

# Maternal Anxiety Related to Prenatal Diagnoses of Fetal Anomalies That Require Surgery

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## ABSTRACT

**Objectives:** To investigate maternal anxiety in women with pregnancies complicated by fetal anomalies that require surgery.

**Design:** Prospective comparison pilot study.

**Setting:** A fetal care center in a Northeastern U.S. academic medical center.

**Participants:** Women in their second or early third trimesters of pregnancy; 19 with pregnancies complicated by fetal anomalies and 25 without.

**Methods:** After ultrasonography, all participants completed the Spielberger State-Trait Anxiety Inventory and a sociodemographic questionnaire. Participants with pregnancies complicated by fetal anomalies also answered questions about the causes of their anxiety, their awareness of the nurse care coordinator service, and desired methods of emotional support. Obstetric and mental health history data were abstracted from the medical records of both groups.

**Results:** Participants with pregnancies complicated by fetal anomalies had greater mean state anxiety scores than those without (43.58 vs. 29.08,  $p = .002$ ). Maternal age was positively correlated with the state anxiety in women with fetuses with anomalies ( $r = 0.59$ ,  $p = .008$ ). Participants with histories of mental health issues had greater mean trait anxiety scores than those without (39.2 vs. 32.2,  $p = .048$ ). Most participants (68%) reported that knowledge of the fetal care center's nurse care coordinator decreased their anxiety. Participants wanted the opportunity to speak with families who had similar experiences as a source of emotional support.

**Conclusion:** Older maternal age may be a risk factor for anxiety in this population. Knowledge of the fetal care center nurse care coordinator service may have a positive effect and should be studied further.

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An increasing number of fetal anomalies is being detected and managed during pregnancy, in part because of advancements in ultrasonography and prenatal screening. Some of the most prevalent diagnoses are nonlethal fetal anomalies that can be corrected or treated surgically after birth (Parker et al., 2010). These newborns often undergo surgery within the first few days of life. The diagnosis and management processes for surgically treatable fetal anomalies are associated with significant maternal anxiety (Aite et al., 2006; Leithner et al., 2004; Rosenberg et al., 2010; Skari et al., 2006). However, women whose pregnancies are complicated by these fetal anomalies are often excluded from studies on the emotional effects of prenatal diagnoses, usually because of their more favorable

prognoses compared with lethal and chromosomal conditions. The risk for this population cannot be overlooked, because negative outcomes are associated with maternal anxiety in pregnancy. These outcomes can be severe, including preterm birth, newborns who are small for gestational age, and childhood neurodevelopmental delays (Blair, Glynn, Sandman, & Davis, 2011; Kramer et al., 2009). Furthermore, evidence suggests that pregnancy-related anxiety is more strongly associated with preterm birth and adverse child outcomes than general anxiety and depression (Lobel et al., 2008).

Multidisciplinary prenatal care through a fetal care center is the recommended standard practice for women whose pregnancies are

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complicated by fetal anomalies (American College of Obstetricians and Gynecologists Committee on Ethics & American Academy of Pediatrics Committee on Bioethics, 2011). Coordinated multidisciplinary care and consultations by maternal–fetal medicine specialists, neonatologists, and pediatric medical and surgical subspecialists have been shown to decrease maternal anxiety associated with the diagnosis of a fetal anomaly that requires surgery (Aite et al., 2002; Kemp, Davenport, & Pernet, 1998). In some centers, further steps to decrease maternal anxiety have been taken by integrating mental health professionals and emotional support services into the prenatal care team (e.g., psychologists, religious services, social workers, palliative care and/or child life specialists). The use of these interventions has shown to significantly decrease maternal anxiety, and they are widely recommended (Aite et al., 2002; Gorayeb, Gorayeb, Berezowski, & Duarte, 2013; Kemp et al., 1998; Langer & Ringler, 1989; Statham, Solomou, & Chitty, 2000).

Although nurses provide care for women during pregnancy and the postnatal period, their role in the provision of psychological support to women and families in fetal care centers has not been well studied. At the center of the treatment team is the care coordinator, usually a nurse with an obstetric or pediatric background. This role has been described as “the linchpin” (Besuner & Imhoff, 2007), “the glue” (Moise, 2014), and “the fulcrum” (Chock, Davis, & Hintz, 2015) in the care of women during fetal diagnosis and treatment. A key aspect of the coordinator’s role involves psychosocial support, and this individual often serves as the primary contact for women and their families during the prenatal period. The nurse coordinator must assess emotional well-being and advocate for a woman’s necessary support (Besuner & Imhoff, 2007; Moise, Kugler, & Jones, 2012). The limited resources of many health care systems may preclude mental health services for all women enrolled at fetal care centers. In many cases, the nurse coordinator may be the primary emotional support for women. In these instances, it is important to assess which women are at increased risk so that resource-intensive interventions can be targeted.

Establishing risk factors can help members of fetal care center teams identify women in need of additional psychosocial support. Staff at the centers can develop patient-directed care by assessing which support methods women would be most likely to use to decrease their anxiety. Knowledge of risk factors for anxiety could contribute to targeting those in need of intervention, whereas factors associated with lower anxiety and feedback from participants could be used to inform development of future interventions.

The objective of this pilot study was to investigate maternal anxiety in pregnancies complicated by fetal anomalies that require future surgery. This was done through (a) comparison of anxiety levels in women with and without pregnancies complicated by fetal anomalies that require surgery, (b) examination of the relationships among maternal anxiety and sociodemographic and clinical characteristics, (c) investigation of how information about the nurse care coordinator affected maternal anxiety, and (d) description of the women’s interest in potential methods of emotional support.

## Methods

### Design and Sample

We conducted a prospective comparison pilot study at a fetal care center in a Northeastern U.S. academic medical center. The University’s institutional review board approved the study. Women were recruited through clinician referral in the fetal care center. Two groups of women who presented at the center for second trimester ultrasonography were eligible for the study. The first group included women with pregnancies complicated by a nonlethal, major structural fetal malformation that would require corrective surgery within the child’s first year of life. These women were not approached at the time of diagnosis but at a follow-up visit to the center once the decision had been made to continue the pregnancy and transfer their care to the center. Women whose fetuses had primary brain anomalies were excluded because of the greater likelihood of a residual impairment and poorer prognosis than most anomalies that require surgery. The second group included women who presented for routine ultrasonographic screening who had no fetal or obstetric complications. These women served as a control group and were approached after physician confirmation of normal ultrasonography results. Eligibility was limited to women who spoke English and were older than 18 years of age.

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