwent amniocentesis and ultrasound for PNGD experienced low levels of attachment just prior to the ultrasound procedure and this recurred again just before the reporting of the PNGD result. These authors were unable to give credence to the hypothesis that ultrasonography affects prenatal attachment.

Initially, when reacting to the crisis, the women more so than the men were fearful and uncertain about the pregnancy, the baby, their own physical health and their ability to adapt and cope with changes that a new baby would bring. The intensity of their fear and uncertainty gradually decreased as they obtained and assimilated new information about the obstetrical/fetal genetic risks and when they saw the fetus on the ultrasound screen. Then as the time drew near for the reporting of the PNGD results their sense of fear and uncertainty resurged and they worried. The women became acutely aware of the unpredictability of the baby's outcome without the PNGD test and they were reminded of how powerless they were in the situation because they perceived themselves dependent on medical professionals for an accurate fetal diagnosis, yet, they lacked confidence or "100 percent sureness" that the test result would be both accurate and favorable. In this study the informants' described a decline in the magnitude of their sense of fetal/pregnancy uncertainty and worrying activities following the ultrasound procedure, but then again while waiting for the amniocentesis results their sense of fetal, abortion, and life event uncertainty became of paramount importance.

In an anecdotal report, Fletcher (1983) purported that ultrasound viewing of the fetus assisted expectant women to resolve their ambivalent feelings toward pregnancy and their desire to have a baby became stronger which theoretically, would reduce the number of abortions. Two of the female informants in this study reported a resolution of their ambivalence following the ultrasound procedure. The third woman held a contradictory point of view, moving both toward and away from attaching to the fetus. Having seen the baby on the ultrasound screen, but knowing that the amniocentesis report would not be available for four more weeks, intensified the agonizing uncertainty about whether an abortion decision would ever have to be made (Sandelowski, 1988). Pendulum-like her hope was abridged by despair.

In addition, Fletcher suggested that seeing the image of the fetus heightened any existing conflict between expectant spouses regarding the moral decision of whether to terminate or continue the pregnancy regardless of the genetic status of the fetus. The two informants, in this study, who terminated their fetus experienced extreme spiritual and emotional pain following the procedure. Perhaps their degree of suffering was influenced by visualization of the the baby on the ultrasound screen.

Paternal attaching

Observance of the process of paternal involvement with the fetus, the three males in this study demonstrated the same attaching behaviors as mapped out by May (1982) in a grounded theory investigation of paternal/fetal attachment. Although the attaching behaviors were the same for the men in this study as those in May's study, there was one obvious deviation. The gestational time period in which these behaviors occurred was different. According to May the attaching behaviors labelled as the focusing phase do not usually occur in men until around 25 to 30 weeks gestation. Visualization of the fetus on the ultrasound screen at 16 weeks gestation marked an early beginning of the focusing phase of paternal involvement for the three men in this study. The pregnancy became more personalized; the baby was perceived as a real live human being; and the husbands began to mentally work out how the baby would change their lifestyles and plans for retirement. Using a study population of only three male informants it is impossible to generalize this finding to all males who undergo PNGD and counseling but the evidence reported here warrants further investigation. Perhaps one explanation for this finding is that the husband was aware of his wife's fear of fetal abnormality and abortion and he wanted to reassure his wife that it was safe to begin to accept and attach to the baby.

Similar to the stressors identified by Glazer (1989) expectant fathers in this study were concerned about: the health of the baby, their role in labor and delivery, family finances and their ability to assume the fatherhood role.

In summary, the process of parental fetal attaching as described by the six informants in this study supported four propositions posited in the prenatal attachment literature. There were differences in the identified tasks of normal pregnancy for each gender (Campbell & Field, 1989; Mercer et al., 1988); parental attaching behaviors gradually increased over the gestational period; expectant mothers and fathers attributed personal and physical characteristics to the developing fetus (Stainton, 1985; Valentine, 1982); knowledge of the gender of the unborn child enhanced prenatal attachment, for example, expectant parents fantasized about having a boy or a girl baby in accordance with the identified sex of the child as they began to prepare the baby's room (Stainton, 1985). Another important finding in this study is the notion that expectant parents suddenly "catch-up" on nesting behaviors after the cytology report indicates that the fetus is normal. Although the women withheld attaching to the baby prior to knowing the PNGD results, at 19 to 21 weeks gestation, there was only inferential evidence to support a relationship between delayed prenatal attachment, worry and uncertainty.

Strengths and limitations

The prospective nature of this exploratory study enabled the investigator to capture informants' responses to events as they occurred. Informants described their reflective impressions of what happened and what was meaningful to them at a single point in time without the next set of events clouding their recall of the previous events and experiences. The researcher elicited frank in-depth, descriptions at three points in time in order to distinguish changes over time. Interviewing at the same three time periods for all informants facilitated comparison of the data and discovery of experiences common to all of them.

Separate interviews with spouses provided an atmosphere of privacy and openness that elicited candid expression of their perceptions and experiences. Differences and similarities in perceptions between genders and variations among all informants rendered a full range of substantive categories that further generated enough diversity of the phenomena to saturate all the core categories that emerged from the interviews with these six informants.

Density and variability in the theoretical sample are important criteria for evaluating the fit and truth value of the emergent theory. The researcher did not employ theoretical sampling and as a consequence did not generate a grounded theory. Instead, a theoretical framework was conceptualized that identified the concepts that were of major importance to the informants and a beginning attempt was made to explain the interrelatedness of these concepts.

A relatively homogeneous group of informants were selected because they were knowledgeable about the phenomenon, able to articulate their experiences and moreover, they were available and met the selection criteria. Two groups of expectant parents (see figure 1) were excluded from data collection, cell (c) were mothers and fathers-to-be who accepted PNGD but opted to termination their normal fetus; and cell (b) who were the group of expectant parents who decided to commit themselves to the child after the fetus was diagnosed as having a genetic abnormality. Looking to the future, it would be important to extend this study to include interviews with these two groups of expectant parents in order to validate the trustworthiness of the emergent conceptual framework.

Another limitation of the study was the small sample size used to generate the research data. However, this limitation did not jeopardize the aim of the study which was to ensure representativeness of the human experience and not generalizabililty of the research findings to a target population.

Implications for future research

It would also be interesting to design a study aimed at documenting the actual scenarios that expectant parents create about their unborn child when they are faced with a fetal genetic risk. Discovery of gender differences and similarities in the content of these imagined scenarios may further assist health professionals to understand how expectant parents find meaning in and cope with a fetal genetic risk.

An other question that deserves further investigation is whether there are differences and similarities in perceptions of pregnancy between parents-to-be who choose to accept PNGD and those who, although eligible, decide not to undergo prenatal testing? Additionally, a fourth interview approximately one week prior to the date of confinement would provide a more complete picture of the impact of PNGD and counseling on the whole process of prenatal parental attachment.

Implications for nursing practice

The conduct of this research study contributed a better understanding of what it was like for informants to undergo prenatal genetic services; how they interpreted and found meaning and significance in the genetic information and how PNGD and counseling influenced their experience of attaching to the fetus prenatally.

A unique theoretical conceptualization of the process of coping with fetal genetic risk was documented from the comments of actual recipients of this prenatal genetic service. Informants perceived that the six coping strategies: waiting, seeking, deciding, protecting, worrying and hoping were amenable to independent nursing intervention.

Although the purpose in this exploratory, descriptive study was to describe human response patterns rather than prescribe changes to the current practice of genetic counseling, the informants themselves suggested strategies designed to better meet their social, psychological and spiritual needs throughout the entire process of PNGD and counseling. To some degree all informants believed that the philosophy and the delivery of genetic services should integrate social support services and include repeat follow-up counseling throughout the entire experience of PNGD.

Supportive counseling throughout the entire process of PNGD

Prior to attending the prenatal genetic counseling session, informants interpreted the word counseling to denote "an interchange of opinions" (Morehead & Morehead, 1981, p.127). The essence of informants' definition of counseling was "support" and open "communication." A counseling philosophy as defined by the informants was not apparent to them during the prenatal genetic counseling session. The genetic counselor did not discuss what PNGD meant to each spouse or how the couple would go about making any decisions regarding the genetic information or the available test. Consequently, all informants perceived the genetic counselor's role as strictly educative. The non-directive approach taken by the genetic counselor and the geneticist was categorized by informants as "information giving." These informants, particularity the women needed more than just factual information. Furthermore, four of the informants interpreted the non-directive approach to counseling as "cold and clinical." Four informants suggested that they would have benefited from the inclusion of services aimed at offering support but without taking away their personal autonomy.

A major criticism of a directive style of genetic counseling is the assumption that the genetic counselor is liable to assert personal beliefs and values that would influence and perhaps even deny the counselees' right to independent decision making. The concept of "existential advocacy" a philosophical foundation in nursing is based on the assumption that people need to exercise freedom of expression in order to liberate and actualize self-determination (Gadow, 1980, p.85). Ideally, existential advocacy occurs when the nurse assists the individual to practice personal authenticity by helping them to reach decisions that are a true reflection of the whole being. Each counselee is a unique being, not withstanding contradictions, changing values and attitudes and should be assisted to clarify, re-examine, and understand what is meaningful and significant wihtin the context of their personal lives. The findings from these six informants support the testing of a "focused" rather than a non-directive style of prenatal genetic counseling; where the counselor assists counselees to understand and make relevant the information that is communicated to them (Welshimer & Earp, 1989).

The female informants expressed a need to discuss their fears about the possibility of fetal abnormality and/or abortion, their preconceived notions about handicapped children and their imagined scenarios of the worst possible pregnancy outcome with someone who was genuinely empathetic and objective. One female informant described a strong sense of support and comradeship when she talked with a women who was grieving the recent loss of her stillborn child. Two of the women in this study indicated that it would have been therapeutic for them to share their personal experiences with a like-minded woman who also faced an uncertain reproductive outcome. All of the informants concurred that supportive counseling services should have been offered to them throughout the entire process of PNGD and counseling, regardless of who provided the service: a "social worker", the genetic counselor or a self-help group. It was emphasized that confidentiality and privacy could be protected by giving each new female counselee the name of a volunteer who had consented to be contacted as an individual resource person or as a representative of a female self-help group. The female counselee could then decide whether or not she wanted to accept the support of a professional or a layperson who had experienced PNGD and counseling.

Supportive counseling before, during and after the termination procedure

The couple who decided to terminate their pregnancy following genetic diagnosis of their fetus recognized the need for a "quick" course in labor and delivery prior to the actual termination of their fetus. Pam had never experienced labor before and had attended only one prenatal class yet she blamed herself for not knowing the physical signs indicating impending birth. The husband, who had only just recently resolved in his own mind whether he would accompany his wife into the delivery room, felt grossly inadequate when suddenly confronted with premature labor and delivery. He expressed feelings of shame and guilt because he did not know how to support his wife, emotionally or physically, during the trauma of a long labor, then the delivery of a dead fetus. Both informants wished that they had received some anticipatory guidance about what was going to happen.

The husband suggested that expectant fathers need a counseling intervention aimed at helping men to perceive the fetal genetic risk realistically. He suggested that, at the onset of genetic counseling, men should be given a questionnaire aimed at exploring how they would like the termination procedure to be handled if the couple decided it was necessary. For example questions like, "Would you like to see the baby after the termination procedure?"; "Would you like to hold a funeral service for the baby?"; and "Would you like to know the sex of the baby?" Ideally, expectant parents would discuss and perhaps resolve spousal differences prior to any decision making. Perhaps couples would be better prepared to grieve the loss of the hoped for perfect child and put the lost child to rest with dignity. This suggestion may have merit but should be approached with caution as it has the potential of driving expectant parents away from PNGD and counseling altogether.

A nurse genetic counselor who has clinical expertise in the areas of labor and delivery, genetic disabilities and bereavement counseling would be in a unique position to practice a holistic model of care to counselees who decide to terminate their pregnancy. If the nurse genetic counselor was available throughout all phases of the PNGD and counseling process and at the bedside during the termination procedure s/he could assist counselees' to cope with their physical, spiritual, psychological and family needs during and after the termination experience.

There is a trend for women with higher education and career aspirations to postpone childbearing until later in life (Winslow, 1987; Dawe, 1986; Blumberg, 1984; Davies & Doran, 1982; Silvestre &

Fresco, 1980). Because of this, the need for nurse counselors in the area of prenatal genetics will continue to expand in the future (Fitzsimmons, 1985; Zander, 1985; Forsman, 1983; Hunter, Thompson & Speevak, 1987; Scott, Walker, Eunpu & Djurdjinovic, 1988). It is imperative that these nurses base their counseling interventions on substan[illegible] nursing theories derived from the scientific observations of those people who engage in prenatal genetic diagnosis.

Conclusions

The purpose of conducting this study was to examine the social psychological experience of prenatal genetic diagnosis (PNGD) and counseling from the view point of expectant mothers and fathers. The findings in this study may hold implications for the provision of genetic counseling services and subsequent follow up care of expectant parents who decide to terminate an abnormal fetus.

The following hypotheses arose following analysis of informants' comments.

1. Both genders of expectant parents utilized the same six coping sub-processes in dealing with the fetal genetic risk: waiting, worrying, seeking, deciding, protecting and hoping. The exception being that the men denied that they worried.
2. The experience of PNGD and counseling influenced the pattern of prenatal maternal and paternal attaching to the fetus. Maternal fetal attaching was delayed until after the fetal diagnosis was known and the experience of seeing the

baby on the ultrasound screen initiated an early beginning to the focusing phase of paternal fetal attaching.

3. Gender differences existed between spouses regarding their perception of the fetal genetic risk, the degree of perceived uncertainty and fear about the normalcy of the fetus and the perception of burden in bearing a genetically abnormal child.

Questions that remain unanswered at the completion of the study are:

1. Do expectant parents perceive anxiety and worry as the same concept?
2. Does the process of PNGD and counseling influence the marital relationship between spouses?
3. Is there a directional relationship between expectant parents' perception of uncertainty and their perception of anxiety?

Concluding remarks

As a nurse researcher I recognize that my past experiences, values/beliefs, life context, and understanding of the extant literature have impacted on every phase of this research process. By consciously attempting to bracket these awarenesses I have truly attempted to actively listen to informants' descriptions of their experience. Through the use of critical thinking, creative abstracting and extension of my mind and heart I strove to let go of preconceived notions about the social setting and the phenomenon as grounded in my nursing perspective. In full awareness that this study is limited to conversations with only six informants, it is offered as an exploratory study meant to anchor and stimulate continued research in the area of prenatal genetics that ultimately will lead to the development of a nursing theory that explains human response patterns within the context of genetic diagnosis and counseling.

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TABLE 1. BIOGRAPHICAL CHARACTERISTICS OF THE INFORMANTS

Couple	Informants	Age	Occupation	Education	Religion	Parity/ Gravida
PRIMARY INFORMANTS						
one	M	38	stockbroker	BA	Protestant	
	F	36	special education teacher	B Ed.	Protestant	0/1
two	M	43	carpenter/ furniture designer	BA English	Protestant	
	F	38	special education teacher/ school counselor	B Ed.	Protestant	1/3
three	M	30	computer store manager	BA architecture	Protestant	
	F	38	homemaker/ hairdresser	Diploma/ Beauty School	None	2/4
SECONDARY INFORMANTS						
four	M	28	pipefitter	grade 12	None	
	F	28	bartender	grade 10	None	3/2

Results of the Amniocentesis
for
Prenatal Genetic Diagnosis

Deciding	Negative	Positive
Continue the Pregnancy	"Winning the lottery" Resuming tasks of normal pregnancy (a)	Making a committment to love and care for a handicapped child (b)
Terminate the Pregnancy	(c) Seeking justification to terminate a normal child	(d) "Taking a chance and losing" Getting it over with

Figure 1. The four possible outcomes of prenatal genetic diagnosis (PNGD).

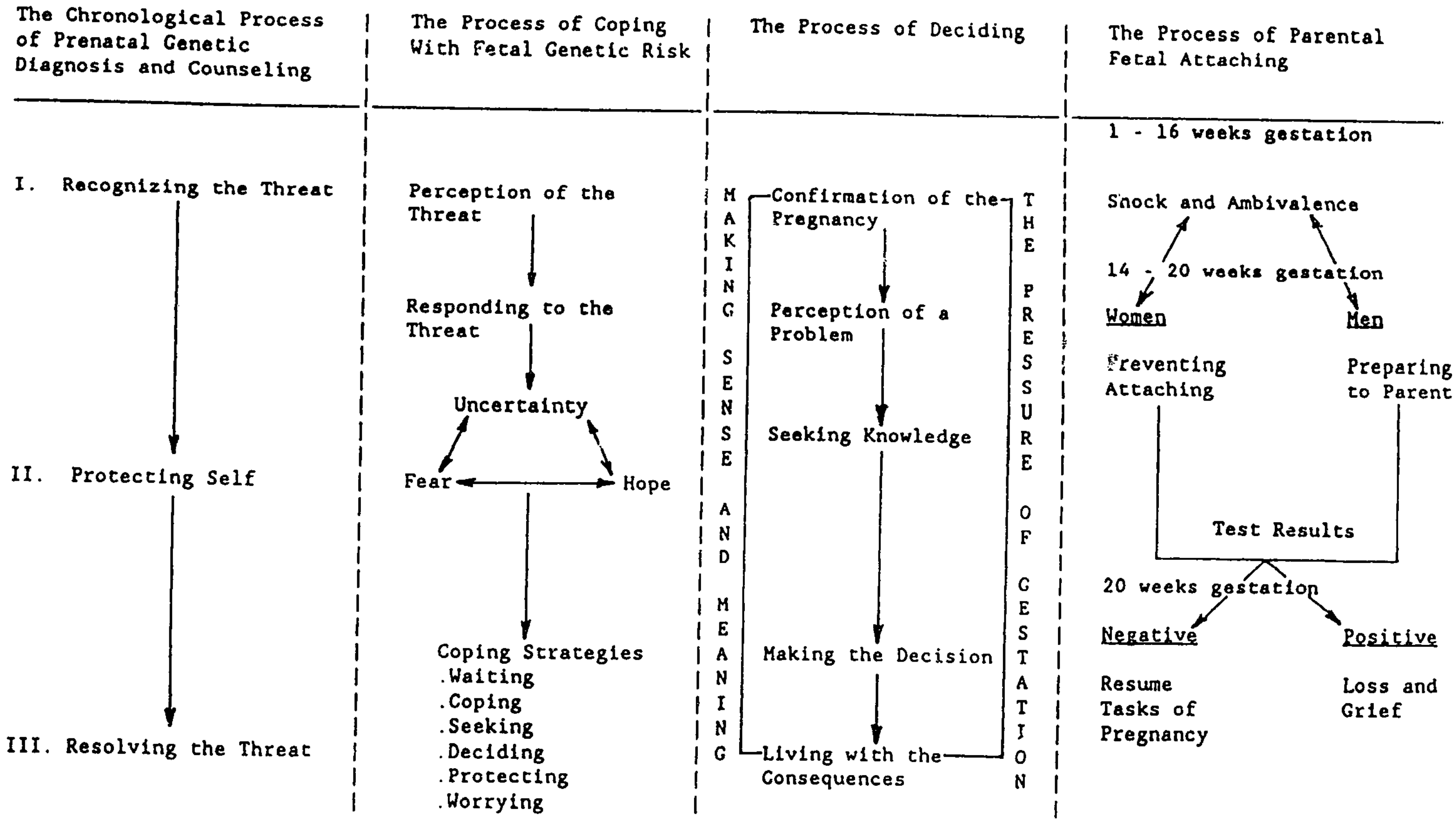

Figure 2. The four parent processes

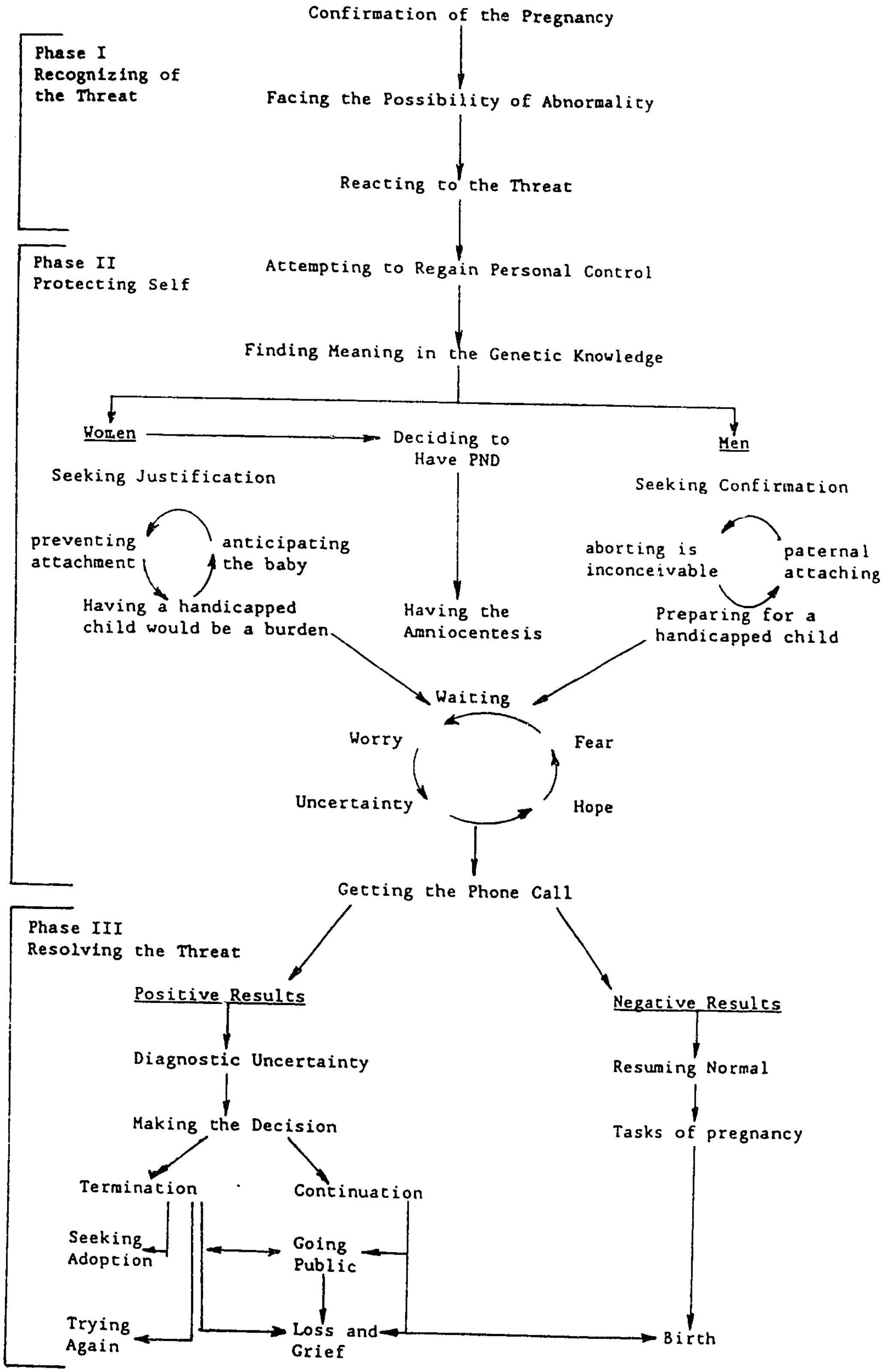

Figure 3. The chronological process of prenatal genetic diagnosis and counseling.

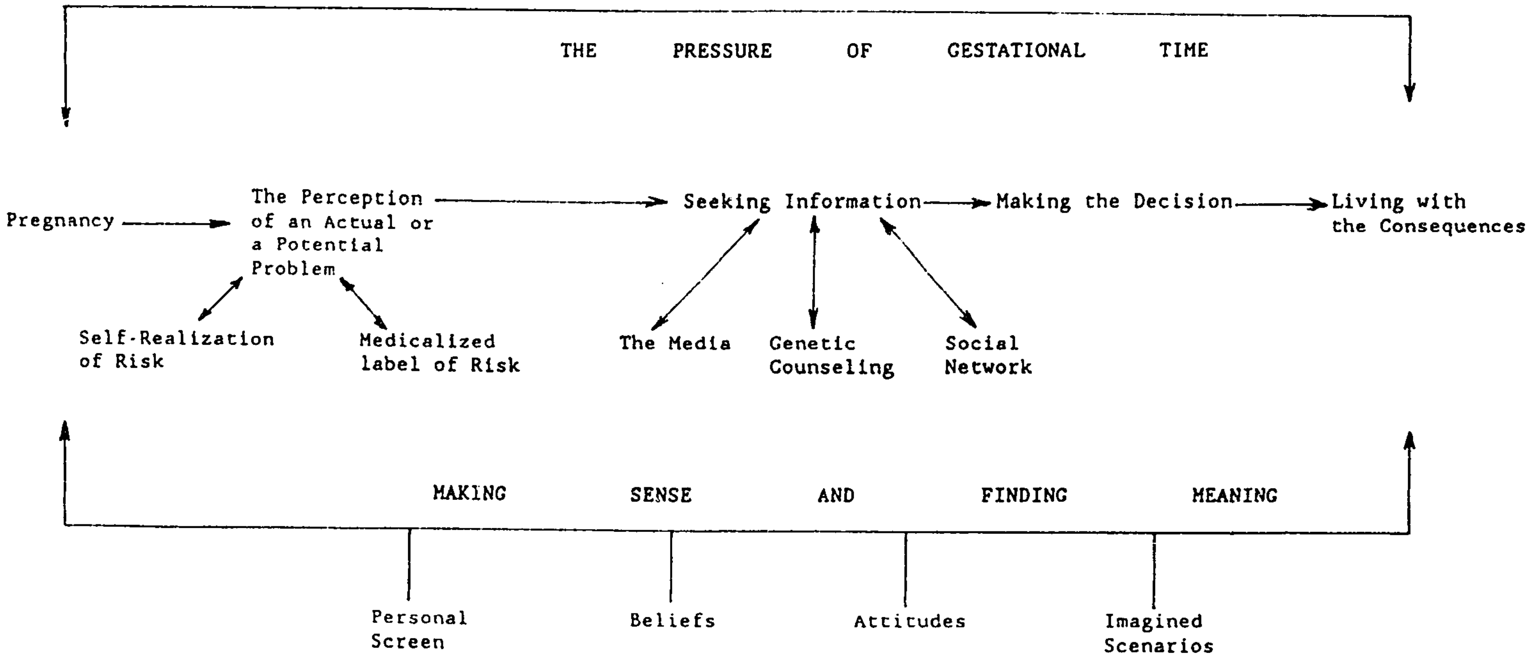

Figure 4 The Process of Deciding: Interrelationships among informant identified factors that influenced their decisions

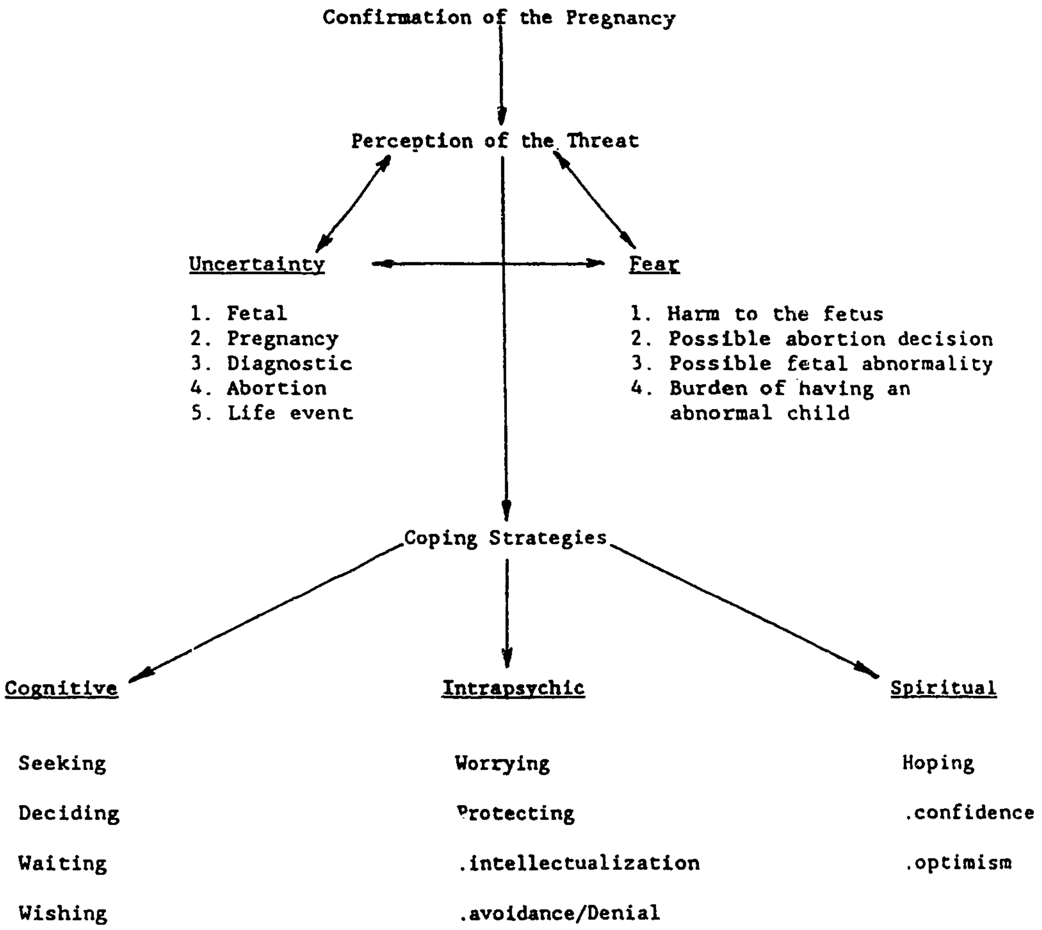

Figure 5. The process of coping with fetal genetic risk.

Appendix I
Informed Consent

Project Title: Finding meaning in the experience of prenatal genetic diagnosis and counseling.

Researcher:	Research Supervisor:
Gwen Schwanke	Dr. Marilynn Wood
5803-105 Avenue	Dean of the
Edmonton, Alberta	Faculty of Nursing
T6A 1A5	University of Alberta
(403) 469-8915	3-119 Clinical Sciences Building
	(403) 432-6761

I understand that the purpose of this research project is to increase nurses' understanding of how couples think and feel when they go for prenatal genetic counseling. The information that I share with the researcher will help nurses to plan future genetic counseling sessions. As a participant in this study, I understand that:

1. I will be interviewed separately from my spouse by the researcher. There will be three interviews lasting about one hour and fifteen minutes each, for a total time commitment of four hours and 30 minutes. These interviews will be recorded on tape and transcribed later by a secretary.
2. The results of any genetic testing procedure I may have, will be obtained by the researcher from Dr. Still's office.
3. My interviews and test results will be identified only by a code number. My name won't be included on the tape recording and will not appear on the typed transcript or in the final report although I may recognize some of the comments made by my spouse or myself that are included in the research report. The information I share with the researcher will not be told to my spouse or to the staff of the University of Alberta Genetics Clinic. The tapes and transcripts of my interviews will be kept in a locked cabinet for three years and may be reviewed again at a later date for a follow-up study on the same topic. After three years, all research data will be destroyed.
4. There are no risks to me associated with my participation in this project and I may withdraw from the study at any time without it affecting the quality of genetic counselling services I receive. If I choose to drop out of the study, the tapes and transcripts of my previous interviews will be destroyed.
5. If I have questions or concerns about the study, I may contact either the researcher or her supervisor at the above telephone numbers. A copy of the final report will be sent to me at the end of the study if I request it.

I have been given the opportunity to ask questions about the study and these questions have been answered to my satisfaction.

THIS IS TO CERTIFY THAT I, ____________________, hereby agree to volunteer in the above named study by Gwen Schwanke, a Masters in Nursing Candidate.

informant	witness	investigator
day,month,year	informant code number	

Appendix II

Introduction of The Study To Each Couple

My name is Gwen Schwanke. I am a graduate student at the University of Alberta, Faculty of Nursing. I am conducting a research study as a requirement of the Masters of Nursing program. The focus of this study is to learn more about how expectant parents think and feel about having prenatal counseling.

You may or may not directly receive any benefit for volunteering for this study, but the information you share with me will help health care professional better understand the needs of parents-to-be who undergo prenatal genetic services.

I am interested in talking to expectant parents who attend genetic counseling to discover their point of view. I will interview each spouse separately. Each partner will be interviewed three times through the time period that you attend PNGD and counseling. The interviews will last about one hour and 15 minutes.

Each spouse can talk openly about his or her point of view of the experience of PNGD and counseling. Each person will be asked to describe their personal thoughts and feelings. All information shared will be kept secret even from your spouse. Your name will not be included in the written report upon completion of the study but some of your exact words will be included so that your experiences are described accurately.

You have the right to refuse to participate in this study or to withdraw from the study at any time and the right to refuse to answer any specific question without fear of personal harm or changes in the genetic counseling services you will receive.

Please discuss this with your partner and think about any questions that you want answered. I will contact you by telephone in one or two days to see if you are interested in taking part in this research study. You may contact Dr. Marilynn J. Wood, my research supervisor if you have concerns at any time through out the study.

Sincerely,

Gwen Schwanke

Appendix III

Example Interview Questions

The first interview

1. I would like you tell me about the events that happened in your life that led you to the obstetrician and the Genetics Clinic?

2. Could you describe what happened to you when you went for genetic counseling? What did you find out?

3. How do you think and feel about what you were told at the Genetics Clinic?

4. What does genetic counseling mean to you?

5. Could you compare how you feel now about genetic counseling with any other event that you have ever experienced?

6. Could you describe how you feel about going for genetic counseling?

7. Tell me about any past experiences that you may have had with genetic counseling?

8. How would you describe your relationships with your friends, family, or people at work after you went for genetic counseling?

9. Do any of your friends or family know that you are going for genetic counseling?

10. Did you talk to your mother/father or a friend about your experience with genetic counseling?

11. How did they respond to what you shared with them? What did they think and feel about your situation? How did that make you feel?

12. Did you feel like the genetic counseling experience was helpful or not helpful?

The second interview

1. Could you describe what it felt like for you and your spouse when the Doctor was doing the amniocentesis and the ultrasound? What were the most predominant feelings?

2. Share with me any differences or similarities between you and your spouse about what this test meant for each of you.

3. What did you feel and think about having to make decisions regarding this or future pregnancies?

4. Could you describe any changes that happened in your thoughts, feelings or daily activities after you went for genetic counseling?

5. Did you notice anything about your relationship with your partner after you went for genetic counseling?

6. Was there any period of time that was more difficult than any other point in time during the whole process?

7. How does the experience of going for genetic counseling compare to any other life experience you have ever had?

<u>The third interview</u>

1. Tell me what it was like for you when you received the fetal diagnosis?

2. Could you describe any differences or similarities between you and your partner in how each of you experienced the process of genetic counseling?

3. How would you describe the meaning of genetic counseling now that you have been through the whole experience? Has the meaning of genetic counseling changed for you over the last five to seven weeks?

4. Would you say that your thoughts and feelings about this pregnancy have changed because you have had genetic counseling or are they pretty much the same as before you went for counseling?

5. Would you describe in your own words what genetic counseling has to offer to pregnant women and their husbands?