Continuing A Pregnancy Following A Fetal Anomaly Diagnosis

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THESIS
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SUMMARY

A qualitative descriptive study was conducted to describe the experiences of pregnant women who continued pregnancy after a fetal anomaly diagnosis. The investigator also sought to explore the nature of the support provided by healthcare providers and the extent to which it met the pregnant woman’s needs and expectations as they continued their pregnancy and prepared for the birth of their baby. A total of ten pregnant women who were diagnosed with a fetal anomaly participated in the study. The women were interviewed twice during their pregnancy using probes and open-ended questions in order to elicit descriptions of their experiences. At the time of the first interview, the women also completed an obstetric-demographic questionnaire.

Continuing a pregnancy following a fetal anomaly diagnosis was fraught with uncertainty and changing expectations for the women in this study. The fetal anomaly diagnosis profoundly impacted the pregnancy experiences of the women. This experience is a complex phenomenon represented through four major themes: (a) becoming vulnerable, (b) navigating the diagnosis, (c) connecting with the baby, and (d) interacting with healthcare providers.

Interactions with healthcare providers significantly impacted the pregnancy experiences of women who continued pregnancy after a fetal anomaly diagnosis. Caring interactions with healthcare providers helped decrease the women’s fear, stress and anxiety and facilitated their coping with the fetal anomaly diagnosis as they continued their pregnancies and prepared for the birth of their babies. Caring was demonstrated through the healthcare provider’s communication, availability, anticipatory guidance related to the fetal anomaly, encouragement, and congruence with a pregnant women’s needs and expectations.
SUMMARY (continued)

However, uncaring interactions did not help to lessen the pregnant women’s psychological burden nor help them as they continued their pregnancy and prepared for the birth. Interactions which were considered uncaring and thus not meeting the women’s needs were the lack of anticipatory guidance related to the emotions and childbirth (primigravidae), not addressing emotional needs, and lack of congruence between the women’s focus and the healthcare provider’s focus. The uncaring interactions contributed to not meeting the women’s needs and expectations.
I. INTRODUCTION

The incidence of fetal anomalies present at birth in the United States (U.S.) is estimated to be from 3% (Center for Disease Control [CDC], 2015) to 5% (O’Leary et al., 2006) with evidence to suggest that this incidence may increase due to the trend in delaying childbearing (Mathews & Hamilton, 2014) and an increased rate of diabetes (CDC, 2013). However, advances in prenatal testing techniques have made it possible to identify a fetus with certain structural or chromosomal anomalies during pregnancy and prior to birth. After a fetal anomaly is discovered, the pregnant woman may be faced with making a decision about whether to continue or terminate her pregnancy. Some may choose to continue the pregnancy. Although there are several studies exploring the experiences of pregnant women who terminate their pregnancies after a fetal anomaly diagnosis, there are limited studies about the experiences of those who decide to continue their pregnancy (Chaplin, Schweitzer, & Perkoulidis, 2005; Edwins, 2000; Hedrick, 2005; Hoeldtke & Calhoun, 2001; Lalor, Begley, & Galavan, 2009; Nusbaum, Grubs, Losee, Weidman, Ford, & Maritza, 2008; Statham, Solomou & Chitty, 2000; Walker, Miller, & Dalton, 2008). The majority of the continuation studies focus on the woman’s reaction to the diagnosis, factors influencing her decision to terminate or continue the pregnancy, and coping strategies. However, there is a paucity of research related to the support and guidance given by healthcare providers to the pregnant woman after she decides to continue her pregnancy, including preparing for the birth. Since healthcare providers may provide care to women who continue pregnancy after a fetal anomaly diagnosis, it is essential that more research be conducted in this area in order to inform and guide practice.
A. **Background**

“Fetal anomaly” is a term used to describe a fetus that is not developing normally (Farrell, 2006) resulting in structural or functional aberrations (WHO, 2014). Some fetal anomalies are considered serious implying that there will be long-term morbidity or that the anomalies will be lethal (Evans et al., 1996, Pryde, Drugan, Johnson, Isada, & Evans, 1993). Lethal anomaly refers to an anomaly that is fatal (Munson & Leuthner, 2007); not amenable to intervention (Hoeldtke & Calhoun, 2001; Sahin & Gungor, 2008); diminishes the ability to survive after birth (Chervenak & McCullough, 1990; Hunfield, Wladimiroff, & Passchier, 1997) and results in a fetus being stillborn or dying within the first month of life (Wapner, Jenkins & Khalek, 2009). There are researchers who use the term “life-limiting” interchangeably with “lethal” (Munson & Leuthner, 2007; Ramer-Chrastek & Thygeson, 2005). Yet, there are others who advocate using the term “life-limiting” because some children with anomalies designated as “lethal” can survive past infancy with treatment (Koogler, Wilfond, & Ross, 2003). Although “life-limiting” or “life-threatening” is a term that has been gaining popularity in the U.S., studies in other countries continue to use the term “lethal” when reporting their findings.

B. **Fetal Anomaly Categories**

Statham et al. (2003), researchers from the United Kingdom, proposed categorization of fetal anomalies based on potential outcomes. They recognized five categories of fetal anomaly outcomes: “lethal, non-correctable with moderate to severe disability, non-correctable with uncertain long term effects, uncertain prognosis, and treatable with varying degrees of associated risk” (p. 165). Anencephaly is an example of a lethal anomaly. It is considered lethal because the forebrain is missing and the majority of babies die soon after birth (CDC, 2014).
Limb reduction is a non-correctable anomaly with moderate to severe disability; limb reduction can involve a missing or reduced upper and/or lower limb which can compromise mobility (CDC, 2014). Klinefelter syndrome is considered a non-correctable anomaly with uncertain long-term effects. Klinefelter syndrome is characterized by abnormalities in physical development and varying degrees of cognitive impairment (National Institutes of Health, 2015). An anomaly with an uncertain prognosis is exemplified by pelviectasis which refers to dilation of the renal pelvis. This prenatally detected anomaly resolves in 20 to 50% of the cases by the time the subsequent post-natal ultrasound is performed; those that are unresolved may require surgical intervention (Gabbe, Niebyl, & Simpson, 2012). The final category, treatable with varying degrees of associated risk, refers to the risk related to the surgical intervention required to treat the anomaly (Statham et al., 2003). An example of this category is diaphragmatic hernia, a condition in which the abdominal organs have migrated into the chest cavity through an opening in the diaphragm (Gabbe et al., 2012); the surgery required for the diaphragmatic hernia repair may be less risky than the repair of certain cardiac defects which require multiple or more extensive surgical intervention (Statham et al., 2003).

Leuthner (2004), an American proponent of neonatal palliative care, categorized fetal anomalies in terms of degree of diagnostic and prognostic certainty. He suggested using these categories to identify appropriate candidates for palliative care. The three categories identified are as follows: diagnostic and prognostic certainty, diagnostic uncertainty and prognostic certainty, and prognostic uncertainty and best interest. A fetal anomaly exemplifying diagnostic and prognostic certainty is anencephaly. This type of anomaly is readily diagnosed (Gabbe et al., 2012) and the associated prognosis is certain (CDC, 2014). Bilateral renal agenesis with unknown etiology is an example of diagnostic uncertainty and prognostic certainty.
Although the diagnosis is not known at the time the oligohydramnios or anhydramnios and pulmonary hypoplasia are identified, these ominous findings place the fetus at risk (Leuthner, 2004). Prognostic uncertainty and best interest anomalies are non-lethal anomalies whose treatment may be considerably onerous and thus a decision regarding what is in the best interest of the baby is required. An example of this category is a fetus/baby with multiple severe anomalies such as hypoplastic left heart, spinal muscular atrophy, and hydrocephalus. These conditions can be treated, but the prognosis is uncertain and the treatment would be taxing (Gabbe et al., 2012).

C. **Incidence**

In the U.S., the incidence rate of fetal anomalies is estimated to be 3% (CDC, 2015) to 5% (O’Leary et al., 2006). However, this incidence rate is based on anomalies identified at birth; this rate does not take into account fetuses with anomalies that were aborted, spontaneously or intentionally or stillborn with anomalies (CDC, 2015). There are deficiencies in the tracking of fetal death data (MacDorman & Kirmeyer, 2009). Most states only report fetal death information for the fetus who is 20 weeks or greater even though it is recognized that the majority of fetal deaths occur earlier in gestation (MacDorman & Kirmeyer, 2009). It is also well known that fetal chromosomal anomalies are considered the primary cause of spontaneous abortion (Lentz, Lobo, Gershenson, & Katz, 2012). Data regarding the reasons for pregnancy termination are also not collected (MacDorman & Kirmeyer, 2009). Only 12 anomalies are tracked through birth and fetal death certificates, five of which were added when the certificates were revised in 2003 (Osterman, Martin, Mathews, & Hamilton, 2011).
Just over half of the states have implemented the revised certificates and some did so five years after the revision was available for use (Osterman et al., 2011). Thus, the actual incidence of fetal anomalies may be underestimated due to incomplete data tracking and reporting mechanisms.

Lethal anomalies occur in 0.2% to 0.3% of babies born in the U.S. (D’Almeida, Hume, Lathrop, Njoku, & Calhoun, 2006). There are several recognized lethal fetal anomalies including chromosomal defects such as trisomy 13 and 18 (Crider, Olney & Cragan, 2008; Ki, Kim, & Lee, 2009; Leuthner, 2004) and neural tube defects such as anencephaly (Leuthner, 2004). Trisomy 13, trisomy 18, and anencephaly were reported as the congenital defects most commonly associated with in-hospital deaths (Morbidity and Mortality Weekly Report [MMWR], 2007). Moreover, fetal anomalies are implicated in the majority of deaths that occur during the infancy period (Howard, 2006; Leuthner, 2004b; Mai et al., 2007; Miquel-Vargas et al., 2009). In addition to chromosomal and central nervous system defects, lethal anomalies can include structural anomalies of the kidney and heart such as polycystic kidneys and acardia (Leuthner, 2004). Certain musculoskeletal anomalies, such as congenital diaphragmatic hernia with hypoplastic lungs, may be severe enough to be lethal (Leuthner, 2004a). The rate of anencephaly was reported as 13.8 for every 100,000 births in the United States (Osterman et al., 2011). Trisomy 13 (Patau syndrome) and trisomy 18 (Edwards syndrome) occur less frequently than Trisomy 21; the rate of trisomy 13 was reported as occurring in 7 out of every 100,000 births and trisomy 18 in 14 out of every 100,000 births (Mai et al., 2013).
However, there may be inaccuracies in the reported incidence rates of trisomy 13 and trisomy 18 may because they are not currently tracked nationally through birth or fetal death certificate data (Osterman, et al., 2011) and pregnancies affected by chromosomal anomalies may end in spontaneous abortion (Lentz, Lobo, Gershenson, & Katz, 2012). Therefore, the incidence of lethal anomalies may also be underestimated.

D. Tracking of Fetal Anomalies

The CDC provides incidence rates for select central nervous system, ocular, cardiovascular, orofacial, gastrointestinal, musculoskeletal, and chromosomal anomalies. The following specific congenital anomaly incidence rates are reported: anencephaly, spina bifida, encephalocele, anophthalmia/microphthalmia, common truncus, transposition of great arteries, tetralogy of fallot, arteriovenricular septal defect, hypoplastic left heart syndrome, cleft palate without cleft lip, cleft lip with and without cleft palate, esophageal atresia/tracheoesophageal fistula, rectal and large intestinal atresia/stenosis, reduction deformity, upper limbs, reduction deformity, lower limbs, gastroschisis, omphalocele, diaphragmatic hernia, trisomy 13, trisomy 21, and trisomy 18. Among the structural fetal anomalies, the most common category is congenital cardiac anomalies (CDC, 2014). Cardiac anomalies occur in 8 out of every 1000 live-births (Sklansky, 2009). Trisomy 21 is the most common chromosomal anomaly identified in liveborn infants (CDC, 2014). However, the data are derived from only 14 state CDC-funded birth defects surveillance programs (CDC, 2014). Therefore, the data may not be representative of the larger population and subsequently the incidence rate may be inaccurate.
Although the CDC has facilitated the tracking of major congenital anomalies since 1978, the tracking has many limitations; not all states participated in tracking the data and there was variation in how the data was obtained in different states as well as which anomalies were tracked (Rynn, Cragan, & Correa, 2008). The National Birth Defects Prevention Network (NBDPN), an organization who collaborates with the CDC in tracking of congenital anomalies, defined major congenital anomaly as an anomaly requiring medical or surgical intervention and which negatively impacts the wellbeing of an individual (NBDPN, 2004). There were no federal mandates requiring tracking of congenital anomalies until 1998, when the Birth Defects Prevention Act was passed (CDC, 2009). However, limitations in tracking anomalies continue; thus, the true incidence of fetal anomalies may remain unknown (Boulet, Correa-Villasenor, Hsia, & Atrash, 2006).

The European Union also has a congenital anomaly tracking system known as the European Surveillance of Congenital Anomalies (EUROCAT). The EUROCAT collects data on 90 anomalies from live births, stillborns, and elective abortions (EUROCAT, 2012). Therefore, the EUROCAT provides more accurate prevalence of anomalies than the CDC because more anomalies are tracked and the anomalies also include those identified from fetal deaths and terminations of pregnancy. However, similar to its American counterpart, not all countries in Europe participate in this tracking system (Loane, Dolk, Garne, Greenless, & EUROCAT Working Group, 2011). Therefore, the true incidence of fetal anomalies in the European Union may also remain unknown.
E. **Prenatal Screening**

Prenatal screening for fetal anomaly has become a standard component of prenatal care in the United States as well as in many other nations (Bryar, 1997; Chaplin, Schweitzer & Perkoulidis, 2005; Lalor & Begley, 2006; Rapp, 1999; Sandelowski & Barroso, 2005; VanPutte, 1988). Even pregnant women considered at low risk for fetal anomaly, can expect to be offered this during their pregnancy. As a result, more fetal anomalies may be identified during pregnancy instead of at birth (Hunfield, Wladmiroff, & Passchier, 1997; Hunfield, Wladmiroff, Passchier, Venema-Van Uden, Frets, & Verhage, 1993; Menahem & Grimwade, 2005; Lalor, Devane, & Begley, 2007; Miquel-Vargas, Woods, Aucott, Boss, Sulpar, & Donahue, 2009; VanPutte, 1988).

Previously, prenatal testing for aneuploidy was only offered to women who were considered at high risk for fetal anomaly. Women at high risk for anomalies included women 35 years old or more and those with a history of chromosomal aberration (ACOG, 2007). However, with the availability of serum biomarkers in the mid 1980’s, there has been a gradual move to screen all women, regardless of risk (Cunningham et al., 2014). Serum biomarkers and more recent advances in sonographic markers are deemed to have high accuracy in identifying increased risk for aneuploidy (Cunningham et al., 2014). Pregnant women with increased risk identified through screening are offered further evaluation which may include invasive testing (Cunningham et al., 2014). Based on the high accuracy of detecting aneuploidy, in 2007, the ACOG issued a recommendation to offer screening to all pregnant women for chromosomal anomalies prior to the 20th week of pregnancy (ACOG, 2007).
The ACOG recommendation and advances in prenatal screening techniques have contributed to a propagation of prenatal screening in the United States. Advances in prenatal screening including the availability of screening in early gestation (ACOG, 2007), and less invasive (ACOG, 2007) and safer techniques (Pryde, Drugan, Johnson, Isada, & Evans, 1993), may have also contributed to the proliferation of screening even among women not considered high risk.

The Royal College of Obstetricians and Gynaecologists (RCOG) also supports screening for fetal anomaly (RCOG, 2000 & 2009). The RCOG published and provides a web link to the antenatal guidelines developed by the National Collaborating Centre for Women's and Children's Health (RCOG, 2008). These guidelines recommend an ultrasound for fetal anomaly screening be performed at 18 to 20 weeks gestation. It is also recommended to offer combined screening (nuchal translucency, β- human chorionic gonadotropin [hCG]), pregnancy-associated plasma protein A (PAPP-A) for trisomy detection between 11 weeks and 13 6/7 weeks gestation. Women who did not undergo combined screening should be offered a triple or quadruple serum screen between 15 and 20 0/7 weeks gestation (RCOG, 2008).

1. **First trimester screening**

Prenatal detection of anomalies involves performing a screening or diagnostic test. Screening tests are used to detect aneuploidy and provide an individualized risk for aneuploidy (ACOG, 2007). These tests are fairly non-invasive requiring a maternal blood sample and/or an ultrasound examination. Some tests, such as nuchal translucency, can be performed as early as the first trimester (ACOG, 2007; Kagan, Avgidou, Molina, Gajewska, & Nicolaides, 2006). Nuchal translucency refers to an ultrasound evaluation of the amount of fluid accumulated behind the fetal neck (Kagan et al., 2006).
An increased amount of fluid can indicate anomalies, including those chromosomal or structural in nature (Beamer, 2001). Nuchal translucency and biochemical markers (PAPP-A, free or total β- human chorionic gonadotropin [hCG]) are measured between 10 4/7 and 13 6/7 weeks gestation. This test can detect trisomy 21 with an 82% to 87% accuracy rate (Malone et al., 2005); it also can identify other aneuploidies such as trisomy 18 (ACOG, 2007; Kagan et al., 2006). In the search for improved aneuploidy detection rates, other biochemical markers are being tested. Some of the other biochemical markers being evaluated in studies include a disintegrin and metalloprotease 12 (ADAM12), total hCG, placental protein13 (PP13), and placental [PIGF] (Koster, Wortelboer, Stoutenbeek, Visser, & Schielen, 2011). A more recent screening tool that has become available utilizes fetal cell free DNA (ACOG, 2012; & RCOG, 2014), obtained from a blood sample from the pregnant woman, to detect aneuploidy, trisomy 21 and 18; it is reported to have 100% sensitivity and 99.97% specificity for detecting trisomy 21 and 97.4% sensitivity and 99.93% specificity for detecting trisomy 18 (Sparks et al., 2012). It may be offered to women at high risk for aneuploidy starting at the tenth week of gestation or may be used later if other prenatal screens were positive (ACOG, 2012).

2. Second trimester screening

In the second trimester, two other screening tests are available, the triple screen (maternal serum alpha-feto protein [MSAFP], hCG, unconjugated estriol) and quadruple screen (MSAFP, hCG, unconjugated estriol, inhibin A). These biochemical markers are used in the detection of aneuploidy and neural tube defects (Wapner et al., 2009). The reported detection rates (DR) for trisomy 21 are 69% with a triple screen test and 81% with the quadruple screen (Malone et al., 2005).
However, the quadruple screen is not used for the detection of trisomy 18 because inhibin A is not used for risk assessment determination (ACOG, 2007). Information related to the detection rates for trisomy 13 and trisomy18 were not available in the literature.

Several large, multicenter studies have conducted research in order to evaluate different aneuploidy screening approaches (Malone et al., 2005; Wald, Rodeck, Hackshaw, Walters, Chitty, & Mackinson, 2003; & Wapner et al., 2003). Notable among the studies were the First Trimester Maternal Serum Biochemistry and Fetal Nuchal Translucency Screening Study Group (BUN), First and Second Trimester Evaluation of Risk Research Consortium (FASTER), and Serum, Urine and Ultrasound Screening Study (SURUSS) studies. The BUN study demonstrated that combined first trimester screening for aneuploidy utilizing nuchal translucency, PAPP-A, and β- hCG (79% DR at a 5% FPR) was comparable to second trimester screening [65%DR at a 5% FPR] (Wapner et al., 2003). However, the researchers in the FASTER study established that combined first trimester screening (87% DR, 5% FPR at 11 weeks) was superior to second trimester screening (81% DR); moreover, the FASTER study results revealed that stepwise sequential screening (95% DR) and integrated screening (96% DR) have high detection rates with low false positive rates [5%] (Malone et al., 2005). Sequential screening refers to the screening performed at designated times during gestation (first and second trimesters) and the results are given to the pregnant woman following each test Malone et al., 2005). An integrated test was defined as screening performed at designated gestational times (first and second trimesters) with only a single result is provided after all testing is completed (Malone et al., 2005).
Lastly, in the SURUSS study, Wald et al. (2003) reported that the integrated test provided an 85% detection rate with a 1.2% false positive rate. These large multicenter studies have demonstrated the efficacy of non-invasive approaches in determining the pregnant woman’s risk for aneuploidy.

F. **Invasive Testing**

If the pregnant woman is identified as being at high risk for aneuploidy through screening, diagnostic testing may be warranted. Tests available to diagnose chromosomal abnormalities include chorionic villi sampling (CVS) and amniocentesis. The CVS test is performed between 10 to 13 weeks gestation; in this procedure, placental cells are obtained through a needle that is introduced through the cervix or abdomen (Wapner et al., 2009). An amniocentesis, is generally performed between 15 and 18 weeks gestation; in this procedure, some amniotic fluid is extracted from the amniotic sac via a needle that transverses the uterus through the abdominal wall (Wapner et al., 2009). However, both CVS and amniocentesis carry the risk of fetal loss of 0.25% when performed by an experienced physician (Gabbe et al., 2012). Ultrasound can also serve as a diagnostic tool by visualization of the anomaly or absence of organs associated with specific anomalies (Ki et al., 2009). The sensitivity of ultrasonography in identifying an anomaly is related to the skill of the sonographer, fetal gestational age when the ultrasound is performed, and the type of anomaly (Gabbe et al., 2012).
G. **Significance**

The incidence of fetal anomalies present at birth in the United States (U.S.) is estimated to be from 3% (Center for Disease Control [CDC], 2015) to 5% (O’Leary et al., 2006) with evidence to suggest that this incidence may increase due to the trend in delaying childbearing (Mathews & Hamilton, 2014) and an increased rate of diabetes (CDC, 2013). The Centers for Disease Control (CDC) reported a nine-fold increase in first births among women in their mid-thirties and beyond than there were 40 years ago (Mathews & Hamilton, 2014). Additionally, from 2008 to 2009, there was a 3% increase in births to women in the 40 to 44 age group (Kochanek, Kirmeyer, Martin, Strobino, & Guyer, 2012). Hamilton, Martin, Osterman, and Curtin (2014) reported that the birth rate for women in their early forties has been increasing by two percent every year since the year 2000. It is well known that the possibility of fetal anomalies related to chromosomal aberrations increases with maternal age (Leon, 1995; Mathews & Hamilton, 2014; O’Leary et al., 2006). In addition to this phenomenon, the rate of obesity in the U.S. has been increasing; the CDC estimated that approximately one out of every three adults is considered obese (CDC, 2014). Maternal obesity and its associated pre-gestational and gestational diabetes have been implicated in an increase in the incidence of fetal anomalies (Biggio, Chapman, Neely, Cliver, and Rouse, 2010; Castro & Avina, 2002). Therefore, pregnant women may find out during their pregnancy that their fetus has an anomaly, not only because screening for fetal anomaly has become a standard of prenatal care but also because maternal conditions which place women at greater risk for fetal anomaly are increasing.
Although there are several studies exploring the experiences of pregnant women who terminate their pregnancies after a fetal anomaly diagnosis, there are few studies about the experiences of those who decide to continue their pregnancy (Chaplin et al., 2005; Hedrick, 2005; Hoeldtke & Calhoun, 2001; Lalor et al., 2007; Statham et al., 2000). Within the continuation of pregnancy after a fetal anomaly diagnosis studies, there was a paucity of information about how the healthcare provider guided and supported the pregnant woman during the rest of the pregnancy after deciding to continue. Although some of the available research describes supportive behaviors at the time the diagnosis is revealed and when the decision is made, there is little information about supportive behaviors during the rest of the pregnancy, including the time preparing for the birth or delivery. The experience associated with continuing after fetal anomaly diagnosis is characterized by fear and uncertainty especially related to the birth (Maijala, 2003) and baby (Askelsdottir et al., 2008; Bryar, 1997; Sennayake et al., 2006; Statham, 2003). The healthcare provider is in a prime position to guide and support the pregnant woman during this difficult time as the impact of the healthcare provider on the pregnant women’s experiences was evident in the literature. In order to develop evidence-based guidelines for the healthcare provider to use in the care of these women, further research must be conducted in this area. This study proposes to add to this emerging body of knowledge.
II. REVIEW OF THE LITERATURE

The framework used for the review of the literature was *Recasting Hope* (Lalor et al., 2009). *Recasting Hope* is the first theory to describe the adaptation of a pregnant woman from the time preceding the fetal anomaly diagnosis through the reordering of her life after making the decision to continue or terminate the pregnancy (Lalor et al., 2009). *Recasting Hope* identifies four phases of the adaptation after fetal anomaly diagnosis: assume normal, shock, gaining meaning, and rebuilding (Lalor et al., 2009). The following section presents an overview of the literature as it relates to these phases. Although the term “phase” is used when describing the model, the pregnant woman’s adaptation after fetal anomaly diagnosis is not linear and she may go back and forth between some of the phases (Lalor et al., 2009).

A. **Assume Normal**

Pregnant women believed everything would be fine with their fetus because they did not perceive themselves to be at risk (Chaplin et al., 2005; Lalor and Begley, 2006; McCoyd, 2007; Ohman, Saltvedt, Waldenstrom, Grunewald, & Olin-Lauritzen, 2006). McCoyd (2007) referred to this way of thinking as “mythical expectations”. The expectations of delivering a healthy baby were based on the women’s belief that they were healthy (Chaplin et al., 2005; McCoyd, 2007), young (Ohman et al., 2006), and had adhered to healthy behaviors during their pregnancies (McCoyd, 2007). They also had no problems with a previous (Chaplin et al., 2005), or the current pregnancy (Lalor & Begley, 2006). Moreover, none of their friends or family had a fetal anomaly (Lalor & Begley, 2006). Therefore, the women did not think that they were at risk for a baby with a fetal anomaly.
Pregnant women reported that they eagerly anticipated having their ultrasound (Lalor & Begley, 2006; Lalor et al., 2007; Lalor et al., 2009; McCoyd, 2009; Ohman et al., 2006) which they considered a routine part of their prenatal care (Lalor and Begley, 2006; McCoyd, 2009, Rapp, 1999). Although they were aware that ultrasonography was utilized to identify fetal anomalies, the pregnant women believed that their baby was fine (Lalor et al., 2009). They thought of it as an instrument with which to view their baby (McCoyd, 2009; Walker, Miller, & Dalton, 2008) and find out its sex (McCoyd, 2009; Rapp, 1999, Sandelowski & Jones, 1996). However, some women wanted verification that their unborn baby was healthy (McCoyd, 2009; Sandelowski & Jones, 1996); yet most women just expected to get a glimpse of their baby not anticipating that there could be a problem (Mitchell, 2004).

Undergoing ultrasound examination during pregnancy has become such a routine part of prenatal care that some healthcare providers may order it without obtaining the women’s verbal consent. This is exemplified in a study of 42 women who had abnormal fetal ultrasound findings; the women reported that their healthcare provider had not asked them if they wanted an ultrasound (Mitchell, 2004). Moreover, 69% of these women stated that they were not given a rationale for performing this type of examination; this contributed to most of the women believing that the ultrasound would be an enjoyable experience. They did not think about the possibility that the ultrasound would detect a fetal abnormality (Mitchell, 2004).
B. **Shock**

The women became aware of the fetal anomaly in a variety of ways. Disclosure about the fetal anomaly varied from being told that there was something of concern to receiving the fetal anomaly diagnosis at the time the ultrasound was performed (Mitchell, 2004) or to being informed about the diagnosis and asking about termination (Tymstra, Bosboom, & Bouman, 2004). Before disclosure by the healthcare provider, some women suspected that there was a problem. Their suspicions were based on how the scan was performed (Askelsdottir, Conroy, & Remple, 2008; Bryar, 1997; Lalor et al., 2009; McCoyd, 2009; Mitchell, 2004, Ohman et al., 2006; Rapp, 1999), as well as by remarks or questions made during the scan (McCoyd, 2009; Mitchell, 2004). The women were dissatisfied with the lack of information from the ultrasonographer when it was suspected that there was a problem (Askelsdottir et al., 2008; Lalor, Devane, & Begley, 2007). However, not all the women received the diagnosis at the time of the scan. Some had to wait several hours (Askelsdottir et al., 2008) or days to find out (Mitchell, 2004) or someone other than their healthcare provider relayed the information (Mitchell, 2004; Tymstra et al., 2004). In some cases, the healthcare provider did not disclose the diagnosis or disclosed the diagnosis in an impersonal manner, by phone (Mitchell, 2004; Tymstra et al., 2004) or by not looking directly at the women (Lalor et al., 2007).

The caring or non-caring approach utilized by the healthcare provider giving the disclosure about the potential adverse diagnosis impacted the pregnant woman’s experience (Chaplin et al., 2005). Actions that conveyed a sense of caring, such as the use of touch and sitting next to the woman at the time of the discussion about the fetus, were appreciated (Chaplin et al., 2005). Some healthcare providers displayed a more personal touch and came to the women’s homes to discuss the diagnosis (Tymstra et al., 2004).
Conversely, certain behaviors were considered non-caring and thoughtless; these behaviors included not providing information at the time the problem is identified or using tactless terms when describing the anomaly (Chaplin et al., 2005) or when inquiring about the family history (McCoyd, 2009). Another non-caring approach was focusing on the fetus and the anomaly while remaining oblivious to the pregnant woman’s emotional state (Schuth, Karck, & Reisch, 1994). At the culmination of their less-than-favorable interaction, some women were not asked what their plans were regarding their pregnancy; instead, they were advised at that point to terminate their pregnancy (Chaplin et al., 2005; Schuth et al., 1994).

Women expressed a need for information after the diagnosis of fetal anomaly. They believed that written information would help them better understand the anomaly, prepare for the consult with the specialist, and describe the diagnosis and its implications to their families and friends (Lalor et al., 2007). Images, radiologic or graphic pictures, in addition to the clinical descriptions also helped them understand the diagnosis. It was less understood if only medical terminology and statistics were utilized in the discussion of the anomaly (Lalor et al., 2007). The women appreciated the diagnosis explained in simple terms (Chaplin et al., 2005). They also sought out other avenues for information such as healthcare providers, other than their obstetrician, (Hedrick, 2005; Tymstra et al., 2004), the library (Tymstra et al., 2004), and the internet (Hedrick, 2005; Lalor et al., 2007). Others found it informative to meet with families who had a child with the anomaly (Helm et al., 1998; Tymstra et al., 2004).

However, at times there was uncertainty regarding the fetal anomaly diagnosis. Factors that may have contributed to this uncertainty included the timing of the ultrasound, the progression or regression of the anomaly and the ambiguity of the description of the severity of the anomaly.
This encompassed going from being informed that the fetus had an impairment to later being notified that there is no impairment or the degree of impairment varied with subsequent sonographic examinations. Use of vague terms, such as “mild” or “moderate”, when describing the degree of impairment further complicated this ambiguity (Sandelowski & Jones, 1996).

Women reported intense reactions to the fetal anomaly diagnosis. They reacted to the diagnosis with fear (Askelsdottir et al., 2008; Allen & Mulhauser, 1993; Cristofalo, DiPietro, Costigan, Nelson, & Crino, 2006; Senanayake, de Silva, Premaratne & Kulatunge, 2006; VanPutte, 1988), shock (Bryar, 1997; Chaplin et al., 2005; Cristofalo, et al., 2006; Hedrick, 2005; Lalor et al., 2007; McCoyd, 2009; Ohman et al., 2006; Rillstone & Hutchinson, 2001; Schuth et al., 1994; Senanayake et al., 2006; VanPutte, 1988), disbelief (Furlong & Black, 1984; Lalor and Begley, 2006; Mitchell, 2004; Senanayake et al., 2006; VanPutte, 1988), anger (Hedrick, 2005; Hunfield, Wladmiroff, & Passchier, 1997), guilt (Hedrick, 2005), surprise (McCoyd, 2009), anguish (Rillstone & Hutchinson, 2001), and grief (Edwins, 2000; Hedrick, 2005; Lalor & Begley, 2006). In addition to the emotional and psychological reactions, some reacted physically to the diagnosis experiencing difficulty in breathing and palpitations (Mitchell, 2004); others reported sleep disturbances (Lalor et al., 2009).

Psychological sequelae continued beyond the initial reaction to the diagnosis (Askelsdottir et al., 2008) proposed that connecting to the baby during pregnancy might be compromised following the fetal anomaly diagnosis. Women diagnosed with fetal anomaly experienced increased anxiety (Brisch, Munz, Bemmerer, Terinde, Kreienberg, & Kachele, 2003). Moreover, this psychological sequelae may have continued after the decision to terminate or continue was made.
Statham et al. (2003) reported that women felt a generalized sense of uncertainty that was pervasive throughout the pregnancy. Hunfeld et al. (1993) reported that 45% of pregnant women in his study who continued pregnancy after a significant or life-limiting diagnosis experienced “severe mental imbalance” (p. 607); this imbalance showed some improvement after delivery.

Although it was difficult to find out about the diagnosis during pregnancy, some women reported it was preferable to find out about the diagnosis during pregnancy rather than discovering it at birth (Lalor & Begley, 2006; Sandelowski & Jones, 1996). Moreover, learning of the problem earlier in pregnancy was presumed to be better than finding out later in the pregnancy (Lalor & Begley, 2006). Knowing about the anomaly antepartally helped women who continued their pregnancies prepare cognitively and emotionally for the birth of their baby (Chitty et al., 1996; Edwins, 2000; Senanayake et al., 2006; Tymstra et al., 2004). Finding out if the fetus was a girl or a boy helped some pregnant women focus on the fetus instead of the anomaly (Lalor et al., 2009; Statham et al., 2003). However, some felt that knowing about the anomaly before the birth negatively impacted their joy of pregnancy (Sandelowski & Jones, 1996; Statham et al., 2003). Since they were aware of the fetal anomaly before pregnancy, they were also faced with having to make the decision to continue or terminate their pregnancy (Tymstra et al., 2004).
C. **Gaining Meaning**

Women were sometimes referred to a specialist following the suspicion or confirmation of a fetal anomaly diagnosis. However, there was some concern related to being referred to the specialist because they were not necessarily chosen by the women and because they were unsure of how they would be treated by the specialist (McCoyd, 2009). Waiting to see the specialist created anxiety if the wait exceeded one day (Lalor et al., 2007). The women wanted confirmation of the diagnosis (Lalor et al., 2007; Lalor et al., 2009) and information about what might have caused the anomaly (Lalor et al., 2009). Some women reported that the specialist was better at helping them understand the anomaly than their primary healthcare provider (Cristofalo et al., 2006). In addition to helping them understand the anomaly, some pregnant women also anticipated that the specialist would help direct them throughout their pregnancy (Lalor et al., 2009). However, some women experienced interactions with the specialist that were less than positive. These interactions included a perceived lack of support and insensitivity from the specialist (Lalor et al., 2007, McCoyd, 2009). The insensitivity was manifested in the way the anomaly was described and the questions about the women’s history (McCoyd, 2009).

Healthcare provider interactions perceived as positive were those in which there were provisions for providing information and the mother was provided care in a supportive (Chitty et al., 1996; Lalor et al., 2007; Maijala, Astedt-Kurki, Paavilainen, & Vaisanen, 2003; Pelly, 2003) or empathetic manner (Pelly, 2003). Being provided with information about the baby’s prognosis was identified as a positive interaction because it allowed the mothers an opportunity to prepare for the birth and passing of their baby (Chitty et al., 1996; Senanayake et al., 2006).
Supportive care was identified as providing “individualized support” (Lalor et al., 2007, p. 85). Empathy was described as an objective appreciation for the mother’s situation and a demonstration of caring, not pitying (Pelly, 2003).

Some interactions with the healthcare staff or healthcare provider were identified as negative. These included situations when the woman perceived that she was treated insensitively (Miquel-Vargas et al., 2009; Senanayake et al., 2006) or disrespectfully (Chitty et al., 1996). Providing information about the baby’s prognosis in a matter-of-fact, impersonal manner was viewed as insensitive (Maijala et al., 2003; Miquel-Vargas et al., 2009; Remple et al., 2003). Lack of knowledge related to psychosocial care of mothers in these situations (Chitty et al., 1996; Remple et al., 2003) or provider assumptions (Remple et al., 2003) also contributed to negative interactions. At times, the healthcare provider did not acknowledge that the woman was distraught or minimized her concerns (Maijala et al., 2003). Moreover, provider’s assumptions about how mothers handle situations related to the pregnancy did not allow for individualized maternal reactions (Remple et al., 2003). These situations contributed to negative interactions with the healthcare staff or healthcare provider.

There were also some negative interactions related to decision making regarding their pregnancy. Women were dissatisfied when they perceived that they were not given adequate information about the choices they had and the implications regarding each choice (Gammeltoft & Nguyen, 2007; Schuth et al., 1994; Walker et al., 2008). After making their decision, some women felt that their healthcare provider was not supportive of their decisions (Helm et al., 1998; Redlinger-Grosse, Berhardt, Berg, Muenke, & Biesecker, 2002), and this subsequently led to a feeling of isolation (Redlinger-Grosse et al., 2002). Some healthcare providers did not initially ask about their decision; these healthcare providers assumed that the pregnant women
would terminate the pregnancy (Helm et al., 1998). The pregnant women who chose to continue felt that they needed to defend their decision to continue (Schuth et al., 1994). Some reported pressure from their healthcare provider to terminate their pregnancy; they felt that the healthcare provider was influenced more by personal values than scientific data (Schuth et al., 1994).

Communication, or lack of communication, also contributed to women’s experiences (Chitty et al., 1996; Maijala et al., 2003). Relaying pertinent information about the woman’s pregnancy to hospital staff and other healthcare providers who might be involved in her care was critical (Miquel-Vargas et al., 2009); it was upsetting to the women when information was not shared with other providers involved in her care (Chitty et al., 1996). Awareness of this information helped to diminish the unintentional insensitivities related to ignorance about the special circumstances involving the pregnancy (Chitty et al., 1996).

After receiving the fetal anomaly diagnosis, the pregnant women used different ways to cope. They found it difficult to adapt after the diagnosis because they had no previous situations from which to draw from (Schuth et al., 1994). They not only needed to cope with the fetal anomaly diagnosis, but they also needed to cope with the decision they had made regarding their pregnancy (Redlinger-Grosse et al., 2002). Denial was one of the coping methods. This denial was fueled by what women perceived as normal fetal behavior such as active fetal movement (Redlinger-Grosse et al., 2002). The concept of denial arose from the Five Stages of Grief proposed by Kubler-Ross (1969). However, since this theory was first made available, several other bereavement theories have been developed. Some of the bereavement theories that have come into focus are meaning reconstruction, continuing bonds, and posttraumatic growth (Lathrop & VandeVusse, 2011).
Several other coping methods were reported in the literature. Some women coped by anticipating the worst case scenario and made provisions during the pregnancy for the potentially bleak future. This future may have included preparing for their baby’s death or long-term care needs. By expecting the worst, they protected themselves from further emotional pain (Redlinger-Grosse et al., 2002). This might explain why some pregnant women reported not feeling a sense of attachment to their baby ((Lalor et al., 2009). Others engaged in the rituals that accompany normal pregnancy in order to cope with the diagnosis. By participating in rituals, such as sewing something for the baby, some happiness was brought into the pregnancy. They felt the need to prepare for this pregnancy the way they had prepared for previous pregnancies (Redlinger-Grosse et al., 2002). Women also reported that family, friends, and healthcare providers were instrumental in helping them cope. Families helped women cope, just by their presence (Maijala et al., 2003). Women’s coping was also positively impacted by their established relationship with their healthcare providers (Detraux, Gillot-DeFries, Eynde, Courtois, & Desmet, 1998) and by the healthcare providers’ use of caring touch (Chaplin et al., 2005; Maijala et al., 2003).

Another coping mechanism was believing they had made the right choice in continuing the pregnancy (Allen & Mulhauser, 1995; Sandelowski & Jones, 1996). They did not regret the decision (Chitty et al., 1996) and later accepted their decision to continue (Redlinger-Grosse et al., 2002). By choosing to continue rather than terminate the pregnancy, women felt that they had given their baby the opportunity to live (Allen & Mulhauser, 1995; Sandelowski & Jones, 1996) and it would make them more a resilient (Hedrick, 2005). They were also able to create memories that would not have been possible if they had chosen to terminate (Chitty et al., 1996).
Lastly, faith was acknowledged as a coping strategy sometimes used when the decision to continue was made (Maijala et al., 2003; Redlinger-Grosse et al., 2002; Senanayake et al., 2006; VanPutte, 1988). Some asked their priest to come to the hospital to provide them spiritual support during labor and to baptize the baby (VanPutte, 1988). Others believed that their faith could make a miracle happen and the baby would no longer be afflicted with the lethal condition (Senanayake et al., 2006) while others hoped for that miracle (Redlinger-Grosse et al., 2002).

D. **Rebuilding**

Once the anomaly is discovered, the pregnant woman is faced with making a decision—to terminate or continue with the pregnancy. As with any decision, there are factors that could influence this decision. A review of the literature demonstrated heterogeneity of study findings related to factors influencing their decision. Given the unique circumstances and background with which each woman enters into pregnancy, this heterogeneity is understandable.

Severity of the anomaly was the most frequently cited factor influencing the decision to terminate a pregnancy after fetal anomaly was diagnosed (Breeze, Lees, Kumar, Missfelder-Lobos, & Murdoch, 2007; Bryar, 1997; Chaplin et al., 2005; Drugan et al., 1990; Evans et al., 1996; Grevengood et al., 1994; Korenromp et al., 2007; Rauch, Smulian, DePrince, Anath, & Marcella, 2005; Sandelowski & Jones, 1996; Schechtman et al., 2002; Souka et al., 2010; Verp et al., 1988; Vincent et al., 1991). Other factors identified as influencing the decision to terminate were (a) protected baby from suffering (Korenromp et al., 2007; Rillstone & Hutchinson, 2001; Sandelowski & Jones, 1996); (b) perceived strain on family (Bryar, 1997; Korenromp et al., 2007); (c) doubted ability to care for a disabled child (Chaplin et al., 2005; McCoyd, 2007; Rillstone & Hutchinson, 2001; Sandelowski & Jones, 1996); (d) counseling by
the physician (Chaplin et al., 2005; Furlong & Black, 1984; Hedrick, 2005; Remple et al., 2003) (e) pressure by the physician (Gammeltoft & Nguyen, 2007; Helm, Miranda, & Chedd, 1998); (f) counseling by the geneticist (Remple et al., 2003); (g) early gestation (Kramer et al., 1998); (h) partner request (Korenromp et al., 2007); (i) non-lethal anomaly (Chitty et al., 1996; Remple et al., 2003; Souka et al., 2010); and (j) viewing the ultrasound image of the anomalous fetus (Drugan et al., 1990). However, two studies identified an ultrasound view of the fetus as a factor that contributed to the decision to continue the pregnancy (Helm et al., 1998; Sandelowski & Jones, 1996). Moreover, some women discovered that their views about pregnancy termination changed when they were faced with the decision after a fetal anomaly diagnosis (Bryar, 1997).

Gestational age also influenced the decision to terminate or continue. The studies that suggested that gestational age was an influencing factor were studies conducted in the U.S.; similar finding were not found in international literature. A woman whose fetus was diagnosed with trisomy 21 was more likely to terminate if the diagnosis was provided early in pregnancy (Kramer et al., 1998). Rauch and colleagues’ (2005) study findings also suggested that pregnancy termination was more likely if a structural anomaly was detected early in pregnancy. Data regarding gestational timing of abortion are available only through research studies; the CDC Abortion Surveillance Summaries do not include data regarding termination of pregnancy for fetal anomaly (CDC, 2012).

Religious beliefs emerged as the most frequently cited factor contributing to continuing the pregnancy after a fetal anomaly diagnosis (Chaplin et al., 2005; Grevengood et al., 1994; Helm et al., 1998; Maijala et al., 2003; Redlinger-Grosse et al., 2002; Sandelowski & Jones, 1996; Tymstra et al., 2004). This would suggest that religion is an important factor when the woman makes a decision about the course of a pregnancy complicated with a diagnosis of a fetal
anomaly. However, value of life (Chaplin et al., 2005; Helm et al., 1998; Redlinger-Grosse et al., 2002) and nonchoice (Helm et al., 1998; Pelly, 2003; Sandelowski & Jones, 1996) also identified as factors, may be considered dimensions of religious belief. Gestational age (Grevengood et al., 1994; Sandelowski & Jones, 1996) and nonchoice may also be interrelated. Termination of pregnancy may not be an option after attaining a certain gestation. Once fetal viability is reached, the woman may have no choice; the choice has been made for her. Sandelowski and Jones (1996) described this as “choice lost” (p. 358).

However, Rapp (1999) identified nonchoice when describing the choice a pregnant woman was faced with after her fetus was diagnosed with Down syndrome; the woman felt that she had no choice other than to terminate her pregnancy so as to avoid giving birth to an impaired baby. Rothman (1986) referred to this as forced choice. Nonchoice was also perceived by a pregnant woman in a study by Statham et al. (2003). Her fetus was diagnosed with anencephaly; she thought it was ridiculous to be asked if she wanted to continue her pregnancy when her fetus was missing part of its brain.

The decision to continue was also influenced by doubt and fear that the fetal anomaly diagnosis was incorrect (Chitty et al., 1996). Some hoped that there was an error in the diagnosis (Maijala et al., 2003). Some continued their pregnancy because the extent of deficits was not always predictable or clear-cut (McCoyd, 2007; Redlinger-Grosse et al., 2002). This type of choice, referred to as “close choice” (Sandelowski & Jones, 1996, p. 358), involves making a choice when there is prognostic uncertainty. Some pregnancies were continued after it was determined that the anomaly was not as severe as they had initially thought (Tymstra et al., 2004).
Several other factors that contributed to continuing the pregnancy were identified in the literature. The perception of fetal movement, history of infertility, and the support of family and friends were also instrumental in some pregnant women continuing their pregnancy (Helm et al., 1998). Others were influenced by knowing or meeting a person with the same anomaly; they were able to get an idea of how the anomaly impacted that person’s life (Redlinger-Grosse et al., 2002; Statham et al., 2003; Tymstra et al., 2004). Ultrasound images of their fetus also played a role in some continuing their pregnancies (Edwins, 2000; Sandelowski & Jones, 1996).

Christian et al., (2000) discovered a temporal trend regarding the continuation of pregnancies diagnosed with sex chromosome aberrations. There were an increased number of pregnancies that were continued in the late 1990’s as compared with the 1970’s. They postulated that this trend was probably related to studies showing a more favorable outcome for children diagnosed with sex chromosome anomalies (Christian et al.).

Acceptance by the healthcare provider and others of the woman’s decision to continue was important to the pregnant women. Healthcare provider acceptance was reflected by the non-judgmental (Edwins, 2000) and respectful care they provided after the decision was made (Redlinger-Grosse et al., 2002). Women appreciated that the care they received was not negatively impacted (Redlinger-Grosse et al., 2002). In addition to acceptance by the healthcare provider, acceptance by others was also important. However, Cote-Arsenault and Denney-Koelsch’s (2011) study findings of women continuing pregnancy after a lethal fetal diagnosis revealed that family and friends did not understand the decision to continue. This led to a sense of isolation and loneliness.
After making the decision to continue their pregnancy, women shared their decision with others in an effort to gain their support; the women received both positive and negative responses to this sharing (Tymstra et al., 2004). Redlinger-Grosse et al. (2002) reported that several women in their study who continued pregnancy after a fetal diagnosis of holoprosencephaly felt unsupported by their friends and families; this led to a feeling of isolation. Consequently, relationships with those who reacted in an unfavorable manner were negatively impacted (Tymstra et al., 2004).

Women who continued pregnancy after a lethal fetal diagnosis expressed discomfort being around pregnant or newly delivered women who had no problems with their pregnancy (Senanayake et al., 2006); they were uncomfortable with remarks or inquiries made by the other mothers (Chitty et al., 1996). Consequently, there was a desire for the healthcare provider to facilitate special arrangements for antepartum, intrapartum and postpartum care in order to minimize this type of interaction (Chitty et al., 1996).

Maintaining a sense of hope regarding the baby’s prognosis was identified as important (Chitty et al., 1996; Miquel-Vargas et al., 2009; Redlinger-Grosse et al., 2002; Spinnato, Cook, Cook & Voss, 1995). Women also wanted the physician to present a sense of hope; this sense of hope was nurtured by highlighting the positive, not just the negative, and by offering to facilitate the most optimal results given the baby’s situation (Askelsdottir et al., 2008; Maijala et al., 2003; Miquel-Vargas et al., 2009).

The mothers expressed several thoughts, wishes, and fears related to childbirth and their baby. Some mothers looked forward to the opportunity to interact with their baby (Chitty et al., 1996; Lalor et al., 2009) even if the time to interact was limited (Pelly, 2003). They did not
appreciate the baby being transferred quickly out of the labor room because they feared their
time with the baby while alive would be limited (Chitty et al., 1996). If the baby did not live, the
women sought and appreciated mementos affirming the baby’s existence and value (Lalor et al.,
2009). These mementos served as a commemoration of their baby (Lathrop & VandeVusse,
2011).

However, some expressed fear about seeing the baby after it was born (Chitty et al.,
1996). Seeing their dead baby was perceived as being emotionally challenging (Spinnato et al.,
1995). Some hoped their baby would die in utero (Edwins 2000; Lalor et al., 2009; Redlinger-
Grosse et al., 2002; Tymstra et al., 2004) and not suffer (Spinnato et al., 1995). They feared that
interventions would prolong their baby’s life (Senanayake et al., 2006). There was also fear
about the delivery (Maijala et al., 2003) and what could happen when the baby was born
(Statham et al., 2003). All the mothers in one study described the birth process itself as a
psychologically unbearable experience (Miquel-Vargas et al., 2009). In spite of these hardships,
some women expressed the possibility that there could be another pregnancy in the future (Lalor
et al., 2009).

E. **Summary**

This literature review revealed a limited amount of research related to the experiences of
women continuing pregnancy after a fetal anomaly diagnosis; this research was further limited
by the lack of racial/ethnic diversity. The majority of this research focused on reaction to the
diagnosis, factors influencing the decision to terminate or continue the pregnancy, and coping
strategies. However, there was a paucity of research related to the support and guidance given to
the pregnant woman after she decides to continue her pregnancy. Although some of the
available research described supportive behaviors at the time the diagnosis is revealed and when the decision is made, there was little information about supportive behaviors during the rest of the pregnancy, including the time surrounding the birth or delivery. The birth is a critical time in these women’s experiences. The birth is not only the normal culmination of pregnancy, but it is also the time that the reality of her baby’s condition is brought to the forefront. The experience associated with continuing after fetal anomaly diagnosis is characterized by fear and uncertainty especially related to the birth (Maijala, 2003) and the baby (Bryar, 1997; Sennayake et al., 2006; Statham, 2003). Studies that did include experiences related to the birth were largely focused on the care the baby would receive at the time of birth and personnel needed to provide that care versus the care of the woman. The majority of these studies involved pregnant women diagnosed with a lethal fetal anomaly and the fears and hopes these women had related the baby.

Guidance and support by the healthcare provider after the decision to continue is essential because the pregnant woman most likely has not had this experience before, and may be fearful because of the uncertainties associated with the birth and her baby. However, some women have reported not receiving the support they anticipated from their healthcare provider (Cote-Arsenault & Denney-Koelsch, 2011). The impact of the healthcare provider on the pregnant women’s experiences was evident in this literature review. Pregnant women look to their healthcare providers for care and guidance throughout their pregnancy. In order to develop evidence-based guidelines for the healthcare provider to use in the care of these women, further research must be conducted in this area. Research that examines the experiences of women from diverse racial and ethnic backgrounds would be particularly helpful.
F. **Purpose and Specific Aims**

The purpose of this study was to explore the experiences of pregnant women who continued pregnancy after a fetal anomaly diagnosis. A qualitative descriptive approach (Neergaard, Olesen, Andersen, & Sondergaard, 2009) was used to collect the data. The following were the specific aims:

1. To describe the experiences of women who continued pregnancy after a fetal anomaly diagnosis.
2. To explore the nature of the support provided by healthcare providers and the extent to which it met the pregnant woman’s expectations and needs as she continued her pregnancy and prepared for the birth.

The long term goal of this research is to develop clinical practice guidelines for the care of women who continue pregnancy and prepare for birth after a fetal anomaly diagnosis.
III. METHODS

The following section describes the methods that were used to conduct this study. This section includes the (a) research design, (b) sample, (c) recruitment, (d) data collection, (e) data management, (f) maintenance of rigor, and (g) ethical considerations. The methodological approach is important as it provides the framework for the study (Parse, 2001).

A. **Design**

A qualitative descriptive research design was used to explore the experiences of women who continued pregnancy following a non-life-limiting and life-limiting fetal anomaly diagnosis (Neergaard, Olesen, Andersen, & Sondergaard, 2009). The goal of qualitative descriptive research is to describe a phenomenon uncovering patterns and themes (Neergaard et al., 2009). For this study, the phenomenon is the complex experience of pregnant women who continued their pregnancy after a non-life-limiting and life-limiting fetal anomaly diagnosis. Qualitative descriptive was chosen for this study because it allowed for a comprehensive description of the experience and because this design facilitated maintaining greater proximity to the data than other designs (Neergaard et al., 2009). Qualitative descriptive is also considered an appropriate design for healthcare research and research involving vulnerable participants (Neergaard et al., 2009). A qualitative research design helped to elucidate the meaning of the experience from the participant’s point of view as revealed through the woman’s own words (Neergaard et al., 2009). These descriptions inherently contained the women’s feelings and attitudes (Corbin & Strauss, 2008). Qualitative descriptive research is considered an appropriate design when there is limited understanding (Neergaard et al., 2009) such as the experiences of women who continue pregnancy after a fetal anomaly diagnosis.
B. **Sample**

For this study, a purposeful convenience sample of 10 women diagnosed with a fetal anomaly who chose to continue their pregnancy were interviewed. By using this sampling strategy, the study yielded “information rich” data about these experiences (Patton, 2002, p. 230). According to Patton (2002), qualitative research involves purposefully sampling a relatively small number in the quest for thorough information about the area of interest. The small number of participants needed for the study is congruent with the relative infrequency of fetal anomalies in the general population (CDC, 2011) and by the number of these pregnancies that are terminated (Breeze et al., 2007; Rauch et al., 2005; & Vincent et al., 1991). As previously described, the incidence of termination of pregnancy for fetal anomaly in the U.S. is unknown. However, inferences can be made from research conducted in this area. Thus, there were a small number of potential participants available in a limited geographic area.

The inclusion criteria for the women were the following: (a) age 18 or older; (b) women diagnosed with a life-limiting or non-life-limiting fetal anomaly and chose to continue their pregnancy; (c) a minimum of 24 weeks gestation and less than 37 weeks gestation; (d) singleton gestation; (e) ability to read, write, speak, and understand English or Spanish. Only women who were 18 years or older were included to avoid the psychosocial factors related to adolescence and adolescent pregnancy. The exclusion criterion included women who: (a) chose to undergo selective reduction for multiple gestation pregnancies, and (b) did not read, write, speak, and understand English or Spanish. These women were excluded because their responses might have been affected by the loss of the fetus who was selectively reduced and the investigator only reads, writes, speaks, and understands English and Spanish.
C. **Recruitment**

Institutional Review Board (IRB) approval was obtained from institutions participating in the study. After IRB approval, participants were recruited utilizing three approaches. One method of recruitment involved a perinatal support services coordinator who met potential participants as she carried out her usual job responsibilities at a Chicago area level three obstetric and neonatal medical center. The second approach recruited participants through flyers posted at another Chicago area level three obstetric and neonatal medical center clinic. A third approach was required because recruitment was slower than anticipated with the first two recruitment methods. With the third approach, the health care provider assisted with recruitment by mentioning the study to potential participants. If the potential participant expressed an interest in learning about the study, the healthcare provider would introduce the pregnant woman to the investigator who was present in the clinic. The investigator discussed the study and eligibility. If the potential participant verbally consented to be enrolled in the study, the interview was scheduled for a later date. In order to protect participants from feeling coerced to participate in the study, potential participants were informed that their participation was voluntary and they could withdraw at any time from the study. They were also informed that if they chose to not participate in the study or if they chose to withdraw from the study, their care with their healthcare provider would not be affected. Recruitment occurred simultaneously at the two sites. Specifically, participants were recruited in the following manner:

1. Chicago area (suburban) level three obstetric and neonatal medical center - After the pregnant woman decided to continue her pregnancy after a fetal anomaly diagnosis, she met with the Perinatal Support Coordinator. The coordinator organizes meetings with
other members of the healthcare team who will be involved in the care of the baby. The coordinator passed out the study flyer to potential participants. Potential participants were told that their participation was voluntary and their care would not be negatively impacted if they declined to participate. If the pregnant woman expressed an interest in participating in the study, the coordinator directed them to contact the investigator directly. Participants were also given a Subject Information Sheet providing detailed information similar to the research information in the consent. A study script was provided to the coordinator which assisted her in explaining the study if a potential participant had any questions. Three participants were recruited with this method over a six month period. Recruitment was slow related to the limited number of potential participants during that period of time.

2. Chicago area (urban) level three obstetric and neonatal medical center - Study flyers describing the study, inclusion criteria, and investigator contact information were strategically posted in patient care clinic areas which were accessible to providers and potential participants. Pregnant women diagnosed with fetal anomaly who were interested in the study contacted the investigator either by telephone or email as indicated on the flyer. The Subject Information Sheet providing detailed information similar to the research information in the consent was available by the study flyers. Only one participant was recruited in four months by this method. Since recruitment was slower than anticipated, an additional recruiting method was utilized. Recruitment occurred as follows: the investigator was on site at the level three obstetric and neonatal center clinic on days when pregnant women diagnosed with fetal anomalies came in for their standard prenatal visits. The health care provider informed
potential participants that the investigator who was recruiting for a study was in the clinic and she could introduce the potential participant to the investigator if the woman was interested in talking to the investigator. The provider then introduced the investigator if the woman expressed an interest in talking to the investigator. In order to protect potential participants from coercion to participate in the study, they were informed that their participation was voluntary and they could withdraw at any time from the study. This recruitment method was the most efficacious in recruiting participants in the shortest timeframe. Some factors that contributed to making this an effective recruitment method was that it was more convenient for potential participants and made it a more transparent process since they met the investigator before agreeing to participate in the study.

When contact was made with the potential study participant, the investigator assessed eligibility from their self-report, explained the purpose of the study, participation requirements including audiotaping of the interviews, and the voluntary nature of the woman’s participation. The investigator also described her clinical experience in nurse-midwifery, high-risk obstetric and neonatal nursing. The investigator’s credibility may have been enhanced by describing her clinical experience as a healthcare provider (Patton, 2002).

If the pregnant woman continued to express an interest in participating in the study, an appointment for the first interview was established. The investigator asked to interview the participant twice during the pregnancy. All the women completed the two interviews. The first interview was scheduled as close to the third trimester as possible and the second interview two to six weeks later. A second interview was conducted to clarify information obtained in the first interview and to assess any changes in feelings or needs since the first interview. The exact date
and location of the interview was determined by the study participant, given these parameters. According to Schmied, Jackson, & Wilkes (2011), participants experience less vulnerability when they are given the opportunity to participate in the decisions about where and when the interview will take place. The second interview was conducted face to face or by telephone as determined by the participant. All interviews were conducted face to face except for one woman who requested the second interview to be conducted by telephone because of a pregnancy-related issue. All interviews were conducted in private, quiet locations. Interview sites included hospital conference rooms, clinic rooms, and physician offices.

The investigator conducted all interviews including the two interviews (one participant) conducted in Spanish. The investigator who is bicultural (Spanish/American) and bilingual (Spanish/English) is fluent in the written and oral Spanish language. The investigator had one year of formal education in Mexico to augment her Spanish language skills. Professionally, during her tenure as a nurse midwife, she provided care for patients most of whom spoke only Spanish. The investigator also facilitated several Spanish “Centering Pregnancy™” groups; Centering Pregnancy™ is a model for providing group prenatal care.

Immediately prior to the interview, the investigator obtained an informed, formal, signed consent. The consent included the following elements: purpose and description of the study, description of their participation, potential risks and benefits, confidentiality, and voluntary participation, including the ability to withdraw at any time. Special attention was used in the wording of the consent so that it communicated a sense of respect; this was accomplished by using the term baby instead of fetus (Kavanaugh et al., 2006).
A consent in Spanish was available for the participant who only spoke Spanish. The consent form was translated into Spanish by the investigator who is bicultural, bilingual and fluent in the written and spoken Spanish language. The translated Spanish consent form was verified for accuracy by a doctorally prepared Women’s Health Nurse Practitioner fluent in Spanish with experience in this clinical area.

D. Data Collection

Data were obtained using an interview guide with probes and open-ended questions (see Appendix B Interview guide). Participants also completed the obstetric-demographic questionnaire after completing the first interview (see Appendix A, obstetric-demographic questionnaire). The probes and open-ended questions were used to elicit study participants’ descriptions of their experiences from the time of the fetal anomaly diagnosis. These descriptions provided insight into their experiences with the goal of identifying common themes including their preparation for the birth of their baby and interactions with healthcare providers. Although each experience has some unique features, knowledge of common themes will assist healthcare providers to better understand what these women experienced and how they can support and guide them during this time.

Using open-ended questions as an interview approach commonly used in qualitative descriptive research (Neergaard et al., 2009). The open-ended strategy facilitated insight into the participant’s experience by having her tell her story (Patton, 2002). Using similar questions also facilitated across-case analysis (Ayers, Kavanaugh, & Knafl, 2003). Although this type of interview technique employed specific probes, the participants responded in their own words thereby relating their thoughts and feelings (Patton, 2002).
The interview guide was developed from a review of the literature which included the Recasting Hope theoretical framework (Lalor, Begley, & Galavan, 2009). Questions were used to elicit the experiences of these women from the time they decided to continue their pregnancy. Questions related to the guidance and support they received from their healthcare provider, including preparing for the delivery, were also included.

The interviews were conducted at a date, time, and location mutually agreed upon by the investigator and the participant. Rooms that were used for the interviews included a private room in another clinic, healthcare provider’s office, and the investigator’s office. Several measures were put into place in order to maintain the women’s confidentiality regarding their participation in the study; these measures included scheduling interviews after regular clinic hours; scheduling the interview in a non-obstetric clinic location; and by the investigator meeting the participant in the designated room at a specified time.

Prior to starting the interview, participants were asked if they still desired to participate in the study. In order to minimize the risk of coercion or undue influence, the women were advised that they could refrain from answering any question they chose; withdraw from the study at any time; and that non-participation in the study would not impact their care.

The consent was reviewed with the participants and they were given an opportunity to ask questions about the study or consent. If the participant confirmed their desire to participate in the study, they were asked to sign the consent. Participants were informed that they would be assigned a pseudonym in order to protect her information and privacy.
The investigator started the interview by explaining the purpose of the study. This was followed by a grand open-ended question about their pregnancy and what the pregnancy meant to them and their family (see Appendix B). After the grand open-ended question, probes and open-ended questions were used to elicit study participants’ descriptions of their pregnancy experiences following the fetal anomaly diagnosis, and the support and guidance from their healthcare provider as they continued their pregnancy and prepared for the birth.

The interviews were audio recorded using digital technology. Audio recording is an invaluable tool for the conduct of the two interviews. By recording the interview, the entire spoken interview was captured, allowing the investigator to concentrate on observing the participant during the interview (Patton, 2002). This facilitated the investigator’s active listening and eye-to-eye during the interview; both of these are essential in demonstrating caring (Kavanaugh et al., 2006).

At the conclusion of the first interview, participants were asked to complete the obstetric-demographic history questionnaire (see Appendix A). The questionnaires were coded, using only the participant’s assigned pseudonym. Information obtained from this questionnaire was used to ascertain participant diversity. A total of a $30 honorarium (total amount) was provided to each participant. The honorarium was a gift card to a bookstore. The honorarium was prorated, $15 for each interview. A $15 gift card was provided after immediately after the first interview and obstetric- demographic questionnaire was completed; the second gift card was also given immediately after completion of the second interview. The participant who requested the option of a telephone interview for the second interview received the gift card by certified mail as agreed upon by her and the investigator. The second interviews were all conducted face to face except for one woman who requested the telephone option due to a pregnancy related issue.
Following each interview, post-interview notes were completed. These notes included information about the interview setting, participant behavior such as body language, verbal intonation, periods of silence, and the investigator’s thoughts about the interview process. Information from the post-interview notes enhanced interpretation of the data (Patton, 2002). Specifically, the notes were read along with the transcript when analyzing the women’s responses and developing the codes. The field notes provided for additional insight such as looking for congruence between the participants’ responses and their non-verbal behavior. In addition to data interpretation, the field notes assisted the investigator in revising interview techniques, probes and open-ended questions in order to develop the best approach. Field notes were also instrumental in adding additional probes or open-ended questions based on new information uncovered during the interviews.

E. **Data Management**

The digital recordings, including the two recordings in Spanish, were transcribed verbatim by the investigator. The Spanish transcripts were translated into English by the investigator, who is bilingual and bicultural. Translation by the investigator was appropriate because translation is essentially used by researchers when describing the experiences of others (Temple, 1997). Also, by virtue of being bicultural, the investigator was aware of the cultural meaning or significance of words or phrases chosen by the participants which served to enhance verification of the Spanish transcripts (Chen & Boore, 2009; Kirkpatrick & van Teijlingen, 2009). In order to ensure that the transcript was translated correctly, the investigator used backward translation (Eboh, Pitchforth, & van Teijlingen, 2007). Additionally, a Women’s Health Nurse Practitioner fluent in Spanish and experience in this clinical area reviewed the transcript translated from Spanish to English against the original Spanish transcript.
This process assured accuracy of the translation and thus, trustworthiness was achieved (Chen & Boore, 2009). Both, the investigator and the Women’s Health Nurse Practitioner completed human subject protection education through the Collaborative Institutional Training Initiative.

The obstetric-demographic data were analyzed using the Excel™ program; the descriptive statistical tests performed through Excel™ were the average, range, and standard deviation. Interview data were coded and categorized through Dedoose™, a qualitative data software program. The data analysis technique utilized was content analysis, the analytical strategy typically employed for qualitative descriptive inquiry (Neergaard et al., 2009). This type of analysis involved the development of codes from the data and subsequent pattern interpretation (Morgan, 1993; Morse & Field, 1995; Patton, 2002; Zhang & Wildemuth, 2009). The fetal anomaly literature was used in the development of the codes. Coding facilitated the maintenance of rigor because no parts of the data were excluded from the coding process (Ayers, 2007). In order to ensure that the data was coded correctly since the investigator is new to this process, the investigator’s dissertation committee chair, reviewed five transcripts against the codes developed from the transcripts (Zhang & Wildemuth, 2009); two transcripts were reviewed at the beginning and three transcripts were reviewed at the midpoint. Any disagreements, which were few, were discussed until consensus was reached. This process of code verification facilitated trustworthiness of the data. Codes allowed for identification of similarities and differences and subsequent identification of themes (Milne & Oberle, 2005; Patton, 2002). Themes were developed by identifying the relationship between the codes. These themes represented the experiences of the women who continued after a fetal anomaly diagnosis (Corbin & Strauss, 2008). Select quotes from the data which represented the themes were included to enhance trustworthiness of the data analysis (Milne & Oberle, 2005).
F. Maintenance of Rigor

Maintaining rigor is important because it validates that research findings reflect reality (Tobin & Begley, 2004; Whitmore, Chase, & Mandle, 2001). Several procedures to assure rigor have been described in this methods section. Rigor was also maintained by keeping an audit trail of the investigator’s decisions about data analysis, reasoning, and thoughts related to the participants, and interviews (Patton, 2002). The investigator documented these through reflexive journaling; reflexive journaling is considered an analytic technique for demonstrating rigor (Whitmore et al., 2001). Reflexive journaling served to ensure confirmability (Lincoln & Guba, 1985). Other procedures used to maintain rigor included establishing credibility, dependability, and transferability (Lincoln & Guba, 1985). Examples of how these were maintained included peer debriefing (credibility), providing thick descriptions (transferability), and the use of an interview guide (dependability). The investigator’s clinical experience and educational background also served to enhance the investigator’s ability to understand the data and to identify links between the concepts in the data (Corbin & Strauss, 2008).

G. Ethical Considerations

Protection of participants was mediated by Institutional Review Board (IRB) approval, coded data, and securing of digital audio recordings and files in a password protected secure University of Illinois network server and a back-up encrypted (PGP Whole Disc Encryption) USB memory stick. The investigator received approval for the study by the Institutional Review Board for the institutions used for recruitment.
Each participant was assigned a pseudonym in order to protect her information and privacy. A key with the participant’s name and her assigned pseudonym was kept in a locked cabinet in the investigator’s private, locked office. In order to protect the identity of the participants during transcription, the digital recordings and the obstetric-demographic questionnaire form were identified by the participant’s pseudonym. The obstetric-demographic questionnaires were destroyed after being transcribed by the investigator and transferred to the password protected secure network server. Transcriptions were encrypted and the digital recording were stored in the same secure network server. After verification of the accuracy of the transcriptions, the digital recordings and patient identifiers were deleted in a manner in which they cannot be retrieved. All electronic files were destroyed after completing the analysis. The participant key was also shredded after analyses were completed. Consent forms were secured in a locked file cabinet, in a locked office. They will be kept for the required six years as required by the University of Illinois IRB. At the six year mark, the consent forms will be destroyed as required through a university approved document destruction service.

The risk of coercion or undue influence to the participant was minimized through the following measures: allowing participants to self-select into the study; advising participants that they could refrain from answering any question they chose; allowing the participants to withdraw at any time from the study; the investigator was not involved in the care of any of the participants; and potential participants were told that non-participation in the study would not impact their care.
There were safeguards in place to protect the participants from emotional risks associated with talking about sensitive subject. Kavanaugh et al. (2006) proposed that topics that are “of a deeply personal nature”, may be considered threatening because they are sensitive topics (p. 245). This certainly would be the case when a pregnant woman is diagnosed with a fetal anomaly because pregnancy is a very personal experience. From over 30 years of perinatal experience, the investigator realized that when a woman whose baby has been diagnosed with a fetal anomaly talks about her baby, strong feelings and emotions can overwhelm her. The feelings and emotions associated with loss can contribute to their vulnerability (Kavanaugh et al., 2006); in the case of fetal anomaly, this loss could be the loss of the anticipated child or the loss associated with intrauterine fetal demise or neonatal death.

The investigator used interview techniques as described by Kavanaugh and Ayres (1998) in an effort to recognize and minimize distress. These techniques included the following: (a) monitored participant behaviors and emotional status during the study; (b) facilitated participants using their own coping methods; and (c) modified the pace of the interview – offered to pause or stop the interview. Participants were also given sufficient time to respond to questions and moments of silence were provided (Schmied et al., 2011).

The investigator has several years of experience providing care for women who have experienced distress related to their pregnancy or baby; given this experience, the investigator was able to recognize signs of distress in the participant and employed previously described techniques to minimize the distress. However, the participants were also be asked how they felt about the interview; this was used to help identify distress that was not recognized during the interview process (Kavanaugh et al., 2006).
IV. FINDINGS

A. **Demographic Information**

A total of ten pregnant women who were diagnosed with fetal anomaly participated in this study (see Table I, Demographic Information). The women ranged in age from 18 to 45 years old with a mean age of 27.7 \((SD = 9)\). The majority of the participants \((n = 7)\) identified their race as Caucasian and the other women \((n = 3)\) identified themselves as African American. Three out of the seven Caucasian women identified themselves as Hispanic. The majority of the women were primigravidas \((n = 6)\). Only two women identified themselves as single, the other women identified themselves as either being married \((n = 3)\) or living with their partner \((n = 5)\). The reported family income ranged from $8,600 to $150,000 per year with an average income of $48,622 \((SD = 53,054)\) with one woman declining to report her family income. The majority of the women \((n = 7)\) identified with having a religion affiliation. Nine out of the ten women completed high school and two had attained master’s degrees.

At the time of the initial interview, the weeks of gestation ranged from 24 to 32 weeks with an average gestational age of 29.6 weeks \((SD = 2.5)\). The second interview was conducted when the women’s gestation was between 30 to 36 weeks gestation with an average gestation of 33.9 weeks \((SD = 1.9)\). The time between the first and the second interview ranged from three to six weeks with an average of 4.3 weeks \((SD = 1.2)\).
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Family Income</th>
<th>Race</th>
<th>Hispanic</th>
<th>First Pregnancy</th>
<th>Fetal Anomaly/ Type*</th>
<th>Gestational Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paula</td>
<td>45</td>
<td>10,000</td>
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<td>Y</td>
<td>N</td>
<td>Down, ventricular defect/²</td>
<td>30/ 33</td>
</tr>
<tr>
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<td>25,000</td>
<td>Caucasian</td>
<td>Y</td>
<td>Y</td>
<td>Gastroschisis/⁵</td>
<td>24/ 30</td>
</tr>
<tr>
<td>Katrina</td>
<td>20</td>
<td>30,000</td>
<td>African American</td>
<td>N</td>
<td>Y</td>
<td>Osteogenesis imperfecta/?</td>
<td>32/ 36</td>
</tr>
<tr>
<td>Anita</td>
<td>21</td>
<td>14,000</td>
<td>Caucasian</td>
<td>N</td>
<td>Y</td>
<td>Gastroschisis/²</td>
<td>28/ 34</td>
</tr>
<tr>
<td>Katie</td>
<td>28</td>
<td>30,000</td>
<td>Caucasian</td>
<td>N</td>
<td>Y</td>
<td>Polycystic kidney/³</td>
<td>32/ 35</td>
</tr>
<tr>
<td>Alma</td>
<td>29</td>
<td>150,000</td>
<td>Caucasian</td>
<td>N</td>
<td>Y</td>
<td>Duodenal atresia/⁵</td>
<td>31/ 36</td>
</tr>
<tr>
<td>Ana</td>
<td>20</td>
<td>8,600</td>
<td>Caucasian</td>
<td>Y</td>
<td>Y</td>
<td>Diaphragmatic hernia/⁵</td>
<td>32/ 35</td>
</tr>
<tr>
<td>Katherine</td>
<td>32</td>
<td>130,000</td>
<td>Caucasian</td>
<td>N</td>
<td>N</td>
<td>Transposition, cleft lips/⁵</td>
<td>29/ 33</td>
</tr>
<tr>
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<td>40</td>
<td>Declined</td>
<td>African American</td>
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<td>N</td>
<td>Dandy walker/³</td>
<td>30/ 34</td>
</tr>
<tr>
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<td>40,000</td>
<td>African American</td>
<td>N</td>
<td>N</td>
<td>Cystic hygroma/⁵</td>
<td>28/ 32</td>
</tr>
</tbody>
</table>

Type ¹ - lethal

Type ² - non-correctable, moderate to severe disability

Type ³ - non-correctable, uncertain effects

Type ⁴ - uncertain prognosis

Type ⁵ - treatable, varying degrees of associated risk
The majority of women ($n = 8$) were diagnosed with a single anomaly, but two were diagnosed with two anomalies (trisomy 21 and mild cardiac valve defect; transposition of the great vessels and bilateral cleft lip). The other women were diagnosed with the following: gastroschisis ($n = 2$), duodenal atresia, diaphragmatic hernia, osteogenesis imperfecta (type unknown during pregnancy), dandy walker malformation, and cystic hygroma. Based on their clinical conditions at the time of interviews, using Statham’s (2003) criteria, the anomalies would be classified as follows: trisomy 21 – “non-correctable with moderate to severe disability”; gastroschisis, duodenal atresia, cystic hygroma, transposition of the great vessels, mild cardiac valve defect, cleft lip and diaphragmatic hernia – “treatable with varying degrees of associated risk; dandy walker and polycystic kidney “non-correctable with uncertain long term effects”; the osteogenesis imperfecta – unable to classify until type determined after birth (p.165).

B. **Themes**

Continuing a pregnancy following a fetal anomaly diagnosis is fraught with uncertainty and changing expectations. The experience is a complex phenomenon represented through four major themes: (a) becoming vulnerable, (b) navigating the diagnosis, (c) connecting with the baby and (d) interacting with healthcare providers. These themes are described in the following paragraphs with quotes from the participants which illustrate the theme. Participants’ identities were protected through the use of pseudonyms.
1. **Becoming vulnerable**

For this study, becoming vulnerable was defined as increased susceptibility to psychological injury. Labile emotions, a sense of isolation, and perceived increased risk for fetal anomaly contributed to the women becoming vulnerable. The vulnerability of the women was evident as they described their pregnancy experiences.

All the women described the constant fluctuation of their emotions throughout the pregnancy following the fetal diagnosis and the decision to continue. Katie stated, “I don’t feel grounded, I feel that my emotions are constantly changing, it’s disconcerting and uncomfortable”. Not only did their emotions change throughout pregnancy, but at times, they changed from the morning to the afternoon. One of the participants Katherine recounted, “You’re okay one minute and then something is said or you think of something then it brings all those feelings to the forefront”. Emotions ranged from sadness to happiness, sadness for the loss of the normal pregnancy and baby contrasted by the happiness for the baby coming into their life. Other emotions described by the women included anger, fear, surprise, and anxiety. All of the women reported that unpleasant emotions reoccurred throughout their pregnancy. At times these emotions were so intense, they interfered with their usual activities. Katherine recounted that she was so upset after a prenatal visit, she could not return to work; she had become overwhelmed with sadness after learning that the fetal anomaly was more severe than originally thought:

They found out about the heart probably, it was only a few days after I had my level two ultrasound. It was relatively soon. So it was all just really overwhelming because as soon as I left the office, after I left my level two, I was going back to work and finish the day,
but I was like no, there’s no way. So we left my son in daycare. Then, I just went home and cried all night.

Although the women had frequent interactions with health care providers, most of the women reported feeling a sense of isolation during their pregnancy from family and friends. For some, this isolation was self-imposed and for others the isolation was a consequence of the frequency of pregnancy-related appointments such as healthcare visits such as prenatal visits, consults, and ultrasounds. For four of the women, the scheduling of appointments ranged from three to four appointments in one day to appointments scheduled every other day. For example, the women whose baby was diagnosed with transposition of the great vessels and bilateral cleft lip had biweekly appointments for a non-stress test, weekly prenatal appointments with her obstetrician, weekly perinatology appointments and cardiology appointments every two weeks during her last trimester of pregnancy. Alma also experienced a significant amount of appointments in the latter part of her pregnancy:

We have been going to the perinatologist on Mondays usually, but this week it was Tuesday. Every week we see the perinatologist then we go to my OB on Wednesdays and Fridays and it’s been going well. They’ve been giving me non-stress tests with all those appointments that have ranged between half an hour to an hour. Then we get an ultrasound every two weeks with the perinatologist. Then they check my fluids every week with the perinatologist.

These women characterized the frequency and scheduling of appointments as overwhelming, and at times, difficult to coordinate. However, Paula preferred scheduling several appointments in one day.
The scheduling provided more days between appointments when she would have time for her usual activities, “On those days it’s just really overwhelming, but in between, I can lead a more normal life”. The appointments also gave the women piece of mind that their baby was growing and no other problems had developed.

The women who self-imposed their isolation reported that they did not want to feel pressured to answer questions about their pregnancy or their baby or they wanted to avoid people feeling sorry for them. Ana talked about her self-imposed isolation, “I keep to myself. I don’t want them asking me any questions. I don’t want to explain things about my baby or have people feeling sorry for me. It’s a private thing”. Two women isolated themselves because they wanted to limit their activities in order to minimize what they perceived as stress to the baby as a result of physical activity. Although none of their healthcare providers had advised them to limit their activity, these women believed that decreasing their activity would help prevent preterm labor. A few women reported limiting their interactions with others because of physical discomforts associated with advancing gestation. Some of the women were negatively impacted by this sense of isolation, regardless if it was by choice or not. Edith spoke about her isolation, “I’m feeling desperate, I’m alone in my house. I don’t go out. I don’t talk to anybody either. I feel bad like our whole life stopped completely”.

Of note, half of the women felt that they were at increased risk for fetal anomaly in advance of receiving the diagnosis. These women believed that they were at risk because of their advanced maternal age, social habits, a prior child with an anomaly, or their family’s history. Although they perceived themselves at risk, they were surprised when their baby was diagnosed. This was especially surprising for the women who had given birth to other children without an anomaly. Katherine recalled when she found out about her baby’s fetal anomaly, “I
was totally and completely surprised because my first pregnancy I had some swelling and some heartburn and that was it, no other problems”. Three of the women experienced a sense of guilt because they believed that it was their fault that the baby had the anomaly. This guilt was intensified for Ana whose best friend blamed Ana’s cigarette smoking for causing her baby’s anomaly; her friend told her, “What’s happening to him is your fault, it’s because of your lack of responsibility”. This caused Ana to feel distraught because she believed that she caused her baby’s anomaly, she eventually asked her healthcare provider if she had caused her baby’s anomaly. Although the healthcare provider assured her she did not, she was still convinced that she was responsible for the anomaly. Another woman, whose baby was diagnosed with gastroschisis, described her reaction to the baby’s diagnosis, “I experienced overwhelming anxiety because of me thinking it’s my fault, because it is from my side of the family”.

2. Navigating the diagnosis

For this study, navigating the diagnosis referred to how the women learned about and coped with the evolving fetal anomaly diagnosis. Pregnant women navigated the evolving diagnosis by actively seeking information, sharing the diagnosis with others, hoping and praying for the best, and seeking normalcy.

Women described how their baby’s diagnosis evolved throughout pregnancy. Ana stated, “Only a little bit of bowel was out so they’re kind of happy because it’s really almost towards the end of my pregnancy. I suppose things could be different in the weeks I have left”. Katie recounted her experience, “In the beginning, they made it seem like it wasn’t a big deal, like we might have seen something. We are going to schedule you for another ultrasound. Then, when they said we are sure, it’s urgent”. Katie further described her experience with an evolving
diagnosis, “My baby’s kidney condition is constantly changing”. During their pregnancy, many women had serial ultrasounds in order to monitor the progression of the anomaly or other complications. Katrina revealed, “They have still not confirmed about whether or not she has it, but with the last ultrasound, they think that they saw another fracture”.

In addition to changes in the fetal anomaly, other complications such as polyhydramnios, were sometimes discovered. Maria described her ultrasound examination, “The extra amniotic fluid cleared up, but the hygroma is still the same size, it hasn’t shrunk. But at least the extra fluid wasn’t there anymore”. Four women were advised to undergo an amniocentesis, after the initial fetal anomaly diagnosis. This was suggested to confirm the diagnosis, or to determine if the anomaly was associated with an aneuploidy. Three of the women decided against testing because they did not want to risk harm to their baby. The woman who agreed to the amniocentesis underwent the test because she wanted to know if her baby had any other problems; her baby had been diagnosed with a significant cardiac anomaly (transposition of the great vessels) after the initial cleft lip diagnosis.

Although the women received information about their baby’s fetal anomaly from their healthcare providers, the nine of the women actively sought more information. A commonly used source of information was the internet. Through the internet, the women accessed websites providing anomaly-specific information as well as information about support groups, on-line forums, and foundations. The internet was also used to connect to social media sites such as Facebook© and blogs. Alma recounted how she obtained information using social media, “I like going onto my mom’s groups, like on Facebook©, and reading about it. I could see what it was going to be like. I’d gotten myself the kind of backup information I was looking for”. Several women thought it would have been very helpful if they would have been able to talk to a woman
who had experienced a pregnancy complicated by the fetal anomaly that their baby had. Two women were able to meet families whose child had the fetal anomaly and they were able to get more information about their baby’s anomaly and they felt more assured that their baby would be okay. Although not specifically seeking information about the fetal anomaly, the primigravida women sought out childbirth classes or watched programs on television which featured women giving birth. They described needing information about labor and the birth so that they would know what to expect.

During their pregnancy, women chose who they shared the baby’s diagnosis with. Some women limited disclosure of the baby’s diagnosis to a select few. They told their friends and family about the baby’s diagnosis, but most did not reveal it to people they considered acquaintances, such as their coworkers. The women revealed that they wanted to avoid intrusion into what they considered a private matter. The intrusion would involve having to respond to questions they did not want to answer. Others limited the revelation of the anomaly because they didn’t want others to pity them. Some women also voiced their frustration when people did not understand the baby’s diagnosis and made comments which they perceived as minimizing the anomaly or the treatment. Katherine voiced her frustration:

Sometimes people have no idea about what all is involved, but they think they do. At least with the cleft, they don’t. They think that they just sew them up and everything is fine. Well, not really. So, I mean they are fine eventually, but there’s lot of little steps before.
Every woman described the support they received after deciding to continue their pregnancy. All described receiving support from their partners, even those partners who initially were unsure if the woman should have continued the pregnancy.

As Katie stated, “He embraced the joy and excitement of fatherhood”. Partners demonstrated their support through words of encouragement, helping with cooking and cleaning, and by accompanying the women to their prenatal appointments.

Seven of the women also reported receiving emotional support from their mothers during their pregnancy. Some stated that this support gave them strength and made them feel cared for. The two women who felt unsupported by their mother received support from their fathers. Katie described this support:

- My dad is my best friend. He was my rock in a way that I was not expecting so he has been a godsend. He was fully on board and supported me, whether it’s emotional or material, he has supported me…been my rock and so in moments when I don’t ...I didn’t know if my partner was going to be there or I’m just scared about my baby.

Three women reported feeling support from a parent who had passed away. They described how their deceased parent was a source of support and strength for them as they continued their pregnancy. Alma described connecting with her father:

- I even went to the cemetery to tell him (her father) I was pregnant, but he probably already knew that. I have gone there since then to tell him we are doing okay, that I was getting fatter so she was growing. I am a very religious person, and I know that I don’t need to go to the cemetery to be with him, but you feel a connection there.
Hope was a very important aspect of the pregnancy experience for all the women. They described several hopes they had throughout their pregnancies. Every woman described hoping for the best possible outcome for their baby. The prevailing hope was that their baby’s anomaly was not as severe as originally thought and that there were no additional complications. One woman recounted the following, “They don’t know exactly what is going to be wrong, so I’m hoping that whatever it is, it’s not as serious as they think it might be”. The women anxiously awaited news of improvement or no clinical deterioration with subsequent ultrasounds or meetings with the specialists. In some of the cases, a less severe anomaly meant that the baby would require less surgical intervention or medical treatment. Two women (fetal diagnoses: duodenal atresia and diaphragmatic hernia) also hoped to not deliver prematurely because they believed that their baby was getting “stronger” with each completed gestational week and would therefore have less complications.

Half of the women believed their baby would do well because of their faith and prayers. Paula spoke about her faith:

I’m a very religious person so I pray every night and every morning that she’ll be okay and I have to believe in my faith that everything will work out on its own. I know that God will hear my prayers and help my little baby.

Some of these women also believed that their faith in God would assure that the nurses and doctors would provide the best care to their baby. Of note, three of the women did not believe it was essential for them to meet with the neonatologist because they believed their baby would “be okay”. For the women whose baby would require surgery, they hoped there would be no complications during the surgical procedure or postoperatively.
All the women sought to normalize their pregnancies to some extent even though they perceived that their pregnancy was different. As Alma stated, “Everyone wants to be normal”. Maria also wanted a normal pregnancy, “I just want it to be like I was a normal pregnancy”. One of the women contrasted a “normal” pregnancy to her pregnancy, “It’s obviously different going three times a week compared to normal pregnancies that are once a week now”. One of the ways that the women sought to normalize their pregnancy was by participating in common pregnancy rituals such as a baby showers. Another woman described having ultrasound pictures taken at a pregnancy photography shop; she stated that many women are going to these photography shops to get ultrasound pictures for their baby album.

Others sought to normalize their pregnancy experience by not thinking about their baby’s diagnosis, either by actively avoiding thinking about it or passively by being distracted. Two women reported not thinking about the baby’s diagnosis on days that they were busy. This was in contrast to another woman who described trying to think positively and not think about the baby’s diagnosis.

Focusing on developmental milestones related to advancing gestational age and growth was another way women tried to normalize their pregnancy. It was important to the women to acknowledge what they considered normal about their baby. Several women described their baby as being strong which was fueled by their healthcare providers pointing out their baby’s normal physical characteristics such as the baby’s heartbeat. Alma stated, “I don’t know if I’d ever get through this if I didn’t try to see the positive side of this”.

The women also wanted to have a “normal birth” which they described as a vaginal birth at term. Maria stated, “I definitely want to do my delivery through the birth canal. I definitely
want to push”. The women were hoping that their baby’s condition would not require them to have a cesarean section, but were prepared to do so if it was safer for the baby. The women wanted to be treated the same way any pregnant woman without a fetal anomaly diagnosis would be treated.

3. Connecting with the baby

In this study, connecting to the baby was defined as the emerging relationship between the pregnant woman and her baby. All the women in this study described feeling emotionally connected to their baby. This connection was evident through their descriptions of seeing their baby on ultrasound, imagining or dreaming about the baby’s physical characteristics, naming their baby, knowing their baby’s sex, and noting fetal movement. The emotional connection was also evident in the women who feared that their baby would suffer; these were the babies who would most likely require surgical intervention after birth.

All the women reported having several ultrasounds and six of them described the baby’s characteristics they noted during the ultrasound. Ana described how the baby looked like her boyfriend:

She (ultrasonographer) printed out 3-D pictures. He (baby) looked just like xxx, my boyfriend. Just like him. Like he’s got big lips, so he’s got his lips, and his heart-shaped chin. So he’s got that. There’s also a picture where he’s like sort of thinking.

One of the women also described the baby’s behavior, “She’s active any time daddy is not around. Daddy comes around and she’s like okay. Maybe she feels more calm or something. She’s a daddy’s girl. She’s definitely like her mother”.
Laura talked about dreaming about her baby, “I have dreams about my baby, how she’s going to look. I think about me fixing her a bottle. I just can’t wait until she comes. I think about her almost every day. I can’t wait until she’s here.”

All the women, except two, had named their baby and knew the sex. Katherine did not want to know the sex of the baby because she wanted to be surprised at the time of birth as she had with her other child. Another woman, Alma, knew the sex of the baby, but did not want to name her baby because she thought it would bring them bad luck, “We decided not to name the baby yet in case she is listening and then comes early. We’re superstitious with that”.

Fetal movement was described by all the women as a pleasurable experience. Katie described her experience with fetal movement:

I can honestly say though that my favorite thing about being pregnant is watching my belly move. If he’s leaning more on this side, then my stomach is bigger this way.

It can look lopsided. When he’s moving, that’s the most connected I feel to him and that’s really wonderful.

Edith also enjoyed feeling her baby move, “Wow, my baby is moving (as she places her hand on her abdomen)! I didn’t know babies could do this. She is the most active at two in the morning”.

Love for their baby developed from feeling connected to their baby. All the women in this study acknowledged that they loved their baby. One woman stated, “I love her already and will do anything for her.” Because of their emotional connection and love for their baby, most of the mothers stated that they were willing to sacrifice themselves for their baby. Edith talked about how being there for her baby, “I have to be there for her and be strong for her. I can’t cry
because she will think there is something wrong with me. I just now have to man up and do what I got to do”. Some of the sacrifices involved restricting their usual activities or modifying their behavior such as stopping smoking. Katie stated, “I want to do what’s best for my child, no matter what”. Anita was also willing to modify her behavior in the interest of her baby, “I swear like a sailor, but I’m trying to get out of teenage phase and into mom phase with language and cut down the bad language”. Although the women were anxious about the birth, they were excited and looking forward to meeting their baby.

Another way that the women demonstrated a connection to their baby was by their concern for their baby’s wellbeing. All of the women whose baby would most likely require surgery feared their baby would suffer during the birth or soon after birth. Six of the women feared the baby would be injured or be in pain during the birth process. Anita, whose baby was diagnosed with gastroschisis, feared that her baby’s organs would be injured at the time of birth since the organs were outside the abdominal cavity. Anita stated, “I got scared because I didn’t know that babies could be born with their organs out. I thought that it was really dangerous”. They also feared that their baby would suffer during or after the surgical procedure. One woman conveyed her fear about the surgery her baby would undergo immediately after birth, “I think about her being in pain and I worry”. Katherine whose baby would require several surgeries stated, “I worry about what they will need to do for her and if she will be in pain. I even have nightmares about it. You know you want to protect your kid, and wish they didn’t have to suffer”. Ana also spoke about wanting to protect her baby:
After the baby is born either my mother goes with the baby or they have to do the surgery in front of me…if I can’t be there for that then I want somebody I trust to be there for my child because she will be brand new to this world and defenseless and doesn’t know what’s going on and I want somebody there older and wiser to see what’s going on.

One of the other women, Maria, was concerned about her baby suffering emotionally later in life:

The only thing I think about is that we live in Chicago where people are very cruel, and I need to deal with the fact that people tease kids with special needs. Just dealing with that is what I think about.

4. **Interactions with healthcare providers**

For this study, interactions with healthcare providers referred to the shared encounters pregnant women had with their healthcare providers which were perceived as supportive or unsupportive. Supportive is defined as “providing encouragement or emotional help” (Merriam-Webster Dictionary, 2015). In this study, supportive was defined as demonstrating a caring approach. The Oxford dictionaries define unsupportive as “not providing encouragement or emotional help” (Oxford Dictionaries, 2015). For this study, unsupportive was defined as demonstrating an uncaring approach. The women interacted with healthcare providers throughout their pregnancy experience; these interactions were perceived as caring or uncaring. Healthcare provider interactions were considered caring if communication was reciprocal, if the healthcare providers were perceived as being available, and if they provided encouragement. Anticipatory guidance during the pregnancy and preparation for birth were also perceived as being caring.
Caring interactions with their healthcare provider helped decrease the women’s fear, anxiety, and helped them cope. Whereas, uncaring interactions with their healthcare provider did not contribute to decreasing their psychological burden nor help them cope.

A caring approach by their healthcare provider was consistently regarded as important by the all the women. Alma described the importance of a caring approach by healthcare providers, “You can’t ask for people to care about you, you just hope that they do”. Caring was demonstrated in several ways by healthcare providers. Three of women remarked that healthcare providers showed that they cared by not appearing rushed during their appointments. One of the women recounted her experience, “He took time explaining things; I didn’t feel like we were being rushed”. Caring was also demonstrated through their choice of words and how they explained things. Katrina stated, “You know really, it’s like, it’s not really what you say but how you say it”. Caring was also evident to the women when they felt that their healthcare provider understood their situation and wanted to help them. Laura described her interaction, “I remember one of my doctors telling me – this is a hard situation, but I will help you through it – it was like she understood exactly what I was feeling”.

It was also considered an act of caring when the healthcare provider facilitated continuity of care. One of the women reported that her healthcare provider personally introduced her to the healthcare provider that would be covering for her while she was out of town; Katie described her experience:
My doctor won’t be here at my next visit, but she introduced me to the other doctor last time I went there and expressed that even though I will see a different doctor they will know what is going on with me and my baby and what the plan is for me. So that’s also really awesome, a really great connection.

Four of the women described how their healthcare providers’ caring went beyond their expectations. These unexpected acts of caring involved their healthcare provider coming unexpectedly to one of their other appointments, staying updated on their pregnancy while on vacation and retrieving test results from another provider. Katherine stated, “My doctor just showed up when I had my appointment with the pediatric cardiologist. That’s why I want to deliver with him, he’s incredible. Very caring, he came there to support me. I had no idea he was coming”. Another woman’s healthcare provider was texting his partner to inquire about the woman’s pregnancy status while he was traveling out of the country. Alma stated, “You do not go looking for that. That is something you will never get unless you have somebody that really cares”.

All the women concurred that a healthcare provider demonstrated caring when they facilitated reciprocal communication between themselves and the women. Reciprocal communication involved actively listening, assuring understanding, and eliciting and responding to questions. Actively listening was considered an essential component of reciprocal communication by every woman. Katherine described this as, “He was talking with us, not at us”.
Anita further described actively listening:

They treat you like a patient, but they do not talk at you. They have a conversation with you and treat you very friendly, but honest, and if there is something bad, they don’t sugarcoat it, but neither are they trying to scare you more.

The women expected thorough and straightforward information in an understandable manner. One of the women stated, “If I had trouble understanding something they would explain it in different ways so I could understand it. They made sure that I felt comfortable with what they were telling me”. Laura stated, “The doctors and nurses listen to me and they explain things to me more than one time if I need to hear it again. You know sometimes you’re unable to hear something because it’s too much”. Reciprocal communication also included answering the women’s questions; Katrina stated, “They do everything to the best of their ability to make sure that they give me the answers that I need and the answers they need I give them. We basically help each other going through this pregnancy”.

Although most communication was in-person, two of the women described communicated by texting or emailing their healthcare providers. One woman described texting conversations she had with the pediatric surgeon before her daughter was born. The women reported liking this type of communication because it was convenient and they got received quick responses from their healthcare providers.

Communication was also facilitated when the healthcare provider talked to the women about topics of conversation other than the fetal anomaly such as movies they had seen. Katherine described her conversation:
It really is just talking to me normally, like I’m a friend. Yes, talking to me about stuff that’s not always about the heart or always about the cleft. Like my husband and Dr. (perinatologist) had a conversation. We were talking about microarray and DNA so I just made a reference to the movie Gattaca. Dr. (perinatologist) and my husband just talked about Gattaca, you feel friendly, and like they are there to help you.

It was considered by the women to be a sign of caring when healthcare providers pointed out the normal structures or features of the baby. Some of the women reported that their healthcare provider would talk to them about the how strong the baby’s heart was or how well the baby was growing; they focused on the positive. Alma stated, “They have talked more about just trying to stay positive and that she is okay.”

Caring by their healthcare provider was also inferred if the women perceived them as being available to them. Healthcare providers were considered to be available if the women felt that they would be there for them when needed. Edith stated, “They helped me a lot because then it doesn’t put so much stress on yourself because it’s like you have somebody, that person can’t always be there but they will be there when you need them”.

Anticipatory guidance from the healthcare provider was described as being a caring approach and important by all the women. The women described receiving anticipatory guidance about the baby’s diagnosis and its implications, and the anticipated treatment. Alma described her experience, “They have supported us in more than just a medical way; they’ve supported us with understanding what’s happening”. Although their primary obstetric healthcare provider provided some information, the women also met, or were scheduled to meet, with other healthcare providers such as pediatric surgeons, advanced practice nurses, or
neonatologists. These meetings occurred as one-on-one meetings or as interdisciplinary team meetings. Although the two women who participated in the interdisciplinary meeting found it informative, one woman found it overwhelming and intimidating. She stated that having so many people in the room, not the information provided, contributed to making her feel overwhelmed. Only three women reported getting guidance regarding their delivery options. One woman stated that she was directed to prenatal classes offered at the hospital.

Since it was anticipated that the babies would require admission to the neonatal intensive care unit (NICU), most of the women were offered a tour of the unit. Four of the women went on a tour of the NICU; however, the women responded differently to the tour. Alma described her experience as very informative and helpful:

They took me to the NICU today and I talked to one of the nurses there as to what happens, what she will do, what are the visiting hours, just what it is like in there. That has helped paint a picture in my head as opposed to knowing NICU is over there and I don’t know. Actually seeing it, you feel comfortable with what is going to happen.

However, two women found the NICU tour helpful, but upsetting because it brought their baby’s anomaly to the forefront. Katherine was one of the women who described the NICU tour experience as upsetting, “It was really emotional going to the NICU, I immediately started crying. It made it all the more real. Like oh, there’s an issue”.

According to the women, their healthcare provider also demonstrated caring when they encouraged the women. Some women stated that their healthcare provider gave them encouragement when they related stories about other babies who were born with a similar anomaly and had good outcomes. Alma related her conversation with her healthcare provider:
They actually tell you stories about their lives, their kids, or people they know, not to make you think that we don’t care about you, but to make you think about other things and relate how others have made it through and come out stronger in the end.

Other women described receiving words of encouragement; Katy stated, “When the nurse sensed that I was upset about the circumstances about my baby, she told me everything would be okay...just because it’s hard now it doesn’t mean it’s going to be hard forever”.

Women described developing a sense of trust in their healthcare provider. Alma stated, “I have faith in the doctors and nurses”. They trusted that their healthcare provider would be there for them when they needed them, that they would provide the best and safest care, and “were on top of everything”. The women also trusted the consultants their healthcare providers had recommended because of the trust they had in their healthcare provider.

Women reported that caring interactions with their healthcare provider helped decrease their fear, “They made me less afraid because they’ll be there”, their stress and anxiety. Anita stated, “It was like a weight had been lifted off our shoulders”. Their healthcare providers also helped them cope. Alma described her thoughts about her healthcare provider, “I feel like it’s not just a doctor patient relationship, I feel like they care. That has helped us too with lessening the anxiety and stress”.

In addition to describing caring interactions, the women revealed some uncaring interactions they had with their healthcare providers. Not addressing a woman’s emotional needs was considered uncaring by the majority of the women. Seven of the women conveyed that their healthcare providers did not provide guidance related to the emotions they might experience as they continued their pregnancy. Of note, several women revealed that they did not mention their
labile emotions to their healthcare providers since the healthcare provider had not asked about their emotional state. One of the woman remarked, “No one’s really talked to me about emotionally how I’ve been feeling. Talking about my worries and my feelings with my doctors would help decrease my anxiety”. Katie reported that her emotions were “swept under the table” and subsequently not discussed or addressed:

I really think talking about the emotions is very important because I did not see it coming and it was like a harsh reality. Instead of saying when you start to feel upset go lay down, go to a calm place, things like that because I found myself in situations which I could have avoided had I known that I was about to lose complete control of my senses.

Other uncaring interactions included when the healthcare provider appeared hurried or used insensitive terms; Laura recounted her interaction with a healthcare provider:

The only thing that bothered me was when one of the doctors I met with very coldly told me that my daughter would be retarded. I was upset. I found it offensive and hurtful. I realize that my baby may have some intelligence problems, but she could be okay too. But it was the cold, uncaring way he stated it.

Women considered it to be uncaring when the healthcare provider’s focus was different than theirs. Katherine felt that a lack of congruence between her focus and that of her healthcare provider:

It’s been tough because I found out about the cleft first and then we found out about the heart. Everything’s been so heart centered that I’ve been really anxious about the cleft and all the things that go with it. Yes, the heart is important, but the cleft is very important too.
One of the women hospitalized due to preterm labor endured uncaring interactions with two healthcare providers whose focus was also not congruent with her needs or expectations. Ana recounted how the nurse caring for her did not follow through with her promises and was insensitive to her needs. She also described an uncaring interaction she had with the on-call physician; Ana wanted to leave the hospital against medical advice because she was worried about a situation regarding her boyfriend. She described her conversation with the physician:

(The physician said) if you leave right now, your baby will die. I started crying harder. I was like why would you say that to me? I was so sad, I was freaking out. She could have been like, you know if you leave something might happen to the baby. She could have said that. Not your baby is going to die. That really broke my heart. She was cruel.

Two of the women reported not receiving guidance from their healthcare provider regarding the activities they should avoid during pregnancy because of the baby’s anomaly. They worried that unknowingly they would harm their baby by participating in their usual activities. Edith stated, “I see pregnant girls running and doing a lot of other things. I don’t know if I can do those things. What if I injure my baby? The little things I do, I’m like whoa, I shouldn’t do that”.

The primigravida women expected to receive information regarding labor, the birth and hospital procedures, but most reported that they did not receive this information. Anita stated, “There are a few other things I probably need to know because I’m a first time mom. Most of our conversations are about my baby which is good, but I have no experience with pregnancies and deliveries”. Edith voiced similar concerns, “I want to know how they are going to get me
into labor. I don’t know what’s going to happen. This is all new for me, I’ve never been pregnant”.

Another example of an uncaring interaction was when there was a mismatch between the healthcare provider’s words and actions. An example of this was described by one of the women who was told that her baby’s condition required an immediate consult, but the consult appointment was scheduled for several weeks later. Katie stated, “I felt like I was in a giant soap opera. I feel like their actions don’t match their words. Why would you call me and say that you want to schedule me right away, and then three weeks elapse”.

Although not considered uncaring, some of the women wished their healthcare provider would have introduced them to or directed them to a family who had given birth to a baby with a similar anomaly. The women would have liked the opportunity to ask the mother questions about their pregnancy experience and the fetal anomaly. Alma stated, “I wish I would have had someone that I could have talked to who had gone through something like I am going through. I think it would have helped me freak out less”. The women thought meeting the families would give them an opportunity to verify that the baby, with a similar anomaly, had a good outcome.
V. DISCUSSION

This study was undertaken to describe the experiences of women who continued their pregnancy after a fetal anomaly diagnosis, to explore the nature of the support provided by healthcare providers and to understand the extent to which their healthcare providers met their needs and expectations as they continued their pregnancy and prepared for the birth. The findings confirm some previously described findings in regards to women continuing pregnancy after a fetal anomaly diagnosis and healthcare provider support. However, there were some findings from this study that were not found or not well described in the literature or conflict with findings from previous research. A discussion of these findings is presented below according to the four themes that emerged from the data: becoming vulnerable, navigating the diagnosis, connecting with the baby, and interacting with healthcare providers. Although the findings were presented according to the four distinct themes, there is some overlapping of the themes because of the interrelatedness of these women’s experiences.

A. Becoming Vulnerable

For this study, becoming vulnerable was defined as increased susceptibility to psychological injury. Labile emotions (Cote-Arsenault & Denney-Koelsch, 2011), a sense of isolation (Chaplin et al., 2005; Cote-Arsenault & Denney-Koelsch, 2011; Redlinger-Grosse et al., 2002), and perceived increased risk for fetal anomaly (Cote-Arsenault & Denney-Koelsch, 2011; Helm et al., 1998) contributed to the pregnant woman becoming vulnerable have been described in previous research. Cote-Arsenault and Denney-Koelsch’s (2011) study of parents who received a life-limiting fetal diagnosis findings revealed that some of their participants experienced labile emotions, a sense of isolation, and a perceived risk for fetal anomaly.
The congruency in findings with the Cote-Arsenault and Denney-Koelsch’s study suggests that becoming vulnerable is part of the experience for pregnant women diagnosed with fetal anomaly diagnosis regardless if the baby’s diagnosis is life-limiting or not life-limiting.

However, in contrast to the findings by Cote-Arsenault & Denney-Koelsch, the participants in this study self-imposed isolation. The women actively isolated themselves in order to avoid answering questions. As their isolation increased so did their frustration with the isolation. A possible explanation for the women’s isolation becoming more pronounced was that their pregnancy became more noticeable, possibly inviting more questions. The discomfort experienced by pregnant women subjected to questions by others has been described in previous research (Smith, Dietsch, & Bonner, 2003). Smith et al. interviewed women whose baby was diagnosed with a serious or lethal fetal anomaly; from their findings, they postulated that women become vulnerable when they are faced with answering questions about their pregnancy. It was noted that the women’s isolation became more pronounced from the first to the second interview.

Some women isolated themselves when they decreased their activities in order to decrease the risk of preterm labor. Of note, two women isolated themselves by staying home to minimize their activity level, fearing preterm labor even though their healthcare providers did not advise them to decrease their activity. These women’s actions may suggest that they continued to feel at risk even when their healthcare providers did not perceive them to be at risk. This is noteworthy as healthcare providers may consider looking for clues that there is lack of congruence between the healthcare provider’s and the woman’s assessments and management plans. Divergence between the healthcare provider and the pregnant woman could lead to care that does not meet the woman’s needs (Walker et al., 2008).
Based on the findings of this study, it is important to assess if the women are experiencing social isolation. Chaplin et al. (2005) discovered that even though women experienced isolation during pregnancy, they did not seek out other’s support. The healthcare provider could actively listen to the women’s concerns that led to the social isolation and then suggest some strategies to deal with their concerns and help them overcome their social isolation.

Half of the women in this study perceived themselves to be at risk for fetal anomaly, but were still surprised when the anomaly was discovered. This finding is in contrast to the findings by Lalor et al. (2009) because all of the women in their study were also surprised with the diagnosis, but none perceived themselves to be at risk for fetal anomaly. This difference in perception of risk could be due to the personal characteristics of the women or possibly differences related to being socialized in Ireland versus the United States.

B. **Navigating The Diagnosis**

For this study, the navigating the diagnosis theme refers to how the women learned about and coped with the evolving fetal anomaly diagnosis. Learning about the diagnosis was very important to the women in this study indicating a need for additional information and resources for these mothers. All women sought information beyond that provided to them by their healthcare providers. This need for additional information by pregnant women with a fetal anomaly diagnosis has been well described in the literature (Askelsdottir et al., 2008; Chaplin et al., 2005; Hedrick, 2005; Helm et al., 1998; Lalor, Devane, & Begley, 2007; Lalor, Begley, & Galavan, 2009; Nusbaum et al., 2008; Redlinger-Grosse et al., 2002; Tymstra et al., 2004).
As technology within the field of prenatal diagnosis has evolved, so has the technology related to information and communication sources. Some women in this study used the internet to access information from websites or through social media platforms such as blogs and Facebook®. This finding is comparable to the findings from a recent study by Lewallen and Cote-Arsenault (2014) which examined internet practices among childbearing women; their findings revealed that childbearing women used the internet to obtain pregnancy, breastfeeding, and parenting and health-related information and to learn about the experiences of others through social media sites. The social media sites allowed them to connect to other pregnant women or mothers (Lewallen & Cote-Arsenault). However, in contrast to the Lewallen and Cote-Arsenault study, the women in this study used the internet not only for obtaining pregnancy-related information, but also to obtain information about fetal anomalies (Askelsdottir et al., 2008; Chaplin, Schweitzer, & Perkoudis, 2005; Hedrick, 2005; Lalor et al., 2007; Maijala et al., 2003; Nusbaum et al., 2008) and to connect with mothers with a child with a similar anomaly.

Connecting with others using these social media platforms allowed for passive and active sharing of information of fetal anomalies. It is important to consider that face-to-face contact with support groups may, in some instances, be replaced by online support groups which may contribute to the social isolation of some women. Social media sharing of fetal anomaly information has not been well described in the literature which merits further investigation. Some of the women in this study expressed the desire to meet families who had a child with a similar fetal anomaly. Those who did not meet families through their families or friends, connected with families through social media available through the internet. This suggests that pregnant women want information about a fetal anomaly from someone who has lived through a similar experience. The results of this study also suggest that women want more information or
different type of information than is currently being provided by their healthcare providers. The information may come from sources which may be outside the purview of the healthcare provider. Furthermore, these information sources may or may not provide accurate information or may not concur with the healthcare provider’s plan of care. It is important for the healthcare provider to assess the information needs and inquire about sources used for obtaining information. The healthcare provider could suggest appropriate websites as warranted.

Helm et al. (1998) reported that connecting with other families served as a form of support in addition to being a source of information. This finding was supported by a study conducted 20 years later by Nusbaum et al. (2008). Although the women in this study did not state that families with a child with a similar anomaly would be a source of support for them, they may experience a sense of support after interacting with them. After assessing if the pregnant woman desires to connect with families who have a child with a similar diagnosis, the health care provider could help facilitate that connection by suggesting specific organizations, social media sites, or known families. Redlinger et al. (2002) reported that anomaly specific organizations were helpful.

In addition to learning about the fetal diagnosis, primigravida women wanted to learn about the birth process and hospital procedures they would encounter when giving birth. The women were given quality information about their baby’s diagnosis and the baby’s management plan, but did not learn about what they felt they need to know when they were admitted to the hospital to give birth. What they felt a lack of was what to expect upon admission, labor and their management plan. This is significant because primigravida women’s learning needs related to preparing for birth were not met; a potential factor contributing to this issue was an increased focus on the baby and preparation for his needs as it related to his anomaly. The need for this
education became more pronounced by the second interview which is understandable because they were closer to their due date. In addition to facilitating education about the baby’s anomaly and management plan, healthcare providers also need to facilitate education for primigravida women such as learning about the birth process.

Another way the women in this study navigated the diagnosis was to decide who they would inform of their baby’s diagnosis. Women described trying to avoid unwanted questions, comments, and pity. The seminal study by Chitty, Barnes, and Berry (1996) revealed that women who had a fetal anomaly diagnosis were uncomfortable with common pregnancy remarks or inquiries made by the other women in clinical settings; some women were seen by their healthcare provider outside the usual clinic hours in order to shield the women from these uncomfortable situations. In contrast to Chitty et al. findings, the women in this study took a more active role in shielding themselves from unsolicited remarks or inquiries rather than depending on the healthcare provider to protect them. It could be inferred from this finding that the women limited sharing their baby’s diagnosis as a way of protecting themselves from others remarks.

Support from others was identified as essential to the women in this study as they coped with their baby’s diagnosis (Astedt-Kurki, Paavainen, & Vaisanen, 2003; Hedrick, 2005; Maijala et al., 2003; Nusbaum et al., 2008). However, what has not been well described in the continuation after fetal anomaly diagnosis literature was coping by feeling supported and receiving strength from a deceased family member. Three of the women described how their deceased parent was a source of support and strength for them as they continued their pregnancy. Although no fetal anomaly studies were found regarding this phenomenon at the time of this thesis, a Danish study reported that one of the ways cancer survivors coped with their condition
was through the bond they had with a deceased relative which was described as “empowering and supportive” (Hvidt, Iversen, & Hanson, 2013, p. 726). Feeling supported and a sense of strength from their deceased parent could suggest that in life, the parent played a very important role in the woman’s life and helped them cope with past stressors. This finding is significant because it underscores the importance of assessing pregnant women’s coping strategies and being aware that some may have unique coping strategies. It is known that healthcare providers play an integral role in supporting the pregnant woman’s coping (Chaplin et al. 2005; Maijala et al., 2003). Interestingly, by the second interview these women did not talk about their deceased parent, but rather spoke more about their healthcare providers and the care and support they provided them. It could be inferred that the source of support was transferred from the deceased parent to the healthcare provider.

Hope was an important feature of navigating the diagnosis. All the women in the study hoped for the best outcome for their baby. This finding is well supported in previous studies (Chaplin et al., 2005; Chitty et al., 1996; Lalor et al., 2009; Miquel-Vargas et al., 2009; Redlinger-Grosse et al., 2002; Spinnato et al., 1995). In addition to hoping for the best, half of the women reported their faith played a significant role in helping procure the best outcome for their baby. The role of faith in helping women cope with a fetal anomaly diagnosis has also been well described in the literature (Maijala et al., 2003; Redlinger-Grosse et al., 2002; Senanayake et al., 2006; VanPutte, 1988). However, it is important to note that three women in this study did not meet with the neonatologist prenatally because they believed that their baby would be “okay”. These findings suggest that while some pregnant women use hope as a way of coping, other pregnant women may exhibit hope through faith and may not come to scheduled neonatology appointments because they have faith that their baby will be not need neonatology
care. This may also be a form of denial that their baby has a fetal anomaly (Cote-Arsenault & Denney-Koelsch, 2011). This finding underscores the need for the healthcare provider to assess why the pregnant did attend a meeting with the neonatologist.

Another way the women coped with the fetal anomaly diagnosis was by seeking normalcy (Askelsdottir et al., 2008; Redlinger-Grosse et al., 2002; Walker et al., 2008). The women in this study sought to normalize their pregnancy by participating in common pregnancy rituals (Redlinger-Grosse et al., 2002), avoiding thinking about the diagnosis (Redlinger-Grosse et al.) and by focusing on developmental milestones (Askelsdottir et al., 2008). Walker et al. reported that women also appreciated when physicians helped promote normalcy by focusing on fetal characteristics such as fetal movement. It could be suggested that seeking normalcy was an important way of coping with the fetal anomaly diagnosis because it took the focus off the anomaly and instead directed the focus on the baby. Unique to this study is one pregnant woman who had ultrasound pictures taken at a non-medical pregnancy photography shop. Although only one woman reported using this service, it may indicate that this is a technology that is starting to be introduced to the public and may be a form of coping. There are ethical implications associated with this type of technology such as the lack of qualified professionals at the photography shops to assist the woman in the event of fetal demise or other unexpected situations when the woman presents for her “baby pictures”. Since this technology is beginning to gain popularity, it would merit some research in this area so as to better understand how it impacts the pregnancy experience.
Navigating the diagnosis also involves coping with a diagnosis which was evolving in nature. The “evolving diagnosis” phenomenon not only included the fetal anomaly diagnosis (Chaplin et al., 2005; Lalor et al., 2009; Sandelowski & Jones, 1996), but also involved maternal complications associated with the anomaly such as polyhydramnios, excess amniotic fluid associated with some fetal anomalies. An “evolving diagnosis” may suggest that pregnant women with a fetal anomaly diagnosis are at increased risk for stress because of the changing nature of the diagnosis (Lalor et al., 2009) and its associated uncertainty. Healthcare providers may want to assess women closely for stress levels during routine prenatal visits especially women who develop complications or their baby’s condition worsens.

C. Connecting With The Baby

Connecting with the baby refers to the emerging relationship between the pregnant woman and her baby. All the women in this study described loving and feeling emotionally connected to their baby. This connection appeared to be stronger from the time of the first interview to the second interview. The women were willing to sacrifice themselves for their baby (Maijala, 2003) because of their emotional connection and love for their baby (Hedrick, 2005). Maijala (2003) and Hedrick (2005) reported that the women sought to optimize their health in order to provide the best environment for their baby. These findings are consistent with this study, as women also sought to optimize their health for the sake of their baby. For example, one woman stopped smoking, even though it was a great sacrifice to stop. Some women reported wishing that their baby got bigger because they believed this would improve their outcome at birth. This finding is consistent with Hedrick’s (2005) study involving women diagnosed with a non-lethal anomaly. Askelsdottir et al. (2008) proposed that connecting to the baby during pregnancy might be compromised following the fetal anomaly diagnosis. One of
the women in their study, whose baby was diagnosed with a non-lethal condition, reported that she had to process the diagnosis before she could think of her unborn baby as a person (Askelsdottir et al., 2008; Hedrick, 2005; Maijala et al., 2003). In contrast to the findings by Askelsdottir et al., (2008), all the women in this study spoke about the emotional connection they had with their unborn baby. This emotional connection to their baby was also evident by the women who feared that their baby might suffer (Maijala et al., 2003; Sandelowski & Jones, 1996; Spinnato et al., 1995).

Another way that the connection to their baby was evident was by the women knowing the sex of her baby and by naming the baby. This finding supports previous research (Hedrick, 2004). In Hedrick’s study involving women diagnosed with a non-lethal anomaly knew the sex of their baby and had given their baby a name. Their connection to their baby was also apparent when they reported that they were willing to sacrifice themselves for their baby. Prior research also supports the findings of this study regarding the willingness of the women to sacrifice themselves for the sake of their baby (Hedrick, 2004; Maijala et al., 2003).

D. **Interactions With Healthcare Providers**

For this study, interactions with healthcare providers refers to the shared encounters pregnant women had with their healthcare providers which were perceived as supportive or unsupportive. Supportive was defined as demonstrating a caring approach and unsupportive as demonstrating an uncaring approach. The data from this study suggests that interactions with healthcare providers impacted the pregnancy experiences of women who continued pregnancy after a fetal anomaly diagnosis. Caring interactions with healthcare providers helped facilitate the women’s coping with the fetal anomaly diagnosis as they continued the pregnancy and
prepared for the birth (Chaplin et al., 2005; Detraux et al., 1998; Maijala et al., 2003). Whereas, uncaring interactions did not contribute to lessening the pregnant women’s psychological burden nor help them as they continued their pregnancy and prepared for the birth (Chitty et al., 1996; Helm et al., 1998; Maijala, 2003; Redlinger-Grosse et al., 2002). Caring was demonstrated through the healthcare provider’s communications, availability, anticipatory guidance, encouragement, and congruence with the pregnant woman’s needs and expectations.

There are two areas that have not been well described in the literature – anticipatory guidance related to emotions and unexpected acts of caring. Although all the women described feeling changing, and often intense, emotions throughout the pregnancy, the majority of healthcare providers did not provide anticipatory guidance about these emotional changes (Schuth, Karck, & Reisch, 1994). In one case, the healthcare provider appeared to downplay the emotions experienced by the pregnant woman. This is a significant finding because women look for guidance and support from their healthcare providers during pregnancy; this may take on a greater significance with a fetal anomaly diagnosis. This finding underscores the need for healthcare providers to inquire about the woman’s emotions, look for clues that might signify emotional distress, and provide anticipatory guidance related to emotions related to pregnancy diagnosed with a fetal anomaly.

In addition to anticipatory guidance related to emotions, all except one primigravida woman identified that the healthcare provider did not provide or direct them to education related to childbirth and hospital procedures. This is a significant finding as all the healthcare providers provided or facilitated education regarding the baby’s anomaly and management, but did not give information that a pregnant woman without a fetal anomaly diagnosis may have received. This might be related to the focus being on the fetal anomaly, not the pregnancy.
Askelsdottir et al.’s (2008) findings support this assumption; women in their study reported feeling that the healthcare provider’s attention was directed towards the anomaly and not the pregnancy. It is important for the healthcare provider to assess learning needs and facilitate the education to meet those needs.

Another area not well described in continuation of pregnancy after a fetal anomaly diagnosis studies was the unexpected acts of caring by health care providers (e.g. coming unannounced to one of the women’s consultation appointment, contacting partner to inquire about the status of the pregnant woman while on vacation) reported by three of the women in this study. These unexpected acts of caring had great meaning for the women as they felt that these actions demonstrated that their healthcare provider genuinely cared about them and their wellbeing. This is significant because it identifies how a small act by a healthcare provider can have such a significant impact on the women potentially helping them cope and feel supported.

Another significant finding from this study was the incongruence between what the pregnant woman and the healthcare provider viewed as important. For example, healthcare providers appeared to place a greater focus on one baby’s cardiac anomaly and less of a focus on the baby’s facial anomaly. Given the gravity of the cardiac anomaly in terms of requiring possibly immediate surgical intervention after birth, it was understandable that greater focus would be given to assessing the extent of the cardiac anomaly and developing a plan. However, the pregnant woman was more concerned about the ramifications of the facial anomaly such as breastfeeding challenges; she was stressed and anxious about not getting the same amount of information and attention as the cardiac anomaly. This reveals that although as healthcare providers realize that some anomalies are more significant because of the gravity of the anomaly, the pregnant woman may not view the anomaly at the same significance level as the healthcare
provider. Although this concern was expressed by only one of the women, it has implications for healthcare providers who may provide care for pregnant women whose baby was diagnosed with multiple anomalies. This finding underscores the importance of healthcare providers inquiring as to the concerns the women have regarding their baby’s anomalies.

Walker et al.’s (2008) study findings suggested that divergence between the healthcare provider and the pregnant woman could lead to care that does not meet the woman’s needs. Similar to Walker, et al.’s findings, the pregnant woman in this study needs for information and guidance were not met.

Other investigators have identified that a prenatal meeting with the neonatologist (Aite, Trucchi, Nahom, Zaccara, La Sala, & Bagolan, 2003; Miquel-Vargas et al., 2009; & Paul, Epps, Leef, & Stefano, 2001) and a tour of the NICU (Griffin, Kavanaugh, Soto, & White, 1997; Miquel-Vargas et al., 2009) were beneficial when a NICU admission is expected. However, one of the women found meeting with the neonatologist, as part of an interdisciplinary team, overwhelming and two women reported the NICU tour was very upsetting and therefore, not helpful. It should be noted that the NICU tours offered at both hospitals in this study were comparable; at each hospital there was a designated healthcare provider who provided the tour. Although healthcare providers offer these options because they believe they will be informative and prepare women for post-birth reality, findings from this study suggest that it may not help some women. Healthcare providers need to assess if the women desire these approaches and are emotionally prepared for them. If the women decline these approaches, healthcare providers need to look for alternative approaches or consider deferring the discussion to a later time.
Another noteworthy finding was the use of “texting” to communicate with healthcare providers. Although only two women described communicating with their healthcare providers in this fashion, there is the potential that this phenomenon might increase as more people use “texting” as a form of interactive communication with others, including healthcare providers. According to the findings from the Pew Research Center’s Internet and American Life Project, 67% of adults who own a mobile telephone use text messaging (Weaver, Lindsay, & Gitelman, 2012). The other women in this study may not have used “texting” to communicate with their healthcare provider because of the woman’s or healthcare provider’s communication preference. Communication takes on a different dimension when there is a possibility of having questions and concerns answered almost instantaneously and having someone supportive available when needed. Healthcare providers need to assess the woman’s communication preferences. This type of communication has implications for both the healthcare provider and the pregnant woman which merit learning more about through research. Research is needed to assess the advantages and disadvantages of “texting” and the impact of “texting” communication on the experiences of women pregnant with a fetal anomaly diagnosis.

The caring behaviors demonstrated by the healthcare providers, as reported by the women in this study, were similar to the caring behaviors described in Swanson’s Theory of Caring (Swanson, 1991). Swanson identified five caring processes: knowing, being with, doing for, enabling, and maintaining belief (Swanson). Several examples illustrating Swanson’s caring processes (1991) were described in this study.

The first caring process, “knowing” was defined by Swanson as the attempt to appreciate the significance a situation has in a person’s life. “Knowing” was evident when the women reported feeling that their healthcare provider understood their situation and wanted to help them.
Being with as described by Swanson (1991) infers that there is a reciprocal relationship between the healthcare provider and the woman; in this relationship, they share their thoughts and feelings. Health care providers in this study demonstrated “being with” when they facilitated reciprocal communication between themselves and the women. Reciprocal communication involved actively listening, assuring understanding, and eliciting and responding to questions.

Doing for others refers to performing things for others that they are unable to do for themselves (Swanson, 1991); “doing for others” was evident when the healthcare providers facilitated continuity of care. One woman reported that her a health care provider personally introduced her to the health care provider who would be caring for her patients while she was out of town.

Enabling was described by Swanson (1991) as guiding others through changes and complex times. Anticipatory guidance from the healthcare provider exemplified “enabling”. The women in this study described receiving anticipatory guidance about the baby’s diagnosis and its implications, and the anticipated treatment.

The last caring process, “maintaining belief” includes maintaining a hope-filled attitude and offering optimism (Swanson, 1991). Caring was demonstrated when healthcare providers pointed out the normal structures or features of the baby instead of just focusing on the anomaly. Another way this caring process was evident was by the health care providers encouraging the women to stay positive.
The caring behaviors demonstrated by the healthcare providers, as reported by the women in this study, support Swanson’s Theory of Caring (Swanson, 1991). Although the caring processes described by Swanson were about the nurse’s relationship with her patient, it could be extrapolated to describe the relationship between other healthcare providers and their patients. Swanson’s theory may prove helpful when used to design research which examines health care provider interactions.

Lastly, although it was not one of the aims of this study, the findings from this study lend support to Lalor et al.’s *Recasting Hope* theory. *Recasting Hope* identifies four phases of the adaptation after fetal anomaly diagnosis: assume normal, shock, gaining meaning, and rebuilding (Lalor et al., 2009). However, it should be noted that there were also some study findings that were not reflected in the *Recasting Hope* theory.

In the first phase of *Recasting Hope* “assume normal”, pregnant women believed everything would be fine with their baby because they had not perceived themselves to be at risk (Lalor et al., 2009). The findings from this study validate that the women were not anticipating being diagnosed with a fetal anomaly. However, in contrast to *Recasting Hope*, five of the women in this study perceived themselves to be at risk for fetal anomaly, but were still surprised with the fetal anomaly diagnosis.

The second phase of *Recasting Hope* “shock” describes the manner in which the pregnant women found out about the fetal anomaly and their reactions to this discovery (Lalor et al., 2009). The descriptions from the women in this study reflect the shock phase as described in *Recasting Hope*. For example, women reported finding out about the diagnosis and their reactions to the diagnosis.
In the third phase of *Recasting Hope*, “gaining meaning” women obtained confirmation and coped with the fetal anomaly diagnosis as well as made a decision about continuing or terminating the pregnancy (Lalor et al., 2009). There were several aspects of the “gaining meaning” phase which were evident in this study. For example, the women described positive and negative interactions with health care providers, coping mechanisms, and additional testing. However, self-imposed isolation, which was reported by some of the women in this study, was not described in the “gaining meaning” phase. Another finding particular to the findings of this study, which was not included in *Recasting Hope*, was some women feeling supported by a deceased parent.

The last phase of *Recasting Hope*, “rebuilding” describes how the women’s goal transformed from having a healthy baby to hoping for the best outcome for their baby; this phase also involves recognizing that the fetal anomaly has impacted their lives and their thoughts about the future (Lalor et al., 2009). All the women in this study reported desiring the best outcome for their baby given their specific situation. The women also described how their baby’s anomaly would impact their lives. However, none of the women in this study talked about future pregnancies.

In conclusion, the findings of this study support *Recasting Hope* as framework to understand the experiences of women adapting following a fetal anomaly diagnosis. Some of the findings from this study may serve to build on this framework as they were not described in *Recasting Hope*. However, more studies are needed to validate these findings.
E. **Study Limitations**

There were some limitations in this study. One of the limitations was the sample included only one woman who was diagnosed with a potentially life-limiting fetal diagnosis. The woman whose baby was diagnosed prenatally with osteogenesis imperfecta had declined genetic testing so the actual diagnosis was unknown. Based on clinical findings osteogenesis imperfecta was diagnosed, but genetic testing was needed in order to confirm the diagnosis. The themes identified may have been different if women with a life-limiting diagnosis had been more represented in this study. The women were recruited from two Midwestern high-risk obstetric medical centers; this might present geographical bias. Another limitation was that the interviews occurred during the prenatal period so the experiences captured were those prior to the birth of the involved fetus. However, the objective of this study was to ascertain the women’s experiences during pregnancy; if the women would have been interviewed after the birth, the pregnancy experiences might have been remembered differently. One of the strengths of the study was the socioeconomic and racial/ethnic diversity of the participants. There was also a diverse age group represented in the study. This diversity may have contributed to some of the differences in their experiences. Although the study results are not meant to be generalized, the study did add to the very limited research in this area and enhanced understanding of these experiences.
F. **Implications For Practice Summary**

This study revealed some implications for practice for healthcare providers involved in caring for pregnant women who continue pregnancy after a fetal anomaly diagnosis. The fetal anomaly diagnosis is a stressful event provoking unpleasant emotions which can profoundly impact the pregnant woman at the time of diagnosis and throughout the pregnancy. However, the findings from this study illustrated the importance of the healthcare provider in helping women cope with the fetal anomaly diagnosis. There are several ways the healthcare provider can positively impact the women’s experience and help them cope during this time. One way is to help normalize the pregnancy by pointing out baby characteristics or behavior that are normal. Healthcare providers also need to inquire about the women’s emotional state including stress levels, sense of isolation, and coping strategies. It is important to consider that some women may not reveal their emotions or stress levels so the provider would need to look for cues suggestive of emotional distress. It was also revealed that women have many educational or informational needs as it relates to her baby, her pregnancy and her preparation for the birth which need to be assessed. Providing or facilitating anticipatory guidance regarding emotions is important for all women and childbirth and hospital procedures education for primigravida women. The healthcare provider also needs to inquire the woman’s thoughts about her baby’s anomaly and her pregnancy, keeping in mind that her focus may differ from the healthcare provider’s focus. Lastly, although interdisciplinary team meetings and NICU tours have been described as beneficial, it is essential to assess the woman’s receptivity before scheduling these activities. The counseling approach needs to be tailored to the individual. As each pregnancy differs, so do the needs and expectations of the women.
G. **Implications For Research Summary**

Some implication for future research became evident from the results of this study. There are a lack of studies examining coping with fetal anomaly by continued bonds with a deceased parent. Another area to consider for further studies is the use of social media for connecting with women or families with a child with a fetal anomaly. The impact of using these social media by women diagnosed with a fetal anomaly has not been well examined. “Texting” as a mode of two-way communication between the pregnant woman and her healthcare provider also warrants further investigation. Lastly, future studies needs to include a more racially and ethnically diverse sample as these women are underrepresented in research involving the experiences of women diagnosed with a fetal anomaly.
APPENDICES
APPENDIX A

Obstetric-demographic questionnaire

Continuing A Pregnancy Following A Fetal Anomaly Diagnosis Study

Demographic and Obstetric Information

Note: you may leave blank any information that you do not wish to answer

1. Today’s Date ______/_____/____
   Month/Day/Year

2. Your Age ________________ Years

3. Highest grade of school completed
   
   Circle the appropriate response
   
   Elementary/High School Grades  College/Years of School
   01 02 03 04 05 06 07 08 09 10 11 12  13 14 15 16 17+

4. Taking into consideration all sources of income, what is the total family income before taxes? $ ________________

5. Which of the following best describes your present relationship status?
   
   Circle the appropriate response
   1. Living with a partner  4. Separated
   2. Never married  5. Divorced
   3. Married  6. Widowed

6. How would you describe your ethnic or racial background?
   
   Circle all that apply
   1. White
   2. Black/African American
   3. American Indian, Eskimo, or Aleut
   4. Asian or Pacific Islander
   5. Other please specify __________________________

7. Are you of Hispanic descent?
   
   Circle the appropriate response
   1. Yes  2. No
8. What is your current employment or work situation?

Circle the response that best describes your situation or fill in #8 other below

1. Employed full time
2. Employed part time
3. Not Employed
4. Student, full time
5. Student, part time
6. Unemployed
7. Homemaker
8. Other ___________

9. What is your religious affiliation?

Circle the appropriate response

1. Roman Catholic
2. Jewish
3. Buddhist
4. Methodist
5. Lutheran
6. Seventh Day Adventist
7. Other ___________
8. Muslim
9. Hindu
10. Baptist
11. Episcopalian
12. Presbyterian
13. None

I would like a little information about your pregnancy history:

10. How many times, including this time, have you been pregnant? ________________

   1. How many children do you have? ________________
   2. Have you had a miscarriage? ________________

11. What problem(s) has been identified in your pregnancy? ________________

12. How many weeks pregnant are you today? ________________
APPENDIX B

Interview Guides

Continuing A Pregnancy Following A Fetal Anomaly Diagnosis Study
Interview Guide - First Interview

Introduction

I am having this interview with you to understand your experience about continuing your pregnancy after you were told that your baby had a problem.

The Experience of Continuing After a Fetal Anomaly Diagnosis

Can you tell me about when discovered you were pregnant? How it felt, what it meant to you and your family.

Tell me about the day you found out there could be a problem. Did you anticipate there would be any problem?

Can you tell me about your decision to continue your pregnancy and what that was like for you? What was the most difficult part of this decision?

What has it been like being pregnant knowing that your baby has a problem?

Support and Guidance Provided by the Healthcare Provider after Decision to Continue is Made

How did your healthcare provider support you since the time you decided to continue your pregnancy? Can you give me examples of actions or behaviors you found supportive?

Can you describe how your healthcare provider guided you during this time?

Were there any behaviors that were not supportive, if so could you tell me about them?

Guidance Provided by the Healthcare Provider in Preparation for the Birth

What you were told to expect at the time you are going to give birth?

How has your healthcare provider prepared you for the birth?

What other behaviors, activities, or information would be helpful to you as you prepare for your upcoming birth of your baby?

Summary

Thank you for sharing your experience with me. Is there anything else that you would like to share with me that is important about the experience of continuing pregnancy and upcoming birth after your baby was diagnosed with a problem? What was it like for you to participate in this interview today?
APPENDIX B (continued)

Interview Guide - Second Interview

Introduction

Since we met last met I wanted to find out if you had anything else you wanted to share with me about your experience of continuing pregnancy. I also would like to ask you some questions I had from the first interview.

Initial Question

When we last met, these ________ were the issues that were troubling you most, how has it been since we last met (this serves to acknowledge her specific story)? Is there anything that you have thought about since our first meeting that you would like to share with me?

The Experience of Continuing After a Fetal Anomaly Diagnosis

What has your pregnancy experience has been like for you since we last met?

Support and Guidance Provided by the Healthcare Provider after Decision to Continue is Made

How has your healthcare provider supported and guided you since the last time we met?

Were there any supportive or non-supportive behaviors, guidance, or information that has been discussed or noticed by you since we last talked? If so, can you tell me what these were?

Guidance Provided by the Healthcare Provider in Preparation for the Birth

Have there been any conversations between you and your healthcare provider about the upcoming birth since we last met? If so, can you tell me what was discussed?

How has your healthcare provider prepared you for the birth since we last talked?

Do you have any further thoughts about what else would be helpful to you as you prepare for the birth of your baby?

Summary

Thank you for sharing your experience with me. Is there anything else that you would like to share with me that would important about the experience of continuing pregnancy and your upcoming delivery after the baby is diagnosed with a problem?

What was it like for you to participate in this interview today?
APPENDIX C

IRB APPROVALS

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 60612-7227

Approval Notice
Initial Review (Response To Modifications)

September 24, 2013

Olga Lazala, MSN
Women, Child, & Family Health Science
363 Stone Creek Drive
Bolingbrook, IL 60440
Phone: (630) 910-4084

RE: Protocol # 2013-0622
“Continuing A Pregnancy After A Fetal Anomaly Diagnosis”

Dear Ms. Lazala:

Your Initial Review application (Response To Modifications) was reviewed and approved by the expedited review process on September 19, 2013. You may now begin your research.

Please note the following information about your approved research protocol:

Please note that Catherine Bennett could not be approved as key research personnel at this time as, under UIC policies, her investigator training expired in 2007. IRB approval must also be submitted or written notice from the Advocate Lutheran General IRB must be submitted stating that IRB approval is not required at Advocate Lutheran General for the research activities proposed there prior to accessing/analyzing identifiable data and/or recruiting/enrolling subjects at that site. A copy of the approval or notice must be accompanied by an Amendment form when submitted to the UIC IRB. If IRB approval is not required by Advocate Lutheran General, Ms Bennett must then update her investigator training to comply with UIC requirements before being eligible for approval.

Please note that IRB approval must be submitted or written notice from the Advocate Good Samaritan IRB must be submitted to cover both Ms Duke and the research activities proposed there prior to accessing/analyzing identifiable data and/or recruiting/enrolling subjects at that site. A copy of the approval or notice must be accompanied by an Amendment form when submitted to the UIC IRB.
APPENDIX C (continued)


Approved Subject Enrollment #: 25

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 Site: UIC

Sponsor: None

Research Protocol:
   a) Continuing a Pregnancy Following a Fetal Anomaly Diagnosis; Version 3; 09/16/2013

Recruitment Materials:
   a) Subject Information Sheet (English); Version 1; 05/23/2013
   b) Informacion para los Participantes en el Estudio (Spanish); Version 1; 05/23/2013
   c) Cont Preg PI Script (English); Version 2; 08/04/2013
   d) Cont Preg PI Script (Spanish); Version 2; 08/04/2013
   e) Cont Preg K P Script; Version 1; 08/04/2013
   f) Flyer (English); Version 3; 09/12/2013
   g) Flyer (Spanish); Version 3; 09/12/2013

Informed Consents:
   a) Cont Preg Consent (English); Version 2; 08/04/2013
   b) Cont Preg Study Consent (Spanish); Version 2; 08/04/2013
   c) A waiver of informed consent for recruitment purposes (release of contact information) has been granted under 45 CFR 46.116(d) (minimal risk; initial identification of potential subjects would otherwise be impracticable)
   d) A waiver of documentation of consent and alteration of consent has been granted for screening/eligibility purposes only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; verbal consent will be obtained to collect screening data and data for ineligible and declining individuals will be destroyed promptly; written consent will be obtained from subjects 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.
APPENDIX C (continued)

Please note the Review History of this submission:

<table>
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<tr>
<th>Receipt Date</th>
<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
<th>Review Action</th>
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<td>06/17/2013</td>
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<td>Expedited</td>
<td>09/19/2013</td>
<td>Approved</td>
</tr>
</tbody>
</table>

Please remember to:

➔ Use your research protocol number (2013-0622) 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" (http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

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 (312) 996-1711 or me at (312) 996-2014. 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
APPENDIX C (continued)

Enclosures:

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Informed Consent Documents:
   a) Cont Preg Consent (English); Version 2; 08/04/2013
   b) Cont Preg Study Consent (Spanish); Version 2; 08/04/2013
3. Recruiting Materials:
   a) Subject Information Sheet (English); Version 1; 05/23/2013
   b) Informacion para los Participantes en el Estudio (Spanish); Version 1; 05/23/2013
   c) Cont Preg PI Script (English); Version 2; 08/04/2013
   d) Cont Preg PI Script (Spanish); Version 2; 08/04/2013
   e) Cont Preg KP Script; Version 1; 08/04/2013
   f) Flyer (English); Version 3; 09/12/2013
   g) Flyer (Spanish); Version 3; 09/12/2013

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
    Patricia Hershberger (faculty advisor), Women, Child, & Family Health Science, M/C 802
APPENDIX C (continued)

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 60612-7227

Approval Notice

Continuing Review

August 7, 2014

Olga Lazala, MSN
Women, Child, & Family Health Science
363 Stone Creek Drive
Bolingbrook, IL 60440
Phone: (630) 910-4084

RE: Protocol # 2013-0622
“Continuing A Pregnancy After A Fetal Anomaly Diagnosis”

Dear Ms. Lazala:

Your Continuing Review was reviewed and approved by the Expedited review process on August 7, 2014. You may now continue your research.

Please note the following information about your approved research protocol:


Approved Subject Enrollment #: 25 (10 subjects enrolled)

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 Site: UIC

Sponsor: None

Research Protocol:
a) Continuing a Pregnancy Following a Fetal Anomaly Diagnosis; Version #4; 02/24/2014

Recruitment Materials:
a) Informacion para los Participantes en el Estudio (Spanish); Version 1; 05/23/2013
b) Subject Information Sheet (English); Version 1; 05/23/2013
APPENDIX C (continued)

c)  Cont Preg PI Script (English); Version 2; 08/04/2013

d)  Cont Preg PI Script (Spanish); Version 2; 08/04/2013

e)  Cont Preg K P Script; Version 1; 08/04/2013

f)  Flyer (Spanish); Version 3; 09/12/2013

g)  Flyer (English); Version 3; 09/12/2013

h)  Cont. Preg. Intro. Script; Version #1; 02/24/2014

Informed Consents:

a)  Cont Preg Consent (English); Version 2; 08/04/2013

b)  Cont Preg Study Consent (Spanish); Version 2; 08/04/2013

c)  A waiver of informed consent for recruitment purposes (release of contact information) has been
    granted under 45 CFR 46.116(d) (minimal risk; initial identification of potential subjects would
    otherwise be impracticable)

d)  A waiver of documentation of consent and alteration of consent has been granted for
    screening/eligibility purposes only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal
    risk; verbal consent will be obtained to collect screening data and data for ineligible and declining
    individuals will be destroyed promptly; written consent will be obtained from subjects 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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<td>Continuing Review</td>
<td>Expedited</td>
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<td>Approved</td>
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</table>

Please remember to:

➔ Use your research protocol number (2013-0622) 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"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)
APPENDIX C (continued)

Please note that the UIC IRB has the right to 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 (312) 996-1711 or me at (312) 355-2764. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Betty Mayberry, B.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

1. **Informed Consent Documents:**
   a) Cont Preg Study Consent (Spanish); Version 2; 08/04/2013
   b) Cont Preg Consent (English); Version 2; 08/04/2013

2. **Recruiting Materials:**
   a) Informacion para los Participantes en el Estudio (Spanish); Version 1; 05/23/2013
   b) Subject Information Sheet (English); Version 1; 05/23/2013
   c) Cont Preg PI Script (English); Version 2; 08/04/2013
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   f) Flyer (Spanish); Version 3; 09/12/2013
   g) Flyer (English); Version 3; 09/12/2013
   h) Cont. Preg. Intro. Script; Version #1; 02/24/2014

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
    Patricia Hershberger, Faculty Sponsor, Women, Child, & Family Health Science, M/C 802

2013-0622  August 7, 2014
APPENDIX C (continued)

January 15, 2014

Olga Lazala, MSN, APN
Advocate Good Samaritan - Perinatal
olga.lazala@advocatehealth.com

Dear Investigator:

On 01/15/14 the IRB reviewed the following protocol:

<table>
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<tr>
<th>Type of Review:</th>
<th>Initial — Expedited</th>
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<tbody>
<tr>
<td>Title:</td>
<td>Continuing a Pregnancy After a Fetal Anomaly Diagnosis</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Olga Lazala, MSN, APN</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>5719</td>
</tr>
<tr>
<td>Funding:</td>
<td>N/A</td>
</tr>
<tr>
<td>Documents Reviewed:</td>
<td>IRB application forms 211/226, protocol, consents, subject recruitment flyers / information sheets</td>
</tr>
</tbody>
</table>

The IRB approved the protocol with a waiver of documentation of consent and HIPAA Authorization from 01/15/14 to 01/14/15 inclusive. The study was approved under Expedited criteria 3(6) Collection of data from voice, video, digital, or image recordings made for research purposes; (7a) Research on individual or group characteristics or behavior; and, (7b) Research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Within 25 business days of study close or 6 weeks before the expiration date of 01/14/15, whichever is earlier, you are to submit a completed "FORM: Continuing Review (HRP-212)" and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 01/14/15 approval of this protocol expires on that date. In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

Joel Hill, JD, MPH, PhD
Chairman, Advocate Institutional Review Board

cc:
APPENDIX C (continued)

January 13, 2015

Olga Lazala, MSN, APN, RNC
Advocate and University of Illinois
Olga.lazala@advocatehealth.com

Dear Ms. Lazala:

On 01/13/15 the IRB reviewed the following protocol:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Continuing - Expedited</th>
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<tr>
<td>IRB ID:</td>
<td>5719</td>
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<tr>
<td>Approval period:</td>
<td>01/15/15 – 01/14/16</td>
</tr>
<tr>
<td>Title:</td>
<td>Continuing a Pregnancy After a Fetal Anomaly Diagnosis</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Olga Lazala, MSN, APN, RNC</td>
</tr>
<tr>
<td>Funding:</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>Documents Reviewed:</td>
<td>HRP-212 dated 12/08/14</td>
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</table>

The IRB approved the protocol for the period stated above.

Within 25 business days of study close or 6 weeks before the expiration date of 01/14/16, whichever is earlier, you are to submit a completed “FORM: Continuing Review (HRP-212)” and required attachments to request continuing approval or closure. If continuing review approval is not granted before the expiration date, approval of this protocol expires on that date and all study activities must cease.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

Joel Hill, JD, MPH, PhD
Chairman, Advocate Institutional Review Board

The AHC IRB is organized under the authority of, and in accordance with, regulations of the United States Department of Health and Human Services, Food and Drug Administration (Title 21 Code of Federal Regulations [CFR] Part 56 [Institutional Review Board]), and Title 45 CFR Part 46 [Protection of Human Subjects].
CITED LITERATURE


Weaver, B., Lindsay, B., & Gitelman, B. (2012). Communication: technology and social media: opportunities and implications for healthcare systems. The Online Journal of Issues in Nursing, 17(3), manuscript 3.


VITA

Olga A. Lazala MSN, APN, CNM, CNS, RNC-OB
Nurse Midwife
Perinatal Clinical Nurse Specialist

TELEPHONE: (630) 910-4084 (home) E-MAIL: olazala@comcast.net

EDUCATION:

1982 Augustana Hospital School of Nursing, Diploma in Nursing
1990 Loyola University, Chicago, IL, Bachelor of Science in Nursing
1993 Loyola University, Chicago, IL, Master of Science in Nursing
1999 University of Illinois at Chicago, Post-Certificate in Nurse Midwifery
University of Illinois at Chicago, PhD candidate (anticipated graduation Summer, 2015)

PROFESSIONAL EXPERIENCE:

1982–1993 Staff Nurse, Special Care Nursery, Michael Reese Hospital, Chicago, IL
1993–1999 Perinatal Clinical Nurse Specialist, Mt. Sinai Hospital, Chicago, IL
1999–2001 Nurse Midwife, Sinai Medical Group, Chicago, IL
2001-present Nurse Midwife, University of Illinois Hospital, Chicago, IL
2004-present Perinatal Clinical Nurse Specialist, Good Samaritan Hospital, Downers Grove, IL
2007, Fall Teaching Assistant: NUSC 210 Health Assessment, University of Illinois
2008-2011 Adjunct Clinical Instructor; Loyola University, Chicago, IL

RESEARCH:

2014 - present Co-Investigator: Postpartum urinary retention following vaginal delivery; Good Samaritan Hospital. Role: research design, data collection.

AWARDS/HONORS:

1982 Honors Graduate, Augustana Hospital School of Nursing
Bess Lang Award, Augustana Hospital School of Nursing
1990 Magna Cum Laude, Loyola University, Chicago, IL.
Sister Helen Jarrel Award, Loyola University, Chicago, IL
2013 American College of Nurse-Midwives (ACNM) Sandy Woods Scholarship for Advanced Study Award
CERTIFICATIONS:

1994  Neonatal resuscitation instructor, American Association of Pediatrics
1995  Cardiopulmonary Resuscitation Instructor, American Heart Association
1999  Nurse-midwifery, American College of Nurse-Midwives
2004  Inpatient obstetrics, National Certification Corporation
2004  AWHONN Fetal Monitoring Instructor, AWHONN

PUBLICATIONS:


PRESENTATIONS:

2007  AWHONN Advanced Fetal Monitoring, Christ Hospital
2007  AWHONN Intermediate Fetal Monitoring, Good Shepard Hospital
2008  AWHONN Intermediate Fetal Monitoring, Advocate Health Care
2009  AWHONN Advanced Fetal Monitoring, Christ Hospital
2009  Communication, collaboration & critical thinking: H1N1 in pregnancy, Grand Rounds, Good Samaritan Hospital
2013  AWHONN Advanced Fetal Monitoring, Advocate Health Care
2014  AWHONN Intermediate Fetal Monitoring, Christ Hospital
PROFESSIONAL SERVICE:

Guest Lectures/Teaching:

2008, 2009 Graduate level course, guest lecturer for the College of Nursing, University of Illinois. Lectures for Health Care of Women course: oligohydramnios, polyhydramnios, intrauterine growth restriction, and large-for-gestational age.


Professional Reviewer:

2013 Gynecology Online Course for Peri-Facts Academy, University of Rochester Medical Center
2014 Research abstract reviewer – Second Annual Advocate Nursing Research Symposium; Chicago, Illinois

COMMITTEE & CONFERENCE ACTIVITIES:

2009 Annual OB Conference planning committee, Good Samaritan Hospital, Downers Grove, Illinois
2009 – 2012 Palliative Care Committee, Good Samaritan Hospital
2010 - present High Risk Pregnancy Interdisciplinary Committee, Good Samaritan Hospital, Downers Grove, Illinois

2010 – present Interdisciplinary OB Education Committee, Good Samaritan Hospital, Downers Grove, Illinois
2014 – present Clinical Excellence Committee, Good Samaritan Hospital, Downers Grove, Illinois

PROFESSIONAL MEMBERSHIPS:

1984 - present Association of Women’s Health, Obstetric and Neonatal Nurses
1989 - present Sigma Theta Tau
1998 - present American College of Nurse Midwives