Women with Correctable Fetal Anomaly Participating in Perinatal Team Counseling: An Exploratory Study.

BY

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THESIS

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I would like to dedicate this thesis to all of the women receiving a prenatal diagnosis of a fetal anomaly. The strength and unyielding love of their infant inspires telling of their journey. I would like to thank the entire faculty that guided me towards completion of a life’s dream; particularly, Dr. Carmen Giurgescu and Dr. Patricia Hershberger, my dissertation chair. The never ending support and encouragement I received made me want to be a better clinician. Finally to my husband and children, Salvador Reyes, Ben and Salina for their unending love and support, without which, this work would not have come to fruition. Mom loves you.
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LIST OF ABBREVIATIONS

FA        Fetal Anomaly
I-Team    Interdisciplinary team of perinatal and pediatric sub-specialists
Chapter I

Introduction

Advances in prenatal care technologies, universal screening standards and changes in maternal characteristics (e.g., advancing maternal age, multiple gestation pregnancies, preconception diabetes, obesity) have increased both the ability to detect (Chitty, 1995; Goldberg, 2004; Shipp & Benacerraf, 2002; Stewart, 2004) and the prevalence of a fetal diagnosis (Correa, Gilboa, Besser, Booto, Moore, Hobbs et al., 2008; Sunderans, Chang, Flowers, Kulkarni, Sentelle, Jeng, & Malcaluso, 2009). Approximately 3% of U.S. births are complicated by major fetal anomalies. Major fetal anomalies involve structural changes in one or more parts of the fetal body (e.g., gastroschisis), are present at birth, and can have a serious, adverse effect on the infant’s health and development (Centers for Disease Control and Prevention). Fetal anomalies are the leading cause of death for infants under 1 year (NVSR, 2013).

Women report intense emotional-distress when confronted with an unanticipated diagnosis of a fetal anomaly with its associated long-term infant disability and health care expenses. Women with pregnancies complicated by fetal anomaly have report negative emotional responses such as heightened stress, anxiety, anger, despair, guilt, perceptions of inadequacy, social isolation, self-blame and grief-like reactions. However, these emotions and cognitive coping may be ameliorated with the counseling strategies employed when women are learning of their fetus' condition. The proposed study was intended to explore the perceptions of pregnant women given a diagnosis of correctable fetal anomaly during pregnancy, who were subsequently counseled by a team of perinatal and pediatric sub-specialists as a method of
counseling used to inform them of what was happening, and what was expected to happen after the birth of their baby. Using Lazarus and Folkman’s Stress, Appraisal and Coping transactional model, a cross sectional, qualitative descriptive design was used to describe the women’s experiences. Women were interviewed once in pregnancy, after their interactions with the interdisciplinary teams were completed. The study sample was recruited from the Fetal Concerns Program, a regional referral center for the Midwest region of the U.S., for obstetrical cases, facing various high risk conditions. The sample size was originally set at 20 cases, or until saturations was achieved. Saturation was attained at 10 cases; however, an additional four participants were recruited. The study’s inclusion criteria were set to include:

1. Prenatal diagnosis of a correctable fetal anomaly. A fetal diagnosis will have been established by ultrasound, MRI, or echocardiographic imaging with a prenatal diagnosis established prior to recruitment.

2. The candidate must have participated in perinatal interdisciplinary team counseling thus being fully aware of the fetal condition. Two distinct methods of perinatal interdisciplinary team counseling are currently offered: one involves individual specialist counseling with participants, with session spread out throughout the day, and the second involves team group counseling session at one sitting. Both groups will be sampled. Sample size of 15 participants will be obtained or until saturation has been achieved.

3. Participants must be (a) pregnant at the time of recruitment, (b) 18 years of age or older; (c) > 24 weeks and < 37 weeks gestation; (d) are able to read at a 5th grade level (for consent) (e) be comfortable speaking English (telephone interview), (f) have means of communicating either by telephone, and lastly (g) agree to digital recording of the interview.
Presented as two manuscripts, the following chapters include the findings of one research study (chapter II) and one integrative literature review (chapter III). The first manuscript includes the findings from original qualitative research work, designed to provide empirical evidence of the experiences of women diagnosed with a correctable fetal anomaly, who in the course of their pregnancy, received interdisciplinary team counseling by perinatal and pediatric sub-specialty teams. Using Lazarus and Folkman’s theory of Stress Appraisal and Coping to guide the study, a semi-structured interview format was used to explore women’s perceptions of their experiences. The tables reflect maternal demographic data, the iterative process used during data collection, description of the teams used during counseling, and description of coding procedures used. In the appendices, I have included data collection forms specifically developed for this study, approval letters for this research from the Institutional Review Boards at the University of Illinois at Chicago and the Medical College of Wisconsin, and lastly my vita.

The second manuscript, an integrative review, sought to identify what women seek in prenatal counseling after an anomalous fetus is diagnosed. A comprehensive review of empirical studies was undertaken to support the premise that coping is affected in pregnancy when interdisciplinary counseling is made available. This integrative review captured the current state-of-the-science of this emerging field.

The purpose of this integrative review was to identify and describe the counseling strategies used to counsel women who have been informed of a prenatally detected structural (non-lethal) fetal anomaly, addressing (a) methods of counseling strategies used, (b) team composition when teams are used, (c) women’s described perception of the effect of counseling when correctable fetal anomaly is noted, and lastly, (d) implications for practice. The figure
depicts the search strategy used for item selection and the enclosed tables reflect studies included fort the review and their findings, and lastly implications for practice.

Both the study and the integrative review support a described benefit in same-day consultations with the interdisciplinary team and all women describing not feeling overwhelmed with one-day counseling sessions. Women described the counseling sessions as ‘necessary to coping’, which was also a finding in the integrative review. Noted in the study, was the need to establish trust bonds with the healthcare providers and perinatal staff. The medical staffs responsible for the counseling sessions were described as communicating not only clinical expertise, but also caring and compassionate behaviors; creating a sense of comfort and trust, which was essential to women’s coping.

Team counseling when communicating difficult information has been shown to be successful in other areas of medicine (e.g., cancer care teams). The study’s findings supported perinatal interdisciplinary team counseling in helping women facing a prenatal fetal anomaly diagnosis. Nurses are part of the interdisciplinary team providing non-directive and supportive counseling. Nurses interacting with these women would benefit by gaining an understanding of women’s emotional state, cognitive and emotional needs and offering opportunities to promote personal growth when planning care and testing procedures. Understanding their role in trust development would continue to help women during these encounters. Gaining insight into women’s coping behaviors, nurse can facilitate and strengthen their patient’s support system and advocate for their needs.
Chapter II

*Exploring the Experiences of Pregnant Women Diagnosed With Correctable Fetal Anomalies*

**Abstract**

**Objective:** We delved into women’s cognitive, emotional and coping responses after meeting with a perinatal interdisciplinary team of specialists for a correctable fetal condition. With little known of the effects of interdisciplinary perinatal team counseling, we set out to describe women’s experiences with interdisciplinary team counseling after receiving a diagnosis of a fetal anomaly.

**Design:** A qualitative descriptive design, guided by Lazarus and Folkman’s Stress, Appraisal and Coping transactional model was used.

**Setting and Participants:** Fourteen pregnant women who were between 25 to 36 weeks gestation, diagnosed with correctable fetal anomalies, and participated in interdisciplinary counseling were recruited. Study participants were recruited from a Midwest referral program.

**Methods:** In this qualitative descriptive study, semi-structured telephone interviews were completed with each participant. Interviews were recorded and transcribed verbatim. Qualitative content analysis procedures were used to guide the data analysis.

**Data Analysis:** Content analysis was used during initial incident coding through an inductive process using constant comparison of transcribed data to group into incident codes. Four hundred and thirty four selected interview incidents resulted in an initial 37 codes. Code tag application (the number of times a participant used a particular code during an interview) resulted in 851
code tags among the 37 initial codes. We examined inductively to derive in vivo codes, sub-themes and emergent theme. Then, data analysis continued using a deductive process relating the emergent themes to the main component themes of Lazarus and Folkman’s model of stress appraisal and coping. Dedoose, a web-based program, assisted with data management and analysis.

**Results:** Three themes and 6 subthemes emerged. The themes were: (1) defining the issue, (2) establishing trust, and (3) learning to deal. The sub-themes were: coping behaviors, effects of additional testing, seeking stability, information gathering, creating bonds with the interdisciplinary team and integrating the information fetal condition. The themes and sub-themes describe women’s various coping behaviors with what gave them strength to how their perception of their infant’s condition evolved, to the need to establish trust with the healthcare teams. Stress appraisal was consistent with the Lazarus and Folkman’s model.

**Conclusion:** Counseling strategies used prenatally influence women’s perception of their fetal diagnosis, help establish trust and ultimately facilitate coping when a fetal anomaly is diagnosed. Understanding how women perceive provider interactions during pregnancy offers a unique opportunity to facilitate coping for the remainder of pregnancy and into the post-partum period.

Keywords: birth defect; team counseling; woman’s response, pregnancy, qualitative research.

Pub-med Mesh headings: Fetal Diseases / diagnosis non-directive counseling.

**Background**

In the United States (U.S.), birth defects affect 1 in every 33 babies born each year, resulting in nearly 120,000 births affected by an anomaly (Centers for Disease Control and Prevention [C.D.C.], 2008). Approximately 3% of U.S. births are complicated by major fetal
anomalies, structural changes present at birth (e.g., abdominal wall defects), mandate correction after birth and are responsible for 1 in every 5 infant deaths in the first year of life (Kung, Hoyert & Xu, 2007; Lui, Joseph & Wen, 2002). Surviving infants can have neurobehavioral developmental delays, impaired physical movement and learning difficulties (Heron and Smith, 2007).

Advances in prenatal care technologies, universal screening standards and changes in maternal characteristics (e.g., advancing maternal age, multiple gestation pregnancies, preconception diabetes, obesity) have increased both the ability to detect (Chitty, 1995; Goldberg, 2004; Shipp & Benacerraf, 2002; Stewart, 2004) and the prevalence of a fetal diagnosis (Correa, Gilboa, Besser, Booto, Moore, Hobbs et al., 2008; Sunderans, Chang, Flowers, Kulkarni, Sentelle, Jeng, & Malcaluso, 2009). Most major fetal anomalies are identified during the 18-20 week fetal anatomical survey ultrasound (Goldberg, 2004; Shipp & Benacerraf, 2002; Stewart, 2004), an ultrasound many women have come to welcome (Garcia, et al., 2002).

Women are often off-guard when a fetal diagnosis is made. Women liken fetal anomaly detection to a traumatic event: with loss of the idealized child, fear associated with unclear prognosis and the anxiety of long-term infant disability affecting the family structure (Aite et al, 2011; Hunfeld, Tempels, Passchier, Hazebroek, Tibboel, 1999; Jones, Statham, & Solomou, 2001; Pelly, 2003). These women report intense stress, anxiety, anger, despair, guilt, perceptions of inadequacy, social isolation, self-blame and grief-like reactions (Lalor, Begley, Galavan, 2008; Lobel, Dias & Meyer, 2005; Statham & Solomou, 2001; Skari, Malt, Bjornland, Egeland, Haugen, Skreden, 2006). Women report a driving need to receive information about the fetal anomaly and the infant’s anticipated postnatal course using the information as a means of coping (Lalor, Begley & Galavan, 2008). Those receiving information about the fetal anomaly and
prognosis prenatally described feeling better prepared for the birth over those women finding out after delivery (Statham, Solomou & Chitty, 2000).

**Theoretical Framework**

We used the Lazarus and Folkman Stress Appraisal and Coping transactional model to guide this study. Lazarus and Folkman (1984) describe stress appraisal and coping as mediated by individual personal attributes and set resources; these transactional variables are influenced by the interactions of the person and their environment in a given situation. During *primary appraisal*, the threat is the fetal anomaly, with a potential for future harm or loss (Lazarus & Folkman, 1984). *Secondary appraisal*, or what might be done about the threat, is viewed as an evaluative process that tabulates coping options available. Coping stems from reappraisal, a changed perception, based on new information from the environment (Figure.1). In applying this model women respond to a fetal diagnosis, with an acute emotion focused coping while fervently seeking cognitive reappraisal of the threat the anomaly represents; meeting with an interdisciplinary team may alter reappraisal of the threat.

**Counseling After Fetal Anomaly Detection**

The counseling method used in delivering information about the fetal anomaly and how well the information is received has been directly linked to women’s perception of provider’s sensitivity and support (Statham & Solomou, 2001). Researchers from the United Kingdom noted women value the receiving immediate, clear, non-directive and unbiased information about the fetal anomaly, follow-up infant care, privacy during counseling, and a sensitive approach to counseling (Pelly, 2003; Statham & Solomou, 2001). Women described wanting to be supported to make an autonomous decision about their pregnancy, but felt limited by the information provided or by services offered (Statham & Solomou, 2001). Women described provider
insensitivity when the information about the fetal anomaly was not readily shared, was presented in a biased fashion, or when the obstetrical provider could not outline a post-delivery course (Alkazaleh, Thomas, Grebenyuk, Glaude, Savage, Johannesens, et al 2004).

European researchers noted with use of pediatric sub-specialists during counseling, decrease maternal anxiety, increased knowledge of the fetal anomaly and infant prognosis resulted (Aite, Trucchi, Nahomn, Spina, Bildaro, Boglan 2002; Crombleholme, D’Alton, Cendron, Alman, Goldberg, Krauber, et al, 1996). However, most of these studies recruited women with both correctable and non-correctable fetal conditions (lethal or genetically inalterable), making findings difficult to interpret (Skari et al, 2006). With a growing number of perinatal centers offering perinatal interdisciplinary team counseling in the U.S., more research is needed in establishing the effects of this counseling method. This exploratory study sought to describe women’s experiences with interdisciplinary team counseling after fetal anomaly detection.

**Purpose**

The purpose of the proposed study is to explore the perceptions of pregnant women given a diagnosis of correctable fetal anomaly who participate in perinatal and pediatric interdisciplinary team counseling. Using Lazarus and Folkman’s Stress, Appraisal and Coping transactional model, a cross sectional, qualitative descriptive design will be used to explore the experiences of women between 24-36 weeks gestation. The use of a semi-structured interview guide will elicit women’s experiences related to their emotional responses, coping strategies, knowledge of fetal anomaly and prognosis, and perceived sensitivity and support. Interviews will be digitally-recorded, transcribed verbatim and analyzed using content analysis. Data on the descriptors of the team members will be collected from the medical records and participants’
reports. The specific aims included: exploring women’s perceptions of (a) emotional responses to fetal anomaly diagnosis, (b) coping strategies used, (c) knowledge of fetal anomaly and prognosis, (d) perceptions of provider’s sensitivity / support and (e) description the composition of the perinatal interdisciplinary team providing the counseling.

Research on the experiences of women with correctable fetal anomalies that participate in perinatal interdisciplinary team counseling would increase our understanding of the needs of women with pregnancies complicated by a fetal condition. This information would contribute to the development of interventions that have the potential to improve women’s emotional responses and facilitate coping.

Methods

Design

A qualitative descriptive study design (Sandelowski, 2000; 2010). This design served to detail the experience of the participants, seeking a comprehensive summary of their perception of the event, in their terms. Descriptive methodology affords the opportunity to summarize data excerpts in describing the participants’ experiences (Sandelowski, 2000, 2010).

Sample and Setting

Using a purposive sampling method participants were recruited from a Midwest perinatal-fetal referral center. The referral center offers a specialty program that provides advanced prenatal diagnostics, joined perinatal and pediatric specialty team care and interdisciplinary team counseling to women affected by fetal anomalies (Table 1). Becoming a point of contact and resource, specialty-trained nurses guide women referred to this program through the process of care for the remainder of pregnancy, coordinate delivery plans and
arrange all team consultations. The counseling sessions are either joined in a one-group session or individualized and scheduled throughout the same day. The sessions may also include interactive birth center and neonatal unit tours.

The sample consisted of 14 pregnant women with a fetal anomaly diagnosed during the current pregnancy. Women were eligible to participate in the study if they were: (a) 18 years or older; (b) between 24-37 weeks gestation; (c) pregnant with a fetus having a correctable anomalous fetal condition; (d) completed interdisciplinary team counseling session(s); (e) able to read, write, and speak English; and (f) were willing to be digitally-recorded. We did not recruit women less than 24 weeks gestation as 24 weeks is considered the point of fetal viability (Allen, Donahue & Dusman, 1993) and women greater than 37 weeks may have more stress due to imminent birth (Russell & Brunton, 2008). Women with known pre-existing high-risk medical conditions (e.g., pre-gestational diabetes) or obstetrical conditions (e.g., placenta previa) were excluded as these conditions may influence women’s stress perception (Brisch, Munz, Bemmerer-Mayer, Kachele, Terinde, and Kreienberg, 2002). One woman became ineligible to complete the interview prior to 37 weeks gestation; thus results for 13 women are described.

**Procedures**

After receiving Institutional Review Board approval from University of Illinois at Chicago and the participating clinical site, potential participants were approached by the research specialist who described the study, invited participation, and completed an informed consent process. The medical record was reviewed to confirm the fetal diagnosis.

Using the Lazarus and Folkman model a semi-structured, open-ended interview guide was developed for this study. The interviews, conducted by the first author, were completed with each woman by telephone at a time convenient for each individual participant and at a location
outside of the medical setting (Frazier, Miller, Horbelt, Delmore, Miller, Paschal, 2010; Rubin & Rubin, 1995). All interviews were digitally audio-recorded.

All interviews began with a broad open-ended line of questions, such as “What do you know about your baby’s condition? How were you told?” This ultimately led to the central question: Have you met with the interdisciplinary teams? How has this helped (if at all)? Has this affected how / what you do to cope?” Probes were used to elicit descriptors of emotional, cognitive and coping responses. Probes were also interjected, when appropriate to increase reflection or to clarify statements Examples of probes include: “How did you feel when you were first told of the condition?” and “How has that changed from what you know now?” Interviews ranged in length from 28 to 53 minutes.

Analysis

All interviews were transcribed verbatim with field notes used during the interview and analytic memos initiated after each interview. To enhance rigor an iterative process was used throughout (Table 2). Content analysis, as described by Krippendorf (2013), was used during initial incident coding through an inductive process using constant comparison of transcribed data to group into incident codes. Four hundred and thirty four selected interview incidents resulted in an initial 37 codes. Code tag application (the number of times a participant used a particular code during an interview) resulted in 851 code tags among the 37 initial codes. Codes were then assessed for similarities and 3 codes were converged to reach a final total of 34 codes.

A deductive process ensued applying the Lazarus & Folkman (1984) model to the codes, with the resultant three broad themes and six sub-themes. Lastly, clustering technique was applied to the codes / themes using hierarchical ranking based on participant’s using code and frequency of code tag application (Table 3). The denogram, a diagram revealing meaningful
similarities in the codes / units being merged was created using this clustering technique. (Krippendorff, 2013). Redundant responses were identified after participant 10.

Additional efforts to enhance rigor included having co-investigators that are experts in maternal-fetal medicine, neonatal medicine, women’s health, and qualitative research. The first author has extensive work experience as an advanced practice nurse with mothers diagnosed with prenatally detected fetal conditions (Tong, Sainsbury & Craig, 2007). To minimize potential bias, the principal investigator (first author), who conducted the interviews, did not have a clinical relationship with participants.

Results

Participant Characteristics

Women’s ages ranged from 20-38 years; fetal gestational ages ranged from 25-35 weeks (35 weeks was mode). Three women were single and, 11 women were either married or living with their partner. All participants reported support from their immediate family members. The racial composition was: (1) African American, (1) American Indian and (11) Caucasians. Thirty-five percent of the women reported this as their first pregnancy; 42% had one other child, and 21% reported having two or more children at home. All study participants reported a source of health insurance. Income, religion and level of education are listed in Table 4.

Study Findings

Women described behaviors and coping strategies that were helpful in dealing with the information of their infant’s conditions, the impact of specialty team counseling and ultimately, decreased anxiety after counseling was evident for all participants. One woman described her interaction with specialty teams as “necessary” in coping. Three broad themes emerged. Firstly,
defining the issues reflected how women needed to reappraise and redefine what the fetal anomaly consisted of and how they were coping with the changes in information. The second emerging theme, establishing trust, was a theme which relayed hopefulness and a need to connect with the healthcare providers; describing the interactions as necessary to coping. Women described feeling that the healthcare teams had unique insight and understanding of their circumstance, fostering a much needed bond. The third emerging theme was learning to deal. In this theme, women described how they integrated the counseling received, searching for meaning, and trying to accept what is: seeking a higher power, being grateful, and verbalizing compassion for others was categorically evident.

**Theme 1: Defining the Issue.**

‘Defining the issue’ a theme that was accountable for 18 of the 34 codes (see Table 5), described the challenges the women faced while attaining a working knowledge of the fetal anomaly; women described insight into their new reality. Seeking to define the fetal anomaly into their lives, women described feeling anxious, fearful and uncertainty as the fetal diagnosis changed or layers of unanticipated tests were added to their prenatal course. Expressions of loss of control, feeling conflicted and confidence issues emerged. Categorical sub-themes noted here were coping behaviors, effects of additional testing and seeking stability.

**Sub-theme of Defining the Issue: Coping Behaviors.**

All of the women described personal variations of ‘coping behaviors’ a sub-theme that varied with each individual and noted when changes in fetal diagnosis’ were encountered. Two women described maladaptive coping behaviors (e.g., increased tobacco use). Often women described how their behaviors came into vision after team consults. Women described the
importance of family inclusion in the team sessions, with family participation providing them with a source of supportive strength. Woman (11) discussed how stress had led her to behaviors she knew were unhealthy, but meeting with the interdisciplinary team brought a level of clarity for her.

“ummm, kind of back and forth, because I hate to admit it – but I’m going to anyway, but I am a smoker. And I lately –oh man you should have seen me, when we got back from [original providing center], I know this is bad but I was chain smoking like really bad, but after ,[team meeting] I was like down to 3 cigarettes per day. Yeah literally I was going through like half a pack, it was horrible...shows you how stressed out I was”

Woman (4) and woman (6) described coping by controlling the flow of information; one by limiting her intake pregnancy related information, the second by filtering the technical information of the fetal condition; helping place focus on normalizing the pregnancy. “I keep my mind occupied, and trying to stay off the internet, not looking at anything else, like pregnancy issues and that sort of thing.” (Woman 4).

“The things –helping-- having our crib come and we set it up and we’ve gotten certain things in the nursery together. Having a tight belly and it's like ‘oh this is--you know this is really happening’ you have to feel it and you have to see it through moms eyes instead of medical eyes, instead of he is an omphalocele – no he’s not-- he’s a baby. You know I was really stressing myself out, learning about ventilators and feeding tubes and stuff like that and then I had to cut myself off. And since I cut myself off I just tried to focus on the other aspects of pregnancy like the kicks and stuff I’ve done a lot better.” (Woman 6).
Sub-theme of Defining the Issue: Effects of Additional Testing.

Eighty-four percent of women described feeling conflicted with the addition of prenatal tests conversely two women described the comfort additional testing offered in “knowing he’s ok”. Women described a financial/physical hardship in completing the additional antenatal appointments demanded by the fetal diagnosis (testing, meetings). These hardships included arranging for childcare, travel expenses (gas) and missed work. Women appreciated the coordination of meetings and same day testing procedures; they reported value in “hearing it all” during the same day consultations. Woman (3) described her interaction with different members of the team. She expressed trying to balance/interpret comments.

“I like hearing it all sometimes the news is not so good, then I find out from the next perinatologist the next time I go there, and that one would say you know that’s not something you needed to be concerned about, I’m really not certain why they would say that to you, so I don’t know if there’s discrepancy with this thing with to each other or if one of them is not really, you know...like I said it’s kind of just, I’d rather hear all of it I’d rather know a little more than less.”

Woman (8) with fetal aortic valve stenosis describes feelings on weekly fetal echocardiograms.

“I felt like as the time got closer to the echo I would get more and more anxious and worried because I didn’t know if something was going to change or how the baby’s heart was going to be doing.”

Woman (13) with a fetal Tetralogy of Fallot described the stress in the ‘newness’ this pregnancy brings.
“I kind of compare it to when you are first having your first baby all that stuff about delivery and having a baby is all brand new, you don’t know what to expect until you’re in it. But now ... all this testing is new and I still don’t know what to expect when I’m in the delivery room... they’ve done a great job of explaining to me who all will be there and kind of what role they all will play... you know when you think about it like ok that’s kind of stressful, cause you think the more people the worse it is... they are very good at explaining these things to me... you [want] to know as much as possible up front.”

Women (3), diagnosed with a fetus renal cyst, described how she dealt with weekly amnionic fluid checks assessing fetal renal status.

“Well it is kind of the same but then it can change and then you hear the same and then you go in and hear something different has happened. Usually we talk of these things there really isn’t much more we can do except keep monitoring it, watching the fluid levels, and then after he’s born then we will find out ...the damage to the kidneys.”

**Sub-theme of defining the issue: Seeking Stability.**

Women sought clarity and parameters as they were defining the issue and seeking stability in the fetal condition. When seeking stability, three women described the need to validate the information received. They would compare information between providers or via public sources (the internet). Four women described just wanting the fetal diagnosis to stay consistent. Woman (8) described her loss of control, wanting to be able to make a decision (like choosing to breast feed). Her fetus with aortic valve stenosis would be taken to NICU immediately after delivery. “It’s another aspect that I have so little control over, there’s nothing that I can do... Yes I would love to breast feed but there’s nothing I can do, I may not be able to
breast feed.” Woman (5) sought validation with her original doctor expressing concern when the information varied. “Because it felt like my doctors up here and the doctors down there weren’t on the same page at first I don’t know how to explain it.” Woman (10) with a fetal gastroschisis was relieved when what she heard during an interdisciplinary consult was later validated.

“Yeah everything pretty much everything that I seen on the internet they pretty much they told us. When we seen the little bag that was holding the baby's intestines--like they told us about that: it's called a silo. Um it’s like they slowly push the intestines back in her stomach and they like to tie it-- and everyday like more and more they push it back in, this made me feel better.”

**Theme 2: Establishing Trust.**

One-hundred percent of the study participants described the need for ‘establishing trust’; a need to connect with the healthcare teams responsible for their infant’s future postnatal care. Interactions during counseling led to establishing connectedness with the specialty teams. The positive attributes of the health care provider were described as the technical expertise in the counseling method used (pictures, use of diagrams) and the nurturing qualities in which information was relayed (how they spoke, eye contact, personable attitudes) ever so important in establishing trust. Trust emerged as trust in the information being given and trust established in anticipation of future interactions (team who will be managing their infant’s future care). Women (84%) described provider sensitivity during counseling. Woman (1) described her encounter with a pediatric surgeon as:
“He’s very nice, he explains everything! He’s awesome! I am very confident in him!
Yep, with diagrams, he draws things all out... explains different things that it could be, he goes through the whole surgery process, he answers all our questions he is really good”.

This perception helped decrease anxiety and diagnostic uncertainty. Women described the providers as being genuine in their efforts to establish a fetal diagnosis. Categorical sub-themes of establishing trust included: information gathering and creating bonds with interdisciplinary team.

**Sub-theme of establishing trust: Information Gathering during Counseling.**

Women described the need to establish a plan for their infant’s care, needing to know what was going to happen. Establishing a connection with the team was described as “necessary” and bringing comfort in the “knowing who will take care of my baby”. During consultation sessions women were gathering information from and of the provider resulting in increased comfort by the end of counseling. They reported feeling “understood”, “they know what’s going on” and “they have experience with this”. Participant (7) describes the before and after meeting with neurology surgeon for her infant diagnosed with spina bifida.

“Um, they just you know like, um they just know more about the whole situation and um the regular doctors that I was going to (referring MD) they just made it seem so down and so sad...that it was really hard to deal with and it was making me more sad every time they would talk about it. But when I got transferred to {referral center} they were like really, really, nice and well informed and they even found stuff I hadn't heard of yet, it was sooo-- just made things a lot easier to deal with.”
Participant (6) describes her interaction with the pediatric surgeon about corrective procedures to be done for an omphalocele.

“He was really good. He made sure we had an understanding of everything, he was majestic. Even before surgery, what to expect, and after surgery how he’s going to be and he was phenomenal, he was very amazing. They told us everything from A to Z.”

*Sub-theme of establishing trust: Creating Bonds with Interdisciplinary Team.*

All women described interactions that superseded mere information gathering; women described looking at the provider attributes and finding solace in the consultation. Woman (1) after hearing much of the information about the fetal duodenal atresia from her primary care provider described how much meaning it had for her to connect with the surgical team and the role of the specialty trained nurses in the process. “But overall I have been very happy with the people [referral center staff] and I think, I think they're very amazing at giving comfort.”

“I am definitely better because I just felt like I was in limbo till I could actually talk to them. I knew that the perinatologist even my OB-GYNE were not going to be involved, I really wanted to talk to the people that were going to be involved in the delivering and the taking care of my baby. So yeah it certainly felt good to see them [pediatric surgeons].I felt so much better after...like we connected.”

Woman (13) described counseling she received for a fetal diagnosis of Tetralogy of Fallot.

“I think it’s all a matter of your physicians and a matter of the teams you have helping you out. If you didn’t have that trust – I couldn’t imagine what this experience was like if I didn’t feel I could trust him. So I really think—what I would think about is that the
physicians that you have and the team that you have helping you really kind of makes or breaks the experience that you’re gonna have. Cause if you feel fully comfortable with them and you feel really happy with them and you’re getting the answers that you need, not necessarily the answers that you want, but the answers that you need and there’s that compassion and you’ve built that trust—it’s one less thing that you have to worry out about.”

Hospital tours created mental images for study participants, offering them insight of their infant’s future care. Most of the women participating described hospital tours as helpful. However four women described stress during the tour as it made things “too real”. “The NICU is probably the most overwhelming part I guess knowing that your baby is going to be there. That was probably the hardest.”

**Theme 3: Learning to Deal.**

Lastly, ‘learning to deal’ a theme which emerged as women described elements of their pregnancy they thought should be. Women described issues in communicating with others, grieving loss of normal state, and faith. Women spoke of the ‘need to deal’ as they assimilated information of the fetal findings, describing filtering communication with family and their support network, being selective (even guarded) about which details of the fetal anomaly they would share and with whom. Women described masking the realities of their fetal anomaly to friends, stating “I just need to deal with this on my own terms” as they described integrating the fetal condition.
**Sub-theme of learning to deal: Integrating and Accepting.**

Women described knowing they needed to share, but did not want to share for fear of not being able to cope with the misperceptions of others. Woman (8) with fetal aortic stenosis described how she felt when could not deal with the uncertainty of the outcome, so avoided questions from friends. “after the 20 week ultrasound it was hard for me to pretend— not everybody knew you don’t want to tell everybody but you still have to act excited and happy but you’re scared …coping has been to be sad.” One woman developed a dedicated internet facebook blog with updates offered to selected invitees. She described this blog as helpful in keeping her invitees informed of the latest updates and happenings, but noted she could control whom she invited in.

Women described “thinking outside of oneself” as helpful in coping; describing being grateful for the people that have come to help them(69%), gratitude for the type of condition diagnosed (correctable)( 38%), compassion for others (38%), thinking positive (30%); and discussed seeking comfort through prayer and in day-by-day thinking (30%). Woman (4) describes how her daily coping strategy came through prayer.

“Like I said I do a lot of praying that gives me a lot of comfort. Then I know that’s it out of my hands there’s really nothing I can do with it it’s all in God’s hands you know?... You can’t go back and you must go forward but, every day is another day I guess, everyone needs to deal, [I] don’t think we ever will truly deal, but there’s nothing we can do, every day is a new day, that’s my the way I look at it we’ll just do it-- that’s the way I look at things.”

Woman (6) found reassurance in re-connecting with her pregnancy.
“I think I turned a corner in the past 2 weeks or so, because for a bit he became a medical diagnosis to me… it was something to research something to try and figure out like how I figure this out. He was becoming sort of like a problem to solve, [more] than a baby… I don’t know what exactly helped me turn the corner, maybe cause he’s kicking more or maybe cause I look pregnant now. And so I don’t know what was the change but it’s really feeling like I needed to stop on the medical nonsense and focus on …holy crap I’m having a baby! I’m not having an omphalocele I’m having a baby! And there was several weeks in there where I was having an omphalocele.”

Discussion

This unique design of the study (recruiting only low risk women with a correctable fetal anomaly) captured the central question of the study: the effect of interdisciplinary team counseling on women diagnosed with a fetal anomaly and their stress appraisal. Previous studies identified information seeking behaviors of women during this stressful time, but the findings add relevance to those behaviors seen as: seeking information while establishing trust, reappraising the fetal anomaly and its meaning, while integrating the diagnosis into their lives.

Insight was gained into the central question of: How has the use of interdisciplinary teams helped (if at all) in coping after a fetal anomaly diagnosis and has this affected how or what you do to cope? Women expressed comfort in meeting and interacting with the providers that would be responsible for their infant’s care. They described gratitude at receiving healthcare in an honest, compassionate way, and described beneficial counseling sessions as informative and supportive. The women described counseling that anticipated their questions and underscored a caring undertone, with “realistic positivity”. Specialty trained nursing staff from
the referral center were crucial in helping women with their experiences, offering comfort and
ultimately influencing how women coped during their visits. Although this study did not set out
to measure communication behaviors during patient interactions, the participants in this study
described positive experiences. Black and Sandelowski (2010) noted ‘relating to others’ was the
most consistent dimension that demonstrated the most change in personal growth after a severe
fetal diagnosis. Positive personal changes noted in the Black and Sandelowski study started with
how those affected by a fetal anomaly related to their partners and family, but also the new
compassion or sympathy they felt for strangers. This finding is consistent with Black and
Sandelowski’s work noting early in their growth trajectory the behaviors of sustained positive
change, as seen in participants demonstrating positive personal growth.

Relevant to any patient interaction is communicating understanding and empathy (Mast,
2007). Women described forming impressions, developing and establishing trust bonds during
consultations; forming a basis by which to establish trust with team members (doctors, nurses,
lactation specialists, etc.). Trust, has been shown to be drawn largely on perceptions or
judgments of reliability and conduct during an interaction (O’Neill, 2002). The specialty trained
nursing staff were instrumental to establishing trust, women described “knowing they could call
them” at any juncture. The medical staffs responsible for the counseling sessions were described
as communicating not only clinical expertise, but also caring and compassionate behaviors;
creating a sense of comfort and trust, which was essential to women’s coping. Often women
compared and contrasted the counseling they received by outside providers and the team
specialists, and the counseling sessions became an experience to be grateful for. An area of
improvement, as described by study participants would include the communication between the
referring center and care received from the referral source.
All participants described benefit in same-day consultations with the interdisciplinary team and all women reported not feeling overwhelmed with one-day counseling sessions. The scheduling afforded them time to digest and discuss the information with their partner, and prepare for the next meeting. Previous researchers noted women’s anxiety and shock related to the fetal diagnosis, these reactions were not described in this study. However, it could be that since all but one of the study participants was in the latter part of the 3rd trimester, and all participants had completed interdisciplinary team counseling; women had begun the process of coping.

We found that participant’s reappraisal of the fetal anomaly, consistent with the Lazarus and Folkman’s transactional model of stress appraisal and coping; however, reappraisal is not a static process. When changes were noted in the fetal status or variation in counseling between providers was encountered, women reported anxiety and a loss of control; both emotion focused coping. Additionally, while additional prenatal tests may be routine to providers, these tests proved stressful to some of the women in this study. More preparation and or discussion of these procedures may help future participants. The majority of study participants reported unit tours as useful. However, recognizing varying reactions to the tours is warranted.

Lastly, women described integration of the fetal anomaly into their lives and accepting the diagnosis. Preparing for the birth (e.g., preparing the crib and room) was identified as useful in coping. Focused reflection on pregnancy and its associated physical changes along with attentiveness to fetal activity were behaviors identified as useful in “moving forward”. Women reported sharing information of the fetal anomaly with a selected few, with whom they relied to comfort them while providing nurturing support; for most it was their partner.
Study Limitations

In this study, the participants were predominantly Caucasian, middle class, educated to the 12th grade or greater and were covered by health insurance. Counseling sessions may be more challenging among women with limited literacy, lack of health insurance and language or cultural differences. We were unable to collect information about the reasons why women opted to not participate in the study and these women may have had other experiences not captured in this analysis. Despite these limitations, there is a dearth of information available about how pregnant women experiences are affected by fetal anomaly and pregnancy, and this study provided relevant insight to women’s experiences with fetal anomalies and the perceived experiences of participating in an interdisciplinary team counseling approach.

Implications for Practice

Team counseling when communicating difficult information has been shown to be successful in other areas of medicine (e.g., cancer care teams). This study’s findings also support perinatal interdisciplinary team counseling in helping women facing a prenatal fetal anomaly diagnosis. Nurses are part of the interdisciplinary team providing non-directive and supportive counseling. Nurses interacting with these women would benefit by gaining an understanding of women’s emotional state, cognitive and emotional needs and offering opportunities to promote personal growth when planning care and testing procedures. Understanding their role in trust development would continue to help women during these encounters. Gaining insight into women’s coping behaviors, nurse can facilitate and strengthen their patient’s support system and advocate for their needs. Knowledge of the perceived loss of control may help nurse understand witnessed behaviors.
Recommendation for Future Research

Further research in understanding how to best help women with a fetal anomaly is needed. Comparing prenatal constructs to post birth experiences may offer additional insight. Research is needed in determining the effect of this counseling method on women’s long-term emotional and cognitive state.

Conclusion

Birth is a major life event. When this event is coupled with the uncertainty of the newborn’s condition, maternal emotional well-being may be compromised. This study’s descriptive findings support perinatal interdisciplinary team counseling in helping women facing a prenatal diagnosis. Nurses play a key role in this process. Joining specialties during one-day sessions was positively accepted and helped women in their journey.
References


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Fig. 1 Women’s Experiences of Fetal Anomaly Detection; Model Stress Appraisal and Coping

- Prenatal diagnosis
- Maternal Fetal Characteristics
- Perinatal I-Team Counselling
- Knowledge of fetal anomaly and prognosis
- Provider Sensitivity
- Stress Appraisal Coping Strategies
- Emotion focused coping
- Problem focused coping to FA diagnosis

Coping reappraisal of Fetal Anomaly
### Table 1 Team Composition

<table>
<thead>
<tr>
<th>Perinatal medicine</th>
<th>Neonatologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perinatal imaging experts: ultrasound; fetal echocardiography, MRI</td>
<td>Pediatric imaging experts: echocardiography, ultrasound, MRI</td>
</tr>
<tr>
<td>Fetal concerns nursing staff-dedicated to case management of mother with fetal condition</td>
<td>Pediatric surgeons</td>
</tr>
<tr>
<td>Lactation Counselors</td>
<td>Pediatric nephrology</td>
</tr>
<tr>
<td>Social workers</td>
<td>Pediatric neurology, neurosurgery, spina-bifida clinics</td>
</tr>
<tr>
<td>Genetics Counselors /geneticist</td>
<td>Pediatric cardiologists: intensivists, cardiovascular surgeons</td>
</tr>
<tr>
<td>Clinical psychology</td>
<td>Pediatric orthopedic surgeons</td>
</tr>
<tr>
<td>Child life specialists</td>
<td>Pediatric ENT Pediatric anesthesiologists</td>
</tr>
<tr>
<td>Pediatric palliative care specialists</td>
<td>Social workers</td>
</tr>
<tr>
<td></td>
<td>Therapists: respiratory, physical, developmental</td>
</tr>
</tbody>
</table>

**Interdisciplinary Team Counseling Sessions may Include:**

- detailed information of the fetal condition, prognosis with anticipated outcome
- additional prenatal testing,
- anticipated birth planned,
- lactation counseling,
- immediate infant post-natal care required at birth
- plans for post natal corrective procedures
Table 2. Analytical Steps

The iterative process:

- Verbal and written informed consent obtained
- Conduct digital audio-recorded interview. Write field notes during the interview process;
- Begin analytic memos within 24 hours of completing interview.
- Complete case summary after interview.
- Wait 24hrs; re-listen to digital recording; and add to analytic memos of thoughts and impressions.
- Re-listen and read transcripts:
  - Begin descriptive coding process by using content analysis by inductive coding by coding each incident in the data with terms that describe the data.
  - Re-read each transcript as a whole for emersion and to gain global understanding of the narrative being told.
  - Re-read each transcript line by line; trying to understand beyond face value, include field notes to contextualize the words and their intended meaning.
- Bi monthly meeting with first and last authors to review analytic procedures, discuss emergent themes, and allow for debriefing and reflection on analytic process and emerging themes.
- Re-examine inductively derived codes, categories and emerging themes using a deductive process to determine how the codes and emergent themes relate to Lazarus and Folkman’s (1984) theoretical framework of coping.
- Review categories and themes with research team member and incorporate analytic insight into emerging findings.
- Re-read each transcript as a whole with memos created to verify preliminary themes. Read all the quotes of each particular preliminary theme collectively.
- Scan Dedoose for key words to survey missing data sets
- Develop frequency hierarchical ranking table (denogram) based on coding, number of participants use, and frequency of use
Table 3: Code by Frequency and by Model to Emergent Themes

<table>
<thead>
<tr>
<th>Code Title</th>
<th>Total# of participants*</th>
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<th>Coping Theme</th>
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<tr>
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<td>Anxiety &amp; Coping behaviors</td>
<td>Defining the issue</td>
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<td></td>
<td>Emotion focused coping and reappraisal</td>
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<td>Behaviors that helped (12) [53]</td>
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<td>Perception of prognosis (10) [24]</td>
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<tr>
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<tr>
<td>Coping Theme</td>
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<td>Effects additional testing and findings</td>
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<td>Learning to deal</td>
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<td>Thinking positive (1) [4]</td>
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(*) Total number of participants where code was applied

[()]* Total number of excerpts (number of times stated)

FA=fetal anomaly
Table 4 Maternal Demo-Graphics, Fetal Gestational Age and Diagnosis

<table>
<thead>
<tr>
<th>Case</th>
<th>M. age</th>
<th>Income</th>
<th>Religion</th>
<th>Education</th>
<th>Fetal Age*</th>
<th>Fetal Anomaly</th>
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<td>30-59,999</td>
<td>Catholic</td>
<td>College</td>
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<td>Hypoplastic Right Heart Syndrome</td>
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<td>32</td>
<td>30-59,999</td>
<td>Other</td>
<td>Associates</td>
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<td>Dilated bladder, renal cyst</td>
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<td>4</td>
<td>24</td>
<td>30-59,999</td>
<td>Catholic</td>
<td>College</td>
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<td>Congenital Diaphragmatic Hernia (CDH)</td>
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<td>27</td>
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<td>High School</td>
<td>35</td>
<td>Venticulo-megal</td>
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<td>6</td>
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<td>&gt;60,000</td>
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<td>Graduate</td>
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<td>Giant omphalocele</td>
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<td>Other</td>
<td>High School</td>
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<td>NTD: spina bifida</td>
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<td>8</td>
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<td>Other</td>
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<td>Aortic Valve stenosis</td>
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<td>9</td>
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<td>Catholic</td>
<td>High School</td>
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<td>&lt;15,000</td>
<td>Other</td>
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<td>High School</td>
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<td>Associates</td>
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<td>Bladder outlet obstruction</td>
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<td>Tetralogy of Fallot</td>
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<td>14</td>
<td>28</td>
<td>&lt;15,000</td>
<td>Other</td>
<td>Associates</td>
<td>33</td>
<td>Congenital-Pulmonary Adenomatoid Malformation</td>
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*Fetal age at time of interview
Table 5 Code Descriptions

<table>
<thead>
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<th>Code Name</th>
<th>Code Description</th>
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<tr>
<td>Coping with fetal anomaly</td>
<td>Coping strategies / behaviors or expressions of concern for pregnancy/ post-delivery time; influence of team counseling</td>
</tr>
<tr>
<td>Emotional behaviors</td>
<td>Emotional behaviors expressed / perceived around fetal anomaly</td>
</tr>
<tr>
<td>Behaviors that helped</td>
<td>Cognitive, social, physical behaviors that helped during pregnancy</td>
</tr>
<tr>
<td>Perceptions of fetal prognosis</td>
<td>Counseling on FA prognosis; how they are counseled on future fetal well-being; felt about counseling on post birth expectations.</td>
</tr>
<tr>
<td>Isolating behaviors</td>
<td>Not feeling comfortable talking to others about fetal condition; withdrawing</td>
</tr>
<tr>
<td>Masking</td>
<td>Demonstrating false emotions for the sake of others</td>
</tr>
<tr>
<td>Effects additional on-going testing</td>
<td>Effects described of additional or ongoing testing</td>
</tr>
<tr>
<td>Unexpected findings</td>
<td>Communication of unexpected / unanticipated findings; things that she felt were stressful as they emerged</td>
</tr>
<tr>
<td>Attributes of providers= stress inducing</td>
<td>Behaviors or expressions demonstrated by HC providers-- perceived as stressing</td>
</tr>
<tr>
<td>Uncertainty=more</td>
<td>Things that created more uncertainty (voiced concerns with the unknown, how they feel about the changes with unknown)</td>
</tr>
<tr>
<td>Conflicting information of fetal issue</td>
<td>Perceived changes in fetal findings or diagnosis; changes from what she heard from various providers or understood to be true</td>
</tr>
<tr>
<td>Perception communication between providers</td>
<td>Perceptions of a communication between or among health care providers;</td>
</tr>
<tr>
<td>Provider Sensitivity= less</td>
<td>Perceived decreased sensitivity with fetal anomaly displayed; decreased communication indicating sensitivity to their experience</td>
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<tr>
<td>Internet as a source of information</td>
<td>Experiences with internet information gathering</td>
</tr>
<tr>
<td>Feeling conflicted</td>
<td>Feelings, emotions, thoughts that create internal conflict; 'should' be thinking or feeling but is not or conflict with sense of self</td>
</tr>
<tr>
<td>Confidence in self</td>
<td>Expressed ability to be able to take care of infant; expressed ability to complete activities during pregnancy.</td>
</tr>
<tr>
<td>Loss of control</td>
<td>Expressions of loss of control, over situation, condition or outcome</td>
</tr>
<tr>
<td>Validating information</td>
<td>Participant is asking the same questions of different providers / internet sources; information checking</td>
</tr>
<tr>
<td>Knowledge anomaly after I-Team</td>
<td>Expressed level of understanding of fetal anomaly after meeting with perinatal team</td>
</tr>
<tr>
<td>Positive attributes of provider</td>
<td>Behaviors demonstrated by provider or communication attributes perceived as favorable, soothing and enhancing to coping and trust</td>
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<tr>
<td>Expressions of trust in facility medical team</td>
<td>Expressions of trust at the medical facility; ease of entry</td>
</tr>
<tr>
<td>Communication with family, social network</td>
<td>Descriptions of ease / lack of ease with communicating with family about fetal status</td>
</tr>
<tr>
<td>Providers sensitivity</td>
<td>Perceptions of medical team; being sensitive to the needs or concerns they are facing with the fetal anomaly</td>
</tr>
<tr>
<td>Uncertainty =less</td>
<td>Things that decreased uncertainty (voiced concerns with the unknown, how they feel about the changes with unknown)</td>
</tr>
<tr>
<td>Hospital Tour as source</td>
<td>Hospital tour as information source ; preparation / planning</td>
</tr>
<tr>
<td>Nurturing trust</td>
<td>Communication that establishes trust and personal rapport, perceived as positive</td>
</tr>
<tr>
<td>Gratitude</td>
<td>Expressions of gratitude for things that are going well, better than others, support.</td>
</tr>
<tr>
<td>Support at home</td>
<td>Perceptions of support / or lack of statements</td>
</tr>
<tr>
<td>Higher power</td>
<td>Relying on higher power for comfort, guidance</td>
</tr>
<tr>
<td>Compassion for others</td>
<td>Feeling compassion for the plight of others</td>
</tr>
<tr>
<td>Grieving L/O normal state</td>
<td>Grieving / mourning loss of perceived normal experience in pregnancy / birth / newborn care</td>
</tr>
<tr>
<td>Diagnostic certainty</td>
<td>Feeling sure of what the outcome would be or look like</td>
</tr>
<tr>
<td>Thinking positive</td>
<td>Reaching for positive comments or connections with those in contact</td>
</tr>
</tbody>
</table>
Appendix A

Demographic Questionnaire Form

Family Information

Marital Status:
____ Single  ____ Married  ____ Separated /divorced  ____ Partnered

Size of household: ______

Other children: _____________  Ages: _________  others in household: __________

Race / ethnic Background:
____ Caucasian  ____ Latino  ____ Non-white Latino  ____ African American  ____ Asian
____ Pacific Islander

Educational Background:
____ Less than HS  ____ Completed HS  ____ Trade /vocational  ____ Associate Degree
____ Bachelor’s Degree  ____ Graduate school or higher

Religious affiliation:
____ Buddhist  ____ Catholic  ____ Muslim  ____ Protestant  ____ Other

Financial Demographics

Insurance:
____ Public Assistance  ____ Private insurance  ____ WIC

Employment status
____ Full time (40 hours/week)  ____ Part-time (<40hours /week)  ____ Occupation

Household Income:
____ <15,000  ____ 15,000-29,999  ____ 30,000-59,999  ____ >60,000
____ No disclosure

Scheduled date and time for interview:
______________________________________________________________

Preferred method confirmed:
______________________________________________________________
Appendix B

Medical History Form

Medical History:

Do past chronic medical conditions exist?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Obstetrical history

Gravida: ______  Para: _____  Age at time of conception: ______

H/O previous pregnancy loss: __________________________________________________________

Past Ob complication / history: __________________________________________________________

H/O infertility: _____________  Infertility therapy: _____________

Familial H/O birth anomalies: _____________  Genetic issues: _____________

Complications in this pregnancy:

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Fetal Diagnosis:

____________________________________________________________________________________

Gestational age of current pregnancy: ______  Anticipated due date: ______

EGA at time of diagnosis: _________________  How did she find out of fetal diagnosis: _________________

Time between diagnosis and referral to center: _______________________

Time between diagnosis and Meeting with I-Team: _______________________

Social History

Any medications / OTC taken:

____________________________________________________________________________________

Use of substances:

____________________________________________________________________________________
Appendix C

Perinatal I-Team Consultation Form

Mother Met with:

List specialist_________________________________  Date of Meeting:____________

Content validated____________________________________________________________________________

____________________________________________________________________________________

Mother Met with:

List specialist_________________________________  Date of Meeting:____________

Content validated____________________________________________________________________________

____________________________________________________________________________________

Mother Met with:

List specialist_________________________________  Date of Meeting:____________

Content validated____________________________________________________________________________

____________________________________________________________________________________

Mother Met with:

List specialist_________________________________  Date of Meeting:____________

Content validated____________________________________________________________________________

____________________________________________________________________________________

Mother Met with:

List specialist_________________________________  Date of Meeting:____________

Content validated____________________________________________________________________________

____________________________________________________________________________________
Appendix D

Eligibility Screen Form / Tool

Introduction: Hello, my name is: __________. I am here to ask you to participate in study involving women who have a condition in the baby-to-be, and have met with the team of specialists. Your participation would be completely voluntary and would not influence or determine the care you will get with the Fetal Concerns Program. This study would involve a 1-hour telephone call by the researcher, Maria Reyes, who is interested in gathering information around your experience. Your verbal consent would is all we need for now, but we will need written permission to gather medical information if you are to participate. Shall I continue?

Subject’s response: ____________________________________________________________

Study participants are now being recruited for a research study entitled: “Women with correctable fetal anomaly participating in perinatal I-Team counseling: an exploratory study”. This form is meant to serve as a guide in determining eligibility status for potential study participants. The study will involve a one-time, 1 hour long telephone interview in a sample of 30 women which have been informed of a correctable condition noted in their fetus during the course of prenatal care. More specifically, this study involves women who have received counseling of their fetus’s condition by a team of perinatal specialists. The research is being conducted by Maria Reyes, a Doctoral candidate in the College of Nursing at the University of Illinois at Chicago (UIC). Please contact if questions arise on participant’s potential eligibility.

Inclusion criteria:

- All study participants must be pregnant at the time of recruitment.
- All study participants must have been previously identified/diagnosed with a correctable fetal anomaly. Examples of a correctable fetal anomaly may include: gastroschisis, omphalocele, C-CAM (congenital cystic adenomatoid malformation of lung), etc.
- All study participants will have completed their counseling session(s) with the perinatal team specialist(s) and MFM. Participants which have met with the perinatal team specialist on a one-day counseling session or multiple visits counseling will both be recruited.

Additionally, study participants must be:

- 18 years of age or older;
- > 24 weeks and < 37 weeks gestation;
- are able to read at a 5th grade level (for consent)
- be comfortable speaking English (telephone interview);
- have means of communicating either by telephone or internet

Exclusion criteria:

- Women with a medical diagnosis complicating their pregnancy (e.g. major depression, chronic hypertension)
- Women with an obstetrical condition complicating their pregnancy (e.g. preterm labor, pre-eclampsia).
- Women presented with a lethal fetal anomaly (non-correctable)
- Women presented with a fetal genetic anomaly (non-correctable)

Sample size:

A sample size of 30 pregnant women diagnosed with FA is sufficient to explore their perceptions of this event. The intent is to sample 15 women which meet with all the perinatal team specialists within a one-day session and 15 women which meet with the perinatal team specialists on separate visits.

Thank you for your time your consent will be directed to the investigator so she may set up a time to complete the interview. A polite notification will be sent your way if you are not eligible to participate.
Appendix E

Prenatal Interview Guide

Introduction

As I mentioned previously, I am interested in learning more about the emotions and thoughts you experienced when you were told of your baby’s condition. How you were told and the issues you are facing are unique to you, but will those in similar circumstances counsel future mothers-to-be. I would like to ask questions pertaining to your experience. I will be recording our conversation so that I may refer to it later, but I wanted to assure you that your answers, both written and recorded, will be kept completely confidential. This interview will take about 45 minutes.

Note: The order of the categories of questions will flow from the participants’ responses.

The story:

First, could you tell me a bit about your other pregnancies (if not a primiparous)?

Could you tell me a bit about your other pregnancies?
What was the experience like?
How old are your children?
How did you feel during your previous pregnancies?

Now could you tell me a bit about your experience with this pregnancy?

What is your understanding of your baby’s condition?
How were you told?
How did you feel? (Emotional reactions)
What were your initial thoughts?

Looking back —do you feel any differently now than you did when you were first told of your baby’s condition? What have been the most helpful things that have gotten you to feel the way you do? Not so helpful?

Knowledge of FA and Prognosis

After meeting with the team: were your questions answered? Did you have a better understanding (specifically knowledge) of your baby’s condition? What was that understanding?

Did you talk about what will happen after your baby is born? Did you feel your questions about your baby’s future condition were answered?

How did you feel after you spoke to them?
How do you feel about your baby’s condition? (Does she have a different understanding of the condition?)
Probe: How did this meeting has influenced your perception of the baby’s condition?
Probe: Do see you baby differently? If so how?
Prenatal Interview Guide (cont’d)

Coping

What personal strengths kept you going? How have you managed to cope?

What do you feel is the greatest source of comfort to you?

What about your baby’s condition helps you? What does your baby’s condition mean to you?— could you talk about it? What has helped you get through?

Are there any things in particular that you have tried to do (that you are doing differently)?

What has not helped? What are her greatest challenges?

(now I would like to turn the focus on the meeting and how well it did or did not go)

Perinatal I-Team

You met with the team specialists to discuss your baby’s condition—could you tell me about your experience?

Would you describe who the professionals in the meeting were?

Probe: pediatrician, OB, anybody else if so who?

What was your general impression? How did they make you feel?

Did you find the counseling met your needs? Explain.

Was it too much or too long?

Provider Sensitivity

What did she think of the provider / providers?

What emotional reactions did she have after meeting with them?

Did meeting with them (and how sensitive she felt they were / were not) change her views on how she felt about the pregnancy? Could you explain? Did you feel they providers met your needs? Were they sensitive? Caring?

Concluding statements.

Is there anything else you would like to say?

Are there any questions I can answer for you?

What has it been like to talk to me today? Do you have any suggestions for improvement for me?

Close: Thank you so much for talking to me today, I sincerely appreciate your participation in this study.
Appendix F

Post Participation Thank You Card

Thank you for participating in the research study entitled: “Women with correctable fetal anomaly participating in perinatal I-Team counseling: an exploratory study”.

The research is being conducted by Maria Reyes, a Doctoral candidate in the College of Nursing at the University of Illinois at Chicago (UIC).

Your participation in this voluntary study brings to light important information about your experience. Your decision to participate will not affect your current or future relationship with the Children’s Hospital of Wisconsin or University of Illinois, in Chicago.

Your participation was truly appreciated and valued. Enclosed is a $10 gift card as compensation for your time and involvement with this study. This concludes your participation with this study.

Team Counseling Thank; You Letter Version: 2; December, 2012  IRB #:2012-0920
Appendix G

Recruitment Flyer

Study Participants Are Now Being Recruited for a research study entitled: “Women with correctable fetal anomaly participating in perinatal I-Team counseling: an exploratory study”. The research is being conducted by Maria Reyes, a Doctoral candidate in the College of Nursing at the University of Illinois at Chicago (UIC).

What is involved in this study?

The study will involve a one-time, 1 hour long telephone interview in women who have been informed of a correctable condition noted of their fetus / baby during the course of prenatal care. This study involves women who have received counseling in pregnancy by a team of specialists.

What is required?

- Must feel comfortable speaking English. Be pregnant and have participated in a team counseling session for a fetal condition
- Must be more than 18 years of age
- With access to a telephone

Your decision whether or not to participate will not affect your current or future relationship with the Children’s Hospital of Wisconsin or University of Illinois, in Chicago. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Will you be compensated or reimbursed for your participation in this research?

You will be compensated for the interview with a one-time $10 gift card mailed to your home address. The gift card will be mailed at the completion of the interview.

If you are interested and would like to see if you qualify please contact the Fetal Concerns Program Research Specialist at [contact information] or the principal investigator at [contact information].
Appendix H

Study Staff Script

Hello,

You are being asked to participate in a research study titled: **Women with correctable fetal anomaly participating in perinatal I-Team counseling: an exploratory study.**

Not much is known about the counseling of women with a fetal condition. The researchers are interested in your experience and eager to understand what was helpful / not helpful in your counseling sessions.  This study will not benefit you directly, but ideally will help future mothers facing a similar situation in the course of their pregnancy. The study involves a telephone interview from an out-of-state location (Illinois), for a one time, one hour session. The interview will be audio recorded. This study does not involve any specimen collections or additional testing. Your decision to participate or not will not affect the remainder of your care.

The research staff would like to make sure you understand that your participation in this study is completely voluntary. You can withdraw from the study if you choose not to participate, even after signing the consent.

Access to some of your medical records / protected health information will be needed. Giving your consent to be interviewed would allow the research staff to access your medical record. Only information needed for the study will be accessed, and all efforts to protect your privacy will be made; including storing the data in secure fashion, and destroying the data at the end of the study.

If you would like to discuss this with the study investigators, they can be reached at:

Nancy Wojciehowski MS, RN, [Redacted]

Steven Leuthner, MD [Redacted]

Maria Reyes, PhD (c), CNP, [Redacted]
Appendix I: IRB Approval

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7237

Approval Notice

Initial Review (Response To Modifications)

December 13, 2012

Maria Reyes, BSN, MSN
Women, Child, & Family Health Science

e, IL 6

Phone: / Fax:

RE: Protocol # 2012-0920

“Women with Correctable Fetal Anomaly Participating in Perinatal I-Team Counseling An Exploratory Study”

Dear Ms. Reyes:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on December 10, 2012. You may now begin your research.

Please note the following information about your approved research protocol:

Please remember to obtain a data transfer agreement from each non-UIC site transferring data to UIC. Data transfer agreements originate with the non-UIC site releasing the data and must be completed by the UIC ORS (Office of Research Services) before being submitted to the UIC IRB, accompanied by an Amendment form.
Please remember to add new research personnel via a revised Appendix P prior to their involvement in the research activities. Appendix P must be accompanied by an Amendment form when submitted to the UIC IRB.

Please remember to submit a copy of IRB approval from the Children’s Hospital of Wisconsin and Wayne State University Medical School prior to accessing/analyzing identifiable data and/or recruiting/enrolling subjects at those sites. A copy of IRB approval from non-UIC sites must be accompanied by an Amendment form when submitted to the UIC IRB.

**Protocol Approval Period:** December 10, 2012 - December 10, 2013

**Approved Subject Enrollment #:** 30

**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.

**Performance Sites:** UIC

**Sponsor:** UIC College of Nursing PhD Student Research Award

**Research Protocol:**

a) Women with correctable fetal anomaly participating in perinatal I-Team counseling: an exploratory study; Version 2; 11/05/2012

**Recruitment Materials:**

a) Team Counseling Thank You Letter; Version 2; 12/01/2012
b) Team Counseling Flyer; Version 3; 12/01/2012
c) Team Counseling Screen Form; Version 2; 12/01/2012

**Informed Consents:**

a) Team Counseling; Version 2; 12/01/2012
b) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 for recruitment/screening purposes only (minimal risk; verbal consent for screening data will be obtained; signed consent will be obtained at enrollment)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and
social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

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<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
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<td>Response To Modifications</td>
<td>Expedited</td>
<td>12/10/2012</td>
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</table>

Please remember to:

- Use your **research protocol number (2012-0920)** on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at [redacted] or me at [redacted]. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Data Security Enclosure**
3. **Informed Consent Document:**
   a) Team Counseling; Version 2; 12/01/2012
4. **Recruiting Materials:**
   a) Team Counseling Thank You Letter; Version 2; 12/01/2012
   b) Team Counseling Flyer; Version 3; 12/01/2012
   c) Team Counseling Screen Form; Version 2; 12/01/2012

cc:  Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
     Patricia Hershberger (faculty advisor), Women, Child, & Family Health Science, M/C 802
To: Maria Reyes  
Date: May 22, 2013  
Re: Study Full Title: Women with Correctable Fetal Anomaly Participating in Perinatal I-Team Counseling: An Exploratory Study  
Study # & Link: PRO00019553

**IRB Approval Date:** 5/21/2013  
**IRB Expiration Date:** 5/20/2014

The MCW/FH Institutional Review Board #5 has granted approval for the above-referenced submission in accordance with 45 CFR 46.111 by expedited review, Category #7. The IRB also granted approval under 45 CFR 46 Subpart B as the specific regulatory requirements have been met and this protocol was determined to be no more than minimal risk.

Approval has been granted for the following institutions:  
Froedtert Hospital including the Clinical Cancer Center  
Children's Hospital of Wisconsin

The consent form and related HIPAA authorization are effective as of 5/21/2013. Signed consent forms for each subject must be kept on file as part of the project records.

The items listed below were submitted and reviewed when the IRB approved this submission. Research must be conducted according to the IRB approved protocol listed below:

MCW study protocol  
Recruitment Flyer  
ICF

The IRB also granted approval of a waiver of HIPAA authorization requirements at 45 CFR 164 and a waiver of informed consent requirements at 45 CFR 46.116 for the purpose of Records Review for Potential Subjects.
Any and all proposed changes to this submission must be reviewed and approved by the IRB prior to implementation. When it is necessary to eliminate hazards to subjects, changes may be made first. This should be followed promptly by a protocol deviation and amendment.

In accordance with federal regulations, continuing approval for this submission is required prior to 5/20/2014. The Continuing Progress Report (CPR) must be received by the IRB with enough time to allow for review and approval prior to the expiration date. Failure to submit the CPR in a timely manner may result in the expiration of IRB approval.

A Final CPR must be submitted to the IRB within 30 days of when all project activities and data analysis have been completed.

All Unanticipated Problems Involving Increased Risk of harm to Subjects or Others (UPIRSOs) must be reported promptly to the MCW/FH IRB according to the IRB Standard Operating Procedures.

If your study involves the use of any Froedtert Health resource such as, space, staff services, supplies/equipment or any ancillary services - lab, pharmacy, radiology, protected health/billing information or specimen requests, OCRICC approval is required before beginning any research activity at those sites.

If you have any questions, please contact the IRB Coordinator II for this IRB Committee, Dee Burns, at [removed] or [removed]@mcw.edu.

Sincerely,

Kathryn Gaudreau
David Clark, PhD

IRB Chairs

MCW/FH Institutional Review Board #5
October 2, 2012

Maria Reyes, PhD, APN
Doctoral Candidate
University of Illinois at Chicago
College of Nursing
Chicago, IL 60612

Ms. Reyes,

This letter is written support of your research proposal entitled, “Women diagnosed with correctable fetal anomalies participating in perinatal I-Team counseling: an exploratory study” that is being submitted for review to the Institutional Review Board, University of Illinois, Chicago. Based on our previous discussions and mutual interests in this area of research, I know you are interested in exploring the experiences of women diagnosed with a fetal condition.

My department and I look forward to our continued collaboration in relation to this important area of study. We affirm our commitment to be a data collection site for this study, pending IRB approval.

Sincerely,

Steven R. Leuthner, MD, MA
Professor of Pediatrics and Bioethics
Medical College of Wisconsin
Chapter III

Prenatal counseling in women diagnosed with a structural fetal anomaly. Do teams influence maternal perceptions?

Abstract:

With 3% of U.S. births being affected by fetal anomalies, responding to women during what is often a tumultuous period is imperative. The objective of this integrative review is to (1) assess current methods of team counseling after a fetal diagnosis, (2) describe what is known about maternal responses to team counseling, and (3) provide implications for practice.

Organizing construct: A literature review was conducted to identify primary source publications that described the experiences of women who were counseled prenatally for a structural fetal anomaly. Only published research studies that used perinatal team counseling (e.g., perinatal and pediatric specialty and sub-specialty teams) after a correctable fetal structural anomaly was diagnosed were examined for this review.

Methods: Cumulative Index to Nursing and Allied Health (1990-2014), PubMed, Cochrane Library, OVID, and Scopus were queried using the phrase counseling for fetal anomaly; hand searches in peer reviewed journals for counseling for fetal defect was also completed, to identify existing literature from 1990-2014.

Findings: Fifteen studies were identified and included in the review. In these studies, pregnant women affected by a fetal anomaly, described benefit in counseling received by perinatal and pediatric specialty teams (teams including nurses, advanced practice nurses, genetics counselors and psychologists). Decreased anxiety with improved understanding of their future infant’s
condition was described. Repeat sessions with the pediatric specialist and sub-specialist teams had negative correlation with maternal anxiety.

**Conclusion:** Interdisciplinary perinatal and pediatric sub-specialty team counseling influenced the maternal experience. Decrease in maternal anxiety and altered maternal perceptions of fetal anomaly were noted.

Keywords: fetal anomaly; team counseling; woman’s response, pregnancy.

Pub-Med MeSH headings: Fetal Diseases/ diagnosis; non-directive counseling

**Background**

Congenital birth anomalies affect 1 in every 33 babies born each year, resulting in approximately 120,000 affected births annually and are the leading cause of infant death in infants less than 1 year of life (Centers for Disease Control and Prevention [CDC], 2008). In Europe, approximately 15.8% of every 10,000 births are affected by congenital anomalies (Calzolari, Barisic, Loane, Morris, Wellesley, Dolk, et al 2014). The high rates of pre-gestational and gestational diabetes, preconception obesity in women, advanced maternal age and failure to consume recommended amounts of folic acid, have been related to higher risk of experiencing a pregnancy with a fetal anomaly (Correa, Gilboa, Besser, Botto, Moore, Hobbs, et al, 2008). Rising pre-conception diabetic states, particularly during embryogenesis, and or diabetes diagnosed in pregnancy, increases the occurrence of both cardiac and non-cardiac anomalies (Morgan, Relaix, Sandell, Loeken, 2008). Pre-gestational diabetes was noted to be associated with 70% of the isolated anomalies and up to 90% of multiple anomalies, such as spina bifida and various heart defects (Waller, Shaw, Rasmussen, Hobbs, Canfield, Seiga-Riz, et
Advanced maternal age, starting at age 25 years, has a linear steady increase in fetal structural anomalies (Hollier, Leveno, Kelly, McIntire, & Cunningham, 2000). Moreover, from 1970 to 2012, women 35-39 years of age have had a gradual rise in birth rate (Mathews & Hamilton, National Center for Health Statistic [NCHS] Data brief No. 152, 2014). With the birth rate for the 40-44 year old cohort more than doubling from 1990 to 2012 (NCHS, 2014), evidence for fetal anomaly propensity continues to emerge, making attending to women’s needs around this experience increasingly relevant.

Fetal anomalies are defined as structural changes in one or more parts of the fetal anatomy, are present at birth, and have serious, adverse, effect on the infant’s health and development (Mathews & MacDorman, 2012: NVSS; 60{5}; Lui, Joseph, Wen, 2002). Although some fetal anomalies can be identified in early pregnancy (Stewart, 2004), most major structural anomalies are noted at the 18-20-week ultrasound; an anatomical survey of the fetus routinely offered during prenatal care to all women in the United States, independent of risk (ACOG, Practice Bulletin No.77; 109, 2007; Goldberg, 2004; Shipp & Benacerraf, 2002). Fetal anomalies are grouped by their outcomes or diagnostic and prognostic certainty (Leuthner, 2004). Fetal anomaly categorical groups range from lethal, non-correctable with severe disability, to treatable with varying degrees risk (Leuthner, 2004; Statham et al., 2003). Correctable anomalies are amenable to post natal surgical or medical intervention (Raboei, 2008). Transfer of care to tertiary centers or regionalized perinatal care for correctable anomalies, is demonstrating significant improvement in infant survival (Calisto, Oriolo, Giannino, Molle, Buffone, Donadio, 2012).

Women describe the experience of receiving a prenatal diagnosis of any fetal anomaly as a traumatically devastating life event (Aite, Zaccara, Mirante, Nahom, Trucchi, Capolupo, et al, 2007).
Aite et al, (2011) noted that couples diagnosed with a fetal anomaly reported the loss in the joy of being pregnant, the loss of the idealized child and greater uncertainty in their lives. Women, in particular reported intense emotional-distress responses such as: heightened stress, anxiety, anger, despair, guilt, perceptions of inadequacy, social isolation, self-blame and grief-like reactions (Hunfeld & Passchier, 1993; Jones, Statham & Solomou, 2005; Lalor, Begley &Galavan 2008; Leithner, Fischer-Kern, Hilger, Loffler-Staska & Ponogny-Selider, 2004; Lobel, Dias &Meyer, 2005; Pelly, 2003). These reactions may be tempered during the prenatal periods, with noted re-emergence as the birth nears and may persist years after the birth (Hunfeld, Wladimiroff, Verhage & Passchier, 1995; Rillstone & Hutchinson, 2000; Hunfeld, Tempels, Passchier, Hazebroek, Tibboel, 1999). Women use different coping strategies during pregnancy with a fetal anomaly including: acceptance, attachment, detachment, denial, optimism, pessimism, privacy, information control, religiosity/spirituality and social support (Brisch, Bemmerer-Mayer, Terinde, Kreienberg & Kachele, 2003; Hedrick, 2004; Lalor & Begley, 2006; Leithner et al, 2004; Leuthner, Bolger, Frommelt & Nelson, 2003).

Although women report negative emotional responses when given the fetal diagnosis, they report a driving need to receive information about the fetal anomaly when informed about the fetal diagnosis, and in particular, the anticipated postnatal infant course (Labor & Begley, 2006; Statham & Solomou, 2001). Women with a structural fetal anomaly reported benefit in having knowledge of the structural defect, detail of the corrective postnatal procedures and anticipated prognosis of their future infant prior to the birth (Alkazaleh, 2004; Statham & Solomou, 2001). Compared with women who received information about congenital defect at the time of birth, women who received information about the fetal anomaly and prognosis during
pregnancy felt better prepared physically and emotionally (Ralston, Wertz, Chelmow, Crago & Bianchi, 2001).

The method used to counsel women prenatally about a fetal anomaly has been shown to be directly related to women’s perception of provider sensitivity and support. Women reported increased anxiety and uncertainty when the information about a fetal anomaly and or prognosis was presented in a vague and or ambiguous way (Lalor & Begley, 2006). Women reported value in receiving immediate, clear and unbiased information about the fetal condition, follow-up, infant care, privacy during counseling, and a sensitive approach to counseling by supportive providers (Kaasen, Helbig, Naes, Skari & Haugen, 2011; Lalor & Begley, 2006). When information of the fetal anomaly was not readily shared or was presented in a biased fashion, women reported feeling a lack of provider support, negatively affecting their experiences, often resulting in additional stress (Statham, Solomou & Chitty, 2000).

Interdisciplinary perinatal team counseling (consisting of both experts in women’s health and pediatric sub-specialists) joining together to counsel women in pregnancy about a fetal condition is an emerging approach. The aim of prenatal counseling is to provide information to prospective parents on the fetal condition, possible prenatal interventions, appropriate setting, time and route of delivery and expected postnatal outcomes, immediate and long-term (Lakoo, 2013). Comparable to the interdisciplinary team based counseling used for medically complex patients (Haidet, Fecile, West, 2009), the team counseling strategy used for women has the potential to increase knowledge of the fetal anomaly and infant prognosis, decrease maternal anxiety and foster coping in the short term (Aite, Trucchi, Nahom, Spina, Bilardo, Bogolan, 2002; Crombleholme, D’Alton, Cendron, Alman, Goldberg, Krauber, et al, 1996). To that end, the Agency for Healthcare Research Quality (AHRQ) developed national guidelines for
counseling women with a fetal structural anomaly. The guideline recommendations include the need to: present abnormal findings in a sympathetic and timely fashion, provide a supportive environment and refer to pediatric sub-specialties (Agency for Healthcare Research Quality: National Quality Measures Clearinghouse). However, assess to pediatric counseling is not universally offered or implemented at present (Aite, Zaccara, Cuttini, Mirante, Nahoum, Bagolan, 2013). Limited research exists on how these recommendations are put in to practice and more importantly, how this may influence a woman’s experience. Understanding counseling strategies offered will aid in determining future need of women facing a fetal condition. The purpose of this integrative review is to assess existing research literature for studies that used perinatal team counseling after a correctable fetal structural anomaly was diagnosed, with descriptions of maternal responses to counseling. This integrative literature review will address what is known about: (a) methods of counseling strategies used; (b) team composition if teams are used; and (c) perceived effect of counseling.

Purpose Literature Review

The purpose of this integrative review is to identify and describe the counseling strategies used to counsel women who have been informed of a prenatally detected structural (non-lethal) fetal anomaly. This descriptive summary will seek to address:

1. Methods of counseling strategies are used
2. Team composition if teams are used
3. Women’s described perception of the effect of counseling when correctable fetal anomaly is noted; variables measured in quantitative design
4. Implications for practice cited
**Search Strategy**

Integrative reviews are well suited in defining a concept, or reviewing the available evidence of a particular topic, this method allows for the inclusion of experimental and non-experimental research for broader understanding of the phenomenon (Whittemore & Knafl, 2005). The topics of interest are the counseling strategies used in the prenatal course under the specific conditions of the presence of a structural, correctable, fetal anomaly. A search for peer-reviewed articles published in English, from January 1990 to January 2014, using the search phrases “counseling for fetal anomaly” and “counseling for fetal defect” was conducted. The search included studies dating back to 1990 to include articles relevant for when prenatal imaging and diagnosing were increasingly utilized in prenatal care (Neilson, 2007). Cumulative Index to Nursing and Allied Health (1990-2014), PubMed, Cochrane Library, OVID and Scopus were queried. Abstracts were reviewed for relevant titles with the following inclusion criteria applied:

1. All published research from peer-reviewed journals, literature reviews, and case-reports were included (discussion papers, editorials, opinion papers were excluded).
2. Included were studies involving counseling completed during the prenatal course of affected pregnancy, or within the immediate post-delivery time. Retrospective post-delivery studies greater than five years after the event were excluded do to potential recall bias.
3. Included were studies involving counseling conducted for prenatally detected correctable fetal anomalies if described; studies recruiting exclusively lethal, genetic or non-correctable fetal conditions were excluded. While lethal, non-correctable / genetic conditions may involve team counseling; the focus may be altered e.g., focus
towards palliative care. The decision to include only correctable anomalies was intended to create homogeneity among studies included.

The initial search (see Figure 1) resulted in studies principally describing prenatal diagnosis, medical or surgical management of anomaly, and or suggested practice issues with particular fetal condition (N=41,668). Search criteria were adjusted to include counseling of the fetal anomaly, as the focal topic (N=11,964). This search criterion was further narrowed to counseling of the fetal condition versus counseling on uptake of screening tests, decision to interrupt or continue pregnancy or genetic counseling strategies to use in the wake of an anomalous condition. The search criterion included a fetal diagnosis deemed correctable in the post natal period; excluding counseling for genetic abnormalities / palliative care as these conditions have a different focus and expectant outcomes (N=11,937 were not eligible). Lastly, a journal hand-searching strategy was used in obstetrical journals to identify potential articles of interest (Whittemore & Knafl, 2005). Counseling with correctable conditions resulted in (N=27) studies. Twelve studies were removed for lack of clarity of study design, low study sample size and failure to describe how conclusions were attained; a total of 15 studies were included for this review.

**Results**

**Data Evaluation**

The final sample for this review included 15 research studies with 1,127 study participants. The selected studies contained in their aim statement—women’s responses to, expectations with, satisfaction of, perception of, or impact of team counseling after a fetal anomaly diagnosis.
A broad range of methodological approaches were used to assess women’s responses to post fetal anomaly detection counseling. Both qualitative (n= 11) and quantitative (n=4) study design methods were included in this review. Empirical reports using case study, cross-sectional, grounded theory, phenomenological, descriptive and observational study designs were included (Table 1). Four studies used prospective study designs, the remaining 11 studies were retrospective, and all were purposive samples, concentrated at tertiary centers (one or multiple sites) where parents interfaced with various pediatric sub-specialty teams. All but two studies included detailed description of teams performing counseling. Data were extracted from primary sources on sample characteristics and the closeness of fit to study purpose (to assess maternal responses to fetal diagnosis after team counseling).

Data Synthesis

The data reduction process involved an evaluation of sample descriptive data sets, maternal age, maternal education and fetal anomaly diagnoses were reviewed for study sample homogeneity and for similar study purpose (see Table 1). The data reduction process also included an evaluation and coding of data results using constant comparison method (Patton, 2002). Themes, or each study’s focus, were centered on: (1) the women’s experiences with the fetal diagnosed and (2) subsequent counseling.

Four studies included both parents (Aite, 2003; Aite, 2004; Aite, 2011; Berggren, 2012). Of 10 studies, three listed less than high school education. However, only one study cited maternal ‘understanding’ of the concepts as a potential issue. The mean maternal age was range was 25-34; with fetal age at counseling in mid to late second trimester. Eight studies used pediatric general surgical teams for counseling sessions, three studies used cardiology teams, two
used cranio-facial (cleft lip and palate) teams, one used neonatology perspective and one used the term ‘various teams’, but did not describe team in detail.

The next step in the data evaluation process was to review questionnaire content, establish instrument validity and response rate (Table 1). Six of the 15 studies used a questionnaire to gather data of the women’s experiences. The questionnaires all used Likert scales for scoring and response rates ranged from 76% to 100%. All psychometric instruments used in four studies) have well established reliability and validity; but individual study reliability measures were not included (Spielberger’s State Trait Anxiety Inventory {STAI-S}, General Health Questionnaire {GHQ-28} and the Impact of Event Scale {IES}) (Aite, 2002; Aite, 2003; Kemp, 1998; Skari, 2006).

**Emerging Themes**

Three themes emerged from the data: perception of team consults, women’s preferences to counseling and affective experiences. These themes are listed in detail in Table 2.

**Perception of team consults**

Ten of 15 studies examined maternal perception after perinatal team counseling (Aite, 2004; Aite, 2005; Aite, 2011; Berggren, 2012; Menahem, 2004; Menahem, 2004; Patel, 2008; Ter Porten, 2002; Miguel-Verges, 2009; Yang, 2007). Study participants expressed positive perceptions stemming from their consultation with the teams (teams described by each individual study). For example, Aite (2002) found that more than one consult was preferred by women with repeat sessions decreasing maternal anxiety and greater than two sessions were negatively correlated with maternal anxiety (Aite, 2003). Berggren (2012) reported consultation with the pediatric cleft-lip and palate team fostered clearer understanding of the fetal diagnosis and
postnatal course. In Berggren’s study, counseling was completed by two plastic surgeons and specialty trained nurses (registered nurse, advanced practice nurse and clinical nurse’s aide), all described as helping women during the post natal period adjust to the feeding techniques particular to their infant’s anomaly. Hedrick (2004) described women found it beneficial in their adjustment to discuss their infant’s future treatment with the pediatric sub-specialist.

**Women’s preferences to counseling**

In seven of the 15 studies reviewed, women offer particularly helpful ways of information delivery (Aite, 2002; Aite, 2003; Aite, 2005; Berggren, 2012; Kemp, 1998; Menahem, 2004; Yang, 2007). Given a choice, women preferred receiving information during the prenatal period versus after delivery (Aite, 2002; Berggren, 2012; Hedrick, 2004). Women preferred when providers presented both written and oral presentations of the fetal condition, with drawings used to help understand complex issues (Aite, 2005). Offering more than one consultation session, dedicated to the explanation of complex fetal anomalies was much appreciated in reducing stress (Aite, 2004) and gaining an understanding of the condition (Menahem, 2004).

Women described empathy and attachment with their fetus in spite of uncertainty. They preferred counseling be presented in a balanced way (realistic presentation of medical information balanced with the opportunity to hope) (Miguel-Verges, 2009). On the one hand, being presented with realistic, pragmatic, supportive planning (hearing defined management plans from the pediatric surgical teams) was perceived as less stressing (Kemp, 1998). Women reported benefit in meeting with the hospital staff who will care for their infant; meeting with the neonatologist and neonatal intensive care nurses provided them with answers specific to their situation (Miguel-Verges, 2009).
While on the other hand, counseling in an empathetic, supportive and hopeful manner was appreciated. Researchers for three studies reported women’s expressed desire to have a spiritual person available to them during or after sessions (Hedrick, 2004; Patel, 2008; Ter Porten, 2002). Additionally, Aite (2011) noted benefit for couples when clinical psychologist was part of the team.

*Affective experiences and coping*

In 10 of the 15 studies reviewed women described their experience as an emotional event, with regular vacillation in moods and emotions; however, notable decrease in anxiety was appreciated after meeting with the teams (Aite, 2004; Aite, 2002; Aite, 2003; Aite, 2005; Berggren, 2012; Kemp, 1998; Menahem, 2004; Patel, 2008; Skari, 2006; Yang 2007). Maternal states of fear, worry and helplessness with gradual lessening as the pregnancy progressed were described (Berggren, 2012). Women describe feeling conflicted, in wanting to continue the pregnancy to nurture their fetus, but also wanting the experience to end (Hedrick, 2004). Dominating in the early phases after diagnosis was made was grief and shock, later reported as anger and guilt, with a mixture of fear and positivity always hoping for the best as the delivery was closer. Hedrick described adaptation expressed with increasing use of support networks, increase in spiritual activities with noted organization and prioritizing of activities.

*Implications*

This integrative review offers insight to women’s experiences with team counseling for a correctable fetal structural anomaly. Women describe distinct benefits when team counseling was made available. Women preferred more than one single counseling session with increased value in various team compositions. A realistic and balanced, but positive presentation of the
fetal condition and anticipated post natal course is favored. Perception of providers in counseling influence decisions women make; Crombleholme et al (1996) evaluated the impact of pediatric involvement in prenatal counseling and noted the favorable outcomes of including pediatric sub-specialists, (3.8% of parents opting to reverse their decision to terminate after the consult). Halamek (2001) described the beneficial effect of neonatology presence during prenatal consultation; adding prenatal to post-natal continuity, easing the newborns’ transition. In the studies reviewed, women that were counseled voiced an appreciation of nurse involvement in the sessions. Since nurses play a vital role; awareness of women’s needs and preferences is critical to improving care for women.

*Pre-conception implications*

Nurses are often called to provide direct patient education (Table 3); they are in a unique position to provide pre-conception counseling, offering patient education on weight management (Nodine & Hastings-Tolsma, 2012), glucose control and folic acid supplementation prior to pregnancy. According to the Core Preconception Health report 43% of pregnancy were unintended, with of 25% of women using tobacco and 54% ingesting alcohol within 3 months prior to conception (MMRW; 63; {3}; 2014).

*Post conception implications*

The counseling that follows fetal anomaly diagnosis has been shown to influence the anxiety experienced, decisions made, affect ability to understand the information presented and lead to decreased satisfaction (Aite, 2003; Patel; 2008). The potential for adaptation in pregnancy and personal growth in the long term is possible; however, this review brings to light necessary elements in fostering a better experience (Lalor, Begley & Galavan 2009; Black & Sandelowski,
Nurses are in a unique position to participate in team conferences and advocate for their patient’s needs. Registered nurses and advanced practice nurses (NP/CNM/CNS) would be duly suited to participate in team counseling. Women described their experiences with an interdisciplinary team of specialists as helpful and ‘necessary’ to coping during their affected pregnancy (Reyes, 2014 publication pending). Women described counseling teams favored in the prenatal period, with repeat consultations helpful, and the counseling received by nurses and advanced practice nurses as helping them adjust. Women described wanting genetic counselors added to the teams, and request that spiritual support be made available. Aite et al, (2011) urged a collaborative approach between obstetrician, pediatric sub-specialist and mental health specialist during counseling at the time of diagnosis and thereafter to ameliorate the effects this event may have.

Post birth implications

Nurses can help parents who will soon face having a newborn with intensive needs. Introducing them to their newborn through early skin contact and kangaroo care when able, will help ease the transition to home (Hartman & Medoff-Cooper, 2012). Supporting mothers supply breast milk and helping them participate in care and feedings when tolerated will offer nurturing tasks to mothers when they are ready. Understanding the emotional and psychological toll this takes on women would help nurses increase the support needed during the immediate post birth period; a time noted to be exquisitely difficult for mothers (Sydnor-Greenberg, Dokken & Ahmann, 2000). Recognizing this event as a stress-inducing event would help nurses identify women at risk for post-partum depression (PPD). Nurses can identify women in need of screening for PPD and identify barriers to care for PPD, easing the transition from hospital to home (Logsdon, Tomasulo, Eckert, Beck, Dennis, 2012). Nurses can play a role in helping
women find their path to meaning making from this experience. Creating a supportive framework for parental involvement in the prenatal period would ease transition to the postnatal world (Sydnor-Greenberg; Dokken; Ahman, 2000). The limitations of this review include the limited studies available for inclusion. More studies are needed to attain a better understanding of the experience.

Conclusions

Prenatal fetal anomaly detection and the devastation associated with this finding are making the need for utilization of perinatal team counseling. Still needed are studies seeking evaluation of team collaborative process and parental perception of support with that process. Additionally an understanding about the decision-making process for parents when they are counseled by teams. Longitudinal designs would help gain insight to what do women see as the quality markers of this method of counseling? Do women see this experience as women-centered? This review brought women’s preferences for counseling to light. Adding specialty trained nurses to the teams was well received, thus women may benefit from the presence of an APN (NP/CNM/CNS); given that many women have an already established relationship with their midwives; their participation in counseling may add the support women need to the process. Women appreciate the continuity and presence of an APNs in counseling and uptake of diagnostic prenatal testing (Martin; Van Dulmen; Spelta; De Jonge; De Cock & Hutton, 2013).

This review summarized the existing literature on a specific topic area, thus is limited in generalizability. However, benefits of interdisciplinary team counseling have been supported. Much more research is needed on the roles nurses can assume in team counseling.
References

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behavioral surveillance system, 2009. Center for Disease Control and Prevention [C.D.C.]; Morbidity and Mortality Weekly Report, Surveillance Summaries; 63(3); April, 2014.


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Fig. 1 Flow diagram of articles selected for inclusion

Studies related to fetal diagnosis; management procedures; intrauterine correction deleted. (N=11,924)

Studies related to genetic counseling / genetic testing / counseling and management of non-correctable or lethal diagnosis deleted. (N=11,037)

Focus topic of counseling in correctable fetal anomalies. Remaining articles (N=27)

Counseling occurred in pregnancy; descriptions of counseling methods included; study focus women.

Remaining articles (N=15)
<table>
<thead>
<tr>
<th>Author</th>
<th>Study Aim Post counseling</th>
<th>Study Design</th>
<th>N=</th>
<th>Age</th>
<th>Maternal Education</th>
<th>Mean Gest Age</th>
<th>Fetal anomaly</th>
<th>Team description</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aite, Trucchi, Nahom, Casaccia, Zaccara, Giorlandino, &amp; Bagolan (2004). Italy</td>
<td>Assess emotional and cognitive reactions to CDH post counseling.</td>
<td>Quant. Cross sectional survey;</td>
<td>40 (couples)</td>
<td>29</td>
<td>HS=27; college=10</td>
<td>25 weeks</td>
<td>CDH*</td>
<td>MFM + pediatric surgeon</td>
<td>All parents reported single consult insufficient</td>
</tr>
<tr>
<td>Aite, Trucchi, Nahom, Spina, Bilancioni &amp; Bagolan (2002). Italy</td>
<td>Assess impact of maternal anxiety with multidisciplinary approach.</td>
<td>Quantitative: Case controlled; Prospective; STAI-S</td>
<td>32</td>
<td>26.4 (case)</td>
<td>HS=12 College=4</td>
<td>23 weeks</td>
<td>AWD*</td>
<td>MFM + pediatric surgeon + psychologist Together; repeat sessions</td>
<td>Repeat sessions decreased anxiety scores</td>
</tr>
<tr>
<td>Aite, Trucchi, Nahom, Spina, Bilancioni &amp; Bagolan (2003). Italy</td>
<td>Assess correlation of repeat consultations with maternal anxiety.</td>
<td>Quant. Prospect described STAI-S.</td>
<td>31</td>
<td>29.69</td>
<td>HS &amp; college (not specified)</td>
<td>25-27 weeks</td>
<td>AWD=10 CDH=8 Abdominal mass=4</td>
<td>MFM + sonologist + pediatric surgeon + psychologist Together repeat sessions.</td>
<td>Negative correlation between number of team consults and anxiety scores Cutoff&gt;2</td>
</tr>
<tr>
<td>Aite, Zaccara, Nahom, Trucchi, Icobelli, Bagolan (2005). Italy</td>
<td>Assess applicability of Drotar’s model of adaptation.</td>
<td>Qual.</td>
<td>50</td>
<td>27</td>
<td>HS=41 College=9</td>
<td>22 weeks</td>
<td>AWD=11 IA*=14 CDH=25</td>
<td>MFM + pediatric surgeon</td>
<td>Adaptation is possible in the prenatal period. 78% reached adaptation.</td>
</tr>
<tr>
<td>Aite, Zaccara, Mirante, Nahom, Trucchi, Capolupo &amp; Bagolan (2011). Italy</td>
<td>Counseling A/W trauma diagnosis.</td>
<td>Qual.</td>
<td>145</td>
<td>25</td>
<td>HS=103 College=42</td>
<td>26 weeks</td>
<td>CAM*=42 CDH=56 IA=83; Mass=89</td>
<td>MFM + pediatric surgeon + psychologist Team available on on-going basis</td>
<td>Traumatic event in 88% mtr/83% ftr; no correlation between anomaly type and trauma</td>
</tr>
<tr>
<td>Berggren, Hansson, Uvemark, Svensson &amp; Becker (2012). Sweden</td>
<td>Compare how families receiving the diagnosis pre vs post nataly receive team consultation.</td>
<td>Quant. Observe Questionnaire.</td>
<td>36 prenatal 46 post</td>
<td>ND</td>
<td>ND</td>
<td>ND</td>
<td>CL*=30 Lip/palate=5 2</td>
<td>OB alone OB + cleft lip / palate team (Plastic surgeon, pediatric cleft team)</td>
<td>81%prenatally referred; 19% self referred. 93% content good. 97% time counseled good. Parents told at birth 56% would have preferred prenatal</td>
</tr>
<tr>
<td>Hedrick, J. (2004). USA</td>
<td>Gain understanding of the experience of pregnancy w/ child with a known, non-lethal congenital anomaly.</td>
<td>Qual. Phenomenological</td>
<td>15</td>
<td>27.5</td>
<td>HS=7 College=8</td>
<td>29.9</td>
<td>CAM=3; CL=2 NTD*=5 ; cardiac=5</td>
<td>Not described Informed in 2nd tri of pregnancy</td>
<td>Mothers described benefit in discussion with pediatric specialist during pregnancy</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Country</td>
<td>Outcome Measures</td>
<td>Design Details</td>
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<td>Menahem &amp; Grimwade (2004).</td>
<td></td>
<td>Quant. Observe</td>
<td>30 cases</td>
<td>Australia</td>
<td>Assess perception of counseling in prenatal CDH.</td>
<td>Important for parents of major anomaly to understand.</td>
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<tr>
<td>Menahem &amp; Grimwade (2004).</td>
<td></td>
<td>Quant. Observe</td>
<td>21 cases</td>
<td>Melbourne, Australia</td>
<td>Assess perception of counseling in prenatal diagnosis of CHD.</td>
<td>Important for parents of major anomaly to understand.</td>
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<tr>
<td>Porten &amp; Louw (2002).</td>
<td></td>
<td>Quant Observe descrip</td>
<td>43 cases</td>
<td>Africa</td>
<td>Understand counseling preferences with fetal cranio-defects.</td>
<td>Mothers preferred team counseling prenatally and support present during counseling.</td>
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<tr>
<td>Skari et al, Oslo, Norway (2006).</td>
<td></td>
<td>Quant Observe STAI,G HQ-28;IES</td>
<td>16 cases</td>
<td>Norway</td>
<td>To test whether postnatal distress in parents is reduced by prenatal diagnosis.</td>
<td>MFM + pediatric surgeon. 53% acute anxiety after diagnosis-62% distress.</td>
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<tr>
<td>Miguel-Verges, Woods, Aucott, Boss,</td>
<td></td>
<td>Qual. interview</td>
<td>22 cases</td>
<td>USA</td>
<td>Assess expectations of a prenatal consultation with neonatologist for fetal anomaly</td>
<td>Neonatologist. Women voiced neonatologist should be part of team counseling parents.</td>
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<tr>
<td>Yang, Wen, Walker, Beduz &amp; Kim (2007)</td>
<td></td>
<td>Quant. Cross-sectional survey</td>
<td>251 cases</td>
<td>Canada</td>
<td>To assess prenatal care satisfaction of five perinatal units for pregnancies complicated by fetal anomaly.</td>
<td>Improve communication strategies during prenatal care leads to increase satisfaction.</td>
<td></td>
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</tbody>
</table>

*ND=not described in their study

*CDH=congenital diaphragmatic hernia; *AWD=abdominal wall defect; *IA= intestinal atresia *CAM=congenital cystic adenomatoid malformation of lung; *CL= cleft lip; *NTD=neural tube defect; SCT=sacral coccygeal teratoma

MFM=Maternal Fetal Medicine; HS=High School; STAI-S=State Trait Anxiety Inventory-State; GHQ-28=General Health Quality; IES= Intrusive Event Scale
<table>
<thead>
<tr>
<th>Theme</th>
<th>Findings</th>
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</thead>
</table>
| Perception of team consults | -Single prenatal consult with pediatric surgeon inadequate to have clear understanding of anomaly.  
-Positive impact on maternal anxiety (reduced) with this approach.  
-Negative correlation between prenatal consultation and maternal anxiety scores at delivery.  
-Repeat consultation was helpful; Women with > 2 consultations had significantly lower anxiety scores.  
-Post natal group would have desired prenatal consult.  
-Support and comfort described when information relayed.  
-Majority felt clear explanation; with enough detail; understanding was good to excellent.  
-Majority (>90%) were satisfied with interdisciplinary counseling.  
- Felt they understood future pregnancy risk.  
- Statistically significant association between women’s knowledge of prenatal condition during counseling sessions and level of satisfaction with care.  
-Women’s satisfaction correlated directly with the perception of kindness in HCP. |
| Women’s Preferences to Counseling | -Emphasize the positive effects of multi team counseling on moms during prenatal period with known fetal surgical dx.  
-Targeted maternal information needs.  
-Women appreciate written information.  
-No correlation of trauma scores and type of surgically correctable FA.  
-Both simple and complex equally traumatic.  
-Parents related better to defined management plans > than pragmatic “wait till baby is born” counseling.  
-Want realistic medical information.  
- Parents expressed concern with feedings & travel to center, along with surgical correction.  
-Severity of the crisis depends not only on nature of abnormality but if correctable.  
- Felt counseling by religious person warranted.  
Irrespective of gestational at diagnosis mothers required emotional support.  
- Both prenatal and postnatal groups had greater satisfaction when CLP team was consulted.  
-APNs & RNs in these specialties positively add to experiences.  
-Perceived consult with neo as preparing them for the perinatal course.  
-Specific to their situation-Empathetic provider to deliver consult. |
| Affective experiences and Coping | -Gradual lessening of the intense emotional experience.  
-Experienced definition of trauma post prenatal consultation for FA.  
25-30 weeks gestation with greatest distress, anxiety scores, acutely, at 6 weeks and at 6 months.  
Intense stressors =fear, terror, helplessness.  
-Longer gestation ability to nurture, prepare, learn of defect, gather information, but more time to worry & consider uncertainty, with increasing anxiety during the wait.  
-Grief presented as the loss of the perfect, idealized baby; including shock, anger and guilt (reported as negative reactions).  
-While positive coping was noted with organization and prioritizing activities, using support framework, increased spiritual activities.  
-Mothers described empathy & attachment with their fetus in spite of uncertainty.  
-Mothers recognized lifelong commitment to their baby with an abnormality—yet they accepted (and loved) the baby.  
Reduction in anxiety levels was more consistent in FA with good prognosis. Prefer when realistic focus is on positive.  
- Interaction with other parents of children with CL.  
-Be allowed to hope for the best possible outcome.  
- Mothers higher anxiety scores than fathers in affected cohort (both prenatal and at delivery). Being mom independent predictor of anxiety.  
-Prenatal diagnosis was a significant independent predictor of acute parental psychological distress after birth.  
-Multiple anomalies and low perceived health status related to increased burden of grief. |
### Table 3 Nursing Implications

<table>
<thead>
<tr>
<th>Nursing Directive</th>
<th>Outcome Behaviors</th>
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</table>
| **Pre-conceptually**<br>Reduce modifiable maternal risk factors | -educate women on benefits of attaining targets for BMI prior to conception with diet and exercise  
-have all childbearing age women supplement with folic acid / consume fortified foods  
-assist women achieve tobacco cessation  
-educate women on the effects of alcohol use prior to / in pregnancy  
-provide contraception counseling to sexually active women, not seeking pregnancy |
| **In pregnancy**<br>assist and support women diagnosed with fetal condition | -provide supportive environment  
-provide pragmatic education on anticipated post natal care  
-participate in team counseling  
-provide unit tours giving realistic feedback  
-offer non-directive counseling  
-education of anticipated special needs e.g., feedings in CL/CP  
-link with support groups when ready |
| **Post pregnancy care** | -offer meaningful involvement in infant care  
-provide supportive environment  
-observe for depression /post traumatic symptoms and refer  
-assist in joining support groups  
-facilitate coping in future pregnancy |
| **Monitoring ongoing quality** | -participate in research facilitating evidenced based practice  
-assess maternal satisfaction with teams  
-assess team outcomes |
### Academic Background

<table>
<thead>
<tr>
<th>INSTITUTION AND LOCATION</th>
<th>DEGREE (if applicable)</th>
<th>YEAR</th>
<th>FIELD OF STUDY</th>
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<tbody>
<tr>
<td>University of Illinois, College of Nursing</td>
<td>PhD</td>
<td>June 2014</td>
<td>Nursing</td>
</tr>
<tr>
<td>Chicago, IL.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University of Minnesota, St. Paul, Minnesota</td>
<td>Post Masters Certificate</td>
<td>1999</td>
<td>Women’s Health Care Nurse Practitioner</td>
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<tr>
<td>Minnesota</td>
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<tr>
<td>Rush University, Chicago, IL.</td>
<td>Post Masters Certificate</td>
<td>1997</td>
<td>Acute Care Perinatal Nurse Practitioner</td>
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<tr>
<td>De Paul University, Chicago, IL.</td>
<td>Post Masters Certificate</td>
<td>1996</td>
<td>Nursing Case Management</td>
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<tr>
<td>Rush University, Chicago, IL.</td>
<td>Masters of Science Degree</td>
<td>1996</td>
<td>Nursing</td>
</tr>
<tr>
<td>Rush University, Chicago, IL.</td>
<td>Bachelors of Nursing Science</td>
<td>1994</td>
<td>Nursing</td>
</tr>
<tr>
<td>American Society of Psych prophylaxis in Obstetrics (ASPO) Lamaze, Chicago, IL.</td>
<td>Certificate</td>
<td>1984</td>
<td>Childbirth Education Instructor</td>
</tr>
<tr>
<td>Illinois Masonic School of Nursing, Chicago, IL.</td>
<td>RN Diploma</td>
<td>1983</td>
<td>Nursing</td>
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## Certifications

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<tr>
<td>High Risk Obstetrics</td>
<td>1997</td>
<td>6/2017</td>
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<tr>
<td>Women’s Health Nurse Practitioner Board Certification</td>
<td>1999</td>
<td>6/2017</td>
<td>National Certification Corporation</td>
</tr>
<tr>
<td>Advanced Practice Nurse</td>
<td>1997</td>
<td>5/2016</td>
<td>Illinois Department of Professional Regulation</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>1983</td>
<td>5/2016</td>
<td>Illinois Department of Professional Regulation</td>
</tr>
<tr>
<td>DEA</td>
<td>2011</td>
<td>4/2017</td>
<td>Drugs Enforcement Agency</td>
</tr>
<tr>
<td>CPR</td>
<td>1983</td>
<td>4/2016</td>
<td>American Heart Association</td>
</tr>
<tr>
<td>ACLS</td>
<td>2009</td>
<td>11/2014</td>
<td>American Heart Association</td>
</tr>
<tr>
<td>American Academy of Pediatrics, NRP instructor</td>
<td>1985</td>
<td>10/2014</td>
<td>Hospital based neonatal resuscitation instructor, AAP, Chicago, IL.</td>
</tr>
<tr>
<td>RTS Trainer</td>
<td>1996</td>
<td></td>
<td>Regional Perinatal Bereavement Counselor Trainer</td>
</tr>
<tr>
<td>ASPO / Lamaze instructor</td>
<td>1984</td>
<td></td>
<td>Certified childbirth educator</td>
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</tbody>
</table>

## Professional Experience

**Rush University Medical Center**  
3/2014 to present

Adolescent Family Center

Women’s HealthCare Nurse Practitioner
St. Anthony Hospital Midwifery Group  6/2011 to present
Women’s HealthCare Nurse Practitioner

St. Xavier University  1/2010 to 7/2014
Adjunct Nursing Faculty School of Nursing

Rush University Medical Center  5/2009 to present
Adjunct Clinical Faculty
College of Nursing

Program Coordinator  2005 - 5/2011
Rush University Fetal & Neonatal Medicine Program

St. Anthony Hospital  2005-2011
Labor & Delivery Unit/ Mother Baby Unit
Staff Nurse

Rush University Medical Center  1997-2005
High risk Antepartum / Acute Care Triage Units
Perinatal Nurse Practitioner

Rush University Medical Center  1990-1996
Staff Nurse High Risk L&D/Maternal transport coordinator

University of Chicago Hospitals  1994 - 1996
Perinatal Clinical Nurse Specialist / Staff Educator

Holy Cross Hospital  1988-1990
Staff Nurse
Operating Room

**Saint Anthony Hospital** 1978 - 1988
Staff nurse, Labor & Delivery Unit
Nurse Manager Labor & Delivery Unit

**Professional Memberships**

American College of Nurse Practitioners, Member, 1998 to present

Midwest Nursing Research Society, Member, 2001 to present

Association of Women’s Health Obstetric and Neonatal Nurses, Member, 1990 to present

Sigma Theta Tau Nursing Honor Society, Alpha Lambda Chapter Induction as a new member 2001

Board Member: Pilsen Homeless Services, 2006 to present

Greater Chicagoland March of Dimes Program Services Committee, Member, 2006-2011

**Recognition and Awards**

2012  PhD Student Research Awardee, University of Illinois at Chicago, College of Nursing, Graduate College

2009  Sigma Theta Tau, Alpha Lambda Chapter, Excellence in Clinical Practice, *Mary Kelly Mullane*

2009  Certificate of Recognition Rush University *Community Service Award*

2008  Recipient Illinois March of Dimes *Jonas Salk Health Leadership Award*

2008  Recipient *Hero of the Heart* Rush University, Department of Pastoral Care

2007  Recipient *Alice Sachs* Family Advocate Award, Rush University Medical Center
2000  *Luther Christman Clinical Nursing Excellence* Rush University (nomination)

2004  Recipient Association of Women’s Health, Obstetric and Neonatal Nurses, *National Excellence in Clinical Practice Award*

2000  *AWHONN National Excellence in Clinical Practice Award* (nomination)

**Presentations**

  
  Poster presentation.  Midwest Nursing Research Annual Conference, Dearborn, M.I.

  
  Poster presentation.  Annual AWHONN convention, San Diego, C.A.

  
  Rush University Medical Center, Pediatric Grand Rounds, Chicago, IL.

  
  Presentation Rush University Medical Center, Special Care Nursery Nursing Didactics,
  Chicago, IL.


Presentation as part of APN course. Rush University Medical Center, Chicago, IL.

Presentation 35th Annual Maternal-Child Conference, Chicago, IL.

Presentation Rush Copley, Nursing Didactics, Chicago, IL.

Reyes, M. (2003). Nursing labor support: what have we demonstrated?
Presentation Rush University Medical Center, 2nd annual Labor Support Conference, Chicago, IL.


**Research Activities**


Funding: University of Illinois at Chicago, College of Nursing, and College Alumni Research Fund

Women with Correctable Fetal Anomaly Participating in Perinatal Team Counseling: An Exploratory Study

- **Amount:** $500.00
- **Role:** Principal Investigator
- **Dissertation Committee Chair:** Hershberger, P.
- **Dissertation Committee Members:** Kathleen Norr, Barbara Dancy, Steven Leuthner, Randall Kuhlmann, Carmen Giurgescu


Staff Specialist: In the Project Wish Mucosal Immunity Project as in Nursing in the Section of Infectious Disease. Responsibilities included specimen collection, sexually transmitted disease identification and treatment, with patient education. December 2001-2002.