

Following is an Executive Summary and additional information including key observations from focus groups and family interviews completed throughout the state. This firsthand information was sought and is presented here to allow providers a better understanding of the perceptions and issues confronting women and families who might be facing perinatal depression.

Executive Summary

Four focus groups and five family interviews (three in English and two in Spanish) were conducted in different cities and towns throughout Nebraska between the dates of August 2006 and October 2006. Each participant was recruited in cooperation with healthcare agencies in each of the towns where meetings were held. Focus group participants that attended were compensated \$50 for their time, and the family interview attendees were collectively given \$100. Dinner or snacks and beverages were served, depending upon the time of the meeting.

Focus Group Participant Numbers and Locations

1. Recruited participants – 45 women agreed to participate
2. Total participants – 41 women attended the focus groups
3. No-show participants – 4 women agreed to participate but did not show up

<u>Focus Group Location</u>	<u>Attendance Numbers</u>	<u>No-Show Numbers</u>
Columbus	9	2
Gering	11	1
Lincoln	10	-
Omaha	11	1

Family Interview Participants and Locations

Columbus – Spanish-speaking
Gering – English-speaking
Lexington – Spanish-speaking
Lincoln – English-speaking
Omaha – English-speaking

Demographics

Focus Groups (4 total)

- Women aged 18–45
- Women who are currently pregnant or have a baby that is 12 months or younger

Family Interviews (5 total: 3 English-speaking and 2 Spanish-speaking)

- Women who are currently pregnant or have a baby that is 12 months or younger
- Husbands/partners of the women that are either pregnant or have had a baby that is 12 months or younger
- Extended family may include mothers/fathers of the mothers or mothers-to-be, aunts, sisters, etc.

Focus Group and Family Interview Goals

Goals

1. Assess the amount and type of information that is being given to women who are expecting or who have recently delivered a baby.
2. Learn whether the participants are familiar with or understand perinatal depression and its symptoms.

3. Understand what types of messages and materials would best help women and their families understand perinatal depression and encourage them to seek help if needed.
4. Assess the specific barriers to treatment and how they can be overcome.
5. Identify distribution and media avenues to reach women and their families.

Focus Group and Family Interview Key Observations

1. General information about pregnancy and post-pregnancy given by doctors and clinics is incomplete and inconsistent. Women from the same town and many with the same doctors indicated that they were given different information regarding their pregnancy expectations—and there was little about post-pregnancy. Virtually all of the information distributed focused on details of the baby's physical changes and not on the mother, either emotionally or physically.
2. Emotional changes, baby blues, and depression information are not discussed and information was not distributed by the vast majority of doctors' offices and clinics that were visited by these women. Most women referred to books, friends and family, and the Internet as sources for information about the blues or depression associated with being pregnant.
3. The majority of women, including those that had experienced it, had little to no familiarity with pregnancy-related depression. And the depression information they were aware of was primarily from the Internet, books, friends, and family members. Most indicated that in the pregnancy books there are maybe a couple of sentences mentioning only the extreme mood changes such as suicidal thoughts or thoughts of harming your baby.
4. The majority of the women who experienced some form of depression or the blues indicated that it was difficult to define what it was that they were feeling—especially while they were going through it. There were a few that said looking back they now know it was depression, but at the time they felt like they were rational and that the world just didn't understand or was better off without them. Of the women that did admit to experiencing depression, most said they would not have been able to self-diagnose. They relied on others to help them see that the emotions they felt were beyond what would be considered normal for a pregnant or postpartum woman.
5. The majority of the women who now recognize that they did indeed suffer from depression indicated that they might have known that something was not right, but they would not have labeled it as depression. Many of these women associated depression solely with crying a lot and feeling sad—not realizing that hopelessness, anger, and other extreme emotions could be signs of depression.
6. Approximately half of the women interviewed admitted to feeling depression or the baby blues. The other half of the women had difficulty admitting that they were currently experiencing or had previously encountered depression although, based on the conversations, it became clear that some of these women did indeed suffer from depression. Those who did not recognize or admit to suffering from depression generally attributed their emotional changes to simple stress, lack of sleep, or just life pressures that would be considered normal pregnancy-related emotions.
7. Of the half that admitted to experiencing depression, only 15 to 20 percent sought help. The remaining women cited a number of reasons for not seeking help:
 - They felt like they could take care of it themselves by leaning on friends and family members.
 - They didn't recognize their feelings as depression or the blues.
 - They were not comfortable taking any type of pill to help level out the emotional highs and lows.
 - They felt guilt and embarrassment.
 - They didn't want the county/state to take their children away from them.

8. Family, and to some extent friends, play a large role in the lives of women who are currently going through or have gone through depression—both positively and negatively. The positive is that some of the women have a strong support system; people around them will encourage them to get help and will assist with baby duties until they begin to feel better. The negative role came from women who did not believe that their families (primarily husbands and boyfriends) would acknowledge that what they were feeling was “real.” “Real” to these women meant that their emotional state wasn’t something they could control or just “get over.” They could not simply “pull it together.”
9. The word “depression” has a negative connotation to a lot of the women and, in their estimation, to society in general. There was mention in every group and within the Gering focus group, in particular, that depression is something that no one would want associated with them. This group referred to the fifth floor of the hospital where “they put crazy people.” Others mentioned that they did not like the societal perceptions associated with depression—especially pregnancy-related depression. There was a belief that it had to be really bad (suicidal or homicidal thoughts) to be referred to as depression—and it’s not usually that extreme even though the implications are no less serious to the woman and her family.
10. There are perceived risks associated with admitting pregnancy-related depression. Women indicated that by admitting to depression they would risk the possibility of the county/state coming in and taking their children or that the label would attach a stigma that they did not want to carry around. Another woman told the group that treatment for depression affects life insurance rates. She indicated that rates would rise if depression were diagnosed or included on medical records. There were also social risks such as guilt because from early on women are given the idea that pregnancy is wonderful and having a new baby should be one of the happiest times of their lives. Then, when it isn’t, it’s difficult for others to understand why women may be experiencing negative emotions because that’s not “normal.”
11. Information about pregnancy-related depression needs to be conveyed to the husbands, boyfriends, and families of the expectant mother directly from the doctor or nurses. There is credibility associated with anything that is communicated by healthcare professionals. Women believe that whenever a healthcare professional tells people something, it’s perceived as more factual and people listen.
12. Doctors, clinics, and hospitals need to take an active role in education, awareness, and screening. This relates directly to the idea that healthcare professionals are seen as the experts for physical and mental health. Many of the women interviewed believe that the medical people that assisted them throughout their pregnancy should have asked them questions about their emotional well-being and should be trained to better detect pregnancy-related depression. These women believed these people should take the lead in helping women learn the facts, detect the symptoms, and ultimately seek help.
13. The perception that pregnancy-related depression isn’t real or is simply a side effect of being pregnant that women need to just “get over” needs to be changed.
14. Increased awareness starts with the healthcare professionals and the clinics that see these women on a regular basis throughout pregnancy and after delivery. In addition, women mentioned the use of posters, brochures, videos, and screening sheets in clinics and in doctors’ offices. Some of the other ideas were using traditional media such as outdoor, television, radio, and the Internet to increase awareness and reduce the stigma associated with pregnancy-related depression.
15. Over half of the women expressed a desire to see and publicize support groups for women who are currently experiencing perinatal depression. And among those who did not bring it up, there were a lot of nods of approval. They indicated that it would be a comfortable environment that would allow women to realize that they are not alone and would provide support.

Isolation is a real problem for women suffering from depression and having a small group or community where they feel like they belong is necessary to face the issues associated with perinatal depression. And the idea of publicizing these groups would be a way of telling the rest of the

community that this is a “real” problem and possibly legitimizing perinatal depression as a legitimate medical issue/problem.

16. Variations in experiences between Spanish-speaking and English-speaking families were few, but notable differences were focused primarily on places and sources that they rely on for information and comfort. The Spanish-speaking families had a sense of a larger community to rely on outside of their families—and they relied on the church or religious community for assistance as well. However, the strong ties to the church sometimes made it more difficult to diagnose or treat depression since some believe that the women needed to pray harder and ask God for help.
17. Pregnancy-related depression did not discriminate by age or economic status although the small sampling evident in the focus groups revealed differences in the ability or willingness to seek help. Barriers included time, money, and lack of awareness and understanding.