Abstract

Purpose: To describe experiences of women disclosing a nonlethal fetal anomaly diagnosis to family and friends from initial prenatal diagnosis through postpartum.

Study Design and Methods: A descriptive, qualitative approach was used to explore women's perceptions of nonlethal fetal anomaly diagnosis in a high-risk obstetric clinic. In-depth interviews were conducted with 10 pregnant women, followed by postpartum interviews with 8 women. Data were analyzed using thematic analysis.

Results: Analysis of semistructured interviews revealed an overarching theme, *Pregnancy Forever Changed*, which captured the experience when expectant women first heard the news about their fetus. Prenatal themes were *News of a Diagnosis, No Going Back; A Mother's Response: Managing Information; and Words from Others Matter.* Women's struggles continued into postpartum, *The Journey Continues: Echoing Past Concerns;* and *Not the Journey We Planned.*

Clinical Implications: Women with a nonlethal fetal anomaly diagnosis experienced distress and stigma about disclosure of the diagnosis to others. Distress with disclosure continued throughout the pregnancy and extended into postpartum. Women described negative responses from others and ongoing management of information as stressful and painful. Clinicians are aware disclosing a lethal diagnosis is distressing for women but may not understand the experience of women with a nonlethal diagnosis. An appreciation of women's distress on disclosure of nonlethal fetal anomaly diagnoses can guide practice for maternity, neonatal, and pediatric nurses providing interventions that include information and anticipatory guidance.

Key words: Abnormalities; Behavior; Congenital; Disclosure; High-risk pregnancy; Maternal; Prenatal diagnosis.

MATERNAL DISTRESS IN DISCLOSING A NONLETHAL FETAL ANOMALY DIAGNOSIS TO FAMILY AND FRIENDS

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Pregnancy is often considered a time of great excitement, anticipation, and joy when a woman imagines the future with her baby and adding to her family. Expectant women access health care to ensure the best start for their babies, and prenatal visits are often considered supportive by expectant women, as tests, examinations, and ultrasounds provide reassurance that baby is healthy and growing normally (Simo et al., 2019). Some women in the United States discover during their pregnancy that there is concern for the baby's health when a screening test or ultrasound examination reveals an abnormal finding, or a diagnostic test reveals abnormal chromosomes (Greene et al., 2019).

Although 97% of pregnant women are unaffected by a prenatal diagnosis of a fetal anomaly, the remaining 3% or 120,000 have a fetal anomaly diagnosis (lethal and nonlethal) annually in the United States (Almli et al., 2020). Fetal anomalies are responsible for one in five U.S. infant deaths annually and are the leading cause of infant mortality (Almli et al., 2020). Fetal anomalies range from nonlethal anomalies, those that will not require any surgical interventions to those that will limit the newborn's physical and intellectual development, to lethal anomalies resulting in the newborn's death (Greene et al., 2019). Nonlethal anomalies detected prenatally include ventral septal defects, Trisomy 21, and spina bifida; and lethal anomalies include Trisomy 18, anencephaly, or renal agenesis. Families of these infants are significantly affected by the diagnosis and health care needs of the infant, and concerns about the future.

Abnormal findings in the fetus can occur as early as the first trimester of pregnancy and as late as a few weeks before birth. Although expectant women understand that screening tests and ultrasounds are offered to detect health problems in the fetus, it is universally shocking and unexpected to receive news of a fetal anomaly (Lou et al., 2017). As increasingly sensitive screening

and diagnostic tests have enabled prenatal diagnosis to occur earlier in pregnancy, women often live with the knowledge of a fetal anomaly for many months before giving birth. Pregnancy and childbirth are often celebrated within a woman's circle of family and friends as they wait for news about an ultrasound or prenatal visit. On receiving news of a fetal anomaly, women experience distressing emotions including shock, denial, stress, and anxiety followed by disclosing the fetal anomaly news to her family and friends (Lalor et al., 2009). As pregnancy progresses, women may experience decision-making dilemmas, isolation, fragmented health care, and loss and grief while simultaneously processing new information about the health of her baby (Cote-Arsenault & Denney-Koelsch, 2011; Lalor et al., 2008; Smith et al., 2013). Expectant women continue to share information and answer questions of family and friends throughout pregnancy.

Most of the literature related to disclosing news of a fetal anomaly diagnosis to family and friends and the subsequent maternal emotions and responses has focused on pregnant women disclosing news of a lethal fetal anomaly (Cote-Arsenault & Denney-Koelsch, 2011; Hutti, 2005; Lang et al., 2011; Wool, 2013). Maternal distress related to disclosure as a predominant theme was identified in only one study of women with a severe or lethal fetal anomaly diagnosis (Smith et al., 2013). Women felt unprepared for how their pregnancy was viewed publicly and the subsequent questions, comments, and unsolicited advice they received that was even more distressing with the lethal fetal anomaly diagnosis (Smith et al., 2013). There is little in the literature focusing on aspects of disclosure and sharing news of fetal anomaly diagnosis among women experiencing a nonlethal diagnosis during pregnancy and postpartum. In studies that included women with both lethal and nonlethal diagnoses, women reported they censored conversation about the fetal anomaly diagnosis during pregnancy and changed relationships after disclosing the news to family and friends (Hickerton et al., 2012; McKechnie et al., 2015).

Recasting Hope Theory by Lalor et al. (2009) provides a framework of the process of adaptation for pregnant women following the diagnosis of a fetal anomaly. Their sample was comprised of 41 women in Ireland with lethal and nonlethal diagnoses. It is the only theory that is specific to the expectant mother who receives a diagnosis of a fetal anomaly. "Assume Normal" is the first stage of adaptation in which women anticipate a healthy pregnancy and a normal ultrasound (Lalor et al.,

There is limited research on the impact of fetal anomaly diagnosis on women.

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2009, p. 462). The "Shock" of receiving the news is the second stage followed by "Gaining Meaning" as women wait to meet the experts and demonstrate information preference behavior (Lalor et al., 2009, p. 462). Finally, the "Rebuilding" stage occurs as women reconstruct the future.

The purpose of our study was to explore women's disclosure of nonlethal fetal anomaly diagnosis to family and friends during pregnancy through postpartum.

Study Design and Methods

Design and Sample

A descriptive, qualitative approach was used to explore women's perceptions of fetal anomaly diagnosis as this approach is indicated when the experience has not been well defined or conceptualized (Polit & Beck, 2021). Inclusion criteria were English-speaking pregnant women 19 years of age or older with a prenatal diagnosis of a nonlethal fetal anomaly based on genetic or ultrasound findings who were receiving care at a fetal center located within an urban pediatric hospital. We used age 19 because the legal age for consent in Alabama is 19 years as required by the Institutional Review Board. Exclusion criteria included pregnant women who were too distressed to participate in an interview. Recruitment of a convenience sample began during prenatal visits at the fetal center. Nurses served as intermediaries for the researcher, providing written study informational flyers to all eligible women in the clinic. After women expressed interest, a screening interview was conducted via phone or in-person by the principal investigator (PI). After obtaining written consent, prenatal interviews were conducted in the last trimester because the expectant woman would have known about the diagnosis for weeks or months and would have more observations. A second interview was conducted postpartum to capture the women's perspectives of the experience over time as they shared their birth experience and subsequent journey with their newborn.

Measures and Procedures

Semistructured interviews were conducted to explore the experiences of expectant women who received a prenatal diagnosis of a nonlethal fetal anomaly. Open-ended questions were developed based on an understanding of clinical practice, the current literature, Lalor's theory, and recognized gaps in knowledge. All prenatal interviews were conducted in person in a private room at the fetal center. Postpartum interviews were conducted between 2 and 11 weeks after birth and held in the neonatal intensive care unit (NICU), cardiovascular intensive care unit, fetal center, or via phone (n = 1) based on participants' choice. Interviews were audio-recorded and ranged from 30 to 90 minutes. All interviews were conducted by the PI between February 2015 and February 2016. They were transcribed verbatim by the PI. Redundancy in themes were noted across the interviews.

Data Analysis

Data were analyzed using thematic analysis that involved first reading the entire interview to get the overall sense of the data, then reading once again to divide into themes and categories, and finally synthesizing the units into the structure of the experience (Polit & Beck, 2021). A preliminary codebook was developed after the first three interviews but evolved with categories added and collapsed with further data analysis. Codes with themes and categories were identified and reflected the experiences of women with fetal anomaly diagnosis during prenatal and postpartum. All interviews were conducted by the PI (maternal–child nursing clinician) and data analyzed in collaboration with the research team that included a qualitative researcher (second author, child health nursing), three nurse practitioners, and a maternal fetal medicine physician. All data coding was done by the PI. To establish credibility, peer debriefing was conducted during data collection and analysis with the research team.

Results

Ten pregnant women with a diagnosis of nonlethal fetal anomaly participated in individual prenatal interviews, and eight of those same women participated in postpartum interviews. All women learned about the prenatal diagnosis in the second trimester (average gestational age at prenatal diagnosis was 20 weeks). The fetal anomaly diagnoses varied and involved the following systems: urology, skeletal, gastrointestinal, neurology, cardiac, and pulmonary. Diagnoses such as gastroschisis and complex heart defect indicated a need for neonatal surgery. However, some women experienced prognostic uncertainty about the need for surgery or length of NICU stay with more to be learned after giving birth. For example, some of the diagnoses such as a renal mass, ventral septal defect, or lung lesion needed further evaluation in the neonatal period to determine if surgical intervention was necessary. The sample was comprised of women ranging in age from 23 to 33 years, Caucasian (70%) and African American (30%) race and ethnicity, with some college education (70%). The majority (60%) were married; 40% were in their first pregnancy. Eight of the 10 newborns were hospitalized in the NICU; five had surgery prior to discharge and three had surgery after NICU discharge.

Themes

The overarching theme, *Pregnancy Forever Changed*, captured the experience when expectant women first heard the news about their fetus having a nonlethal fetal anomaly diagnosis and how their pregnancy was forever changed. Women continued to experience pregnancies that differed from those uncomplicated by fetal anomaly diagnosis for the remainder of the pregnancy and into postpartum. Three themes were identified from the prenatal interviews through content analysis: (1) *News of a Diagnosis, No Going Back;* (2) *A Mother's Response: Managing Information;* and (3) *Words from Others*

Matter. With the postpartum interviews, two themes were identified: (1) *The Journey Continues, Echoing Past Concerns;* and (2) *Not The Journey We Planned.* The focus of this study is the distressing aspect of disclosure to family and friends. Pregnant women verbalized how knowledge about the fetal anomaly diagnosis instantly changed their pregnancy as they learned to live with new information about their fetus. Within the overarching theme, subthemes that were identified from data analysis demonstrated that disclosing the news to others was a significant source of distress for the majority of the women. The distress described about disclosure occurred in a sample of women all experiencing nonlethal fetal anomaly diagnosis. Women described how stressful it was to share the initial news of the fetal anomaly diagnosis. This stress was magnified by the continued sharing of information and disclosure to others following each prenatal visit. Women described still managing information about the fetal anomaly and the stigma associated with disclosure following birth during postpartum.

Prenatal

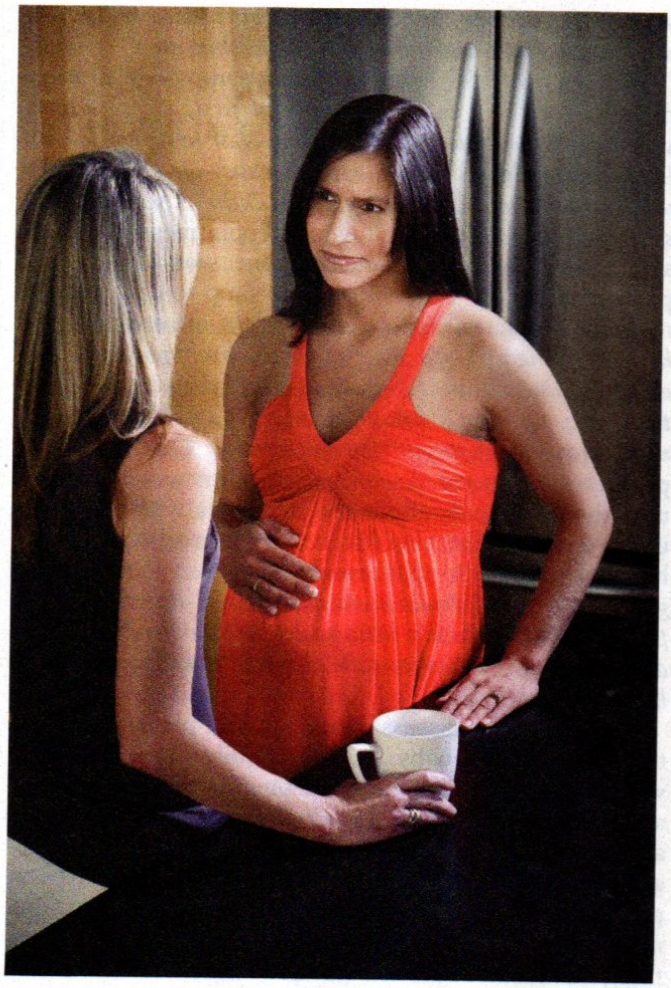
Mother's Response: Managing Information

Following the initial and shocking news of a fetal anomaly diagnosis, the women were often immediately presented with the challenge of receiving complex yet sometimes incomplete information. As women were still processing the news, they were confronted with disclosing this information about fetal health with family and friends. Women described how the words and reactions of friends, family, and clinicians negatively affect their pregnancy. They managed a large amount of new information throughout pregnancy with prenatal care visits and specialty consults with women demonstrating their information preferences and decision-making ability about what specific information to share with friends and family.

Sharing the News. All women described the stressful nature of sharing and disclosing the news of a fetal anomaly diagnosis to friends and family. They described how friends and family did not understand the fetal anomaly diagnosis. The response to disclosure of the diagnosis was stressful when friends or family members either minimized the importance of the diagnosis or assumed the prognosis was much worse than it was.

Women carefully chose to whom and what to reveal, with some disclosing the news only to close family members or a trusted friend. The cost of disclosure added to women's emotional pain and was eloquently described. One woman felt social stigma as she described that people *looked at her differently* once the news of the diagnosis spread at her church and among her friends and described feeling *That made things worse. So, I did stay home for three weeks.* The women expressed how difficult it was to share information about the diagnosis while still trying to understand the diagnosis themselves. For example, one woman stated *Because I didn't really want to share and not know what I was talking about... And then of course, we were trying to have time to process it ourselves... they want to ask you a lot of questions, and I didn't know if I could handle all the questions at that point.* Along with not wanting to be peppered with questions, the women expressed not wanting to be questioned when they did not have answers as one woman explained, *you have people asking you – well what's the update and how is he doing...But at first when they were asking questions...you're kind of I just don't know, I don't know how to answer that question, that was...difficult.*

The women expressed frustration when they felt the diagnosis and/or prognosis was not understood, as one woman described, *I don't know if they all really understood how really serious it could have been.* Women acknowledged that they felt like people meant well, as one



This study explored women's experiences in disclosing nonlethal anomaly diagnosis with family and friends prenatally and postpartum.

woman stated, *people make comments like...I know you mean well, but I just wish you would shut up.*

Women made deliberate choices about whom to share news about their baby. *Probably at first, we just told, you know, our parents and siblings...at first, we wasn't [sic] really telling a lot of people because we didn't know what to tell them... at first, we just didn't know what to say, what to tell them.* Following appointments with obstetric and pediatric specialists, one woman and her partner went to a local snow cone shop to discuss how to share the news. *Yes, so we thought we are going to have to come up with a way to tell them and not everyone freak out about it. So, we just told them this is what they saw, and we'll know more next week, there's no need to panic or anything right now....* Describing her progression toward disclosure, another woman noted that she could talk about the diagnosis without being upset, stating that she felt it was more helpful than harmful to talk. *So that was hard at first, but once we got answers and could kind of break it down and explain it, that made it a little easier to explain it and give answers.... It's easier to talk about it than leaving it all bundled up inside.*

Many women discussed one specific person, such as the father of the baby or close family members, with whom they could freely share their feelings and news about the baby. Women explained how they deliberately and continually made decisions about disclosure to manage the information about the fetal anomaly and their pregnancy. Women made conscious decisions about how much to share and when to protect themselves from further painful comments.

Postpartum

Not the Journey We Planned

During the postpartum interviews, the women revealed that managing and sharing news about the newborn continued as part of their journey as they coped with additional information regarding the newborn's condition.

Still Managing News about the Baby. Following birth, the women were faced with friends and family wanting to know more information about their newborn. These women discussed how they managed sharing information and making decisions about what they shared. *It was nice to know that everybody cared ...we were trying to call and text people, but I did eventually put stuff on Facebook... It was too hard to try to call everybody.* Another woman described their process for managing news about their newborn. *We would just kind of update, usually once a day or... and we kept up with our church through an email system...that cuts down on your phone calls 'cuz [sic]... we were there to focus on her and talk with doctors and all those things. So, letting people know what's going on...worked good [sic], and they could spread the word for anyone else that needed to know.* As noted during the prenatal period, some people could be both supportive and hurtful simultaneously. The women demonstrated selective disclosure as seen in behavior associated with stigma. For example, one woman was being protective by not telling many people but found it painful when people minimized the diagnosis. *I kind of didn't tell many, many people. The people that I did tell, they've been supportive, real supportive now. I think it's just they don't understand. I know I had never heard of it before and most people, "Yeah, my cousin was born with a little hole, she's going to be ok"... No, that's not that. My baby had to have surgery at 6 days old, you don't understand that.*

These women's experiences highlighted how they managed disclosure of sensitive information about the nonlethal fetal anomaly diagnosis that continued from the time of prenatal diagnosis into postpartum. Several women commented that meeting other NICU mothers who understood their journey was helpful. One woman had discovered a support group on social media that was supportive.

Discussion

It is well documented in the literature and in clinical practice that maternal disclosure of a lethal diagnosis to others is a stressful and difficult experience throughout pregnancy for women (McKechnie et al., 2015; Smith et al., 2013). However, the experience of women disclosing a nonlethal diagnosis has not been recognized or has been minimized as a significant distressing aspect of the prenatal and postpartum experience. Our research team with extensive experience in high-risk obstetrics did not understand that disclosing to others was as distressing for women with nonlethal fetal anomalies until these qualitative data provided more insight into their experience. It may be that maternal distress related to disclosure of nonlethal diagnoses is not recognized as a distressing part of the prenatal experience because much of the prenatal visit discussion centers on pregnancy management, birth decisions, meeting pediatric specialists, and the neonatal course. Perhaps women experiencing a lethal fetal anomaly diagnosis receive greater attention and assessment of their emotional state and coping during prenatal visits. Although it is easily understood by clinicians that any women would experience a sense of grief and loss of the healthy child on learning of any fetal anomaly diagnosis, the distressing aspects of disclosure may be a universal experience for all women experiencing a fetal anomaly diagnosis, regardless of severity or prognosis.

In our study, sharing the news of a fetal anomaly diagnosis was initially distressing as well as aspects of disclosure and the accompanying distress and stigmatization that continued throughout the pregnancy and into postpartum. Women described vividly negative responses from others and the ongoing management of information as being stressful and painful. They identified the social stigma they felt when they described not feeling heard and feeling different from other expectant women. Maternal response to disclosure of a nonlethal fetal anomaly to others in this study was similar to the maternal response of lethal fetal anomaly diagnosis reported in the literature (McKechnie et al., 2015; Smith et al., 2013).

Providing anticipatory guidance to woman may help them share the prenatal diagnosis with others. Clear, easy-to-understand information should be provided so women are able to share information if they desire.

Women reported not sharing a lethal fetal anomaly diagnosis or its severity to avoid uncomfortable interactions and further questions as well as intentionally adjusting their social circles (Smith et al., 2013). Most women in this study stated that sharing the news was a stressful, negative, and distressing aspect of their pregnancy, a pregnancy forever changed and that the distress related to disclosure continued into postpartum.

The similarities in the women's descriptions of their experiences in this study support Lalor's *Recasting Hope Theory* (Lalor et al., 2009), extending development of the theory. Women's description of the distress related to the initial news about the diagnosis were consistent with Lalor et al. (2009). In contrast, the most significant finding in this study was the distressing aspect of disclosure to others. This finding of how disclosure to others creates additional distress extends Lalors' theory as another important aspect of the women's adaptation following fetal anomaly diagnosis (Lalor et al., 2009). Women decide how to initially disclose the news and they must also manage disclosure while handling negative responses from others.

In studies with women experiencing a nonlethal prenatal diagnosis, stigma has been rarely identified; however, the women in this study exhibited some aspects of stigma as soon as they began disclosing the news to others. Whether the response was minimizing the news or making it worse than what it was, the result was misunderstanding the experience, which was the beginning of stigmatization. Although still processing the fetal anomaly news, women experienced isolation and made deliberate choices about disclosure which was consistent with the findings of other researchers (Hickerton et al., 2012; Lalor et al., 2009; McKechnie et al., 2015). For diagnoses that are considered invisible to the public, individuals with the stigmatizing disorder may exhibit nondisclosure, prevent disclosure, or use protective disclosure (Engebretson, 2013; Goffman, 1963). Similarly, the women in this study expressed feeling misunderstood, isolated, and perceived differently or stigmatized as they described the distress of decision-making on disclosure about their pregnancy with fetal anomaly diagnosis. Several women expressed concerns about their infant being viewed as different. Although some infants with nonlethal fetal anomaly diagnosis may have very positive outcomes following surgery and/or treatment, the mother is still experiencing a different prenatal and postpartum course. In acknowledging hope and positive prognoses, it is still important to acknowledge that women with nonlethal prenatal diagnosis may experience aspects of stigma following disclosure to others.

Although there have been limited descriptions of the negative aspects of disclosing news of a nonlethal fetal anomaly diagnosis to others during pregnancy, the findings about maternal disclosure during postpartum have been lacking. Using the search terms in the database PubMed between 2012 and 2022, "NICU," "maternal experience," "congenital anomaly," "NICU mothers," and "disclosure" scant information related to aspects related to disclosure was found. In one study with NICU mothers of preterm infants, the mothers found it difficult to relate to friends and family who didn't understand (Rossman et al., 2015). Clearly, aspects related to disclosure and sharing news that marked a pregnancy as forever changed due to a fetal anomaly diagnosis continued into postpartum. While recuperating from birth with their newborn hospitalized, women still managed disclosure of information about their newborn. Negative comments and not feeling understood continued to cause distress to the women during postpartum. Continuation of women's distress into postpartum provides indication for ongoing assessment and intervention.

Clinical Implications

Research has identified a women's distress about disclosure to others of a lethal fetal anomaly. This study provides new evidence that disclosure of a nonlethal fetal anomaly diagnosis may also be distressing. If as our findings suggest, all pregnant women with any type of fetal anomaly diagnosis may experience distress about disclosure to family and friends throughout pregnancy and postpartum, then support and anticipatory guidance should be part of their care. When women received the news of a fetal anomaly diagnosis, their experience was affected by sharing the diagnosis, answering questions, and managing information for the remainder of the pregnancy and into postpartum. For women in our study, it is noteworthy that the distress related to disclosure was unrelated to parity, age, educational level, or fetal anomaly diagnosis. This evidence is important to clinical practice for providing anticipatory guidance. Anticipatory guidance on how to share the news and make decisions about managing disclosure of information to others will provide strategies for women coping with managing fetal anomaly diagnosis. Women should receive support from experienced high-risk nurses on how to manage information with others and be provided disclosure strategies that have worked for other women. Information should

CLINICAL IMPLICATIONS

- Listen to expectant women's worries and concerns about nonlethal fetal anomaly diagnosis to identify needs and plan care throughout the continuum of pregnancy, postpartum, and neonatal care.
- Identify increased information needs from the point of diagnosis and continuing into postpartum and neonatal care for expectant women with a prenatal diagnosis of a nonlethal fetal anomaly.
- Identify a woman's information preference style to meet information and education needs in her preferred mode of birth. Provide clear, easy-to-understand information for women to share with family and friends.
- Provide anticipatory guidance to assist women in decision-making about disclosure to others about the nonlethal prenatal diagnosis. Provide support for women as they make the best decisions on how to manage information.
- Create support groups for women and their partners with other parents of infants with fetal anomaly to share strategies that have worked for others.
- Assess the impact of distress related to disclosure during pregnancy on women's mental health and the potential for postpartum depression.
- Build in time into prenatal visits to assess, meet increased information needs, and provide specific anticipatory guidance about disclosure to others.
- Provide hope for the future about their child's abilities and quality of life.
- Provide anticipatory guidance about the newborns' care needs.

be provided that meets individual needs so women are able to share information if they desire. Information provided should meet patient preferences whether in the form of written material, pictures, or reputable internet resources (Loyet et al., 2016). Increased education must begin with the initial fetal anomaly diagnosis and continue throughout the journey when new information about the baby is learned during the neonatal period. By assessing the needs related to disclosure for all women experiencing a fetal anomaly diagnosis, nursing care can be individualized and patient-centered to improve maternal coping ability. ✣

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References

Almli, L. M., Ely, D. M., Ailes, E. C., Abouk, R., Grosse, S. D., Isenburg, J. L., Waldron, D. B., & Reefhuis, J. (2020). Infant mortality attributable to birth defects- United States, 2003-2017. *MMWR. Morbidity & Mortality Weekly Report, 69*(2), 25–29. https://doi.org/10.15585/mmwr.mm6902a1

Cote-Arsenault, D., & Denney-Koelsch, E. (2011). "My baby is a person": Parents' experiences with life-threatening fetal diagnosis. *Journal of Palliative Medicine, 14*(12), 1302–1308. https://doi.org/10.1089/jpm.2011.0165

Engebretson, J. (2013). Understanding stigma in chronic health conditions: implications for nursing. *Journal of the American Association of Nurse Practitioners, 25*(10), 545–550. https://doi.org/10.1111/1745-7599.12009

Goffman, E. (1963). *Stigma: Notes on the management of the spoiled identify.* Simon & Schuster Inc.

Greene, M., Copel, J., Silver, R., Resnik, R., Lockwood, C., & Moore, T. (2019). *Creasy and Resnik's maternal fetal medicine* (8th ed.). Elsevier Sanders.

Hickerton, C. L., Aitken, M., Hodgson, J., & Delatycki, M. B. (2012). "Did you find that out in time?": New life trajectories of parents who choose to continue a pregnancy where a genetic disorder is diagnosed or likely. *American Journal of Medical Genetics. Part A, 158A*(2), 373–383. https://doi.org/10.1002/ajmg.a.34399

Hutti, M. H. (2005). Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 34*(5), 630–638. https://doi.org/10.1177/0884217505279998

Lalor, J. G., Begley, C. M., & Galavan, E. (2008). A grounded theory study of information preference and coping styles following antenatal diagnosis of foetal abnormality. *Journal of Advanced Nursing, 64*(2), 185–194. https://doi.org/10.1111/j.1365-2648.2008.04778.x

Lalor, J., Begley, C. M., & Galavan, E. (2009). Recasting Hope: A process of adaptation following fetal anomaly diagnosis. *Social Science and Medicine, 68*(3), 462–472. https://doi.org/10.1016/j.socscimed.2008.09.069

Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: the challenge of ambiguity and disenfranchised grief. *Omega (Westport), 63*(2), 183–196. https://doi.org/10.2190/OM.63.2.e

Lou, S., Jensen, L. O., Petersen, O. B., Vogel, I., Hvidman, L., Moller, A., & Nielsen, C. P. (2017). Parental response to severe or lethal prenatal diagnosis: A systematic review of qualitative studies. *Prenatal Diagnosis, 37*(8), 731–743. https://doi.org/10.1002/pd.5093

Loyet, M., McLean, A., Graham, K., Antoine, C., & Fossick, K. (2016). The Fetal Care Team: Care for pregnant women carrying a fetus with a serious diagnosis. *MCN. The American Journal of Maternal Child Nursing, 41*(6), 349–355. https://doi.org/10.1097/NMC.0000000000000278

McKechnie, A. C., Pridham, K., & Tluczek, A. (2015). Preparing heart and mind for becoming a parent following a diagnosis of fetal anomaly. *Qualitative Health Research, 25*(9), 1182–1198. https://doi.org/10.1177/1049732314553852

Polit, D., & Beck, C. (2021). *Essentials of nursing research: Appraising evidence for nursing practice* (10th ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.

Rossman, B., Greene, M. M., & Meier, P. P. (2015). The role of peer support in the development of maternal identity for "NICU Moms". *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 44*(1), 3–16. https://doi.org/10.1111/1552-6909.12527

Simo, S., Zuniga, L., Izquierdo, M. T., & Rodrigo, M. F. (2019). Effects of ultrasound on anxiety and psychosocial adaptation to pregnancy. *Archives of Women's Mental Health, 22*(4), 511–518. https://doi.org/10.1007/s00737-018-0918-y

Smith, S. V., Dietsch, E., & Bonner, A. (2013). Pregnancy as public property: The experience of couples following diagnosis of a foetal anomaly. *Women & Birth, 26*(1), 76–81. https://doi.org/10.1016/j.wombi.2012.05.003

Wool, C. (2013). State of the science on perinatal palliative care. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 42*(3), 372–382; quiz E54–E55. https://doi.org/10.1111/1552-6909.12034