

Research Article

DECISION MAKING FOR DEPRESSION TREATMENT DURING PREGNANCY AND THE POSTPARTUM PERIOD

Sapana R. Patel, Ph.D.^{1*} and Katherine L. Wisner, M.D. M.S.²

Background: To explore women's perspectives about the treatment decision-making process for depression during pregnancy and after birth. **Method:** One hundred pregnant and postpartum women completed an anonymous web-based surveys regarding treatment decision making for depression. **Results:** Survey data reveal that most women in this sample prefer an active collaborative role in treatment decision making for depression. Sixty-five percent of the sample made a decision for treatment of their major depressive disorder, including a decision for no treatment, and 34% reported not having made a decision or feeling unsure about their decision. More than half of the sample preferred combination treatment with medications and counseling (55%) followed by counseling (22%), no treatment (8%), and medications (8%). Overall, respondents in this sample had low levels of decisional conflict (uncertainty) with younger women in the sample reporting higher levels of decisional conflict. **Conclusions:** Treatment decision making for depression during the perinatal period is complex. Asking women about their preferences for participation in decision making, their treatment preferences and their decision making needs during the clinical encounter may lead to improved communication, decision making and quality of care. *Depression and Anxiety* 28:589–595, 2011. © 2011 Wiley-Liss, Inc.

Key words: decision making; perinatal; depression

INTRODUCTION

Depression is a leading cause of disability among women worldwide.^[1] The peak prevalence of major depressive disorder (MDD) in women is during the childbearing years. Depression can have devastating consequences, not only for the women experiencing it but also for the women's children and family.^[2–5] A recent population-based survey of more than 15,000 women found that the prevalence of MDD during pregnancy is 8.4 and 9.3% during the postpartum period.^[6] Although the prevalence of depression during pregnancy and after birth is high, women are usually neither identified nor treated.^[6,7] Even when depression is detected by health professionals, women rarely obtain assistance, despite research suggesting that treatment is available.^[8,9]

Recent research on help-seeking barriers of women during the prenatal and postpartum period has found that structural barriers (i.e. inability to pay, transportation, and childcare), lack of motivation for treatment and hopelessness, fear of adverse reproductive outcomes,^[10–13] uncertainty about appropriate provider and treatment type,^[14,15] lack of knowledge of illness,

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*Correspondence to: Sapana R. Patel, Department of Clinical Psychology (in Psychiatry), College of Physicians and Surgeons, Columbia University, New York State Psychiatric Institute, Anxiety Disorders Clinic & Hispanic Treatment Program, 1051 Riverside Drive, Unit #69, New York, NY 10032. E-mail: sp2309@columbia.edu

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¹New York State Psychiatric Institute, Columbia University, College of Physicians and Surgeons, New York, New York

²Women's Behavioral HealthCARE, Western Psychiatric Institute and Clinic, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania

social stigma, and fear about custody loss^[9,13] inhibit women from accessing treatment. Research on engaging pregnant and postpartum women in treatment suggests that women prefer psychotherapy with mental health specialists, informal sources of support such as family and friends, and treatments that are easily accessible (i.e. treatments delivered by telephone or in the home).^[14,16–18] Potential solutions to the underutilization include improved education about depression and its treatment, quality communication between patients and provider, and customized patient-centered care.^[9,14] In particular, there has been a call for better understanding of the components of personalized care for depressed perinatal woman such as treatment preferences, preferences for participation in decision making (DM), and family involvement that can help guide the decision-making process between women and their providers to arrive at a mutually agreed upon treatment decision.^[19] However, little is known about factors that influence depressed women's treatment decisions during pregnancy and the postpartum period.

Clinical experience tells us that treatment decisions during pregnancy and after birth are often complex for both provider and patient due to the uncertainty and magnitude of the risks for adverse reproductive outcomes, women's preferences and values, perceived liability risk, breastfeeding, and maternal morbidity.^[20,21] However this has never been systematically studied. To help guide the treatment decision-making process, Wisner et al.^[20] developed a Risk-Benefit model for DM for treatment of MDD during pregnancy. The process emphasizes skilled DM on behalf of the physician in structuring the problem and a discussion of the likelihood of outcomes. While the Risk-Benefit model includes general guidelines for the physician to follow, there is a dearth of research on women's perspectives and preferences for treatment DM and care. For example, Bonari et al.^[12] found that despite receiving evidence-based counseling, more pregnant women discontinued their antidepressant medication compared to their gastric and antibiotic medications. This study demonstrated that evidence-based information is applied differently to psychotropic medications compared to other types of drugs.

A better understanding of women's perspectives will inform and enhance the existing Risk-Benefit model and develop decision-making interventions to guide the woman and her provider through a decision-making process toward optimal childbearing outcomes. Using the Ottawa Decision Support Framework, an evidence-based conceptual framework to guide healthcare DM,^[22] the following descriptive exploratory study presents results of a web-based survey to understand the treatment decision-making process for depressed women during pregnancy and after birth. Our study sought to explore the following questions: (1) What role do perinatal women prefer while treatment DM for depression with their providers?; (2) What are their preferences for involvement in depression treatment

decision-making tasks, such as determining treatment options or making the final decision?; (3) What are their treatment preferences among the evidence-based treatments available for perinatal depression?; and (4) Among those women who have made a depression treatment decision, what is their level of uncertainty regarding their treatment decision? What are the modifiable factors associated with this uncertainty? Based on the literature reviewed, we hypothesized that women would prefer an active role in treatment DM and prefer treatment with counseling over any other type of evidence-based treatment. Given the dearth of research on preferences for role and participation in DM among women with perinatal depression, we did not have any hypotheses regarding these outcomes. Additionally, we surveyed women about needs and services that may help in making depression treatment decisions with their providers.

METHODS

SAMPLE AND PROCEDURE

Women of childbearing age who were pregnant or had given birth within the past year (the period used for point prevalence estimates of perinatal depression^[23]), and had been diagnosed with MDD by a healthcare professional were recruited to the survey via a web-link on five perinatal mood disorders websites including www.MedEdPPD.org, Postpartum Depression Resource, Postpartum Support International, Women's Behavioral HealthCare at the University of Pittsburgh Medical Center, Postpartum Progress, and the Mom Source.net. From April to October 2010, participants completed the anonymous online self-report survey on surveymonkey.com. This study was approved by the New York State Psychiatric Institute Institutional Review Board.

OTTAWA DECISION SUPPORT FRAMEWORK

The Ottawa Decision Support Framework (ODSF) is an evidence-based, transdisciplinary, conceptual framework used to guide people through health decisions in which they are experiencing decisional conflict. Decisional conflict is the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values. Studies on DM reveal that a high proportion of women experience decisional conflict about the choices they faced including breast cancer treatment, maternity care options, and osteoporosis treatment.^[24] The ODSF has guided the DM needs assessment, development, and evaluation of more than 30 decision support interventions and lends itself to adaptation for different stages of the treatment process, health conditions, and treatment settings.

The framework has three elements: assessing the needs or determinants of decision, providing decision support, and evaluating DM and outcomes of decisions. The concepts in the framework apply to all participants involved in the choice, such as the woman, couple, or family and their provider. The survey was designed by first author (S.R.P.) with a focus on the first element, assessing the needs or determinants of decisions, for depressed perinatal women.

SURVEY

The survey (See Appendix A of the Supplementary Material) consisted of demographic and clinical questions (i.e. age, marital status, education, race, ethnicity, pregnancy, or postpartum status including weeks), decision-making preferences using the Control

Preferences Scale (CPS)^[25] and the Problem-Solving Decision Making Scale (PSDMS).^[26] Participants were also surveyed about their MDD treatment preferences among a list of evidence-based treatments including the options of being unsure and preference for no treatment, their treatment decision status (made a decision versus has not made a decision) and uncertainty about this decision using the Decisional Conflict Scale (DCS).^[27] Although no instruments are available to measure DM specifically for perinatal depression, the CPS, PSDMS, and DCS are among the most widely used instruments for the assessment of decision-making preferences in medical populations thereby allowing for results to be compared among studies. We included multiple measures of preferences for participation in DM to capture as much of the complexity of interaction during DM for perinatal depression.

The CPS^[25] measures preferred role treatment in DM. Participants were presented with the following statement, “When deciding on what treatment is best for your emotional/mental health problems, what is your preferred role in treatment decision-making?” and asked to choose among five response statements: the first two represent an active role, one response indicates shared or collaborative role, and the final response statements represent a passive role. Higher scores on the CPS indicate preferences for a passive role in decision-making. The CPS is an easily administered, valid, and reliable measure of preferred roles in healthcare DM in a variety of women’s health populations;^[28,29] however, it has also been criticized as misleading for classifying patients as “active” or “passive” with regard to healthcare DM since patients have different desires for different dimensions of the decision-making process. It is well established that patients want to receive information from their providers almost universally,^[26,30,31] but less is known about information exchange, that is, patient preferences for providing information to their physicians. Preferences for deliberation (i.e. formal discussion about options) and preferences for final selection of treatment are known to differ substantially among patients^[32] although it is unclear whether patients who prefer discussing treatment options also prefer making the final decision about treatment.^[33]

The PSDMS^[26] examines two dimensions of the decision-making process: problem solving (PS) and DM. The PS dimension can be conceptualized as the information exchange part of the DM process. There are four PS tasks defined as those that require factual knowledge: determining diagnosis, treatment options, risks and benefits, and the likelihood of risks and benefits. The DM dimension incorporates both factual knowledge and individual preferences and is comprised of two tasks: determining acceptability of risks and benefits (termed “utilities”) and selection of a treatment option. The PSDMS was adapted for this study “You are pregnant or have already given birth and you have been feeling sad and down lately. You decide to visit your doctor about this.” Participants were asked to indicate for a set of four PS tasks and two DM tasks, “Who should determine/decide...” using a 5-point scale: (1) Doctor alone; (2) Mostly the doctor; (3) Both equally; (4) Mostly me; and (5) Me alone. To determine preferred role, a mean overall score was computed and to explore patterns in preferences by dimension and tasks mean scores are computed separately for each dimension and each PS and DM task for each respondent, and placed into one of three classifications: defer (mean score <3); share (mean score between 3 and 3.99); or keep (mean score >4). Reliabilities of the PSDMS are very good to excellent: full scale— $\alpha = .71-.90$, PS— $\alpha = .79-.90$, and DM— $\alpha = .67-.93$.^[34] The PSDMS has been used to assess preferences for information and DM in samples of women making decisions about contraception, fertility treatments, and breast cancer treatment.^[35-37]

The DCS^[27] is a 16-item Likert type questionnaire that measures uncertainty while making healthcare decisions. This may occur especially when a choice has to be made involving risks or uncertainty

and when significant potential gains and losses are involved. The DCS asks the respondent to reflect on a decision just made or about to be made. This scale measures the constructs of uncertainty about an impending decision and factors contributing to uncertainty (such as feeling uninformed, unclear about values, and unsupported in DM). The DCS has been validated in several women’s health populations including decisions regarding osteoporosis treatment, breast cancer screening, hormone replacement therapy, maternity care options, and prenatal testing.^[38-43] The internal consistency coefficients of all subscales ranged from 0.78 to 0.89, the test-retest reliability indices exceeded 0.80.^[44] The scale is reliable, discriminates between those who make or delay decisions and is sensitive to change.^[22] Scores vary from 0 (low decisional conflict) to 100 (high decisional conflict). Scores lower than 25 are associated with implementing decisions and scores exceeding 37.5 are associated with decision delay or discontinuance of chosen option, regret and the tendency to blame provider for bad outcomes.^[27]

Participants were also surveyed, using open- and close-ended questions, about needs and services that may facilitate the treatment decision-making process. This included preferences for information about treatment options including format (i.e. pamphlets, internet, or DVD etc.) and venue for receiving information (i.e. physician, internet, nurse, peer support, public library, etc), and potential usefulness of a video-based decision aid.

ANALYSES

Statistical analyses employed the Statistical Package Social Sciences, version 16.0. Analyses included descriptive frequencies, means, and standard deviations for sociodemographic characteristics (including age, marital status, race, ethnicity, and education) and survey items. We examined relationships between demographic, clinical (pregnant or postpartum) and decision status (made a decision versus has not made a decision) variables, treatment preference, CPS score, PS and DM dimensions of the PSDMS and DCS scores using χ^2 and one-way ANOVA. Due to the exploratory nature of the study, an $\alpha = .05$ was used as a measure of significance.

RESULTS

Out of the 254 participants who clicked on the link to the survey, 159 participants began the survey and 125 participants completed the online survey. Twenty-five respondents were excluded from the sample because they were more than 52 weeks postpartum. As seen in Table 1, the sample consisted of 100 women. Respondents were predominantly postpartum (73%; average 15.8 weeks since delivery), married (98%), white (96%) women with a College or Graduate degree (90%). All women in this sample self-reported a diagnosis of MDD by a healthcare professional.

According to the CPS (Table 2), 53% of women preferred an active role and 40% preferred a collaborative role in the depression treatment decision-making process with their provider. Results of the PSDMS (Table 2) revealed similar results in that that respondents overall preferred to keep (62% (analogous to “active” on the CPS)) or share (32% (analogous to “collaborative” on the CPS)) PS and DM. Preferences by dimension reveal that respondents preferred to defer problem tasks and keep decision-making tasks. Further exploration by PS and DM tasks reveal variation in

TABLE 1. Characteristics of survey respondents (N = 100)

	N (%)
Age, in years (<i>M</i> (<i>SD</i>))	31 (5.0)
Marital Status	
Single	2 (2%)
Married/living with partner	98 (98%)
Education	
High school diploma-some college	10 (10%)
College degree	56 (56%)
Graduate school	34 (34%)
Ethnic background	
Hispanic	4 (4%)
Non-Hispanic	96 (96%)
Race	
White	93 (93%)
Other (Black, Asian/Pacific Islander, Other)	7 (7%)
Pregnant	27 (27%)
Weeks (<i>M</i> (<i>SD</i>))	5.6 (10.4)
Postpartum	73 (73%)
Weeks (<i>M</i> (<i>SD</i>))	15.8 (15.2)

TABLE 2. Decision-making preferences (N = 100)

<i>Control preferences scale</i>	N (%)		
Active	53 (53%)		
Collaborative	40 (40%)		
Passive	7 (7%)		
<i>Problem solving decision making scale</i>	Defer	Share	Keep
Overall	6 (6%)	32 (32%)	62 (62%)
Dimension			
Problem solving tasks	72 (72%)	24 (24%)	4 (4%)
Tasks			
Diagnosis	37 (37%)	59 (59%)	4 (4%)
Treatment options	28 (28%)	60 (60%)	12 (12%)
Risks/benefits ^a	46 (46%)	46 (46%)	7 (7%)
Probabilities	57 (57%)	35 (35%)	8 (8%)
Dimension			
Decision-making tasks	4 (4%)	41 (41%)	55 (55%)
Tasks			
Utilities	2 (2%)	37 (37%)	61 (61%)
Selection of treatment option	5 (5%)	29 (29%)	66 (66%)

^aN = 99.

preferences for participation for the PS tasks. Respondents preferred to share involvement in determining diagnosis and treatment options and less involvement in determining the probabilities of risks and benefits of treatment options. There was less variation the preferences for involvement in DM tasks, most participants preferred increasing involvement in determining acceptability of risks and benefits (termed "utilities") and selection of treatment option (Table 3).

With respect to treatment preferences, more than half of the sample reported preference for combination treatment with medications and counseling (55%) followed by counseling (22%), no treatment (8%), medications (8%), and some unsure about their preferences (7%). Sixty-five percent of the sample

TABLE 3. Treatment preferences, decision status and decisional conflict (N = 100)

	N (%)
Treatment preferences	
Medication	8 (8%)
Counseling	22 (22%)
Combination (Medication and Counseling)	55 (55%)
No treatment	8 (8%)
Unsure	7 (7%)
Treatment decision status ^a	
Yes (including a decision for no treatment)	65 (65%)
No (including unsure about my decision)	34 (34%)
Decision Conflict Scale (DCS; <i>M</i> (<i>SD</i>))	29.0 (19.0)
DCS Subscale scores	
Uncertainty	20.6 (11.9)
Informed	11.7 (9.9)
Values clarity	9.3 (8.9)
Support	11.8 (10.1)
Effective decision	10.9 (7.9)

^aN = 99.

made a decision for treatment of their MDD, including a decision for no treatment, and 34% reported not having made a decision or feeling unsure about their decision. DCS scores reveal low decisional conflict ($X = 29.0$, $SD = 19.0$) but slightly higher than the cutoff of 25 which is associated with implementing decisions and less than 37.5, the score associated with decisional delay. Using these DCS cutoff scores, 69% of the sample had DCS scores associated with implementing decisions and 31% of the sample had DCS scores associated with decisional delay or uncertainty. Further exploration of the DCS subscale scores revealed an elevated score, relative to other subscales, in the uncertainty subscale ($X = 20.6$, $SD = 11.9$).

Analyses examining the relationship between predictor variables of interest (i.e. demographic, clinical) and outcome variables (i.e. decision status, preferences for DM, treatment preference and decisional conflict) scores revealed that younger respondents [$F(2, 96) = 4.073$, $P = .020$] had higher decisional conflict scores compared to older respondents. Exploratory analyses of decisional conflict subscale scores in younger versus older women revealed that younger women felt more uninformed than the older women in this sample (DCS Informed: Younger $M = 17.0$ ($SD = 9.1$) versus Older $M = 8.9$ ($SD = 9.2$)). Further, those who had made a decision about their treatment had lower decisional conflict scores ($F(1, 95) = 29.12$, $P = .000$) compared to those who had not made a decision. No other significant associations were found (all P values $> .10$).

Results of the decisional needs survey showed that most women prefer to learn about treatment options through a discussion with their doctor or nurse (75%). Half of the sample (52%) reported they would watch a 40-min videotape to obtain information about their decision and more than half (57%) reported they would most likely use information materials through the

Internet or booklets or pamphlets (33%). Open-ended question data revealed that women in this sample used the Internet to research providers, treatment options as well as peer-reviewed journal articles on the treatment of perinatal depression. When asked about the information format that would most likely be useful one participant commented, *“Doctor advice and research provided by the doctor. I don’t want some glossy handout. I want the facts, figures and stats from real and reliable research.”*

DISCUSSION

The results of this online survey revealed that pregnant or postpartum women have identifiable preferences regarding their participation and role in the depression treatment decision-making process. Comparable to other women’s health samples, most women preferred an active and collaborative role in treatment DM, amenable to shared DM and decision support interventions.^[28,29] With respect to decision-making tasks, respondents in this sample preferred to defer control of the PS tasks, which require evidence-based information about depression treatment, to the physician and preferred to share or keep control of decision-making tasks. This finding is consistent with previous studies of women facing decisions about contraception, fertility, and breast cancer treatment.^[35–37] These data as well as open-ended question data demonstrated a desire to be involved in DM, the importance of communicating evidence-based information, and the need for patient-specific decision support tools and guides to assist women in healthcare DM with their providers.

Contrary to our hypothesis, we found combination treatment to be the preferred treatment among women in our sample. Other studies showed that most participants preferred treatment with psychotherapy alone, although other studies did not include combination treatment as an option.^[13,14,16] There may be several reasons for this. Preference for combination may also be a reflection of our sample, 60% of whom had already made a treatment decision about their treatment and presumably discussed concerns about medications and a risk-benefit discussion with their healthcare providers. Further, respondents were predominantly postpartum and the reticence for medications is often greater during pregnancy; however, being pregnant or postpartum did not influence treatment preference in this sample. Treatment preference results should be rendered tentative due to our sample size; however, they merit consideration as identifiable patient-level factors to be aware of and address during the treatment decision-making process. Several studies have found that discussing treatment preferences facilitates treatment negotiation and better uptake of recommendations.^[45–48] Thus, it is reasonable to hypothesize that providers who engage pregnant or postpartum women in the risk-benefit discussion will likewise facilitate treatment alliance and uptake if they

not only provide evidence-based information and offer their treatment recommendation but also discuss patients’ treatment preferences.^[49,50]

Notably, in our sample approximately one-third of women who accessed and used perinatal mood disorders websites and reported receiving a diagnosis of MDD from their healthcare professional had not made a treatment decision about their depression. Overall, respondents in this sample had low decisional conflict compared to other samples of women facing health decisions.^[38–43] Several small pilot studies have found a considerable portion of their respondents expressed uncertainty about what to choose (% uncertain ranging from 52%^[41] to 69%^[38]). In our sample, those who already made a decision had lower decisional conflict relative to those who had not. We believe this is due a biased sample of well-educated, highly motivated and recruited through perinatal mood disorders websites to which their providers referred them. Decisional conflict was greater among the younger women in this sample, which identifies them as a group at risk for decisional delay. Subscale analyses revealed that younger women report feeling less informed as compared to older women in this sample. Increasing patient knowledge of treatment options is a modifiable factor that providers can address using decision support during the treatment decision-making process, especially with young pregnant or postpartum women experiencing depression.

To our knowledge, this is the first quantitative study to examine depressed women’s perspectives and preferences for the treatment decision-making process during pregnancy and after birth. Unlike previous studies assessing treatment preferences, we examined preferences for participation in DM, surveyed treatment decisions and uncertainty surrounding this decision as well as needs and services to facilitate patient–physician communication about treatment decisions for depression during the perinatal period. However, our study should be rendered tentative given several limitations, which constrain their generalizability to depressed perinatal women in the general population. First, we were limited to a small convenience sample of predominantly white well-educated depressed women who self-report a diagnosis of depression. We were also unable to include in our analyses data on 20% of our sample that was excluded because they were more than 52 weeks postpartum (20%). Second, we examined preferences for DM among a sample in which more than half of the participants who had already made a decision regarding their treatment with their provider. We did not collect information on treatment history or current treatment. This limited our ability to fully examine demographic, treatment (i.e. preference and status), and clinical variables and their influence on decision-making preferences. Third, our sample is likely biased by the likely exclusion of women who do not use a web resource for perinatal depression and women who do

not use a computer or have access to one. Finally, we were limited by quantitative measurement of decision-making preferences at one single point in time. Preferences could change with passage of time, remission of depression, education about treatment options, cost of treatments, access to care, therapeutic discussion with a clinician, and actual treatment experience. Future research will need to assess a larger and more representative sample using qualitative and quantitative methods to allow for comparisons of preference patterns, enrich our understanding of preferences for treatment decision-making and explore factors that influence them. In addition, it will be important to capture women at different stages of their help seeking to understand how preferences vary and determine appropriate timing for a shared decision-making intervention. Future studies will address these issues as well as other influences on treatment DM during the perinatal period.

Pregnancy and the postpartum period are developmental and situational transitions for women, which sets up a cascade of decisions that may directly or indirectly affect the health of women and their families. For many of these decisions there is no right or wrong answer and women need to carefully deliberate on the best option for them. Supporting women and families through these decisions can start with asking them about their preferences for the approach to DM with the physician. Exploring the patient's expectations for the physician's as well as her own will improve communication and congruence between patient and provider beliefs about participation and thereby enhance outcomes to treatment and satisfaction with care,^[51] top priorities for both parties.

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