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Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) National Child and Maternal Health Education Program (NCMHEP)

Understanding Perceptions of Postpartum Depression To Inform Educational Outreach Efforts

60-Minute Telephone or 90-Minute In-Person Focus Group with *MOTHERS WITH POSTPARTUM DEPRESSION*

MODERATOR GUIDE

[Note: The facilitator will adjust the following talking points and time allotments per section based on whether the focus group is via telephone or in-person.]

Background (5 minutes)

Welcome and good afternoon or good evening, depending on your time zone. My name is [facilitator's name] and I will be facilitating our discussion.

The main purpose of our discussion is to talk about moms' and children's health shortly after birth. There are no right or wrong answers during the entire discussion—I am interested in your experiences and ideas.

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, one of the 27 institutes and centers that make up the National Institutes of Health, is the sponsor of this project. I am <u>not</u> an employee of this Institute. I am an independent researcher, so feel free to be honest with your feedback—you will not hurt my feelings.

We have a very limited amount of time together—our discussion will end in about 1 hour [1½ hours for in-person], at X:XX p.m. Eastern. So, if I interrupt you, please don't take it personally —I am simply trying to make sure we cover all of our discussion topics before our time is up. It is also critical that each of you speaks one at a time and that you allow each other to get more or less equal "air time."

I am audio-recording our discussion and my colleague is taking notes. This means your feedback is secure to the extent permitted by law. With that in mind, do I have everyone's permission to proceed?

Participant Self-Introductions (5 minutes)

All of you on this call are mothers with at least 1 child less than 5 years of age. [I am a mother of two myself.]

Public reporting burden for this collection of information is estimated to average 60 minutes for telephone focus groups and 90 minutes for in-person focus groups, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0532). Do not return the completed form to this address.

I am now going to go around the virtual table and call your name. Please introduce yourself:

- (1) using your <u>first</u> name only (no last names);
- (2) let us know your geographic location; and
- (3) let us know how many children you have and their genders and ages.

During the discussion, please state your first name before each comment that you share.

Promoting the Topic of Postpartum Depression: Communication Channels (5 minutes)

- 1. How do you prefer to learn about your health in general, and this includes your mental health?
 - a. How much influence does your partner have in decisions about your health in general, including your mental health?
- 2. What sources of information on postpartum depression would you most trust?
 - a. What organizations would you trust to give you information on postpartum depression?
- 3. What would be the best ways to communicate that postpartum depression is not just "feeling moody" or overwhelmed shortly after birth?
 - a. Who would be most appropriate for helping women determine where the line is drawn between expected mood swings and postpartum depression?
 - b. What point during a pregnancy would be ideal to receive information on postpartum depression?

[Listen for: obstetricians, family medicine doctors, lactation consultants, pediatricians, nurses, psychiatrists, pharmacies, websites (which ones?), baby merchandise stores, parenting magazines (which ones?), mothers, sisters, friends, etc.

Probe for formats: Web/Internet, social media, print, audio, visual.

Probe specific products: For example, print ad in *Parenting* magazine, video for waiting area, poster in exam room, blog with other moms, BabyCenter forum, faith-based communication channels (e.g., church bulletin, faith leader communication), etc.]

Knowledge, attitudes, behaviors, and beliefs (20-30 minutes)

Something else that ties all of you in this group together is that all of you have been diagnosed with postpartum depression at some point in your lives.

[If necessary, read definition: Postpartum depression is moderate to severe depression in a woman after she has given birth. It may occur soon after delivery or up to a year later. Most of the time, it occurs within the first 3 months after delivery.]

1. At any point during your pregnancy, immediately after birth or during the first year of your child's life, did anyone talk to you about how your mental health may be affected after birth? If so, who spoke with you and what were those conversations like?

[Listen for what type of health professional may have addressed mental health and what was the specific focus or topic.]

[If no one spoke to participant:] At what point during your pregnancy or the first 12 months after the birth of your child do you feel it would have helped to have someone talk to you about postpartum depression?

a. Did anything unexpected occur during your pregnancy?

[Listen for: Learned mom was having multiples, learned about mom's or baby's new health condition, baby needed to spend time in the NICU.]

- b. Did someone talk to you about postpartum depression during this period? If so, what was that conversation like? What were you told to expect?
- c. Please describe when and how you were diagnosed with postpartum depression by a health care professional.
- --What prompted you to seek help from a health care professional before this diagnosis?
- --What reasons may explain why you may have hesitated to discuss how you felt at that time?
- d. Whom did you rely on for social support?

 [Listen for: Partner, family members, friends.]
- e. Did you join a support group?

If so, what was that experience like? What were you told to expect?

- f. Did you receive educational materials about postpartum depression during this period? If so, what were those materials like?

 Which materials did you like the best and why?
- g. What kind of support and information do you wish you had received?
- h. Who diagnosed you with postpartum depression? Were you seen by a mental health professional?
- i. What treatment was recommended for you and did you complete the treatment course?
- j. With which health care professional would you have felt most comfortable discussing postpartum depression feelings?
- k. How comfortable were you visiting a mental health professional to treat postpartum depression?

- 6. If a friend told you she thought she had postpartum depression, how would you advise her? a. Where would you recommend that she seek help?
- 7. How do you think postpartum depression is viewed generally?
 - a. How might your family background or community view postpartum depression?

[Listen for thoughts such as those related to some cultures paying extra attention to the mother right after birth and those cultures that heavily rely on family networks.]

Message Testing (10-15 minutes)

[Note: Participants will receive a 1-page sheet of messages related to postpartum depression prior to their focus group.]

We are now going to review a few messages related to postpartum depression to inform a campaign to raise awareness about postpartum depression. These messages may end up in campaign materials. I would like you to tell me which messages you like most and which messages you like least and why. Please let me know if there are any words that might be confusing or offensive. Let's start with...

Message #1: Many moms often feel changes in mood after birth.

- Any woman can suffer from mood swings after the birth of a child.
- There is no shame in feeling depressed or anxious after the birth of a child.
- Hormones, genetics, and brain chemistry all play major roles in the onset of these mood swings after the birth of a child.
- Approximately 70% to 80% of all new mothers experience some negative feelings or mood swings after the birth of their child.

Message #2: Postpartum depression is not just "feeling moody" or overwhelmed shortly after birth.

- If these feelings have gone on for a long time and they have interfered with your daily activities, speak with a health care professional.
- It might be hard to recognize depression or anxiety when you are tired, overwhelmed, or adjusting to life with a new baby.
- It is important to talk to your partner, family, friends, or health care provider if you don't feel like yourself.
- Symptoms can start anytime in the first year postpartum.
- Symptoms may include feelings of anger, lack of interest in the baby, loss of interest in things you used to enjoy, being unable to care for your baby or yourself, and thoughts of harming yourself or the baby.
- These symptoms may be signs of postpartum depression.
- A family history of depression or anxiety, family stress, complications in the pregnancy or birth, or a multiple birth can all increase the risk of postpartum depression.

Message #3: If you suffer from postpartum depression, you are not alone.

- There is no shame in feeling depressed or anxious after the birth of a child.
- Unexpected life circumstances can affect a mom's mental health after the birth of a child.
- Over half a million women a year suffer from postpartum depression.
- Having a baby is a major life change and transition. Big changes can cause significant stress and may lead to depression.
- Postpartum depression may make you feel isolated, like you are the only one in the world who has this experience. Hearing other women's stories in a support group or from a support organization can provide hope for recovery.
- Your health provider can provide a list of resources and support groups in your community.
- 10% to 15% of women experience significant symptoms of depression or anxiety after the birth of a child.

Message #4: Postpartum depression can be treated.

- Getting treatment is important for you and your family.
- With proper care, you can fully recover.
- Without treatment, the depression and all of its symptoms will get worse and may put you and your family in danger.
- Your health care professional may ask you a set of questions to decide on the best treatment for you.
- Some women find a support group helpful in coping with postpartum depression.
- There are many treatment options for postpartum depression. Some women may participate in therapy and some women may require medication.

Wrap Up and Thank You

Finally, what else should the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development keep in mind as it develops health education materials for families?

Thank you very much for your time and valuable input. Your contributions today will inform the Institute's outreach efforts to families across the country.