

WOMEN'S DECISIONAL CONFLICT, ANXIETY AND COPING STRATEGIES
FOLLOWING DIAGNOSIS OF FETAL ABNORMALITY

By

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To my beautiful daughter Annelise

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CHAPTER I

INTRODUCTION

Statement of the Problem

For most women pregnancy is a positive transition in their life. According to Mercer (2004), pregnancy is a time of transformation because the woman's self image changes to incorporate new responsibilities, commitments, and roles. This transition begins with the adjustment to and acceptance of the pregnancy, imagining the future child, preparing for parenthood, and assessing important relationships and how they will change. This process facilitates realistic expectations, relatedness to the fetus, and family preparation for the expected child (Leifer, 1998).

The provision of prenatal care influences the transition to parenthood. In the United States (US), the standard of prenatal care routinely includes offering pregnant women a variety of screening and diagnostic tests to assess the well-being of the fetus (Gates, 2004). Almost all pregnant women receiving prenatal care in the US accept and undergo some form of prenatal screening and diagnosis (American College of Obstetrics and Gynecology [ACOG], 2006). Prenatal screening and diagnosis is most often performed through blood tests, ultrasound, or chromosomal analysis, and is used to identify genetic and congenital abnormalities in a developing fetus (Evans, 2004).

The diagnosis of a fetal abnormality creates an uncertain outcome for the transitional process of becoming a parent (Meleis, Sawyer, Im, Hilfinger, & Schumacher, 2000; Van der Zalm & Byrne, 2006). A prenatal diagnosis of a fetal abnormality is

characterized as an emotionally devastating and profoundly stressful event for women because it involves making difficult reproductive choices such as continuation of pregnancy with no intervention, elective termination, or, in selected cases, experimental fetal therapy (Evans & Britt, 2004; Higgins, 2001; Leuthner, 2007; Rempel, Cender, Lynam, Sandor, & Farquharson, 2004; Singer, 2004). These reproductive choices are emotionally laden, permanent, and consequential, often making foreknowledge of fetal abnormality one of profound decisional conflict (Rapp, 2000; Rothman, 1994; Sandelowski, 1996; Sandelowski & Baroso, 2005).

Decisional conflict is the uncertainty about which course of action to take when choice among competing options involves risk, loss, regret, or challenge to personal life values (North American Nursing Diagnoses, 2004). Anxiety, uncertainty, knowledge deficits, and difficulty coping often coexist with decisional conflict (O'Conner 1995). Emotional distress is manifest in behaviors such as verbalizing uncertainty, ambivalence about choice, procrastination in making a choice, questioning personal values, and preoccupation with choice options. The manifestation of decisional conflict also varies by the situation and the individual. For example, the difficulty of the decision dilemma can be complicated by variables associated with the specifics of the choice situation, such as personal anxiety, unrealistic expectations, and lack of information and/or support resources (Llewellyn-Thomas, 2003; O'Connor, 1995).

Once prenatal diagnostic testing has occurred, there is high maternal anxiety during the time of waiting for definitive results (Kenen, Smith, Watkins, & Zuber-Pittore, 2000). Qualitative studies note that the emotional distress women experience upon receiving information that a fetal abnormality has been detected is considerable (Bijma,

Wilschut, Van Der Heide, Passchier, Vladimiroff, & Van Der Mas, 2005; Sandelowski & Baroso, 2005; Van der Zalm & Byrne, 2006). The emotional distress and the coping strategies women use following the diagnosis of fetal abnormality is a unique experience. Having to face difficult life-altering decisions involving loss influences an individual's emotional responses (e.g., anxiety) and, consequently, the resolution of the decisional conflict (Janis & Mann, 1977).

Coping with the experience of perinatal loss has been studied in similar contexts such as miscarriage and stillbirth (Layne, 2003; Peppers & Knapp, 1980). The results of these studies revealed the challenges women face when coping with perinatal loss. However, the diagnosis of fetal abnormality is significantly different from the experience of perinatal loss (e.g., miscarriage), because it involves the need for the individual to make a series of active, complex and time sensitive decisions that challenge emotions and coping. Women's emotional responses (e.g., anxiety) and the coping strategies used for dealing with decisional conflict following diagnosis have not been studied. This dissertation study addressed this major limitation and gap in the perinatal literature.

Purpose

The purpose of this study was to examine the relationships between women's decisional conflict, anxiety, and coping strategies following a diagnosis of fetal abnormality. Efforts to understand women's decisional conflict experiences following diagnosis has the potential to yield important insights about their emotional responses (i.e., anxiety) and the coping strategies they use to deal with the unique stressors of the decisional conflict situation.

Specific Aims of the Study:

Specific Aim 1: Determine the level of decisional conflict women experience following diagnosis.

Specific Aim 2: Examine the level of anxiety women experience.

Specific Aim 3: Investigate what coping strategies women use.

Specific Aim 4: Investigate the relationships among women's decisional conflict, anxiety, and coping strategies.

Significance to Nursing

Decisional conflict within the context of a diagnosis of fetal abnormality is a unique experience. The results of this dissertation study could potentially yield important insights into the factors associated with decisional conflict and its resolution. For example, a major assumption of the theoretical framework used in this study (i.e., Janis and Mann's Conflict Theory Model of Decision Making, 1977) is that coping with the time sensitive nature of the decision-making process following a stressful event, influences the individual's emotional responses and resolution of the conflict. In the context of prenatal diagnosis of fetal abnormality, nurses are in a strategic position to facilitate appropriate multidisciplinary support and coping resources within the care environment during this critical time. Understanding decisional conflict and the personal factors (i.e., anxiety and coping strategies) associated with this stressful situation would be a major contribution to advancing knowledge for nursing practice and future research.

Significance to Healthcare and Society

Much of the research on decision-making in the context of prenatal diagnosis has focused on the importance of informed consent. This work on the consent process is partially driven by the litigious climate that defines healthcare. Thus, the importance of full disclosure of benefits and risks of care has become an important component of the provider-patient relationship. The literature on understanding and accepting prenatal screening tests identifies the wide individual variations in understanding of tests and their uses, particularly as it relates to prenatal diagnosis (Asche, 1998; Shulman, 1994; Wertz, 2002). Studies that specifically address informed consent in prenatal testing show that provider variation in counseling style (Levy, 1999), amount of information given (Singer, 2004), and access to tests (Singer, 2004) all affect the percentage of women accepting prenatal diagnostic testing. Additionally, the quality of counseling (Singer, 2004), comprehension of health information (Mitchell, 2004), quality of care (Mitchell, 2004), and the availability of maternal fetal specialists (Leuthner, 2006) all affect how women decide whether or not to undergo diagnostic testing.

A goal of this dissertation study was to highlight the importance of interdisciplinary collaboration to establish care processes that decrease women's experiences of vulnerability and alienation that can occur in a highly technologic healthcare system (Sandelowski, 1987). The complexity of the interplay between the personal and situational factors that shape the phenomenon of decisional conflict creates a challenge for healthcare systems within a global arena. Addressing this challenge could lead to developing supportive systems that seek to thoughtfully integrate prenatal technologies into the care of all patients coping with difficult life-altering choices.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Theoretical Framework

Janis and Mann's Conflict Theory Model of Decision Making

Janis and Mann's (1977) Conflict Theory Model of Decision Making (CTM) is based on the key assumption that an individual faced with a life-altering situation that produces a decision dilemma is a reluctant decision maker. The decision maker is marked by doubts, worries, incongruous longings, and seeks relief by procrastinating, rationalizing, or denying responsibility for choosing alternatives. A main assumption of the CTM is that the stressful nature of choosing (influenced by risk, ambiguity, and loss), is strongly associated with the level of stress an individual experiences during the process of decision making.

Janis and Mann (1977) postulated that decision makers must use three specific criteria to effectively cope with their stressors during the process of choosing an alternative. These criteria are the following: Carefully weighing the negative and positive outcomes, searching for relevant information about choice alternatives, and executing the chosen course of action, with special attention to identifying contingency plans that may be required if unknown risks materialize.

A key assumption of the CTM is that in coping with the stress of a choice dilemma the individual uses a combination of five coping patterns during the process of trying to resolve the decisional conflict. Each pattern can involve different coping

strategies (see figure 1). First, the state of unconflicted adherence follows an individual's evaluation that the risks for not making a choice are negligible. Because little or no stress has been generated, the individual emotionally detaches from the situation rather than becoming more vigilant about assessing available options. Second, when an individual recognizes that the risks are high for not choosing an option, a choice is made without a thorough canvassing of the alternatives (e.g., unconflicted change). Third, when an individual believes the risks for choosing or not choosing an alternative are both serious and further believes that prospects for finding a good solution are unrealistic, defensive avoidance may be used (e.g., denial that a problem exists). Conflict is high and pursuit of new possibilities is prematurely curtailed. Fourth, when the risks for choosing or not choosing an option are perceived by an individual as time restricted, hypervigilance or panic ensues. Although a good solution may exist, the individual believes there is insufficient time to find it. Decisional conflict is high and an alternative choice is hastily selected without careful consideration of all possible consequences. Last, when an individual believes that the risks for choosing or not choosing are serious and that there is hope for and sufficient time to find a satisfactory solution, an individual's use of vigilant coping, such as planful problem solving (in contrast to the first four coping patterns), often will result in more careful consideration of choices and less stress (Janis & Mann, 1977).

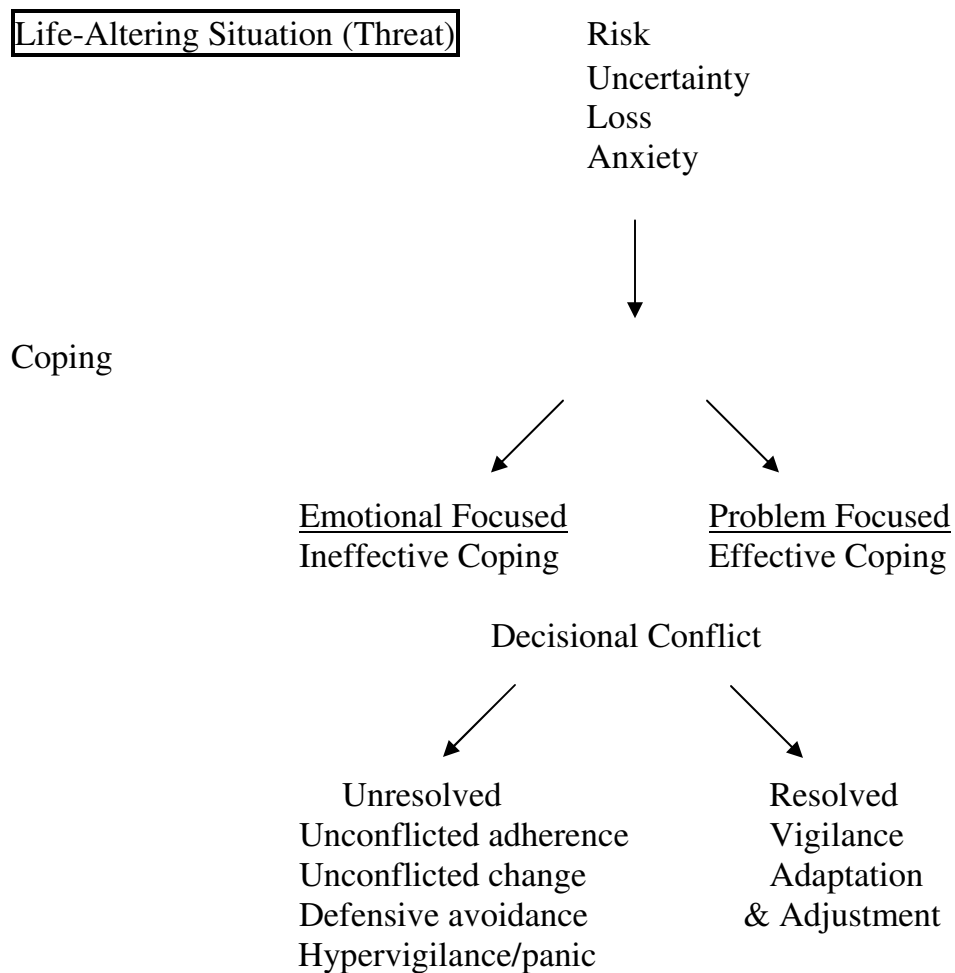


Figure 1: Conflict Model of Decision Making (Janis & Mann, 1977)

Thus, Janis and Mann's (1977) theoretical model includes both the *meaning* attached to the decision dilemma and the *pattern of coping* as important factors affecting resolution of the decisional conflict. However, the authors have not designed an instrument specifically aimed at measuring the construct of decisional conflict or the five

coping patterns. The lack of a measurement tool seriously limits their theory's testability.

To address this limitation, O'Connor and Jacobsen (1995) developed the Decisional Conflict Scale (DCS), which is based on the theoretical assumptions of the CTM (Janis & Mann, 1977). The DCS measures an individual's degree of uncertainty in making a healthcare decision, knowledge of options, values clarity, support for making a decision, and satisfaction or perceived effectiveness of the decision. This dissertation study used the DCS to measure women's decisional conflict. Studies that have used the DCS are discussed in the quantitative section of chapter 2 and the psychometric properties of the DCS are discussed in depth in the instrument section of Chapter 3.

The results of numerous coping studies have shown that coping strategies can be reliably measured in various contexts: Coping can be assessed either as a style or as a process. Coping style (e.g., Pearlin & Schooler, 1978; Weinberger, Schwartz, & Davidson, 1979) refers to the tendency of an individual to use a particular type of coping across a variety of stressful encounters. Coping as a process (Lazarus & Folkman, 1984) refers to the strategies individuals actually use during a specific situation. The choice of a coping measure will be guided by the theoretical assumptions and conceptual model as well as by the type of stress situation to be studied.

Lazarus and Folkman (1984) define coping as a process of changing cognitive and behavioral efforts to manage a specific stressful situation. According to their Process Coping perspective, coping strategies unfold during stressful situations that are appraised as personally significant to an individual's well-being and as taxing and/or exceeding her or his resources for coping with the stressful event. For example, when a pregnant woman learns that her fetus has an abnormality, she is faced with unanticipated and unwanted

decision alternatives. Thus, the coping process is elicited in response to an individual's evaluation or appraisal that important goals have been threatened, harmed, or lost (Folkman, 2004).

Coping as a process emphasizes that there are two main forms of coping: Emotion-focused coping and Problem-focused coping (Lazarus, 1998). Both forms of coping are likely to be used during the course of a stressful event (Lazarus & Folkman, 1984). These two forms of coping serve either to palliate the emotions or distress produced by the situation (e.g., distancing oneself from the situation), or by direct efforts to change or manage the situation (e.g., planful problem solving). Specific strategies are not judged to be more or less adaptive. The usefulness of a coping strategy is evaluated in terms of whether the use of a strategy or a combination of strategies is appropriate for controlling the emotional distress (e.g., decreasing anxiety) and managing a specific stressful situation (e.g., decision dilemma) by actively considering alternative or competing options.

Significant parallels exist between Janis and Mann's CTM (1977) and Lazarus and Folkman's (1984) Process Coping Theory. Problem-focused coping strategies, such as when an individual seeks out information, develops a plan of action, and follows it, are comparable to Janis and Mann's coping pattern of vigilance. Emotion-focused strategies, such as denial and distancing, parallel the coping pattern of defensive avoidance and unconflicted change. Within Janis and Mann's five coping strategies, the first four closely parallel emotion-focused coping, while the fifth strategy, vigilance, is a problem-focused form of coping (see Table 1).

Table 1. Parallels Between the Conflict Theory Model and the Process Coping Theory

Conflict Theory Model (Janis & Mann, 1977)	Examples	Process Coping Theory (Lazarus & Folkman, 1984)	Examples
Vigilance	Seeking out expert opinion, advice of family, friends, counselors	Problem-focused Seeking Social Support	Efforts to seek tangible and emotional support
Vigilance	Thorough information seeking and evaluation of options, weighing of positives and negatives	Planful problem solving	Analytic approach to solving or managing a problem
Vigilance	Acknowledgement and expression of emotions	Confrontive	Expressing emotions such as hostility and anger
		Emotion-focused Positive reappraisal	Focusing on the positive, personal growth, or religious faith
		Accepting responsibility	Acknowledging one's role in the situation
Defensive avoidance	Choice made hastily without seeking out information or alternatives	Self-controlling	Trying to keep feelings to self
Defensive avoidance	Construction of wishful rationalizations to bolster least objectionable alternative	Escape-avoidance	Rationalizing by . hoping a miracle would happen (e.g., wishful thinking)
Hypervigilance	Panic, overreaction, choice made without thinking through options		
Unconflicted change	Worry, making a selection without thorough consideration of options Uncritical adoption of most salient choice		
Unconflicted adherence	Denying a problem exists Complacency Procrastination	Distancing	Minimizing the significance of event

In summary, decisional conflict results when there is a choice between two or more options and there is uncertainty as to which alternative provides the most favorable outcome (Janis & Mann, 1977). According to Lazarus and Folkman (1984), personal factors (e.g., anxiety) play an important role in reframing a stressful event. Additionally the appraisal of what coping resources are available influences the choice of coping strategies used. Situational factors, such as temporality (e.g., gestational age at time of diagnosis), also may influence how an event is appraised and what coping patterns are selected (Balneaves, 1999; Janis & Mann, 1977). Within the context of prenatal diagnosis of fetal abnormality, women's decisions are the result of multiple and competing demands inherent in the experience. Choosing between available options is a stressful and iterative process that reflects the complex and dynamic relationships between person and environment. Thus, the combination of Janis and Mann's Conflict Theory Model (CTM) and Lazarus and Folkman's Process Theory of Coping were the theoretical models chosen to guide this dissertation study.

Literature Review

Qualitative Studies

The majority of studies examining decisional conflict in the context of a diagnosis of fetal abnormality have been conducted using qualitative methodologies. Synthesis of the qualitative studies evaluating women's experiences reveal that decisional conflict and the time sensitive nature of decision making in the context of prenatal diagnosis of abnormality is paramount in the process of evaluating the treatment options

available (Kolker & Burke, 1993; Sandelowski & Baroso, 2005; Sandelowski & Jones, 1996). Additionally, this conflict is intensified by the social and personal meanings attached to pregnancy termination, disability, and loss of a healthy child (Gregg, 1999; Matthews, 1991; Rapp, 2000; Rothman, 1994). Last, the burden and responsibility for making a reproductive choice often centers on how the choice affects significant others in the family (Gilligan, 1982).

Sandelowski (1996) used a grounded theory methodology to evaluate women's and/or couples' responses to foreknowledge of fetal abnormality. The study included in-depth interviews of 15 women and 12 of their male partners. Using thematic analysis, the themes of burden of choice, uncertainty, the problem of knowing, denial of futures, the end of normalcy, foreknowledge of the abnormality as theft, and interruption in the fantasy of pregnancy were specifically noted as stressful by the participants. The most salient finding of this study was that the decisional conflict generated by the choice dilemma was more stressful to the couple than the information that a fetal abnormality had been diagnosed. Sandelowski identified the dual burdens of choice and loss as an unexpected, but important, finding.

Sandelowski (1996) re-analyzed the same interview transcripts, focusing specifically on couples' explanations of their decision. The study evaluated how couples framed their decision within the conflict and the subsequent reproductive choice they made. Using interpretive methods of analyzing transcripts, only the information on the perception of choice, both before and after it was made, was extracted for analysis. Five themes of choice emerged in the analysis.

The dominant theme found was that the responsibility for the choice to terminate

or continue the pregnancy following a diagnosis of fetal abnormality was attributed to being either internal or external to themselves (Sandelowski & Jones, 1996). Parents recounted choice in the following ways: 1) The choice of terminating a fetus with a lethal abnormality produced less decisional conflict because the couples perceived it as what nature intended; 2) Women who accepted a fetus diagnosed as having a lethal abnormality felt that the decision to terminate was not theirs to make, and so chose to continue the pregnancy; 3) Women who had to deal with a fetal abnormality diagnosed after the time period in which termination was no longer an option (i.e., after 24 weeks gestation) had to resolve the dilemma of not having a choice. However, the woman/couple in this dilemma still sought out and defined choices such as choosing a mode of delivery, setting, or provider; 4) Following diagnosis, the choice options were unclear to women/couples but all options were considered carefully in light of perceived best interests of themselves, family, and fetus; and 5) Women/couples in conflict construed themselves as competing against significant odds when making a choice.

The women and couples who located the agency for decision-making outside themselves, such as in making the choice that nature intended or in construing that there was no choice, distanced themselves from a portion of the burden of conflict and psychological pain associated with choosing. For example, couples dealing with a diagnosis of a lethal fetal anomaly, such as anencephaly, described the choice to terminate the pregnancy as "nature's choice". In doing so, their burden of responsibility for making a choice to terminate the pregnancy was lessened. Additionally, they highlight the time-sensitive nature of prenatal diagnosis as it relates to choice; those diagnosed after a time period in which termination of the pregnancy was an option, construed their

dilemma differently. The authors conclude that constructions of a critical life event, such as choosing in the aftermath of prenatal diagnosis of abnormality, may provide insight as to which promotes optimal psychological adjustment.

Sandelowski and Baroso (2005) conducted a metasynthesis of the qualitative literature on the experience of prenatal diagnosis of fetal abnormality. Metasynthesis (Sandelowski, 2003) uses content analysis, interpretive analysis, and discourse as analytic techniques to synthesize and quantify collective qualitative findings. Qualitative studies involving expectant parents living in the US who learned about fetal abnormality during any time in pregnancy were eligible for inclusion. Seventeen studies, including unpublished dissertations, were analyzed using metasynthesis techniques. The major finding of this metasynthesis was that choice presents a dilemma; prenatal diagnosis offers information and options, but the options are difficult to approach as they all involve loss, risk, and uncertainty. This theme emerged in all 17 of the research studies analyzed.

Rothman (1988), Rapp (1998), and Gregg (1999) extracted data from open-ended interviews with women who had received abnormal results from amniocentesis. Women articulated the difficult negotiations they had to make when evaluating the choice options available. The difficulties were influenced by their experiences with disability, the concern the choice would have on family members, and the burden of responsibility of having to make a choice.

Decision difficulty and concern for how the choice could affect significant others was the focus of Gilligan's (1982) grounded theory study of women's decision making in the context of an unplanned pregnancy who were considering termination. The conflict

associated with the decision centered on women's need to maintain significant relationships and connections and the concern for how the choice might impact or change those relationships. Gilligan's research identified the importance of support resources and significant others and the need to maintain those relationships during times of decisional conflict and the resolution of the conflict. Women who felt more support from significant others during the decision-making process used more problem-focused coping such as planful problem solving. While this research on women making a decision regarding the termination or continuance of an unplanned pregnancy presents a different decision dilemma than prenatal diagnosis, the findings shed light on how women resolve a decision dilemma and what coping resources are effective.

Rapp's (1998) study of women undergoing amniocentesis is an ethnographic account of their experiences of dealing with a diagnosis of a fetal abnormality. This study revealed that the intense grief a woman experienced following the diagnosis of a fetal abnormality reflected the loss of hope for a healthy child, the fear that one's role or actions caused the defect (e.g., taking a medication inadvertently or passing on a genetic defect), and maternal attachment to the fetus. Unlike stillbirth or pregnancy loss, the decision to terminate a pregnancy for fetal abnormality is an intentional and deliberative, rather than passive, experience. Gregg's (1999) grounded theory research provides further support for these findings. Gregg noted that the burden of choice and decisional distress are factors present when contemplating choice alternatives.

Additional research on selective termination for fetal abnormality supports the difficulty of this choice, noting that acute grief reactions are similar to those experiences following a stillbirth or neonatal death (Lloyd & Laurence, 1985; Zeanah, Dailey,

Rosenblatt, & Saller, 1993). Similarly, phenomenological inquiry into the experiences of women choosing to continue a pregnancy with a known lethal anomaly reveals intense grief reactions, difficulty of choice, and lack of appropriate support (Chitty, Barnes, & Barry, 1996). Thus, the effects of diagnosis are traumatic and long lasting, regardless of the choice made (Sandelowski & Baroso, 2005).

The qualitative studies reviewed reveal the intense grief and responsibility women feel associated with the choice they selected, the concern for how their decision will affect others, and how the social and personal meanings attached to both pregnancy termination and disability intensify the choice dilemma. They further reveal that regardless of choice, the psychological impact is longstanding. However, the results of these accounts and/or studies offer only limited insight about how decisional conflict following abnormal prenatal diagnosis influences women's emotional responses and coping during the resolution of the decision dilemma. Only Sandelowski and Jones (1996) noted in their study that the way individuals reframe and narrate their personal stories provide an understanding of what coping strategies women use in managing emotional pain and the burden of decision making.

Quantitative Studies

Few quantitative studies have examined decisional conflict in the context of an abnormal prenatal diagnosis. Quantitative studies have mainly focused on examining informational interventions and consultation modes used by women during decision making to assist them in evaluating their choice options.

The Cochrane database contains six systematic reviews to evaluate informational

interventions, such as interactive decision aids (i.e., computer software programs that elicit patient treatment preference) and group information, that focus on reducing anxiety, uncertainty, and lack of information and support resources. One Cochrane review (2003) included 35 of the 62 randomized controlled trials that have been conducted using the Decisional Conflict Scale (DCS). Overall, the decision aided interventions reviewed reduced decisional conflict scores, particularly in the knowledge subscale and the values clarity subscale. Decision aids were found to decrease decisional conflict by improving the quality of patients' decision making. This has been defined as an individual's knowledge about options and outcomes, realistic perceptions of outcome probabilities, and agreement between individual values and choices (O'Connor, 1998). Additional benefits found with decision aids include improved decisional comfort, more active participation in decision making, and less indecision (O'Connor et al., 1998). However, decision aids were not found to decrease anxiety (Llewellyn, 2001; Montgomery, Fahey, & Peters, 2003; O'Connor, 2002).

A randomized trial of women ($n=117$) dealing with an abnormal fetal screening evaluated two different modes of consultation: decision aided consultation vs. face-to-face routine counseling. Women were randomized to usual care (face-to-face counseling) or decision-aided counseling via the internet (Bekker, Hewison & Thornton, 2003). The findings of this study revealed that consultation, whether face-to-face or decision-aid, influences the emotional responses of women, their level of decisional conflict, and the coping strategies they use when making difficult healthcare choices. When confronted with difficult choices, women with higher anxiety articulated fewer reasons about their choice (e.g., number of advantages and disadvantages of choice options available). An

evaluation of information about options available was associated with greater decisional conflict when the options provided were perceived by the women as having negative outcomes. At follow-up, information seeking (a vigilant coping strategy) was associated with greater decisional conflict. Only the perceived usefulness of consultation outcome differed by group. The face-to-face routine consultation group rated the usefulness of the consultation higher than the decision-aided consultation group, but neither intervention was evaluated as superior to the other for helping women decrease their anxiety and level of decisional conflict during this stressful time.

Systematic research evaluating situations involving decisional conflict have identified that the competing options associated with the choices available generate negative emotions such as anxiety and distress. These emotions strongly influence decisions involving the choices individuals make when there are uncertain outcomes with large consequences, such as inadvertent termination of pregnancy during fetal surgery and/or potential disruption of future fertility (Lowenstein, 2001; Slovic, 2001). For example, a prenatal diagnosis of spina bifida involves making difficult choices between uncertain quality of life for the child and the risk of undergoing an experimental maternal-fetal surgery that potentially could terminate a wanted pregnancy. The competing choices are emotionally laden because no matter how the individual imagines resolution, highly negative potential outcomes are at stake. Additionally, choice options that compete with the individual's social and personal views on abortion and/or experiences with disability also can generate negative emotions causing distress (Luce, Bettman, & Payne, 2001).

According to Luce, Bettman, and Payne (2001), compromises between choice

options are central to making difficult choices. The need to consider difficult compromises is what generates negative emotions such as anxiety and decisional conflict. Because weighing the differences in choice characteristics are integral and meaningful aspects of choice, especially when the decision is emotionally laden, it is important to understand how women cope with the conflict generated by the choice alternatives.

Summary

Women confronted with a diagnosis of fetal abnormality must consider difficult treatment options that potentially impact their personal well-being and the well-being of their unborn child (Bijma, Wildschut, & Van Der Heide, 2005). Following a diagnosis of fetal abnormality, consideration of choice alternatives generates decisional conflict, stressful emotions, such as anxiety, and subsequent coping behavior (Luce, 2005; Leuthner, 2007; Payne, 2001).

Qualitative studies evaluating women's experiences following diagnosis of fetal abnormality revealed the significance of decisional conflict and its impact on women's lives. While these studies document the difficulty of decision making in this context, they also show that the response to the decision is variable. No qualitative studies have evaluated the strategies women use to cope with decisional conflict or emotional distress generated by the experience of dealing with an abnormal fetal diagnosis. More qualitative studies that replicate or build on previous work are needed to evaluate this phenomenon.

Quantitative studies revealed that decisional conflict, negative emotion (e.g., anxiety), and coping behaviors coexist. Willingness to confront rather than avoid the conflict depends on the meaning an individual attaches to the choice dilemma (Luce,

2005). Systematic studies evaluating the types of decision aided interventions in the context of prenatal diagnosis (e.g., such as decision aids with counseling or routine face-to-face counseling) designed to help women choose a treatment alternative are not conclusive. These interventions have been helpful in showing how knowledge and values clarification impact decisional conflict. However, these interventions were shown to have little impact on reducing emotional distress. Further, there are no quantitative data evaluating what coping strategies women use when faced with an abnormal fetal diagnosis. More systematic study is needed to evaluate decisional conflict, the emotions generated, and the strategies women use to cope with the stressful experience of dealing with a prenatal diagnosis of fetal abnormality.

Research Questions

- 1) What level of decisional conflict do women experience following the diagnosis of a fetal abnormality?
 - 1a) Does the level of decisional conflict vary by characteristics of the women (e.g., women's age, gestational age at diagnosis, gravidity, parity, and marital status) or type of fetal abnormality (e.g., lethal, nonlethal)?
- 2) What level of anxiety do women experience?
 - 2a) How does the level of anxiety vary by characteristics of the women or type of fetal abnormality?
- 3) What coping strategies do women use?
 - 3a) How does the use of specific coping strategies vary by characteristics of the women or type of fetal abnormality?

- 4) What are the relationships among decisional conflict, anxiety, and coping strategies women use following a diagnosis of fetal abnormality?
- 4a) Is there a relationship between decisional conflict and coping strategies used?
- 4b) Is there a relationship between anxiety and coping strategies used?
- 4c) Is there a relationship between decisional conflict and anxiety?

CHAPTER III

RESEARCH METHODOLOGY

Research Design

A descriptive correlational design was used in this dissertation study of women's decisional conflict, anxiety, and coping strategies following an abnormal prenatal diagnosis.

Sample

A convenience sample of 55 women who received an abnormal prenatal diagnosis were the participants in this study. To be eligible for the study, participants met the following criteria: (a) able to understand English; (b) at least 18 years old; (c) willing to participate in a face-to-face interview; (d) diagnosed as having a fetal abnormality prior to 24 weeks gestational age; (e) able to be interviewed within the time period following diagnosis and within two weeks following their chosen option (e.g., before two weeks postpartum or two weeks status post pregnancy termination); and (f) consented to have their medical records reviewed for demographic data.

Description of the Setting

The study took place at an academic health sciences center (HSC) that has a women's and infants' hospital (WIH) in New England. The HSC has a large,

comprehensive obstetric service that includes a Maternal-Fetal Medicine department, a Prenatal Diagnosis Center that has genetic counseling services, and a Fetal Therapy and Treatment Program. The hospital serves as a major tertiary care referral center for Southern New England, and it is one of the largest teaching programs for obstetric residents in the US. When a woman has an abnormal prenatal test result at her midwife or physician's office, she is referred to the Prenatal Diagnosis Center at WIH where she will have additional tests to evaluate and confirm if a fetal abnormality is present. All women referred to the Prenatal Diagnosis Center at WIH receive genetic counseling. Once an abnormal diagnosis is confirmed by a maternal-fetal medicine specialist, the woman/couple receive additional counseling about available options by the physician and genetic counselor. If a woman is within the legal timeframe for pregnancy termination (e.g., prior to 24 weeks gestation) and chooses that option, it will take place in the labor and delivery unit at WIH. The unit is staffed with 10 nurses assigned to provide one-to-one care for any woman terminating her pregnancy. If the possibility of a fetal therapy or surgery exists, women are referred for additional consultation. A woman continuing her pregnancy may choose to stay with her community obstetric provider, or choose to be a patient of the maternal-fetal medicine specialty at WIH. Regardless of the woman's choice, her care is coordinated through the Prenatal Diagnosis Center at WIH.

Instruments

Decisional Conflict Scale

The Decisional Conflict Scale (DCS) developed by O'Connor and Jacobsen

(1995) was used. The scale contains 16 items with five empirically derived subscales. The first four subscales (measuring uncertainty, knowledge, values clarity, support, and effective decision making) contain three items each. The last subscale contains four items and measures satisfaction with or perceived effectiveness of the decision made (Table 2).

Table 2. The Decisional Conflict Scale (O'Connor and Jacobsen, 1995)

<i>Subscales</i>	<i>Examples</i>
Uncertainty	Choice is clear Decision is easy to make Certainty in what option to choose
Knowledge	Aware of options Understands the benefits of each option Understands the risks of each option
Values Clarity	The benefits of each option are clear The risks of each option are clear The importance of benefits/risks are clear
Support	Choice is made without pressure from external sources Adequate support to make a choice Adequate advice received about available Options
Effective Decision Making	Satisfied with the decision made Perception that decision was informed Decision reflects personal priorities Expectation that decision is final

Responses on the DCS are given on a five-point Likert scale ranging from 0 (strongly agree) to 4 (strongly disagree). The total for the first four subscales are added and then divided by 3. The last subscale is added together, and then divided by four. Higher scores indicate higher decisional conflict. The DCS is a widely used measure to determine the usefulness of decision aids in clinical situations in which there is a high

degree of uncertainty or preference sensitive choices (O'Connor, 2002; Stacey et al., 2002). The psychometric properties of the instrument have a satisfactory degree of internal consistency for the five subscales of the DCS, with Cronbach alphas ranging from .78 to .84 (O'Connor, 2002). In this dissertation study, the internal consistency of the DCS was good as evidenced by a Cronbach alpha of .89. Subscale scores in this study were also good and ranged from .66 - .88. These psychometric data across studies further substantiate the claim that the DCS is a widely validated and reliable instrument in the field of decision-making research. The instrument took approximately ten minutes to administer (Appendix A).

Anxiety

Anxiety was measured using Spielberger's (1983) State-Trait Anxiety Inventory (STAI). Anxiety may be measured as either a state or a trait. Because this study examined a situation-specific stressor, only the 20 item state anxiety portion of the instrument was used. The state anxiety version of the instrument determines an individual's perception of the threat of stress by measuring current level of anxiety. This portion of the STAI consists of 20 empirically derived items that ask how a person feels now, and reflects situational factors that may influence anxiety levels. The State Anxiety Scale consists of 20 questions that evaluate how subjects feel at the moment of responding. Responses are recorded on a four-point Likert scale ranging from "not at all" to "very much so." Scores can range from a minimum of 20 to a maximum of 80, with higher scores indicating higher anxiety. The STAI is a widely used and reliable measure of anxiety in behavioral health research and shows good internal consistency and evidence of construct validity

(Seckel & Birney, 1996). The psychometric properties are excellent, with the alpha-coefficient for the state anxiety scale above .85, and there is good test-retest reliability of .64 to .93 (Spielberger, 1983). In this dissertation study, the internal consistency of the STAI was excellent as evidenced by a Cronbach alpha of .93. The instrument took approximately ten minutes to administer (Appendix B).

Coping

Individual coping strategies was measured using the Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988). The WCQ consists of 66 items with eight empirically derived subscales that represent generalized coping functions, namely the use of problem-focused coping functions or emotion-focused coping functions for coping in diverse stressful encounters. The problem-focused subscales include seeking social support, planful problem solving, and confrontive coping. The emotion-focused subscales include positive reappraisal, self-controlling, distancing, escape-avoidance, and accepting responsibility. Implicit in the instrument's design is the understanding that each individual's appraisal of the situation is the key to understanding the ways of coping (e.g., problem-focused coping; emotion-focused coping) chosen by the individual at a particular point in time or situation. The WCQ is designed to assess situation-specific coping strategies used in a stressful transaction. Prior to administering the WCQ, the participant is asked to "take a few moments to think about the stressful situation" they have encountered. In this study, each participant was asked to recall the stress of receiving an abnormal prenatal diagnosis and to describe that experience. Following their

description of the stressor, the 66 item coping questionnaire was administered (Appendix C).

Scoring

Each item on the eight subscales is rated on a four-point Likert scale according to the degree to which a person used a particular coping strategy. Scores range from “never used” to “used frequently,” with the higher score representing increased use of that particular coping strategy. In addition, a total problem-focused coping score was formed by summing the three problem-focused subscales, and a total emotion-focused coping score was formed by summing the five emotion-focused subscales.

The WCQ can produce both raw and relative scores for each of the eight subscales (Folkman & Lazarus, 1988). Raw scores represent the sum of each person’s responses to the items that comprise a given subscale (i.e., frequency of coping efforts). Relative scores describe the contribution of each coping scale relative to all of the subscales combined. The relative score calculation controls for the unequal numbers of item scores across all eight subscales and for individual differences in response rates. In doing so, relative scores describe the proportion of effort represented by each type of coping. For example, relative problem-focused scores are a function of raw problem-focused scores divided by the sum of raw problem-focused, wishful thinking, and other raw scores. In this respect, both the pattern of the differences and the number of coping differences observed suggest an advantage of using relative scores. Relative scores allow a clinical researcher to differentiate individuals with identical raw scores by taking

account of each raw score's magnitude relative to an individual's total coping efforts. The type of scoring method used is determined by the research questions asked in a particular study. Because the research questions in this dissertation study involve relationships among variables, the percentage of coping efforts (relative scoring method) was used to assess the coping strategies of women.

The psychometric properties of the instrument have a satisfactory degree of internal consistency for the eight subscales of the WCQ, with alphas ranging from .61 to .79 (Folkman & Lazarus, 1988). These psychometric data across studies further substantiated the claim by process-oriented coping investigators that the WCQ is a widely validated and reliable instrument in field coping research. In this dissertation study, the internal consistency of the WCQ was good as evidenced by a Cronbach alpha of .88 for both emotion-focused and problem-focused subscales. The instrument took approximately 20 minutes to administer.

Socioeconomic Status

Socioeconomic status (SES) (a demographic factor assessed in this study) was measured using the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975). Each participant's level of social status was based on four factors: occupation, years of schooling, gender, and marital status. Five social strata are proposed by Hollingshead: major business and professional (scores ranging from 66-55); medium business, minor professional and technical (scores ranging from 54-40); skilled craftsmen, clerical, and sales workers (scores ranging from 39-30); machine operators and semi-skilled workers (scores ranging from 29-20); and unskilled laborers and menial

service workers (scores ranging from 19-8). SES was scored as a continuous variable.

Demographic Information

Specific demographic information was extracted from the patient's medical records to minimize length of interview and subject burden. This information was age, gravidity, parity, marital status, religious affiliation, gestational age at time of diagnosis, type of diagnosis (lethal or nonlethal fetal abnormality), prognostic certainty, and availability of surgical corrective option.

Perception of the timeframe available for making a choice among options was the only question (on the demographic information form) that was not accessed from the patient's medical record, thus this question was asked by the investigator following the administration of all instruments (Appendix D).

Data Collection Methods

Potential participants had received confirmation regarding an abnormal prenatal diagnosis from their physician at the Prenatal Diagnosis Center (PDC) at WIH. Women who met eligibility criteria for this study were provided a card that was included in an informational packet the women received by the genetic counselors in the PDC. The card described the nature and purpose of the study and provided the name of the nurse researcher doing the study and how to contact her should they be interested in learning more about the study (Appendix E). Potential participants also were identified by their nurse or their obstetric provider and asked if they were interested in learning more about

the study. Participants interested in learning more about the study were approached by the principal investigator following diagnosis and counseling at the PDC.

Women who agreed to participate in the study were interviewed one time by the principal investigator. This interview occurred after diagnosis and within two weeks following their chosen option in a room selected for privacy in either the prenatal clinic or within WIH. Except for gathering demographic information from the participant's medical records, all instruments were verbally administered by the principal investigator. The Demographic Questionnaire was given first, followed by the Decisional Conflict Scale, the State Anxiety Questionnaire and the Ways of Coping Questionnaire. The first question of the coping questionnaire (open-ended) asks the participant to describe the stress associated with receiving an abnormal prenatal diagnosis. This response was tape-recorded. Following the response to this question, the principal investigator verbally administered the coping questionnaire to the participant. The total time of the interview took 40 minutes to one hour.

Protection of Human Subjects

Permission to conduct the proposed study was obtained from Vanderbilt University's Institutional Review Board, Nashville, TN (Appendix F), and Women and Infants' Hospital Institutional Review Board, Providence, RI (Appendix G). After approaching potential participants and explaining the voluntary nature of the study, women were told that the purpose of the study was to understand women's emotional responses and coping strategies following diagnosis. Potential participants were told that the length of time of the face-to-face interview would be approximately 45 minutes to

one hour and conducted in a room selected for privacy in either the prenatal clinic or WIH at a time that was convenient for them. It was explained that one question about how they described the stress associated with diagnosis would be tape-recorded. Participants were told that the study was voluntary and nonparticipation or deciding to stop participation would not affect their care. They were told if they became upset at any time during the interview, they could ask the investigator to stop the interview. They were told that their participation in the study could help nurses, doctors, and counselors have a better understanding of how women cope after receiving an abnormal fetal diagnosis and what role feelings play during this stressful time. The potential participants were told that the principal investigator was a doctoral student at Vanderbilt University School of Nursing, Nashville, Tennessee, and was a nurse employed at Women and Infants' Hospital of Rhode Island. If they agreed to participate in the study, they signed and were given a copy of the consent form (Appendix H).

Data Analysis

Data were entered into SPSS for cleaning to ensure accuracy of data entry, and then data entered were printed out and double-checked. Data were examined using frequencies and descriptive statistics (SPSS) to identify any outliers and the distributions of all variables. All outliers were checked against raw data to ensure accuracy of data coding and entry. For any variables whose distributions were markedly non-normal appropriate transformations were considered. SPSS files were saved as portable files and read into SAS for the main statistical analyses.

Following are the analyses for addressing each research question:

1) What level of decisional conflict do women experience following the diagnosis of fetal abnormality? The mean scores and standard deviations for the total Decisional Conflict Scale and Subscales (Uncertainty, Knowledge, Values, Clarity, Support, and Effective Decision Making) were computed.

1a) How does the level of decisional conflict vary by characteristics of the women (i.e., women's age, gestational age at diagnosis, gravidity, parity, marital status) or type of fetal abnormality (i.e., lethal, nonlethal)? To assess the relationship between decisional conflict and continuous variables (i.e., age and gestational age at diagnosis) Pearson correlations were computed. To assess differences on decisional conflict between groups (i.e., marital status, type of abnormality) Analysis of Variance (ANOVA) was used.

2) What level of anxiety do women experience? The mean score and its standard deviation was computed.

2a) How does the level of anxiety vary by characteristics of the women or type of fetal abnormality? To assess the relationship between anxiety and continuous variables (i.e., age), Pearson correlations were computed. To assess differences on anxiety between groups (i.e., marital status, type of fetal abnormality), ANOVA was used.

3) What coping strategies do women use? The mean relative scores on each of the Ways of Coping subscales was computed.

3a) How does the use of specific coping strategies vary by characteristics of

the women or type of fetal abnormality? To assess the relationships between the coping strategies and continuous variables (i.e., age), Pearson correlations were computed. To assess differences on the coping strategies between groups (i.e., marital status, type of fetal abnormality), ANOVA was used.

4) What are the relationships between decisional conflict, anxiety, and coping strategies of women following a diagnosis of fetal abnormality? Both correlational and multiple regression analysis were used.

4a) Is there a relationship between decisional conflict and coping strategies used? Correlations between the decisional conflict score and each coping subscale was used.

4b) Is there a relationship between anxiety and coping strategies used? Correlations between the anxiety score and each of the coping subscales was used.

4c) Is there a relationship between decisional conflict and anxiety? Correlational analysis assessing the relationship between decisional conflict and anxiety was used.

Multivariate relationships among decisional conflict, anxiety, and coping strategies were explored using multiple regression analysis.

CHAPTER IV

RESULTS

This chapter begins with a description of the sample. Following the sample description, the results of the four research questions are presented. First, the results for level of decisional conflict women experience following diagnosis of fetal abnormality and characteristics of the women are presented. Second, the level of anxiety women experienced and the relationship between anxiety and characteristics of the women are presented. Third, the coping strategies used by women following diagnosis and the relationship between coping and maternal characteristics are presented. Last, the multivariate relationships among the main study variables, decisional conflict, anxiety, and coping strategies, are presented.

Description of the Sample

A convenience sample of women ($N=55$) who ranged in age from 18 – 41 years ($M= 30$, $SD = 6.8$) participated in this study (see Table 3). Approximately sixty six percent of the women were married (66%, $n=36$), 14% were single living with partner (14%, $n=9$) and the remaining participants were single (20%, $n=11$). Participants self-identified their religious or spiritual preference as protestant (54.5%, $n=30$), Catholic (34.5%, $n=19$), Jewish (7.3%, $n=4$), or other (e.g., Buddhist, $n=2$, 3.6%). Approximately 70% of the women were Caucasian ($n=38$), 16.4% were Hispanic ($n=9$), 12.7% were

African American ($n=7$), and one participant was Asian (1.8%, $n=1$). According to Hollingshead's (1975) Four Factor Index of Social Position, the women's social status ranged from Class I (unskilled laborers) to Class V (professional), with the largest percentage being in class I (29.1%, $n=16$).

Table 3. Summary of Sample Characteristics (N=55)

<i>Variable</i>	<i>Mean (SD)</i>	<i>Range</i>	<i>Frequency</i>	<i>Percentage</i>
Age	30.04 (6.736)	18-41		
Marital Status				
Married			36	66%
Single living with partner			8	14%
Single			11	20%
Religious Preference				
Protestant			30	54.5%
Catholic			19	34.5%
Jewish			4	7.3%
Other			2	3.6%
Race/Ethnicity				
Caucasian			38	69.1%
African American			7	12.7%
Hispanic			9	16.4%
Asian			1	1.8%
Social Position/ Class				
Class I			16	29.1%
Class II			8	14.5%
Class III			8	14.5%
Class IV			14	25.5%
Class V			9	16.4%
Gravidity				
1			17	30.9%
2			14	25.5%
3			12	21.8%
4			9	16.4%
5 \geq			3	5.4%
Parity				
0			23	41.8%
1			17	30.9%
2			11	3.6%
3 \geq			4	7.2%
Gestational Age at Diagnosis		9-23		
Lethal Abnormality			20	35%
Non-lethal Abnormality			35	65%
Prognosis of Abnormality				
Good			10	18.2%
Fair			2	3.5%
Poor			23	41.5%
Uncertain			20	36.4%
Type of Corrective Option				
In utero			5	9%
Post -delivery			11	21.8%
No option			39	70.9
Availability of Corrective Option				
Yes			18	29.1%
No			39	70.1%

Gravidity (i.e., total number of pregnancies) ranged from 1-7. Approximately 57% ($n=31$) of women were experiencing their first or second pregnancy. Thirty-eight percent ($n=21$) were experiencing their third or fourth pregnancy and the remainder of participants were in their fifth or more pregnancy ($n=3$). Parity (total number of live births) ranged from 0-5. Approximately 42% ($n=23$) of the women had not experienced a live birth. Gestational age at diagnosis ranged from 9-23 weeks. During this time, prenatal diagnostic testing revealed 22 different types of fetal abnormalities. Approximately 35% of women ($n=20$) received a lethal fetal abnormality diagnosis and 65% ($n=35$) received a non-lethal fetal diagnosis (see Table 4).

The prognosis associated with the type of fetal abnormality diagnosed varied. Approximately 18.2% ($n=10$) of the fetal abnormalities had a good prognosis, 3.6% ($n=2$) had a fair prognosis, 36.4% ($n=20$) had an uncertain prognosis, and the majority of prognoses were poor (41.5%, $n=23$). Twenty-nine percent of women had some type of corrective option available (e.g., in utero ablation procedure or post-delivery surgical repair of the abnormality). The majority of women (70.9%) did not have a corrective option .

Table 4. Types of Fetal Abnormalities Diagnosed

<i>Type of Fetal Abnormality</i>	<i>Frequency</i>	<i>Percentage</i>	<i>Lethal</i>	<i>Non-Lethal</i>
Trisomy 13	3	5.5	x	
Trisomy 18	4	7.3	x	
Trisomy 21	3	5.5		x
Holoprosencephaly	1	1.8	x	
Cardiac Defect	2	3.6		x
Gastroschisis	4	7.3		x
Anencephaly	2	3.6	x	
Structural Anomalies	10	18.2		x
Anhydramnios	6	10.9	x	
Twin -Twin Transfusion Syndrome (TTTS)	4	7.3		x
Cleft Lip/ Palate	2	3.6		x
Prune Belly Syndrome	1	1.8	x	
Lymphangioma	1	1.8		x
Cystic Hygroma	1	1.8	x	
Renal Agenesis	1	1.8	x	
Encephalocele	1	1.8	x	
Congenital Cystic Adenomatoid Malformation	3	5.5		x
Spina Bifida	1	1.8		x
Partial Molar Pregnancy	2	3.6	x	
Cystic Kidney	1	1.8		x
Polydactyly	1	1.8		x
Hydrocephaly	1	1.8		x
Total	55	100.0	35%(20)	65%(35)

Level of Decisional Conflict Following Diagnosis of Fetal Abnormality

The possible scores on the Decisional Conflict Scale (DCS) and all of its subscales range from 0-4. Higher DCS scores indicate a greater level of decisional conflict. In this sample, the total DCS score ranged from 0-2.31 ($M=.93$, $SD=.54$),

suggesting that women experienced lower levels of decisional conflict. Scores on the DCS subscales (except for the Uncertainty subscale) also were low, indicating that women in this study had low conflict levels on the Knowledge subscale, range 0-2 ($M=.84, SD=.6$); Values Clarity subscale, range 0-2 ($M=.77, SD=.57$); Support subscale range 0-2.3 ($M=.92, SD=.62$); and the Effective Decision Making subscale, range 0-2.25 ($M=.65, SD=.58$). Scores on the Uncertainty subscale ranged from 0-4 ($M=1.5, SD=1.2$), revealing that women had higher levels of uncertainty in choosing among available options.

Decisional Conflict and Maternal Age and Gestational Age

There was no significant relationship between maternal age and level of total DCS ($r=.124, p=.36$) or with any of the DCS subscales. Gestational age at time of diagnosis was not significantly related to decisional conflict on the total DCS or on any of the subscales except for the Uncertainty subscale ($r=-.40, p=.003$). This result indicates that women whose pregnancies were at a higher gestational age at time of diagnosis had lower scores on uncertainty.

Decisional Conflict Gravidity and Parity

There was no significant relationship between gravidity (i.e., number of pregnancies) and total DCS ($r=.23, p=.08$) or with any of the DCS subscales. There was a significant relationship between parity (i.e., number of live births) and the Knowledge subscale of the DCS ($r=.27, p=.04$). Women with higher parity had higher knowledge scores. The results indicated that women with higher parity had higher conflict regarding

knowledge of options available and the risks and benefits of each option.

Decisional Conflict and Marital Status

There was no significant difference between marital status groups on level of decisional conflict. There was one significant relationship between marital status and the Values Clarity subscale of the DCS; $F(2,52) = 3.6, p = .03$. The mean Values Clarity score for single women was .94, the mean value for single women living with partner was 1.2, and the mean value for married women was .67. Tukey's post hoc test revealed that the single women living with a partner scored significantly higher on values clarity than either of the other two groups (married or single). This result indicates that women living with a partner had higher levels of conflict in assessing the positive and negative outcomes of each available option and its importance to them.

Level of Decisional Conflict and Type of Fetal Abnormality

There was no significant relationship between decisional conflict and type of fetal abnormality on the DCS or any of its subscales except the Uncertainty subscale. Women diagnosed with a lethal fetal abnormality had higher scores on the Uncertainty subscale of the DCS ($M = 1.97$) than women with a nonlethal fetal abnormality ($M = 1.50, F(1,53) = 5.6, p = .02$). This finding indicates that women in whom a lethal fetal abnormality is diagnosed have higher uncertainty about choosing among available options than women with a nonlethal fetal abnormality.

Anxiety and Characteristics of the Women

The mean anxiety score for the women in this study was $M=52.1$, $SD=10.8$. This result indicates that women experienced moderate levels of anxiety (possible scores range from 20-80). There was no significant relationship between maternal age and level of anxiety. There was a significant negative relationship between anxiety and gestational age ($r = -.27$, $p = .05$). Women whose fetal abnormality was diagnosed at an earlier gestational age had greater anxiety than women whose fetal abnormality was diagnosed at a later gestational age. There also was a significant relationship between anxiety and type of fetal abnormality. Women in whom a fetus with a lethal abnormality was diagnosed had higher anxiety ($M = 58$) than women whose fetus had a nonlethal abnormality ($M = 49$, $F(1,53) = 9.75$, $p = .003$). There was no significant relationship between maternal anxiety and gravidity, parity, or marital status.

Coping Strategies Women Used Following Diagnosis

The relative coping score for each strategy was computed by dividing the raw score for that strategy by the total score for all the coping strategies. Therefore, each relative coping score is the percent that a particular coping strategy was used. Figure 2 displays the coping strategies women used proportionately more often for dealing with their prenatal diagnosis of fetal abnormality.

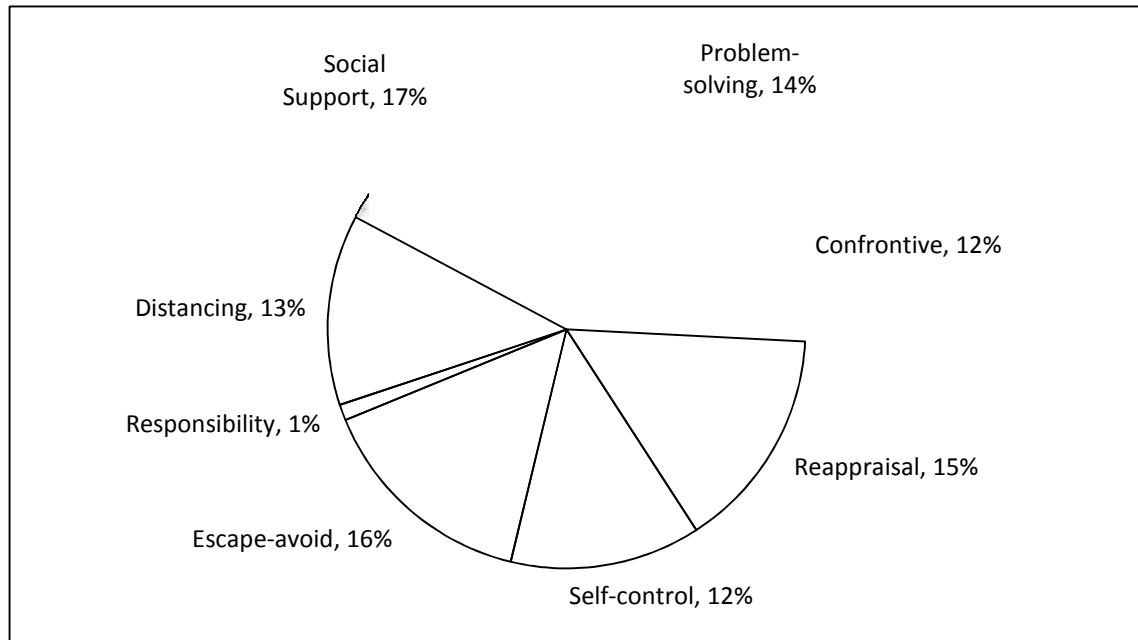


Figure 2. Proportion of Total Effort by Type of Coping

Problem-focused coping = patterned (total = 40%)

Emotion-focused coping = solid (total = 60%)

Coping Strategies and Maternal Characteristics

There were two significant relationships between the Social Support coping subscale and maternal characteristics. There was a significant relationship between maternal age and seeking social support ($r=.35, p = .009$). These results revealed that as age increased, women sought social support more often than younger women. Gestational age at time of diagnosis had a negative relationship with seeking social support ($r = - .38, p = .005$). This result indicates that women of higher gestational age sought less social support.

There was a significant negative relationship between maternal age and the Distancing subscale ($r = - .27, p=.05$), and a significant positive relationship between

maternal age and the Problem Solving subscale ($r = .31, p = .02$). These results revealed that as age increased, women were less likely to use distancing (e.g., minimizing the significance of the event) as a coping strategy and were more likely to use problem solving coping.

Coping and Marital Status

Significant group differences were found among the marital status groups and coping on distancing ($F(2,52) = 5.5, p = .007$), seeking social support ($F(2, 52) = 4.1, p = .02$), accepting responsibility ($F(2,52) = 5.6, p = .006$), escape avoidance ($F(2,52) = 3.7, p = .03$), problem solving ($F(2,52) = 9.2, p = .004$), and positive reappraisal ($F(2,52) = 4.1, p = .02$). Tukey's post hoc tests revealed which marital status groups were significantly different from each other in using these coping strategies. For distancing, the married group ($M = .10$) scored significantly lower than the single women ($M = .15$). For seeking social support, no significant post hoc differences were found. For accepting responsibility, the married group ($M = .07$) scored significantly lower than single women living with partner ($M = .13$). For escape-avoidance, no significant post hoc differences were found. For problem solving, the married group ($M = .14$) scored significantly higher than either single women ($M = .12$) or single women living with a partner ($M = .10$). For positive reappraisal, no significant post hoc differences were found.

The results of the significant findings for coping and marital status suggest that the married group used less distancing coping than single women in this study. Women living with a partner scored higher on accepting responsibility than married women. Married women used more problem solving coping strategies (e.g., methodically

evaluating available options) than single women or single women living with a partner.

Coping and Type of Fetal Abnormality

Significant differences were found between women receiving a lethal fetal abnormality diagnosis and those not receiving a lethal fetal abnormality diagnosis for confrontive coping ($F(1,53) = 4.3, p = .04$), distancing ($F(1, 53) = 11.6, p = .01$), and seeking social support ($F(1, 53)=13.21, p <.01$). These results indicate that women who had fetuses diagnosed with lethal abnormalities used more confrontive coping ($M = .12$) than women whose fetuses were diagnosed as having a non-lethal abnormality ($M = .10$). Women who had fetuses with lethal abnormalities used less distancing ($M = .09$) than women whose fetuses were diagnosed as having a non-lethal abnormality ($M = .13$). Women who had fetuses with lethal abnormalities used more seeking social support ($M =.20$) than women whose fetuses were diagnosed as having a non-lethal abnormality ($M=.15$).

Decisional Conflict and Coping

There were three significant relationships found between decisional conflict and the Confrontive coping subscale. There was a significant positive relationship between the total score on the DCS and confrontive coping ($r=.30, p=.02$). Confrontive coping also was positively related to the DCS subscales of Uncertainty ($r=.33, p=.01$) and Support ($r=.28, p=.04$). Higher levels of decisional conflict, uncertainty, and perceived lack of support for decision making were associated with higher use of confrontive

coping strategies.

There was a significant positive relationship between decisional conflict and the Escape/Avoidance coping subscale ($r=.45, p<.01$). This finding suggests that the higher the level of decisional conflict, the more often escape/avoidance strategies were used. The escape/avoidance coping strategies also had significant positive relationships with the DCS subscales of Knowledge ($r=.47, p=.04$), Values Clarity ($r=.33, p=.02$) and Support ($r=.36, p=.01$). These results suggest that the higher the conflict in knowledge (e.g., awareness of options available), the higher the conflict in values clarity (e.g., benefits of each option), and support (e.g., adequate advice on options) were associated with higher scores on escape/avoidance coping strategies (such as hoping a miracle would happen).

There was a significant negative relationship between the DCS support subscale ($r=-.33, p=.02$) and the coping subscale of Seeking Social Support. This finding indicates that women with higher conflict in support on the DCS (e.g., adequate support to make a choice) used less seeking social support as a coping strategy. There also were significant negative relationships between problem solving ($r=-.34, p=.01$) and positive reappraisal coping strategies and the DCS Values Clarity subscale ($r=-.30, p=.03$). These results indicate that the use of problem solving and positive reappraisal coping strategies were associated with increased awareness of the benefits and risks of available options for dealing with a fetal abnormality.

Anxiety and Coping

There were two significant relationships between the Anxiety scale and Coping

subscales. There was a significant positive relationship between anxiety and confrontive coping ($r=.49, p<.01$) and a significant negative relationship between anxiety and distancing ($r=-.56, p<.01$). These results indicate that women with higher anxiety levels used more confrontive and less distancing coping strategies.

Decisional Conflict and Anxiety

There were three significant relationships between decisional conflict and anxiety. Anxiety was positively related to the total DCS score ($r=.45, p<.001$), the Uncertainty subscale ($r=.50, p<.001$), and the Effective Decision subscale ($r=.47, p<.001$). Women who had more anxiety had higher total decisional conflict, higher uncertainty, and higher effective decision conflict (e.g., were less satisfied with the decision made).

Multivariate Relationships Among Decisional Conflict, Anxiety, and Coping Strategies

With the intent of further clarifying the relationships found in this study, multivariate relationships among decisional conflict, anxiety, and coping strategies were explored using multiple regression. Decisional conflict was regressed onto anxiety and coping to investigate possible predictors of decisional conflict.

In the regression model used, all possible predictors of decisional conflict were entered simultaneously (i.e., all coping subscales and state anxiety). The results for the full model revealed that the model as a whole was statistically significant, ($F(8,48)=5.01, p=.01$). The R-square was .47, meaning that the model accounted for 47% of the variance in total decisional conflict. Of the 8 individual predictors entered into the model only 2 were statistically significant, anxiety ($b=.02, beta=.35, p=.03$) and escape avoidance

coping ($b=8.2$, $beta=.56$, $p=.01$). After adjusting for the number of predictors, the R-square was .37, accounting for 37% of the variance in total decisional conflict. Thus, women who experienced more anxiety and/or used more escape avoidance coping strategies had higher decisional conflict.

Decisional Conflict and Uncertainty

When regressing the Uncertainty subscore onto Anxiety and Coping, three of the variables emerged as statistically significant, anxiety ($b=.04$, $beta=.39$, $p=.02$), seeking social support ($b=7.6$, $beta=.37$, $p=.02$), and escape-avoidance ($b=14.33$, $beta=.47$, $p=.01$). The model was statistically significant ($F(8,48)=4.27$, $p=.01$) and accounted for 33% (adjusted R-square) of the variance in uncertainty on the DCS. Thus, women who had higher anxiety and used seeking social support and escape avoidance as coping strategies had higher uncertainty in choosing among available options.

Decisional Conflict and Knowledge

When regressing the Knowledge subscore onto Anxiety and Coping, one predictor emerged as statistically significant, escape avoidance ($b=7.92$, $beta=.48$, $p=.01$). The model was statistically significant ($F(8,48)=2.78$, $p=.01$), accounting for 21% (adjusted R-square) of the variance in DCS Knowledge. Thus, women who used escape-avoidance as a coping strategy had more conflict in understanding types of options available.

Decisional Conflict and Values Clarity

When regressing the DCS Values Clarity subscore on Anxiety and Coping, one variable emerged as statistically significant, escape avoidance ($b=6.57$, $beta=.42$, $p=.02$). The Model was statistically significant ($F(8,48)=2.59$, $p=.02$) and accounted for 19% (adjusted R-square) of the variance in Values Clarity. This result indicates that women who used escape-avoidance as a coping strategy also had more conflict in assessing the importance of the risks and benefits of each option.

Decisional Conflict and Effective Decision Making

When regressing the DCS Effective Decision Making subscore onto Anxiety and Coping, two predictors emerged as statistically significant, anxiety ($b=.02208$, $beta=.41$, $p=.01$) and escape avoidance ($b=7.20$, $beta=.45$, $p=.01$). The model was statistically significant ($F(8, 48)=3.82$, $p=.01$) and accounted for 29% (adjusted R-square) of the variance in Effective Decision Making. Thus, women who had more anxiety and used escape-avoidance coping strategies had higher conflict in evaluating whether their decision (e.g., choice) was effective.

Decisional Conflict and Support

When regressing the DCS Support subscore onto Anxiety and Coping, none of the eight individual predictors was statistically significant.

Ancillary Results

Socioeconomic Status, Decisional Conflict, and Coping

Socioeconomic Status (SES) had a significant negative association with the Uncertainty subscale of the DCS ($r = -.30, p = .03$) indicating that women with lower SES scores had more uncertainty about choosing available options. SES also had a negative association with the Seeking Social Support coping subscale ($r = -.37, p = .01$) and a positive relationship ($r = .37, p < .01$) with the coping subscale of Accepting Responsibility. These findings indicate that women who scored lower in SES used more seeking social support strategies than women of higher SES. Women who had higher SES scores were more likely to use accepting responsibility coping strategies than women who scored lower on SES.

Prognosis of Fetal Abnormality

There were significant differences among the prognosis groups (e.g., uncertain, poor, fair and good) on anxiety, $F(3,51) = 3.3, p = .03$. Tukey's post hoc test revealed that women with an uncertain fetal prognosis had significantly less anxiety ($M = 48$) than women whose fetus had a poor prognosis ($M = 57$). These results indicate that the women who had a fetus with a poor prognosis had higher levels of anxiety than women with an uncertain fetal prognosis.

Significant differences were found among the prognosis groups of fetal abnormality in confrontive coping ($F(3,51) = 3.72, p = .02$), distancing ($F(3,51) = 5.1$,

$p = .01$), and seeking social support ($F(3,51) = 7.1, p = .01$). Tukey's post hoc tests revealed that the poor prognosis group ($M = .12$) scored significantly higher than the fair prognosis group ($M = .06$) for confrontive coping. For distancing, the poor prognosis group ($M = .09$) scored significantly lower than the uncertain prognosis group ($M = .14$). For seeking social support all prognostic groups scored significantly different from each other with the exception of the uncertain ($M = .14$) and good prognosis groups ($M = .14$). The poor prognosis group ($M = .19$) had lower scores on seeking social support than the fair prognosis group ($M = .26$).

CHAPTER V

DISCUSSION

This chapter presents a discussion of the study results in four principal sections: (1) Interpretation of the findings related to the four research questions with associated demographic characteristics, (2) Limitations of the study, (3) Implications for nursing, and (4) Recommendations for future research.

Level of Decisional Conflict Following Diagnosis of Fetal Abnormality

Overall, the women in this study experienced low levels of decisional conflict in knowledge, values clarity, support, and effective decision making. However, women experienced high levels of decisional conflict in uncertainty. Considering the nature of counseling women received following diagnosis at WIH, these results are not surprising. All women who received a diagnosis of fetal abnormality were provided face-to-face genetic counseling and a detailed packet that included information about the risks and benefits of available options to help them in their decision making. Studies that tested informational interventions for reducing decisional conflict found that face-to-face supportive counseling and decision-aided interventions decreased decisional conflict, particularly in providing information aimed at helping women understand the benefits and risks of available options (Cochrane Database, 2003).

Decision aids also were found to decrease decisional conflict by improving the quality of patients' decision making. The quality of decision making has been defined by O'Connor (1998) as an individual's knowledge about options and outcomes, realistic perceptions of outcome probabilities, and agreement between individual values and choices. Since the women enrolled in this study were provided information and face-to-face genetic counseling before participating in the study, these support modalities may have had a positive influence on decreasing participants' levels of decisional conflict by the time the interview took place.

However, the finding that women in this study had high levels of uncertainty is noteworthy. Despite the counseling and information provided the women in this study, they still had high levels of uncertainty about what option to choose. This finding is supported by research that revealed that women in whom a fetal abnormality was diagnosed articulated the uncertainty they felt related to the difficult negotiations they had to make when evaluating choice options (Gregg, 1999; Rapp, 1998; Rothman, 1988). Higher levels of uncertainty also was found to be intensified by the social and personal meanings attached to the choice options, such as pregnancy termination, disability, and loss of a healthy child (Rapp, 2000). Additionally, this reflects the Conflict Theory Model's key assumption that the stressful nature of choosing is influenced by both loss and uncertainty (Janis & Mann, 1977).

Further, Sandelowski and Baroso's (2005) metasynthesis of women's experiences following diagnosis of fetal abnormality, revealed that women had significant distress in choosing an option because all options available involved loss, risk, and uncertainty. Thus, the burden of responsibility and the level of uncertainty it

generates may be intertwined. Consequently, the decision making process may be more stressful for women who have higher uncertainty about what option to choose because they are more affected by the limited time available to weigh and rank each option. Time to explore, examine and reflect on available evidence is crucial to decision quality (Janis & Mann, 1977).

Level of Decisional Conflict and Sample Characteristics

There was no significant relationship found between women's age (18-41 years) and level of decisional conflict in this convenience sample ($N=55$). However, gestational age (age in weeks of the fetus) at time of diagnosis revealed that women who received the diagnosis at a later gestational age in this study had lower levels of decisional conflict. According to Lazarus and Folkman (1984), individuals who have a better sense of actualizing an outcome are more tolerant of the ambiguity associated with having to make a difficult or challenging decision. It is possible that the women whose pregnancies were of higher gestational age were able to visualize the fetal abnormality more clearly on ultrasound because the fetal defect was more anatomically apparent. This notion is supported by Christian, Koem, Pillay and Williams's (1999) who found that visualization of a fetal abnormality on ultrasound was helpful to women during the decision making process. In another study, Lalor, Devane, and Begley (2007) found that most women felt that the use of a combination of fetal ultrasound images, percentile charts and diagrams enhanced their understanding of what, at the time, seemed incomprehensible. Based on these results, it is possible that having a clear image of the abnormality allows women to anticipate the future, plan for it and work through some of

the difficulties in advance, because they now have a comprehensive picture of the situation they are facing.

Women of higher parity had higher conflict in knowledge (e.g., understanding the risks of each option) of available options and in evaluating the risks and benefits associated with each choice. Having a fetus diagnosed with an abnormality may be a particularly stressful event for women of higher parity because consideration of choice is contingent on and reveals something about responsibility and relationships. For example, Gilligan's (1982) research on decision making revealed that choice difficulty is associated with a woman's need to maintain cohesiveness of family relationships. She asserts that the resolution of conflict is context dependent and the conflict resolution involves the consideration, protection, and sustenance of others who may be affected by the choice made. Although general knowledge may be sufficient for interpreting the event, it may be inadequate for predicting the outcome of a choice and its effect on all members of the family. Carefully weighing the negative and positive outcomes, searching for relevant information about the choice alternatives and executing the chosen course of action is required to resolve the decision dilemma (Janis & Mann, 1977). For these reasons, women of higher parity may need more informational support or different information modalities from clinicians to facilitate their understanding of all options available before being able to make an informed decision.

Marital Status and Decisional Conflict

In assessing differences among the marital status groups on the decisional conflict variables, only one statistically significant effect was found. Single women living with a

partner experienced higher levels of conflict on values clarity than married or single women. According to O'Connor and Jacobsen (1995), values clarity involves clarifying the benefits, risks, and importance of available options during decision making. Having an abnormality diagnosed in a fetus is a life experience that can challenge personal values associated with choosing among alternative options when all options involve risks and loss. For example, in Kolker and Burke's (1993) study of married women in whom an intrauterine fetal death had been detected the couple shared the same values in terms of the decision of when and how to proceed with induction of labor.

It is plausible that the type of emotional support women receive when faced with a decision dilemma has a role in the process of decision making. Support commonly implies that sharing personal values are influential aspects of any type of important relationship. Values may be particularly critical when couples have to make life-altering decisions, because each individual in the relationship may attach different meanings to the outcome (Veiel & Bowman, 1994).

According to Valentine (2000), women may rely on their spouse or family and friends to validate and share the burden of decision making by encouraging them to participate in the process. There is limited literature on how single women living with partner make difficult decisions (Alan Guttmacher Institute, 2007). However, in this study, some of the women in this group discussed the relative newness of the relationship and that another conflict for them was that the pregnancy had been unplanned. Thus, single women living with a partner may not have the same type of support for clarifying values about the risks and benefits of each available option. It is plausible that partners may not share the same filial obligation during the decision making process when the

options available involve life-altering outcomes for the well-being of the woman. This interpretation is limited by the lack of current data about how single women living with a partner make difficult decisions (Alan Guttmacher Institute, 2007).

Decisional Conflict and Type of Fetal Abnormality

Overall, the women in this study in whom a lethal or nonlethal fetal abnormality was diagnosed had higher levels of conflict in uncertainty (e.g., the choice was clear). Uncertainty exists whenever individuals are unable to form a cognitive framework for understanding their situation and to predict the outcomes of their choices (Weitz, 1989).

The finding that women in the current study had higher levels of conflict in uncertainty adds to the evidence that a prenatal diagnosis engenders an existential crisis because it places a demand on women to choose the fate of their unborn child. During this process, they must confront or reconcile their beliefs about human imperfection, disability, their role as parent protector, and the acceptability of pregnancy termination as an option (Rapp, 2000; Rothman, 1998; Sandelowski & Baroso, 2005; Sandelowski & Jones, 1996). Additionally, the emotional distress women experience after receiving a diagnosis of a lethal fetal abnormality is similar to those women experiencing a stillbirth or neonatal death (Zeanah et al., 1993) because the experience involves an intense emotional reaction associated with whether or not to terminate the pregnancy (Chitty et al., 1996).

Anxiety and Characteristics of the Women

There was no significant relationship found between women's anxiety and age, gravidity, parity, or marital status. Most women view prenatal testing (e.g., ultrasonography) as a routine and enjoyable part of their pregnancy because it offers reassurance that the fetus is developing normally during this positive transition (Sandelowski & Baroso, 2005). However, receiving a prenatal diagnosis of fetal abnormality following prenatal testing creates an unexpected highly stressful event. Bijma et al. (2005) conducted a literature review of women's emotional responses following diagnosis of fetal abnormality. The review confirmed that women not only experienced high anxiety levels following diagnosis, but anxiety continued to remain high during the decision making process.

Coping Strategies Women Used Following Diagnosis

The women in this study used proportionately more emotion-focused coping strategies (60%) than problem-focused coping strategies (40%). In general, emotion-focused forms of coping are more likely to occur when there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging events. Problem-focused forms of coping, on the other hand, are more probable when such conditions are appraised as amenable to change. During a stressful encounter, the person is discovering the realities of what is happening and what can be done about it, and this affects coping. For example, learning that one lacks control over the most significant aspects of the situation will encourage the use of strategies for regulating emotions; direct actions (i.e.,

problem-focused strategies) may have to await suitable opportunities (Folkman & Lazarus, 1984).

Thus, it is not surprising that the women in this study used more emotion-focused coping strategies, such as distancing, escape-avoidance, and positive reappraisal. Receiving a diagnosis of fetal abnormality poses a major challenge to future life goals, such as being a parent and having healthy children. Given the stressful nature of the decision making process, it seems appropriate that the use of emotion-focused coping strategies were used more often to palliate the emotional distress generated by the decision dilemma. Emotion-focused coping strategies may have been more useful during the time when women were thoroughly canvassing alternatives and evaluating the consequences of making a difficult choice.

Most abnormalities are detected unexpectedly during a pregnancy, which, until then, was uneventful. Most expectant parents do not seriously consider the possibility of fetal abnormality. The diagnosis of an abnormality often evokes strong emotions about the well being of their future child, forcing the parents to confront the harsh reality that an intrinsically positive event as a desired pregnancy can end with disease and suffering. These findings, support how anxiety can affect both coping and decision making.

For example, distancing describes efforts to detach oneself from the situation and escape-avoidance describes wishful thinking (e.g., hoping a miracle would happen). Decisions about whether to continue the pregnancy and give the unborn child a chance to live and possibly suffer or to prevent suffering by terminating the pregnancy can be extremely distressing. The use of distancing may have been a helpful respite from having

to resolve such a decision dilemma, whereas the use of positive reappraisal also may have been helpful to women in this study because its use involves creating positive meaning of the situation and it has a religious tone (e.g., “I found new faith”).

The problem-focused strategies women used more often in this study were seeking social support, planful problem-solving, and confrontive coping. It is plausible that women sought more support from clinicians, family, and/or friends to help them clarify the available options. Planful problem-solving coping may have been used to develop a plan of action and/or come up with a couple of solutions to the decision dilemma. Folkman and Lazarus (1988) describe confrontive coping as aggressive efforts to alter the situation. Since the situation of having a diagnosis of fetal abnormality is not changeable, this strategy, although used, may not have been as useful during the decision making process.

Common to the coping strategies described above is a distinction that has overriding importance, namely between coping that is directed at managing or altering the problem causing the distress and the type of coping that is directed at regulating emotional responses to the problem. Since coping strategies are likely to change as appraisals of the stressful situation changes over time, problem-focused coping and emotion-focused coping can both facilitate and impede each other in the coping process. Regardless of how each strategy is defined or conceptualized, the prime importance of the coping strategies used is how they affect adaptational outcomes.

Coping Strategies and Maternal Characteristics

As age increased, the women in this study used seeking social support more often than younger women. Seeking social support includes efforts to seek informational support (e.g., talking to a genetic counselor or physician), tangible support (e.g., talking to a perinatologist), and emotional support (e.g., accepting sympathy from a friend). The finding that older women sought social support more often than younger women may be because older women typically rely on previous health experiences in accessing information and thus have greater confidence in seeking the advice of specialists. Older women typically have more established integrated social networks (Alan Guttmacher Institute, 2003; Biele & Bauman, 1994). Thus, the older women in this study may have had access to better social supports in addition to previous experience accessing health information.

Older women in this study were more likely to use planful problem-solving coping strategies than younger women. This refers to attempts to alter the situation by coming up with more than one solution to the problem, doubling one's efforts to get things done, or determining a course of action and following it. For example, a woman in this study stated during the interview indicated that after she received the initial diagnosis of Twin-Twin Transfusion Syndrome, her provider gave her a very grim prognosis and limited options, such as termination of the pregnancy or continuation with knowledge that the twins would have an intrauterine fetal demise. The planful problem-solving strategies she used included seeking additional information on the internet, accessing expert advice, and coming up with another alternative to her situation (e.g., in utero ablation surgery performed by a perinatologist). In her case, the outcome of her

planful problem solving efforts was positive. She was able to continue the pregnancy and have a healthy outcome for both twins.

Women whose pregnancies were of higher gestational age at the time of diagnosis used less seeking social support. According to Ringler et al. (1998), women faced with an abnormal prenatal diagnosis struggle to discuss their choice dilemma with friends and family because they may be acutely aware of the intense feelings that others may have regarding their choice options. When the gestational age of the fetus is more advanced, the more family and friends are aware of the pregnancy and are able to share in the joyful anticipation of the birth of a child. However, when a diagnosis of a fetal abnormality has been detected, it not only poses great stress on the pregnant woman, but also having to share this grief with family and friends adds another layer of stress to the situation. This stress may be compounded, especially if the woman is experiencing an uncomfortable psychological state of conflicting beliefs (e.g., the woman's values or religious beliefs conflict with the resolution of the decision dilemma). To resolve this conflict, she will seek information that validates her chosen course of action. In this case, she is less likely to share her decision with family and friends. For example, a woman enrolled in the current study expressed in the interview that one of the difficulties in disclosing her decision to her family was that their religious beliefs would not support her chosen option. To avoid judgment of her choice, she told her family that she had a pregnancy loss/stillbirth.

Coping and Marital Status

Married women used less distancing than single women. Distancing strategies are associated with efforts to detach oneself from the situation and to minimize the significance of it. It is possible that having a spouse for support while sharing the burden of a major disappointment, such as having a fetus diagnosed with an abnormality, helped married women feel less alone in the process of decision making. Married women also used more planful problem-solving coping than single women or single women living with a partner. This finding also suggests that married women were more able to share the experience with their husbands in planning efforts to alter the situation, and, in the process, were able to take an analytic approach to resolving the decisional dilemma together. Single women and single women living with a partner may need more help from other support sources (e.g., family, friends, clinicians, genetic counselors) to help them clarify and analyze the choice options available to them.

Women living with a partner used more accepting responsibility, an emotion-focused coping strategy than married women in this study. Accepting responsibility often implies self-blame and/or acknowledging one's own role in creating the problem. During the interview with some of the single women living with a partner in this study, they discussed that a significant stressor for them was that the pregnancy had been unplanned. They expressed much guilt and remorse when they were told that a fetal abnormality had been detected. Since the pregnancy was unplanned, these women did not feel they had much support from their partner in sharing the loss and sadness generated by the diagnosis.

Coping and Type of Fetal Abnormality

Women with a diagnosis of a lethal fetal abnormality used more confrontive coping, distancing, and seeking social support strategies than women in whom non lethal fetal abnormalities were diagnosed. Confrontive coping describes aggressive efforts to alter the situation and suggests a degree of hostility (e.g., expressing anger to the person(s) who caused the problem). Confrontive coping strategies are more frequently used in situations that are perceived as changeable (Folkman, 2003). The use of more confrontive coping strategies by the women in this study may have been an expression of the profound anger and disappointment they felt. Additionally, Zeanah et al. (1993) noted that intense grief reactions were significant in women faced with the diagnosis of a lethal fetal abnormality. Thus, confrontive coping strategies may be a manifestation of the intensity of emotion and feelings of loss.

Furthermore, the women in this study used more distancing following a lethal fetal diagnosis. Folkman (2003) suggests that along with an impulse to confront a situation with anger or aggression, there is a simultaneous impulse to regulate the hostile feelings so that the situation does not get out of hand. The use of coping strategies that appear to have opposite purposes, such as confrontive and distancing coping, highlights the consideration that contradictory forms of coping may be mutually facilitative (Folkman, 2003). Detachment from the situation may serve as a valuable way to palliate the affective dysphoria experienced following diagnosis.

Women in whom a lethal fetal abnormality was diagnosed also used more seeking social support coping strategies. The higher use of seeking social support following a lethal fetal diagnosis suggests that the women in this study needed more information about options and expert advice from care providers than from family and friends. For example, it has been shown that women more often choose termination as an option when the diagnosis is considered lethal (Evans et al., 2004). Further, according to Zeanah et al. (1993), women choosing termination feel their decision will not be supported by important people in their lives. This notion is supported by Sandelowski and Baroso (2005) who noted that women will both simultaneously seek information to understand the diagnosis and to affirm their decisions, while also avoiding information from significant others that may provide condemnation for choice, causing regret. Thus, women in this study who sought more social support may have benefited from their efforts to discuss the situation with an expert, receive supportive, non-judgmental counseling, and the need for shared decision making.

Decisional Conflict and Coping

Higher levels of decisional conflict in uncertainty and support were positively associated with confrontive coping. Confrontive coping is a problem-focused effort to cope with threat itself. Individuals experiencing severe stress have been shown to use confrontive coping strategies (e.g., expressing anger and frustration) by actively trying to change the situation for the better. However, having a fetus in whom an abnormality has been diagnosed, may not be amenable to change. This notion may explain why women in

this study who were high in the conflict of uncertainty used confrontive coping. The reality of the diagnosis creates a full-fledged emotional response because the nature of the situation presents major tasks that are wrought with uncertainty. The woman must be helped to come to grips with the reality an abnormality exists. According to Lazarus and Folkman (1984), in most highly-charged encounters that involve conflict, it is fairly clear that the experience may be anger-inducing and there should not be a problem for observers to understand what the reaction is all about. It seems logical that if an individual experienced conflict in uncertainty, a perceived lack of support also may be operating. These findings suggest that women experiencing severe stress, such as a diagnosis of fetal abnormality, may need more support services (e.g., genetic counselors, social workers, ministers) to help them assign a realistic meaning as the situation unfolds.

There were significant positive relationships between the level of decisional conflict and conflict in knowledge, values clarity, support, and escape-avoidance coping. The higher the levels of decisional conflict, the more often escape-avoidance strategies were used. Also, the higher the conflict of knowledge (e.g., awareness of options available), values clarity (e.g., benefits of each option), support (e.g., adequate advice of options), the higher the use of escape-avoidance coping (e.g., wishing a miracle would happen). Escape-avoidance not only describes wishful thinking (e.g., wishing the whole thing would go away or be over with), but it also indicates attempts to make oneself feel better by eating, drinking, smoking, using drugs, or medications. For example, a woman in this study in whom a lethal fetal abnormality had been diagnosed described during her interview how much she appreciated a mind altering pain relief modality (e.g., morphine) during her induction to terminate her pregnancy. She reflected that the emotional pain

took precedence over the physical pain so she chose a modality that would help her escape the painful reality of undergoing a termination.

Furthermore, escape-avoidance indicates an avoidance of significant people in one's life during times of severe stress. Sandelowski and Baroso's (2005) metasynthesis of women's experiences with abnormal prenatal diagnosis revealed that some women avoided others and isolated themselves because of the uniqueness of their suffering, and, as discussed previously, feared condemnation of their choice. Last, escape-avoidance suggests a control of information both coming in (e.g., timing and amount) and information going out (e.g., telling friends and family about the choice). Thus, escape-avoidance is a way of coping with both the cognitive dissonance (e.g., conflicting beliefs about the choice made) women may be having, as well as managing the stigma (i.e., social judgment) of their chosen option in times of high decisional conflict and extreme emotional pain.

There was a significant negative relationship between the conflict of support and seeking social support coping. This finding indicates that women with higher support conflict (e.g., adequate support to make a choice) used less seeking support as a coping strategy. Thus, women in this study who used less seeking support sources were more likely to feel they did not have adequate support for making a choice. It is plausible that, despite the numerous support modalities available to women at WIH, some women may have needed additional teaching on what types of supports were available, concrete methods of accessing those supports, and how to ask the right questions to facilitate their understanding of the information received. Some women may not have the life

experience, confidence, or assertiveness skills to access and absorb adequate informational support.

There were significant negative relationships between the conflict of values clarity and problem solving and positive reappraisal coping strategies. These results indicate that the use of problem solving coping strategies were associated with increased awareness of the benefits and risks of available options. The use of positive reappraisal (e.g., focusing on personal growth or religious faith) allowed women to reflect on what was happening and how to deal with the stressful situation of having a fetus diagnosed with an abnormality.

Anxiety and Coping

The women in this study who had high anxiety were more likely to use confrontive coping strategies and less distancing. The use of confrontive coping and distancing may have been a mismatch between their appraisals or perceived threats of losing a their healthy baby and the actual flow of events. This mismatch may have heightened the threat of loss producing higher anxiety. For example, directly confronting the situation by actively expressing anger and disappointment could have caused more stress and feelings of vulnerability. According to May (1996), anxiety and its associated feelings of helplessness, isolation, and conflict, go hand-in-hand. Women coping with severe stress, such as learning their fetus has an abnormality, may need more guidance and supportive sources (e.g., clinicians, genetic counselors, social workers) to help them adapt to the flow of events.

Decisional Conflict and Anxiety

Level of decisional conflict and conflict in uncertainty and effective decision making were positively related to anxiety. According to Luce et al. (2001), compromises between choice options are central to making difficult choices, especially when choices are emotionally laden. The need to make difficult compromises is what typically generates negative emotions such as anxiety. Thus, it is not surprising that the women in this study who had higher levels of decisional conflict, higher conflict in uncertainty, and were less satisfied with the decision they made had higher anxiety. Because weighing the differences in choice characteristics are integral and meaningful aspects of choice, women in situations when choice alternatives are critical must be helped to engage in strategies of coping that have the potential to decrease the decisional conflict and anxiety generated by the choice dilemma.

Predictors of Decisional Conflict

Predictors of decisional conflict were further explored using multiple regression analyses. In these multiple regression models the decisional conflict variables were the dependent variables and the independent variables (or predictors) were anxiety and the coping variables. Thus, when the significant predictors are discussed in this section, they are predictors that remain significant when all the other predictors are in the same multiple regression model.

In the multiple regression model, there were two significant predictors of decisional conflict: anxiety and escape-avoidance coping. The full model explained a significant amount of the variance in decisional conflict (37%). This mirrors the decisional conflict literature that states anxiety and difficulty coping often coexist with decisional conflict (O'Connor, 1995). Janis and Mann (1977) and Folkman and Lazarus (1984) characterize the individual faced with a life-altering decision dilemma as one marked by doubts and worries. Thus, it is not surprising that anxiety was found to be a predictor of decisional conflict in this study. Escape-avoidance is an emotion-focused coping strategy aimed at palliating negative emotions and avoidance of decisional conflict (Luce et al., 2001). Thus, tailored decision-aided interventions that target women with high anxiety and who use escape-avoidance coping would facilitate decision making efforts and decrease decisional conflict in these women.

In the multiple regression model there were three significant predictors of conflict in uncertainty: anxiety, seeking social support, and escape-avoidance. The full model explained a significant amount of the variance (33%) in uncertainty. Thus, women who had higher anxiety, used more seeking social support, and escape-avoidance coping strategies were predicted to be more uncertain about choosing an available option. A main assumption of Janis and Mann's conflict theory is that the anxiety generated by choosing an outcome is influenced not only by risk and loss, but also by ambiguity and uncertainty. Seeking social support indicates the search for information and understanding of choice options is a means of reducing the uncertainty inherent in the choice dilemma. Escape-avoidance may be used as a means of reducing uncertainty by wishful thinking and hoping a miracle will happen. Thus, continued refinement of informational and expert

clinical support is warranted to meet the specific and complex needs of women faced with an abnormal prenatal diagnosis.

In the multiple regression model there was one significant predictor of conflict in knowledge: escape-avoidance coping. The full model explained a significant amount of the variance (21%) in knowledge. Thus, women who used escape-avoidance as a coping strategy had more conflict in knowledge of risks and benefits of types of options available. Hence, it is not surprising that escape-avoidance coping strategies were used to avoid the stressful nature of the information received about choice options. The willingness to confront or avoid the information depends on the meaning an individual assigns to the choice options (Janis & Mann, 1977). Hence, women who use escape-avoidance coping strategies may need new modalities of information to have a better grasp of the risks and benefits associated with the choice options.

In the multiple regression model there was one significant predictor of conflict in values clarity: escape-avoidance coping. The full model explained a significant amount of the variance (19%) in values clarity. This result indicates that women who used escape-avoidance as a coping strategy also had higher conflict in values clarity. Values are abstract ideals representing a person's belief about ideal modes of behavior. The use of escape-avoidance coping as a predictor of conflict in values clarity indicates a need for shared decision making between practitioner and patient. Shared decision making encourages a high level of patient and provider involvement in the decision making process, which may be particularly beneficial to women in clarifying values and determining importance of each option.

In the multiple regression model there were two significant predictors of conflict in effective decision making: anxiety and escape-avoidance. The full model accounted for a significant amount of variance (29%) in effective decision making. Thus, women who had more anxiety and used more escape-avoidance had higher conflict in evaluating if they had made the right choice.

Limitations of the Study

In this study coping with decisional conflict was assessed at one point in time. To better understand how women cope when unexpectedly confronted by a situation having major relevance for their welfare (such as carrying a fetus in whom an abnormality had been diagnosed), coping must be evaluated over the course of the decision making process. When evaluating coping as a process, coping strategies are likely to change as the situation unfolds.

Only one psychological factor, anxiety, was investigated in this study. Other psychological variables, such as high levels of optimism, perceived control, and self efficacy, (cited in Aldwin, 1996) have been linked to decreased appraisals of threat or the negativity of events. Additionally, personality traits such as ambiguity tolerance may facilitate understanding how individuals cope with uncertainty.

Finally, data was collected at one site with English speaking women only. This limits the generalizability of the findings in this study to other populations of women dealing with a diagnosis of fetal abnormality and/or other prenatal stressful events.

Implications for Nursing

This dissertation study has some utility for guiding the practice of perinatal nursing, in particular, by providing a coping framework that is capable of incorporating individual and situation variables of importance to nurses caring for women in whom a lethal or nonlethal fetal abnormality has been diagnosed. Nurses are uniquely capable of fostering informed, preference-based choice by studying and implementing shared decision making models of care. Additionally, nurses are in a critical position to help women in crisis deal with the negative and positive consequences of the decision dilemma, receive full information and psychological support, reduce ambiguity and uncertainty, give anticipatory guidance, facilitate conflict resolution, and to assign meaning to the events.

Recommendations for Future Research

Janis and Mann's (1977) theoretical model used in this study includes both the meaning attached to the decision dilemma and the pattern of coping as important factors affecting resolution of the decisional conflict. The theoretical process-oriented coping perspective of Lazarus and Folkman (1984) also used in this study defines coping as a process of changing cognitive and behavioral efforts to manage a specific stressful situation. According to this perspective, the coping process is elicited in response to an individual's evaluation that important goals have been threatened, harmed, or lost (Folkman, 2004). The key point is that while individuals are sometimes confronted by a situation having major relevance to their welfare, they also engage in active regulation of their emotional reactions, selecting the environment to which they must respond by

planning, choosing, avoiding, tolerating, escaping, and confronting the stressors.

As noted in the limitation section of this study, researchers studying coping must broaden their assessment of coping over a longer time span so that they can determine how coping changes over time and situation. A process-oriented focus with a broad assessment of coping strategies used will be most useful in helping investigators understand how individuals cope with and adjust to stressful situations. The task now is to turn this conviction into increasingly sophisticated and systematic study with the aim of accurately tailoring interventions to the stressful situation and its specific management requirements, the institutional setting, and the psychosocial nature of the person with whom we are dealing.

APPENDICES

Generic Decisional Conflict Scale**My difficulty making this choice**

Now, thinking about the choice you just made, please look at the following comments made by people when making decisions.

Please show how strongly you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree), which best shows how you feel about the choice you just made.

- | | | | | | |
|---|------------------------|------------|---------------------------------------|---------------|---------------------------|
| 1. This decision is easy for me to make | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 2. I'm sure what to do in this decision | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 3. It's clear what choice is best for me | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 4. I'm aware of the options I have
in this decision | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 5. I feel I know pros of each option | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 6. I feel I know the cons of each option | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |
| 7. I know <u>how important</u> the pros are
to me in this decision | 1
Strongly
Agree | 2
Agree | 3
Neither
Agree nor
Disagree | 4
Disagree | 5
Strongly
Disagree |

8.	I know <u>how important</u> the cons are to me in this decision	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
9.	I know which is more important to me (the pros or the cons)	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
10.	I am making this choice without any pressure from others	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
11.	I have the right amount of support from others in making this choice	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
12.	I have <u>enough</u> advice about the options	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
13.	I feel I have made an informed choice	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
14.	My decision shows what is important to me	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
15.	I expect to stick with my decision	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree
16.	I am satisfied with my decision	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree

100010

WAYS OF COPING QUESTIONNAIRE

Susan Folkman, Ph.D. and Richard S. Lazarus, Ph.D.



INSTRUCTIONS

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week*.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something

else important to you. Before responding to the statements, think about the *details* of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced *during* the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate, by filling in the appropriate circle, to what extent you used it in the situation. Please respond to each item.

Does not apply or not used
Used somewhat
Used quite a bit
Used a great deal

- 1. 0 1 2 3 I just concentrated on what I had to do next — the next step.
- 2. 0 1 2 3 I tried to analyze the problem in order to understand it better.
- 3. 0 1 2 3 I turned to work or another activity to take my mind off things.
- 4. 0 1 2 3 I felt that time would make a difference — the only thing was to wait.
- 5. 0 1 2 3 I bargained or compromised to get something positive from the situation.
- 6. 0 1 2 3 I did something that I didn't think would work, but at least I was doing something.
- 7. 0 1 2 3 I tried to get the person responsible to change his or her mind.
- 8. 0 1 2 3 I talked to someone to find out more about the situation.
- 9. 0 1 2 3 I criticized or lectured myself.
- 10. 0 1 2 3 I tried not to burn my bridges, but leave things open somewhat.

CONTINUE ON THE OTHER SIDE

DO NOT MARK IN THIS AREA

WOC-0185

244R, PEI-54321

SHADED AREAS

WAYS OF COPING QUESTIONNAIRE
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Spielberger State-Anxiety Inventory (Adult)

SELF-EVALUATION QUESTIONNAIRE

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seem to describe your present feeling best.

		Not at all	Somewhat	Moderately so	Very much so
1.	I feel calm.....	1	2	3	4
2.	I feel secure.....	1	2	3	4
3.	I am tense.....	1	2	3	4
4.	I feel strained.....	1	2	3	4
5.	I feel at ease.....	1	2	3	4
6.	I feel upset.....	1	2	3	4
7.	I am presently worrying over possible misfortunes.....	1	2	3	4
8.	I feel satisfied.....	1	2	3	4
9.	I feel frightened.....	1	2	3	4
10.	I feel comfortable.....	1	2	3	4
11.	I feel self-confident.....	1	2	3	4
12.	I feel nervous.....	1	2	3	4
13.	I am jittery.....	1	2	3	4
14.	I feel indecisive.....	1	2	3	4
15.	I am relaxed.....	1	2	3	4
16.	I feel content.....	1	2	3	4
17.	I am worried.....	1	2	3	4
18.	I feel confused.....	1	2	3	4
19.	I feel steady.....	1	2	3	4
20.	I feel pleasant.....	1	2	3	4

Demographic and Diagnostic Information

ID# _____

Today's Date:

1. Maternal age: _____

2. Gravidity: _____

3. Parity: T _____ P _____ A _____ L _____

4. Gestational Age: _____

5. Lethal anomaly: Yes No
(If yes, what type?): _____

6. Non-lethal anomaly: Yes No
(If yes, what type?): _____

7. Diagnosis of fetal anomaly: _____

8. Prognosis of fetal anomaly: _____

9. Corrective option: Yes No
(If yes, what type?): _____

10. Genetic risk factor(s) for anomaly: Yes No
(If yes, what type?): _____

11. Obstetric risk factor(s) for anomaly: Yes No
(If yes, what type?): _____

12. Religious affiliation:
 Protestant
 Jewish
 Catholic
 Other (specify): _____

13. Ethnicity:
 White Hispanic or Latino
 African-American Other (specify): _____
 Asian
 American Indian/Alaska Native

14. Marital status:

- Single
- Single, living with partner
- Married
- Widowed
- Other : _____

15. Occupation:

Mother: _____ **Spouse:**

16. Mother's Education:

- Less than 7th grade
- Junior high school
- Some high school
- Some college
- 4 years of college
- Graduate/professional training (greater than 4 years of college)

17. Spouse's Education:

- Less than 7th grade
- Junior high school
- Some high school
- Some college
- 4 years of college
- Graduate/professional training (greater than 4 years of college)

Question to be answered by study participant:

"What time frame do you feel you have for choosing a treatment option?"

July 12, 2006

Elisabeth D. Howard, MSN
Nursing
341 Lloyd Ave
Providence, RI 02906

Lynda L. LaMontagne, Ph.D., RN
Nursing
516 Godchaux Hall, 5th floor 37240-0008

RE: IRB# 060266 "Decisional Conflict, Anxiety, and Coping Strategies of Women Following Diagnosis of Fetal Abnormality"

Dear Ms. Howard:

A sub-committee of the Institutional Review Board reviewed the amendment dated 6/20/2006 for the research study identified above. As suggested by the sub-Committee modifications to the above study were submitted and received by the IRB on July 12, 2006. The sub-committee determined the changes to the study pose no additional risk to participants, and the amendment is approved on July 12, 2006.

Amendment: This is an amendment request dated June 20, 2006 to: 1) modify the consent form and 2) include a separate HIPAA authorization form to be signed by all participants enrolled in the study.

The Consent Form(s) have been stamped with the approval and expiration date and a copy should be used when obtaining the participant's signature. Federal regulations require that the original copy of the participant's consent be maintained in the principal investigator's files and that a copy be given to the subject at the time of consent. An additional record (i.e., case report form, medical record, database, etc.) of the consent process should also be maintained in a separate location for documentation purposes.

As the Principal Investigator, you are responsible for the accurate documentation, investigation and follow-up of all possible study-related adverse events and unanticipated problems involving risks to participants or others. The IRB Adverse Event reporting policy III.G is located on the IRB website at <http://www.mc.vanderbilt.edu/irb/>.

Any further changes to the study must be presented to the IRB for approval prior to implementation. **Please be aware that an amendment form is now available on the IRB website and should be used when submitting any additional amendments.**

DATE OF AMENDMENT APPROVAL: July 12, 2006

Sincerely,

Todd A. Ricketts, Ph.D., Chair
Institutional Review Board
Behavioral Sciences Committee

TAR/ss

Electronic Signature: Todd A Ricketts/VUMC/Vanderbilt : (5A2CD2A6DC6DF9701E3EE8A9FEA5F072)

Signed On: 07/13/2006 02:32:21 PM CDT

**Vanderbilt University Institutional Review Board
Informed Consent Document for Research**

Principal Investigator: Elisabeth D. Howard, CNM, MSN, Ph.D. candidate

Revision Date: 6-15-06

Study Title: Decisional Conflict, Anxiety, and Coping Strategies of Women Following Diagnosis of Fetal Abnormality

Institution/Hospital: Vanderbilt University Medical Center

This informed consent applies to adults.

Name of participant: _____

Age: _____

The following information is given to you to tell you about this research study. Please read this form with care and feel free to ask any questions you may have about this study. All of your questions will be answered. Also, you will be given a copy of this consent form.

Taking part in this study is your choice. The study will take place at Women and Infants' Hospital, RI. You may decide to stop being in this study at any time. The study will involve asking you a series of questions in a private setting at Women and Infants' Hospital, RI or the Prenatal Diagnosis Center. The study will take 30 - 45 minutes. The person doing the study is a Ph.D. student in nursing at Vanderbilt University as well as an employee of Women and Infants' Hospital. This study is being done as part of a doctoral dissertation.

1. What is the purpose of this study?

You are being asked to take part in this study because your test results showed that your fetus has an abnormality. We would like to know how you are doing after being counseled and told about the options you are faced with. This study is being done to learn how hard it is for you to make a choice, how you are feeling, and how you are dealing with your situation. 90 women will take part in this study. All women taking part in this study will be pregnant patients from the Prenatal Diagnosis Center who also have learned of abnormal fetal test results and are faced with making a treatment choice. You will not be asked to talk about the treatment option you have chosen for your child.

2. What will happen and how long will you be in the study?

If you agree to be in this study, the person doing the study will set up a time to ask you a series of questions. This interview will occur one time. This may be scheduled on the same day you have an appointment or at a time that best suits you. The study will take about 30 - 45 minutes to complete and will take place in a private room. The person doing the study will ask you 3 sets of questions. If you do not want to answer certain questions you do not have to. The first set of questions asks how hard it is to choose between the treatment options you are facing. This will take about 10 minutes. The second set of questions asks how you are feeling at the time of the interview. This will take about 5 minutes. The last set of questions asks how you are dealing with the situation right now. In this set, the first question asks you to describe your current stress. This one question is very broad and for this reason, the person doing the study would like

your permission to audio tape-record your answer. If you do not want this question to be audio taped, you can still be in the study. This part will take about 10 minutes. After you have told the person doing the study about your current stress the audio tape-recorder will be turned off. You will then be asked to choose the activities that you are using to deal with your stress. This will take about 20 minutes.

3. Costs to you if you take part in this study:

There are no costs to you to take part in this study other than the time spent.

4. Description of the discomforts, inconvenience, and/or risks that you can expect if you take part in this study:

There are no known risks to you for being in this study. The time it takes to complete the 30-45 minute interview may be a problem for you. You may feel upset talking about your situation. If you want to stop answering questions for any reason, tell the person doing the study and she will stop right away. If you are very upset she can contact a counselor to help you. During the tape recorded portion of the study, the recorder will be turned off at any time you wish. The person doing the study will take notice of how you are doing with the questions. If you show any signs of not wanting to complete the study such as looking distressed or having problems with the questions, you will be asked if you would like to stop.

5. Risks that are known: There are no known risks to taking part in this study.

6. Payment in case you are injured while in this study: There is no known risk of injury while taking part in this study.

7. Good effects that might result from this study:

- a) Your answers to the study questions may help nurses, doctors, and counselors in the future know how women cope after receiving an abnormal fetal diagnosis, how hard it is to make a choice among treatment options, and what role feelings play in making a choice.
- b) Your answers to study questions also may help nurses, doctors, and counselors in the future improve the care of women and their families during this stressful time and in the time that follows.

8. Other treatments you could get if you decide not to be in this study:

If you do not want to be in this study, you will receive standard care.

9. Payments for your time spent taking part in this study or expenses:

There is no payment for taking part in this study. There is no expense to you for

taking part in this study.

10. Reasons why the study doctor may take you out of this study:

If you become upset and the person doing the study thinks you are too upset to go on with the questions she may decide it is best to for you to stop being in the study.

11. What will happen if you decide to stop being in this study?

You may choose to withdraw from the study at any time. Your health care or relationship with the Women and Infants Hospital, RI or the Prenatal Diagnosis Center will not be affected in any way if you choose to withdraw from the study.

12. Who to call for any questions or in case you are injured:

If you should have any questions about this research study or if you feel you have been hurt by being a part of this study, please feel free to contact Dr. Lynda LaMontagne at Vanderbilt University, the faculty advisor of the person doing the study. She can be reached at 615-343-3321. You are also free to contact the researcher at 401-274-1122 X1448.

For more facts about giving consent or your rights as a person in this study, please feel free to call the Vanderbilt University Institutional Review Board Office at (615) 322-2918 or toll free at (866) 224-8273. You may also contact Barbara Riter, Manager, Research Administration at Women & Infants' Hospital. The number is 401-453-7677.

13. Confidentiality:

All efforts will be made to keep your protected health information (PHI) private. PHI is your private health information that can be linked back to you. Using or sharing such information must follow federal privacy guidelines. By signing the consent document for this study, you are giving permission to use and share your personal health information. A choice to take part in this research study means that you agree to let the person doing the study use and share your PHI as described below.

Elisabeth Howard may share the results of your study and/or non-study related medical facts, to the Vanderbilt University Institutional Review Board and the Women and Infants' Hospital Institutional Review Board or the Federal Government Office for Human Research Protections, if you or someone else is in danger or if we are required to do so by law. If you decide to withdraw your permission, we ask that you contact Elisabeth Howard's faculty advisor, Dr. Lynda LaMontagne at Vanderbilt University in writing and let her know that you are withdrawing your permission. Her mailing address is Vanderbilt University School of Nursing, 516 Godchaux Hall, 461 21st Ave. South, Nashville, TN 37240. At that time, we will stop further collection of any information about you. However, the health information collected prior to this withdrawal may continue to be used for the purposes of reporting and research quality.

A choice to not take part in this research study will not affect your care or

enrollment in health plans or your eligibility for benefits. You will receive a copy of this form after it is signed.

STATEMENT BY PERSON AGREEING TO BE IN THIS STUDY

I have read this consent form and the research study has been explained to me verbally. All my questions have been answered, and I freely and voluntarily choose to take part in this study.

Date

Signature of patient/volunteer

Consent obtained by:

Date

Signature

Printed Name and Title

July 12, 2006

Elisabeth D. Howard, MSN
Nursing
Providence, RI 02906

Lynda L. LaMontagne, Ph.D., RN
Nursing
516 Godchaux Hall, 5th floor 37240-0008

RE: IRB# 060266 "Decisional Conflict, Anxiety, and Coping Strategies of Women Following Diagnosis of Fetal Abnormality"

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Sincerely,

Todd A. Ricketts, Ph.D., Chair
Institutional Review Board
Behavioral Sciences Committee

TAR/ss

Electronic Signature: Todd A Ricketts/VUMC/Vanderbilt : (5A2CD2A6DC6DF9701E3EE8A9FEA5F072)

Signed On: 07/13/2006 02:32:21 PM CDT

Women & Infants'

INSTITUTIONAL REVIEW BOARD REPORT ON COMMITTEE ACTION

PRINCIPAL INVESTIGATOR: Elisabeth Howard, CNM, MSN, Ph.D. Candidate

PROTOCOL TITLE: DECISIONAL CONFLICT, ANXIETY, AND COPTNG STRATEGIES OF WOMEN FOLLOWING DIAGNOSIS OF FETAL ABNORMALITY

The Committee appointed to review proposals for clinical research and other investigations involving human subjects has reviewed the application identified above.

DATE OF REVIEW: May 22, 2006

COMMITTEE ACTION: Approval held in abeyance pending response to the Committee.

COMMENT: The Committee made the following recommendations to the consent form and protocol. Please clarify the number of subjects to be enrolled. One area lists 85 another section says 90. In the first paragraph of the consent form, please add "as well as an employee of Women and Infants Hospital after Vanderbilt University. Under #1, please add, "you will not be asked to talk about the treatment option you have chosen for your child" after "making a treatment choice". The investigator must include contact information for herself and the Research Office at Women & Infants in #12 of the consent form which is given to subjects. Subjects should not have to incur long distance charges to contact someone in Tennessee. The subjects recruited are patients of Women & Infants Hospital. We have the right to review all records/data collected for my research study involving our patients. Please include in #13, 2nd paragraph, that results may be shared with the Institutional Review Board of Women & Infants Hospital. A separate HIPAA authorization form for Women & Infants' Hospital must be signed by all subjects enrolled in the trial. This should be done at the time of consent. One copy of the authorization should be given to the subject; one copy put in the research file and one copy in the medical record.

Paul DiSilvestro, M.D.
Chairman

cc: Donald Coustan, M.D.
S. Carr, M.D.

Date issued: May 25, 2006

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