Experience of pregnancy with a fetal abnormality
Abstract

Objective: The purpose of this study was to gain an understanding of the experience of prenatal attachment during pregnancy while carrying a child with a known, non-lethal congenital abnormality.

Design: This was a phenomenological study.

Setting: The participants were interviewed in their own homes, a quiet clinic room, or another location comfortable for them.

Participants: Fifteen pregnant women who were carrying a child with a non-lethal, congenital abnormality participated.

Main Outcome Measure: Analysis of the data revealed the pregnancy experience to be of a paradoxical nature. Knowledge of the fetal diagnosis resulted in both positive and negative consequences.

Results: There were three major themes that were common to the experience for women in the study: Time is good, but it's also the enemy; You grieve, but you don’t grieve; My baby’s not perfect, but (s)he’s still mine.

Conclusion: Due to the paradoxical feelings experienced during this type of pregnancy, women need as much information as they request regarding the abnormality, its treatment, and prognosis. It is beneficial for the women to discuss the plan for care after delivery with the pediatric specialists. Health care providers need to support women’s prenatal attachment during this unique pregnancy.

Keywords

Congenital abnormality, Prenatal attachment, Prenatal diagnosis, Fetal abnormality, Maternal-fetal attachment, Prenatal testing, Pregnancy experience, Antenatal diagnosis, Prenatal Screening
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INTRODUCTION

Unlike women in previous generations, the majority of pregnant women in the United States and other countries with advanced health care are provided with ultrasound images of their babies before birth (Garcia et al, 2002; Sandelowski, 1994). With the availability of detailed images of fetuses in-utero, chromosome analysis, genetic testing, in-utero fetal blood sampling, and fetal surgery, scientific advances are changing women’s experiences of pregnancy.

Although the use of technology to provide more information about pregnancy is often viewed as a positive experience in our culture, the diagnosis of a fetal abnormality during pregnancy may be devastating to parents since prenatal diagnosis usually leaves parents few options for prenatal treatment of the diagnosed abnormality (Kenner & Dreyer, 2000; Matthews, 1990; Sandelowski & Corson Jones, 1996a, 1996b). The impact of such knowledge on women’s feelings regarding their pregnancies remains unclear. Researchers and clinicians have questions whether knowledge of a fetal abnormality could negatively impact women’s prenatal attachment to their fetus (Kemp & Page, 1987; Lemons & Brock, 1990), and if, in turn prenatal attachment would impact women’s attachment to their infants after birth (Müller, 1996; Siddiqui & Hägglöf).

The purpose of this phenomenological study was to gain an understanding of the experience of prenatal attachment of mothers with a child known to have a non-lethal congenital abnormality during pregnancy. An understanding of this experience provides insight into the dynamics of the prenatal attachment process in these pregnancies — pregnancies in which women are provided knowledge of non-lethal abnormalities and are faced with the challenge of becoming mothers to infants with abnormalities. (Callout #1) This concept is important since children with disabilities often demand significant caregiving due to long-term and the possibly severe nature of their disabilities (Marcenko & Smith, 1992; McCubbin, 1989). It has been found that mothers of disabled infants have had lower levels of maternal attachment behaviors in the neonatal period (Capuzzi, 1989), and that there is an increased incidence of child abuse of children with

Stainton, McNeil, and Harvey (1992) found that some women experiencing high-risk pregnancies resisted attaching to their fetuses during their pregnancies because of fear that their child might die. It follows that a lack of commitment and prenatal attachment by mothers during pregnancy could have long-term effects on mothers’ abilities to meet the many needs of children born with non-lethal congenital abnormalities.

LITERATURE REVIEW

Previous studies have examined the impact of prenatal diagnosis of a congenital abnormality on women’s experience of pregnancy. However, in many of those studies the infant had lethal abnormalities or complications from the abnormality that resulted in infant death. One phenomenological study described the experience of pregnancy with a known, life-threatening fetal abnormality (Mathews, 1990). Of the 21 babies delivered, only one survived the neonatal period. Findings described the emotional responses women had after the diagnosis. In the end, all the participants interviewed said that if they had to do it over again, they would have wanted to know about the baby’s problems. Women’s descriptions of their experiences suggested that maternal attachment had developed despite the likelihood of fetal or neonatal death, and that it was important to the parents to validate the reality of the fetus by viewing and holding the infant after birth.

Another study that examined the emotional reactions of women following the diagnosis of a severe abnormality took place in the Netherlands (Hunfeld, et al., 1993). The participants were in the third trimester of pregnancy. Of the 41 women who participated, only 5 infants were living at 3 months of age, all of whom had severe physical or mental disabilities. Findings reflected that ultrasound diagnosis evoked strong emotional reactions from mothers, such as eating and/or sleeping disorders, anger, and sadness. There was no difference between the grief reactions
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of mothers whose fetuses had died in-utero compared to reactions of those women who were still carrying live fetuses shortly after diagnosis of the abnormality. This may indicate that the death and delivery of a fetus with severe abnormalities is not necessarily more of an emotional strain than the diagnosis and carrying of the fetus with a severe abnormality.

Sandelowski and Corson Jones (1996a, 1996b) published two qualitative studies based on data from 40 interviews with both parents who had obtained a diagnosis of a fetal abnormality. Of the 15 women in the study, five terminated the pregnancy after the fetal diagnosis, and six had infants that survived the neonatal period. The first study found that parents reported feeling as though they had “backed into” (Sandelowski & Corson Jones, 1996a, p. 355) prenatal testing. Often one screening test led to further diagnostic tests, and the women had not always fully understood the implications of the testing. The author suggested further study to examine the impact, if any, of choices made by parents during pregnancy and their future parent-child relationship.

A secondary analysis of the data examined the value of knowledge of the fetal abnormality before delivery (Sandelowski & Corson Jones, 1996b). Findings suggested that this knowledge placed a weight or burden of uncertainty on parents.

The process of decision-making by parents whose fetus had been diagnosed with congenital heart disease has recently been reported (Rempel, Cender, Lynma, Sando & Farquharson, 2004). After interviewing parents of 19 babies before and after birth, researchers found that parents considered their antenatal decisions regarding further testing and/or continuing the pregnancy as their first parenting decision for that child. Parents appeared to vary as to the difficulty they experienced in making decisions about their baby and the role that health care providers played in assisting in the decision making process. In fact, the “parents in the study indicated that the professionals lacked an understanding of the experiences and perspectives of
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parents” (Rempel, Cender, Lynam, Sandor, & Farquharson, 2004, p. 68) with antenatal diagnosis of congenital heart disease.

Review of the literature revealed a lack of research focused on prenatal attachment during pregnancy in which a non-lethal fetal abnormality had been diagnosed. Therefore, the research question that guided this study was, “What is the lived experience of mothers during pregnancy with a fetus’ with a known, non-lethal fetal abnormality?”

METHODS

Population

The study took place in an out-patient perinatal center at a large Midwestern hospital. Women eligible to participate in this study met the following inclusion criteria: Participants (a) had knowledge of a non-lethal fetal abnormality and had decided not to terminate their pregnancy, (b) had known about the abnormality for at least one week, so they had time to reflect upon the diagnosis (c) were interviewed before 37 weeks gestation, so the focus was on the pregnancy experience as it was lived, (d) were able to speak and read English and were able to articulate the lived experience of pregnancy, and (e) were oriented to person, place, and time, and were not on any psychotropic medications.

After final approval of this project by the university and the hospital Institutional Review Boards, potential participants were invited into the study based on a first come, first offered basis. All participants signed an informed consent form. In this report of the research study, all names are fictitious in order to protect the identity of the participants.

In this study redundancy of data was noted by the eleventh interview. After noting redundancy during data collection and analysis, an additional four participants were interviewed in order to ensure a description of the full experience was obtained. As a result, this study had a total of 15 participants.
All participants were carrying a child with a known, non-lethal congenital abnormality. The ages of the women ranged from 18 to 44 years, and the mean age was 27.5 years (see Table 1). The gestational age at the time of diagnosis ranged from 17 to 26 weeks; therefore, all of the women learned of their fetus’ diagnosis sometime in the second trimester of pregnancy. The gestational age at the time of the interview ranged from 24 to 36 weeks. The women had known about the abnormality somewhere between 4 to 18 weeks; with average time of knowing the diagnosis 10 weeks. The fetal diagnoses fell into six categories (see Table 1): neural tube defect, cleft lip, congenital heart defect, renal anomaly, cystic adenoid malformation of the lung, and Down Syndrome.

Study Design

This investigation was a phenomenological study. Data from the interviews were analyzed based on four basic steps as described by Giorgi (1985). Step one data analysis was to get a sense of the whole of each interview by reading and reflecting on each interview. The second step identified specific “meaning units” (Giorgi, 1985, p. 11). Each transcription was read carefully and broken down into distinct meaning units. Sometimes these units were a word, sometimes a phrase or sentence, and sometimes a passage of one or more paragraphs.

After six interviews, a professional nurse who is also a qualitative research consultant coded meaning units for interviews separately. This step was done to ensure that meaning units were coded accurately and completely, and that the primary investigator was not missing any pertinent information about the experience. After the meaning units had been identified, the third step was transformation of the participants’ words into the language of the science, in this case, nursing (Giorgi, 1985).

In the final operation, the transformed meaning units were synthesized into a overall description of the phenomenon. This final description contained all transformed meaning units and gave structure to the data, in order to accurately communicate experiences of the lived
phenomenon. This final description was taken to three participants who verified that the
description had captured the essence of their own experience.

RESULTS

The pregnancy experience of prenatal attachment while carrying a fetus with a known,
non-lethal congenital abnormality is paradoxical. (Callout #2) Although women develop prenatal
attachment to their fetus, the pregnancy experience is modified permanently after the news fetus
abnormality. That information affects the experience significantly and results in both positive and
negative consequences.

There were three transformed meaning units, or common themes, identified: (a) Time is
good, but it is also the enemy; (b) You grieve, but you don’t grieve; and (c) The baby’s not
perfect, but (s)he is still mine.

Time Is Good, But It’s Also the Enemy

Time plays an important role throughout the experience of a pregnancy when there is a
known fetal abnormality. The women cannot change the gestational period of pregnancy, and they
experience this time as a paradox: time is good, but time is also the enemy. Time is good because
it is useful for moving from the suspicion that something is wrong to a definitive diagnosis. The
diagnosis generally is not made during one appointment, but usually involves screening tests that
lead to more refined diagnostic tests. Time provides women with the opportunity to confirm the
diagnosis through prenatal testing, to follow up on referrals to high-risk pregnancy centers, and to
interact with health care providers.

Jenny described her appointment after an abnormal blood-screening test this way:

We did see the genetic counselor which is just a woman. She basically just explained
what spina bifida was, and what could happen or couldn’t happen. And um, then we had
the ultrasound and then they had a whole bunch of people. More and more people started
coming in, so I was figuring something was wrong here.
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Once the diagnosis is confirmed, time is good because it allows women to learn more about causes, complications, and prognosis of the abnormality. Many participants used a variety of resources, including health professionals. Mary said her genetic counselor was “...great, she said, ‘You call me anytime if you come up with any questions’...if I’d call or leave her message, you know, she’d call back within a few minutes or even a couple hours.... So that was great.”

Another source of information for some participants was a pediatric specialist who was responsible for treating the babies after birth. Nancy, whose fetus had an ureterocele, saw a pediatric urologist to find out what to expect after delivery. She said,

But he didn’t have any of the films [copies of the ultrasound]…so he just sat down and drew out probably four different scenarios of what could happen…. He gave us like 10 different options of surgery, what could happen from the least minor to the most major and he really made us feel comfortable.

Many participants used the Internet as a resource. Ann, whose fetus was diagnosed with spina bifida, stated, “The Internet sites have just been wonderful. I mean just reading, seeing what the outcomes are sometimes is positive.” Brenda, whose fetus had cleft lip, commented, “I was on the Internet that afternoon looking it up…I looked up several good Web sites.”

Patty also searched the Internet for information about her baby’s fetal diagnosis of a cystic adenoid malformation of the lung. She explained, “I just like to know everything. And with everything [on the Internet], you get every good thing, every terrible thing, I don’t know. So, maybe that’s good, that I’m prepared for the absolute worst and at least I know all the possibilities.”

Time is good because it provided women the opportunity to investigate their options and decide how to handle the remainder of the pregnancy. Some of the decisions included pursuing in-utero treatment or termination, choosing care providers for themselves or their babies, and choosing the institution where they would deliver their babies.
One participant, whose fetus had spina bifida stated,

After they said that, I mean, Dan and I asked them outright, we said, “If this was your baby what would you do?” And the doctor goes… “he probably won’t have any kind of life.” (Silence) (Starts crying) At that point in time, we considered terminating.

However, later in the conversation she said, “We decided we couldn’t do that…I may not understand why, but I do know that if anybody can handle this, I can.”

Time is good since it allowed the fetus to become older, bigger, and therefore stronger, at birth. Women were comforted by the fact that the longer the pregnancy continued, the more the baby would weigh, and the better the prognosis would be for the baby after birth. Another reason that time is good was because it gave women time to prepare and make logistical plans for the period surrounding the birth. This involved finding out about the surgery the baby may require after delivery, verifying or arranging insurance coverage, touring the hospital where the baby would be transferred, and visiting with the baby’s future doctors. Time allowed women to make accommodations both at home and at work for the period surrounding the delivery.

Time is good because it allowed women to realize that they were glad to know the diagnosis before delivery because it gave them the opportunity to prepare themselves emotionally. Ann, whose fetus had been diagnosed with spina bifida, described it this way:

Yeah, ’cause I think if I found out after delivery then it would have been, I mean, terrifying. Because I mean, with me being the person that has to have everything prepared and set up, throwing something like that on me at the last minute would have just thrown me into a total back loop. I mean I would have been like, aaaaaa… I mean it gives you emotionally, physically, I mean everything. If you would just find out at the time of delivery? I think you would be so shocked, that you would be, “What do I do now?”

The other side of the time-related paradox is that time was the enemy because the women worried, wondered, and waited for the birth of their baby. Despite the positive aspects of time
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there were still many uncertainties. The women wondered how their baby would be specifically affected by the abnormality. As Mary described, “It was definite after the two weeks, that it was Down’s. They kept saying the severity, we don’t know what the severity is, we won’t know until she gets here.”

Waiting was a significant part of the experience; women would do nothing but wait to discover the outcome for the baby. Hannah said:

I’m just anxious to see what happens to see what goes on and how everything works out.

… That’s the biggest thing, just waiting. And that’s the hard part.

Brenda summarized the situation this way: “You just kinda feel you are hanging in limbo.”

You Grieve, But You Don’t Grieve

Grief was another aspect of experiencing a pregnancy with a known fetal abnormality. Women experienced a variety of negative emotional reactions as a result of finding out the diagnosis and realized their baby wouldn’t be “perfect.” The loss of this “perfect” baby resulted in feelings of grief, including shock, anger, and guilt.

Ann described her reactions this way:

I talked to a bunch of the parents [of kids with spina bifida] first, you know, when I first found out. And I said, “How did you deal with this, how did you, you know, what process did you go through? I mean, because they’re like, you grieve but you don’t grieve…that type of thing. You know your ideal baby is the perfect baby, and then you find that it’s not going to be perfect, and you’re like. It’s kinda a loss.

The grief that women experienced during this pregnancy was demonstrated in a paradoxical manner. While women described a sense of helplessness, they actually utilized a variety of positive coping strategies in order to assist themselves during this difficult time. Positive coping mechanisms included receiving support from family and friends, utilizing spiritual beliefs,
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and staying busy with work or other activities. They also had conversations with other people who had similar experiences, whether through formal organizations or informal acquaintances. Coping sometimes involved consciously using a positive attitude about this experience. Many women believed that this experience would make them better or stronger people, or that this had happened “for a reason.”

Elaine describes it this way:

I think it’s made me a little bit of a nicer person. Actually, I’m a lot more patient with my kids, and I don’t take them so much for granted. And you know, I’m a little more patient with everybody, and I’m a little more easy going, like you know, I really don’t care because, it could, you know, it made me realize that things could be a lot worse. You know, all my kids could have came out sick and I’m very fortunate to have two great beautiful babies, and this is my special baby, because he’s sick, you know. So he’s going to need special love and attention and extra care, and it just made me a little more easygoing, like, you know, and people tell me, “Oh, I broke a nail.” Yeah, well, you know who cares about your nail.

The Baby’s Not Perfect, But (S)He’s Still Mine

Prenatal attachment, or the development of a unique affectionate relationship between the woman and her fetus, was the other essential aspect of the pregnancy experience of women with a known fetal abnormality. Women experienced prenatal attachment to their babies despite the realization that their baby had an abnormality. This sets up the third and final paradox, in which the women accepted the lifelong commitment to a “not perfect” baby, but they accepted and loved the baby nonetheless.

On one side of the paradox, the women acknowledged their baby’s abnormality and they empathized with their baby. The diagnosis allows them to recognize and address concerns regarding long-term challenges they may face in raising their child, such as developmental or
cognitive delays, additional financial demands, and special child care issues. Brenda said, “I guess it was because, ah, well, for a period of a couple of, maybe a few weeks, after I found out I was sad. Not just for me but for him.” Elaine expressed her concern for her fetus in this way: “Maybe it’s just his illness and everything that I know he’s going to go through…You know when your kids are sick, you know that mother instinct just automatically kicks in. I already know he’s sick.”

On the other side of this paradox, the women say, “(s)he’s still mine.” Women developed prenatal attachment to their baby despite the diagnosed abnormality. Usually they knew the gender of their baby and had pre-named them. The women interacted with their baby in-utero (for example, rubbing their abdomen) and said they knew the baby and loved them for who they were. Brenda said, “The further along I get, the more I realize that, you know, he is who he is…And you know, I just don’t think it’s going to affect me the way it might’ve if I was just looking at some other baby, instead of my baby.”

The women were happy about the pregnancy and were committed to taking care of themselves for the babies’s sake. “I want this baby. I don’t care if he has three arms, six legs, I want him so bad, it’s not even funny.”

DISCUSSION

Knowledge of the fetal abnormality during pregnancy for women in this study did not prevent them from developing prenatal attachment. This supported findings from previous studies that identified no difference between women experiencing high-risk or low-risk pregnancy and their fetus’ (Kemp & Page, 1987).

This study also supported previous qualitative studies that examined the experience of a high-risk pregnancy. As in other studies, (McCain & Deatrick, 1994; Sandelowski & Corson Jones, 1996b; Stainton et al, 1992) women found the uncertainty of the outcome was a great concern and impacted their experience of pregnancy. In addition, similar to findings in this study, Thornburg (2002) found that waiting was a significant and difficult component of the experience.
Specifically, she referred to the “paradoxical realities of waiting” (Thornburg, 2002, p. 245) as an overriding theme for those women.

Although the precise effect has been difficult to define, prenatal testing does appear to impact pregnancy (Heidrich & Cranley, 1989; Lumley, 1990; Phipps & Zinn, 1986). Certainly in this study, the impact of prenatal testing on pregnancy is significant because testing led to the diagnosis of a fetal abnormality. In (Black, 1992) women stated that the ultrasound image of their baby provided strong reinforcement of the reality of the baby as a separate human being. Also, with the exception of one participant, the women stated they were glad they knew about the abnormality before delivery. This supports the findings of Sandelowski and Corson Jones (1996b) that parents value foreknowledge of the fetal diagnosis.

One of the unique findings in this study was that one woman had experienced a previous pregnancy while carrying a child with a congenital abnormality. However, in that pregnancy, the woman had not known about her child’s abnormality until after delivery. In this current pregnancy, she knew of her child’s congenital heart defect. Unlike all the other women in the study, this woman wished that she did not have knowledge of the abnormality until after delivery. Since she already had a child with a congenital heart defect, she may be part of a unique population of women with this previous experience. Rillston and Hutchinson (2001) found that women who had experienced a previous fetal death due to fetal abnormalities delayed attaching to a new pregnancy. Although this woman’s previous baby did not die due to the abnormalities, her life and the life of her baby had been significantly altered by the abnormality, and therefore the previous experience could have a significant impact on her current pregnancy.

Another unique finding of this study was that one participant used journaling as an effective method for coping with the difficult emotions experienced in her pregnancy. Although journaling has been reported as being an effective coping mechanism with other difficult
experience (Vander Zyl, 1997), there has been no report to date of using this for coping during a
high-risk pregnancy.

With the increasing availability of the Internet, how women used—or did not use — the
Internet during pregnancy was uniquely described in this study. Some women found the Internet
very useful for learning more about their fetus’s diagnosis, while others did not. One woman
stated that a physician specifically told her not to use the Internet since it would just confuse her.
This is a topic that needs further study in order to guide women appropriately.

Another technology that is now available for home use is the fetal doppler. This study is
the first study that describes how a woman used the fetal doppler to check fetal heart tones at
home as a method of coping with the emotional stress of her high-risk pregnancy. Again, this is an
area in need of further research.

The results of this study reflect that women experience paradoxical feelings during
pregnancy while carrying a child with a known, non-lethal fetal abnormality. Health care
providers need to be aware of and sensitive to these paradoxes and supportive of the prenatal
attachment these women experience. The women need to be provided with as much information as
they request about the causes, treatments and prognosis of their fetus’s abnormality. Often it is the
nurses who work closely with women who will hear their questions. Nurses need to be able to
answer their questions fully or refer the women to the appropriate health care team member.
Additionally, some women in this study found it beneficial to discuss the baby’s treatment plan
with pediatric specialists. Women should be offered this choice during pregnancy and a meeting
with the pediatric specialist should be facilitated if this is desired.

Since some questions and concerns that the women may have about their fetus’s
abnormality cannot be answered, health care providers need to recognize the difficulty that women
experience while waiting and wondering about the outcome for their child. (callout #3). Nurses
can provide support by using active listening and therapeutic communication or by suggesting
other coping strategies. These coping strategies may include activities such as seeking support from others, especially from the father of the baby and the woman’s mother, if appropriate. The women in this study felt supported by the presence of these people at their doctors’ appointments. Additional emotional support for these women could be found in spiritual beliefs and prayer. One coping strategy that this study found beneficial was journaling.

Finally, health care providers need to recognize that an important coping strategy is their positive attitude. This attitude needs to be acknowledged and positively reinforced by health care providers, even though, when providing the women with truthful information, health care providers may bring to light some difficult challenges that the women, their babies, and their families may face.

In conclusion, the knowledge of a genetic or congenital abnormality during pregnancy is becoming a more common occurrence because of the increasing use of genetic and technological testing. Supporting women’s prenatal attachment through these types of pregnancies may positively impact the mother-infant relationship and enhance a mother’s ability to meet the long-term challenges of effectively caring for children who are born with abnormalities.
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Callouts

#1
In many previous studies the infants had lethal abnormalities or complications from the abnormality that resulted in death.

#2
The pregnancy experience was modified permanently after the news of the fetus’s abnormality.

#3
It is important to acknowledge and reinforce mothers’ positive attitude while providing them with truthful information.
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REFERENCES


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