Depression and Posttraumatic Stress Symptoms After Perinatal Loss in a Population-Based Sample

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Abstract

Introduction: Perinatal loss is often a traumatic outcome for families. While there are limited data about depressive outcomes in small populations, information about depression and posttraumatic stress disorder among large racially and economically diverse populations is sparse.

Methods: We collaborated with the Michigan Department of Community Health to conduct a longitudinal survey of bereaved mothers with stillbirth or infant death under 28 days of life and live-birth (control) mothers in Michigan. The study assessed 9-month mental health outcomes including self-reported symptoms of depression and posttraumatic stress disorder along with information about demographics, pregnancy and loss experience, social support, and past and present mental health and treatment.

Results: Of 1400 women contacted by the State of Michigan, 609 completed surveys and were eligible to participate for a 44% response rate (377 bereaved mothers and 232 control mothers with live births). In multivariable analysis, bereaved women had nearly 4-fold higher odds of having a positive screen for depression and 7-fold higher odds of a positive screen for post-traumatic stress disorder after controlling for demographic and personal risk variables. A minority of screen-positive women were receiving any type of psychiatric treatment.

Conclusion: This is the largest epidemiologically based study to date to measure the psychological impact of perinatal loss. Nine months after a loss, bereaved women showed high levels of distress with limited rates of treatment. Symptoms need to be monitored over time for persisting disorder and further research should identify women at highest risk for poor outcomes.

Introduction

PERINATAL LOSS IS OFTEN a traumatic and unexpected outcome for families expecting a baby. While there has been substantial research about how parents experience and cope with these losses, information about mental health outcomes for bereaved parents has been sparse. Some of the research that has been done is two or three decades old, and most research has used small cohorts, convenience sampling, and is not representative in terms of socioeconomic status of women who actually experience loss. There are particularly large gaps in understanding mental health outcomes for African-American women despite the fact that such women have much higher risks for perinatal loss.

While research has shown that the majority of women with postpartum depression do not receive adequate evaluation and treatment for this condition, there is little data to inform us about treatment rates among perinatally bereaved women, despite existing data which suggests that the existence of mental health problems may confer added risks for fetal outcomes in subsequent pregnancies.[1–3]

Just as each individual grief is unique, we recognize there are differing perspectives in understanding grief, which overlap but are distinct. Many models focus less on pathological reactions, favoring instead to examine adaptation to loss. A self-help guide may suggest a much longer bereavement period, normalizing prolonged intense distress for several years that a more psychiatric approach would consider to be an emotional disorder.[4] Some researchers emphasize the importance of making meaning of this loss or continuing the bond with the deceased baby.[5,6] Still others focus on a normative resilient response in which there may be little overt expression of grief and/or unexpected benefits.[7–9] While we are using a psychiatric, Diagnostic Statistical Manual (DSM) categorization of emotional disorders such as depression and posttraumatic stress disorder (PTSD), we

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respect different approaches to understanding the repercussions of perinatal loss.

We sought to survey a large epidemiologically representative sample of perinatally bereaved mothers to further assess this approach using a much larger and more representative sample of parents. Our analysis is part of a broader study about physical and mental health outcomes for bereaved mothers compared to mothers with live births.

Methods

The broader study is a two-year longitudinal survey of bereaved and live-birth mothers in the state of Michigan to evaluate hospital experiences and long-term health outcomes after perinatal death; this manuscript reports on results from the first of three surveys. Bereaved mothers (''cases'') were included if they had a stillbirth (at least 20 weeks completed gestational age and weight of at least 400 g) or an early infant death in the first 28 days of life. Live birth mothers (''controls'') who delivered in the same month as the case mothers were randomly selected as controls and had a surviving infant. Surveys and invitations to participate were sent out by the Michigan Department of Community Health based on state birth and death registration data. Mailings were sent on a monthly basis to all eligible bereaved mothers in the state until the study goal of 900 cases and 500 controls had been successfully contacted. Nine hundred cases were selected, as this is about two-thirds of the perinatal deaths in the state per year and we felt this would provide a representative sample. We limited the study to women who were ages 18 and older, able to complete an English-language consent and surveys, residents of Michigan at the time of birth, and had no state records showing pending or completed adoption. Protocol was to send identical mailings at approximately 6, 14, and 24 months after the birth (live or stillbirth) or infant death, but we asked women to report the date they completed the survey so we could account for time since birth/loss, as state mailings could not always be distributed at the exact time specified and we knew not all women would answer at the same time. Each mailing wave included up to three identical mailings and a reminder postcard each sent roughly 3 weeks apart. Ten dollars cash was included in the first mailing as a token incentive. This analysis focuses on results from the first set of mailings only, sent 6 months after delivery or loss.

The consent form included a release of the state birth, fetal death, or infant death certificates to obtain demographic and pregnancy data for participating mothers (all except one participant consented to this release). The State of Michigan provided the research team with de-identified demographic data for nonparticipants to allow us to assess representativeness of study subjects. The research was approved by the Institutional Review Boards of the University of Michigan and the State of Michigan Department of Community Health.

The surveys measured symptoms of depression in the past two weeks using the Patient Health Questionnaire-8 over the 2 years of the study. A score of 10 or higher was used to identify women with a positive screen.[10] Symptoms of PTSD over the last month were measured using the PTSD checklist, civilian version, and a score of 35 or higher identified a positive screen.[11,12] We used questions adapted from the national Pregnancy Risk Assessment Monitoring System to evaluate intimate partner violence (IPV) from husband or partner in the recent pregnancy.[13] Current social support was measured using the Medical Outcomes Study - Social Support Scale (MOS-SSS) brief version.[14] We collected data on preexisting mental health diagnoses by asking women if they had ''ever been told by a doctor, therapist, counselor, or medical professional'' that they had specific psychiatric problems, an approach modeled on the National Health and Nutrition Examination Survey.[15] Specific diagnoses were listed, with an explanation if needed (e.g., ''phobias: such as fear of public speaking, spiders, heights, dogs, etc.''), and the option to write in anything missing from the list under the heading: ''Other Emotional Problems.'' We assessed past and current treatment ''with medication, counseling, group therapy, or other treatments.''

For bereaved mothers, we asked about the hospital experience including whether mothers saw or held their infant after death. For mothers who did not see or hold, we queried whether they had been given the opportunity.

We calculated descriptive summary statistics to describe bereaved and live-birth mothers. In univariate analysis, we performed chi-squared analysis and t-tests to compare mental health outcomes with basic demographic variables. We conducted multivariable logistic analysis by first looking at the association between mother's status (bereaved vs. nonbereaved) and the presence/absence of the mental health outcomes. We then added all of the covariates including demographics (maternal age, race, education, insurance), time between loss and survey completion; and potential confounders (past history of depression or bipolar disorder, past history of PTSD, intimate partner violence during the pregnancy, and social support at the time of the survey.) A Hosmer-Lemeshow test was done to assess goodness of fit, and we tested the area under the receiver operating characteristic (AUROC) for each model and include this in our results.

In comparing demographic variables of women who participated in the study and those who did not respond, we noted some demographic differences. Therefore, we performed a sensitivity analysis to assess the potential of such differences to affect the mental health outcomes. The sensitivity analysis used the response propensity method commonly used to adjust for missingness in survey response;[16] specifically, a two-stage process was carried out. In the first stage, we fit a logistic regression model that predicts the likelihood of being a responder using covariates that are significantly associated with the outcome of response. The second stage logistic regression models are fit on the depression and PTSD outcomes, weighted by the inverse of the predicted probability from the first stage model. We then repeated our multivariable logistic regression looking at depression or PTSD outcomes among bereaved versus nonbereaved mothers and including all of the covariates previously tested along with the weighting variable to account for any nonresponse bias.

We tested separately to see whether there was a difference in depression or PTSD outcomes by controlling for differences between women who had or had not experienced a prior loss. To define prior loss, we abstracted variables from the birth and fetal death certificates which indicated either a loss prior to birth (miscarriage, ectopic, stillbirth) or a later death (the variable on the certificates asks about infants born alive but now dead, so does not specify the age at death). In our analyses, adjusting for prior loss did not have a significant

change on either mental health outcome, and the variable itself did not have a significant odds ratio.

Finally, in subgroup analysis we performed univariate analysis using Fisher's exact test to look at the association for women who saw or held their baby and the depression and PTSD outcomes. We did not do multivariable analysis for these groups as few women had no contact with their babies and we did not have adequate power to measure significant differences. Methods and results for this paper are reported according to the STROBE checklist for reports of cross-sectional studies.[17]

Results

Of 1400 mothers surveyed, 609 responded and were eligible to participate in the survey (response rate of 44%). This included 232 control mothers who had live born surviving children and 377 case mothers who had a stillbirth or infant death in the first month of life. Among bereaved women, 191 experienced stillbirth, 181 experienced infant death, and 5 had both a stillbirth and infant death from the same pregnancy. Multiple gestations comprised 1% of pregnancies for the control group but 11% of pregnancies for bereaved mothers. Sixteen case women who had multiple fetuses had at least one live birth from their pregnancy in addition to their loss, and these women were counted in the bereaved cohort.

The average maternal age at birth was 29 years (±6) and two-thirds of women had more than a high school education; these figures did not differ significantly between cases and controls. (Table 1). The median amount of time between the loss/birth and completion of the survey was 9.1 months and this did not differ by case status. Case women (compared with controls) were more likely to report African American race and to have delivered at an earlier gestational age. Case women were also more likely to report a prior past history of depression, PTSD, and intimate partner violence. There was no difference in reported level of social support. There was less than 1% missing data for any demographic or mental health variable.

Women who participated in the survey were no different from nonrespondents in terms of age or maternal smoking status. However, respondents were significantly more likely to have education above high school (65% vs. 47%, $p < 0.0005$) and to be Caucasian (79% vs. 58%, $p < 0.0005$) and non-Hispanic (94% vs. 87%, $p < 0.0005$).

In multivariable analysis (Table 2), bereaved women had nearly 4-fold higher odds of having a positive screen for depression when including all demographic and personal risk variables. Similarly, bereaved women had 7-fold higher odds of a positive PTSD screen. The area under the receiver operating characteristic (AUROC) was 0.83 for the depression model and 0.81 for the PTSD model. The table also shows the contributions of each of the demographic and psychosocial covariates. In our analyses for both depression and PTSD, prior history of depressive disorder, prior PTSD, and intimate partner violence were all independent predictors of current mental health distress. For the depression outcome, the odds ratios and 95% confidence intervals (CIs) for these variables were as follows: prior depression, OR 3.19 (CI 1.85–5.50, $p < 0.0005$); prior PTSD, OR 3.43 (CI 1.69–6.96); IPV, OR 2.01 (CI 1.03–3.92, $p = 0.040$). For the PTSD outcome, covariate results were as follows: prior depression, OR 3.72 (CI:2.34-4.93, $p < 0.0005$); prior PTSD, OR 2.96 (CI 1.42–6.17, $p = 0.004$); IPV, OR 2.12 (CI 1.09–4.13, $p = 0.027$). Having more social support was protective against both depression (OR 0.88, CI 0.83–0.93, $p < 0.005$) and PTSD (OR 0.88, CI 0.83–0.93, $p < 0.005$), and public insurance was a significant predictor of a positive PTSD screen (OR 2.01, CI 1.19–3.39, $p = 0.009$) but not of current depression (OR 1.61, CI 0.90–2.89, $p = 0.107$). Hosmer-Lemeshow testing of our model was not significant, which indicates that logistic regression was an appropriate model to use.

We performed subgroup analysis to look for differences by race or by type of loss (stillbirth versus infant death) but found no significant differences in depression or PTSD outcomes. It was hypothesized that bereaved women who were pregnant again at the time of survey completion would be more likely to experiencing symptoms of depression and

TABLE 1. DESCRIPTIVE FACTORS FOR BEREAVED AND NONBEREAVED MOTHERS

Variable	Bereaved (n = 377)	Nonbereaved (n = 232)	p-Value
Maternal age at delivery, years (mean, SD)	29 (+/−6)	29 (+/−6)	$p = 0.904$
Gestational age at delivery, weeks (mean, SD)	28 (+/−7)	39 (+/−2)	$p < 0.00005$
Time since birth/loss, days (mean, SD)	287 (+/−59)	288 (+/−61)	$p = 0.858$
Education			
High school or less	139 (37%)	73 (31%)	$p = 0.174$
More than high school	238 (63%)	159 (69%)	
Race			
Caucasian	285 (76%)	198 (85%)	$p = 0.001$
African American	73 (19%)	19 (8%)	
Other (including biracial)	19 (5%)	15 (6%)	
Insurance type			
Private	184 (49%)	142 (61%)	$p = 0.003$
Public or none	193 (51%)	90 (39%)	
Past medical history depression	183 (49%)	83 (36%)	$p = 0.002$
Past medical history PTSD	45 (12%)	8 (3%)	$p < 0.0005$
Interpersonal violence	44 (12%)	26 (11%)	$p = 0.862$
Social support (mean score, SD)	16 (+/−4)	16 (+/−4)	$p = 0.410$

PTSD, posttraumatic stress disorder; SD, standard deviation.

TABLE 2. MULTIVARIABLE LOGISTIC REGRESSION FOR DEPRESSION AND POST TRAUMATIC STRESS
DISORDER FOR BEREAVED AND NONBEREAVED MOTHERS

	Depression (n = 591)		PTSD (n = 585)	
	Adjusted odds ratio	p-Value	Adjusted odds ratio	p-Value
Nonbereaved mothers	1.0	—	1.0	—
Bereaved mothers*	3.93 (2.09–7.38)	p < 0.0005	7.08 (3.95–12.69)	p < 0.0005
Age	0.97 (0.93–1.02)	p = 0.291	0.98 (0.93–1.02)	p = 0.284
Race				
Caucasian	1.0	—	1.0	—
Black	0.73 (0.37–1.44)	p = 0.367	0.78 (0.42–1.46)	p = 0.439
Other/multiple	1.37 (0.49–3.84)	p = 0.550	1.62 (0.64–4.07)	p = 0.305
Public Insurance	1.61 (0.90–2.89)	p = 0.107	2.01 (1.19–3.39)	p = 0.009
Education				
High school or less	1.0	—	1.0	—
More than high school	0.57 (0.32–1.02)	p = 0.057	0.78 (0.47–1.30)	p = 0.336
Days from death to survey	1.00 (0.996–1.003)	p = 0.920	1.00 (0.997–1.004)	p = 0.871
Past depression or bipolar disorder*	3.19 (1.85–5.50)	p < 0.0005	3.72 (2.34–5.93)	p < 0.0005
Past PTSD*	3.43 (1.69–6.96)	p = 0.001	2.96 (1.42–6.17)	p = 0.004
Increasing social support*	0.88 (0.83–0.93)	p < 0.0005	0.88 (0.83–0.93)	p < 0.0005
Intimate Partner Violence*	2.01 (1.03–3.92)	p = 0.040	2.12 (1.09–4.13)	p = 0.027

Area under ROC curve = 0.83 for depression model; area under ROC curve = 0.81 for PTSD model.
*p < 0.05.

PTSD based on the literature but this was not the case. Pregnant bereaved women (n = 90; 26% of bereaved cohort) were less likely than nonpregnant bereaved women to have clinically significant depression (14% versus 26%, p = 0.019) or PTSD (27% versus 41%, p = 0.015).

Forty-two percent of women with depression and 36% of women with PTSD reported current psychiatric treatment, and this did not vary by bereavement status. In an analysis which was limited to bereaved women of Caucasian and African American race only who had positive screens for depression or PTSD (n = 137), Caucasian women (n = 107) were significantly more likely than African American women (n = 30) to report current treatment (43% versus 20%, p = 0.022).

In the sensitivity analysis to study whether the differences between study responders and nonresponders impacted risk for depression or PTSD, we found no significant qualitative changes in any of our outcomes when we reanalyzed, including a weighting variable to account for differences between responders and nonresponders. This is reassuring evidence that the response bias did not have a major influence in the maternal outcomes.

In our sample, only 18 bereaved women (5%) reported that they did not see their baby. Of these 18 women, one said she had been asked if she would like to see the baby and 17 reported doctors or nurses told them this was not possible. Fourteen women of these mothers agreed someone described their infant in a way that made them afraid to see the baby, and 11 endorsed feeling too afraid to view. One woman reported that she was unable to see her baby because of her medical condition. When these 18 women were asked if they were glad they had not seen their baby, 6 (35%) agreed, 11 (65%) disagreed, and one did not respond.

Thirty-six women (10%) did not hold their infant. Of these, only two reported that they had been given the chance, and 34 reported they were told they could not hold the infant. Thirty-three of these mothers said their baby had been described in a

way that made them afraid to hold him or her. Two women were medically unable to hold. Of those who did not hold their babies, half (17) stated they were glad and half (17) expressed regret. We queried women who had seen or held their baby to see if they ever wished now that they had not had contact. Among those who had seen their baby and responded to this question, 329 (95%) reported no regret, 11 (3%) reported regret, and 8% were not sure. For women who had held their baby and answered this question, 320 (96%) had no regrets, 5 (1.5%) had regrets, and 7 (2%) were not sure.

Discussion

Main findings

This is the largest epidemiologically based study to date to measure psychological impact of perinatal loss. An average of 9 months after a loss, bereaved women showed remarkably high and persistent levels of distress, measured by symptoms of depression and PTSD. It is notable that there were no significant differences in symptom levels of these disorders among women with stillbirth versus early infant death or among women of different races. However, bereaved African American women with positive screens for either depression or PTSD were significantly less likely to be receiving any type of psychiatric treatment compared with Caucasian women.

The finding that bereaved mothers have four times higher odds of depressive symptoms and seven times higher odds of PTSD symptoms compared with nonbereaved parents underscores the powerful impact of this loss and the severe distress which it can create for parents. While other studies have reported elevated levels of depression, anxiety, and PTSD after perinatal loss, lack of a control group, inclusion of later losses such as sudden infant death syndrome, and variable time at follow-up can make comparison with this research difficult.[18–20]

The difference in treatment rates by race is a concerning finding which mirrors past research on nonbereaved women. Our study used a broad definition of treatment, but still noted low rates of treatment for African American mothers with significant distress. In general, African American women report being less likely to seek treatment in formal mental health institutions and have much lower rates of treatment for postpartum depression and posttraumatic stress disorder in the perinatal period despite similar rates of illness.[21–23] Since African Americans have dramatically higher rates of perinatal loss than Caucasian women, it is critical that we identify culturally acceptable approaches to address unmet treatment needs in this population.

Over the last few decades, parents with perinatal losses have been advised to have contact with their deceased child to facilitate a normal grief process. Seeing and/or holding the infant after delivery or death is widely thought to identify who has been lost and create memories to grieve, thereby leading to improved psychosocial outcomes for parents.[18,24,25] A 2007 systematic review of this practice found 34 published studies in the United States which addressed this approach.[26] The vast majority of parents appreciated contact when it was offered and only a handful in one study believed seeing their baby affected them negatively, with none saying it was traumatic. Many perinatal bereavement organizations have issued guidelines about parental contact with their infant after death.[27–29] In our research, most women did report contact with their babies and those without contact generally reported they were not given the opportunity. This differs from a recent study which found that less than a third of women without contact with their deceased infant were not given the option.[18] However, that study recruited from online bereavement organizations and nearly 90% of the respondents were Caucasian, so it is not a representative U.S. sample.

Most prior bereavement studies have recruited convenience samples, often from in-person support groups or internet forums; while this can lead to large numbers, such recruitment practices lead to selection bias, with overrepresentation of white, married, and well-educated parents.[30] In the United States, African American parents face twice the risk of stillbirth and early infant death and yet are often excluded in studies with convenience sampling methods.[31,32] While we did have some differences between respondents and nonrespondents, sensitivity testing assessed the risk of response bias and found there was no change in the risk for mental health outcomes.

It is interesting that women who were currently pregnant were less likely to have positive screens for depression and anxiety. While a new pregnancy is often a positive event, for bereaved parents, this also raises the specter of a repeat loss, and qualitative work has demonstrated intense anxiety and increased depressive symptoms among perinatally-bereaved women in subsequent pregnancies.[19,33–35] However, many of these studies have been cohort studies of bereaved women and have not included a control group of women with live birth. In addition, most have used convenience sampling.

In addition to the findings of increased vulnerability to depression and PTSD after perinatal loss, it is worth noting that resilience can be a counterweight, mitigating distress in the face of loss and trauma in general and perinatal loss in particular.[7–9] Components of resilience may help explain some of our unexpected findings. With the generally increased psychosocial stressors among African Americans and their significantly lower usage of formal treatment, it is surprising to find that group trending (albeit not statistically significant) toward less distress than Caucasians. In a qualitative study, Van (2010) reports numerous effective coping strategies among African Americans including adaptive distraction (''putting it aside''), giving the loss meaning (''there was a purpose''), active self-reliance (''heal thyself''), and finding benefits from the loss (''he's in a good place'').[36] Several other qualitative studies report African American women often find a spiritual solace in both church affiliation and personal prayer as well as informal social support among family and friends to help cope with perinatal loss.[32,37,38] Similarly, the unexpected finding that bereaved pregnant women were significantly less likely to screen positive for depression and PTSD might be explained by using the dual process model of bereavement which recognizes that a crucial aspect of recovering from loss is actively restoring prior functioning, such as planning a subsequent pregnancy, and not solely resolving grief.[39] Finally, support networks, a major ingredient of resilience, were found to be significantly associated with less depression and PTSD.

It will be important for future research to distinguish the natural trajectories of mental health after perinatal loss. With the DSM no longer considering bereavement as an exclusion factor for depression, it is recognized that major depression can occur during a period of mourning.[40] We must also take account of the increasingly differentiated diagnosis of prolonged grief disorder (also referred to as complicated bereavement) which is a distinct entity from both depression and PTSD, provisionally referred in the DSM V as persistent, complex bereavement disorder.[41–43] We need to be especially mindful that this first report assessed responses an average of 9 months after loss, before the 12-month minimum for symptoms to qualify for prolonged grief disorder. More time will be necessary to accurately distinguish early, intense, but abating grief from an enduring emotional disorder so as not to pathologize normal grief. As we track our subjects over the 14- and 24-month surveys, it will be important to determine the course of symptoms.

Strengths and limitations

This was a retrospective survey study, which may lead to self-selection and participant bias. Overall we had a response rate of 44%, which we believe is good for a mail survey of this population. Despite the lower response rate of African American women, we still ended with a bereaved cohort in which nearly 20% were African American making this the largest study of this population to date. We selected the Patient Health Questionnaire over other depression screens because we planned a longitudinal analysis over 2 years and were measuring beyond the usual postpartum period. Although the survey was designed to assess responses at 6 months, women responded on average 9 months after delivery. We believe that this was due to women not always responding to the first survey mailed and also because the state sent out some surveys later than intended. We did control for time since delivery, but this was not significant for any outcome. We would also caution that our study used screening tools to identify psychiatric symptoms rather than the gold

standard of a clinical interview; mental health screens have the potential to either over- or under-identify women with actual clinical disorders.

Conclusions

This large-scale epidemiologically based study indicated that at 4 months post loss, the rate of depressive symptoms is four times higher and the rate of PTSD symptoms seven times higher than what was found in a nonbereaved control sample of parents. Follow-up data from 14 and 24 months will be extremely important in determining the proportion of the bereaved group whose symptoms remit, suggesting a more normal grieving process, versus those who maintain high levels of symptomatology, indicating an ongoing depression, PTSD, or complicated bereavement.

As found in previous research, the vast majority of mothers endorsed the value of seeing and holding one's deceased baby.[26,44] The finding that almost all of the mothers who did not choose contact were declined the opportunity underscores the importance of ensuring that all bereaved mothers be given this option. In addition to making the loss more real, often identifying that child as a son or daughter with family resemblance, and providing memories for grieving, getting to know and say good-bye through this contact is a valuable way of making sense of this loss. Making meaning can be a critical part of the grieving process, significantly influencing the resolution of grief and subsequent distress.[45,46]

Finally, the discovery that bereaved African American women have low rates of treatment-seeking even when symptomatic after loss is worrisome given health disparities in perinatal loss and the known high risk of depression and trauma during subsequent pregnancies. We hope that this finding can serve as a call for additional research on treatment options for mental health disorders faced by vulnerable populations after stillbirth and infant death as such research is virtually nonexistent to date.

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