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## Anxiety Disorders and Obsessive Compulsive Disorder Nine Months after Perinatal Loss

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## Abstract

**Objective**—Perinatal loss (stillbirth after 20 weeks gestational age or infant death in the first month) impacts 1–2 infants per hundred live births in the United States and can be a devastating experience for parents. We assessed prevalence of anxiety disorders and obsessive compulsive disorder (OCD) among bereaved and live-birth mothers.

**Methods**—We collaborated with the Michigan Department of Public Health to survey Michigan mothers with perinatal death or live birth. We measured symptoms of generalized anxiety disorder, social phobia, panic disorder, and OCD using validated written self-report screens and collected data on maternal demographics, psychiatric history, social support, and intimate partner violence.

**Results**—609/1400 mothers (44%) participated, returning surveys nine months post-delivery. 232 mothers had live birth and 377 had perinatal loss. In unadjusted analyses, bereaved mothers had higher odds of all four disorders. In logistic regression adjusted for covariates, bereaved mothers still had higher odds of moderate-severe generalized anxiety disorder (OR: 2.39, CI: 1.10–5.18, p=0.028) and social phobia (OR: 2.32, CI: 1.52–3.54, p<0.0005 but not panic disorder or OCD.

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**Conclusion**—Bereaved mothers struggle with clinically-significant anxiety disorders in the first year after perinatal loss; improved identification and treatment are essential to improve mental health for this vulnerable population.

#### Keywords

Stillbirth; infant death; perinatal death; anxiety disorders; GAD; panic disorder; social phobia; OCD

#### Introduction

In the United States, for every 100 live births, roughly 1–2 infants die during the perinatal period—the last half of pregnancy and first month after delivery.<sup>1</sup> These losses often are sudden and unanticipated, and may have powerful psychological effects on the surviving parents. Perinatal death strikes many parents as incomprehensible—they may have spent months anticipating birth, and a baby's death is out of order of usual life experiences and a shock to parental expectations.<sup>2,3</sup> Parents may experience the world as no longer feeling safe and predictable and they may realize they are vulnerable in ways they did not previously recognize.<sup>4</sup>

Although grief itself is a normal human reaction, some individuals suffer from complicated grieving experiences, and mental health disorders can be comorbid with normal grief.<sup>5,6</sup> Most parents weather the storm of perinatal loss, but some families struggle to recover from this event.<sup>7–9</sup> Similarly, while anxiety is a normal thread through grief for most parents, for some it can become severe or persistent.<sup>4,10</sup> Such symptoms may impact current functioning and employment, parenting of other children, and can be carried over into a subsequent pregnancy.<sup>11–13</sup>

Prior research on perinatal bereavement has focused primarily on depression and posttraumatic stress as well as the general construct of "anxiety," without narrowing to specific anxiety disorders.<sup>10,12,14</sup> Much of the previous work also has suffered from convenience sampling, small sample size, and lack of control groups, limiting the generalizability of the results.

To address the limitations in prior research we measured the prevalence of Generalized Anxiety Disorder (GAD), social phobia, panic disorder, and Obsessive Compulsive Disorder (OCD) in a large epidemiologically-based sample of bereaved and live birth mothers. We utilized written questionnaires which screened for these disorders using criteria of the American Psychiatric Association. We also evaluated whether mothers who were currently pregnant after their loss would have higher levels of anxiety since this has been previously described in small studies.<sup>4,10,15</sup>

## Methods

As part of a broader study of maternal health outcomes for bereaved and live birth mothers, we conducted a longitudinal survey of mothers in Michigan with a perinatal death—either a stillbirth (above 20 weeks gestational age and at least 350 grams) or an early infant death in

the first 28 days of life. We also surveyed control mothers who had a live birth with a surviving infant. The goal of the larger study was to document maternal mental and physical

well-being, reproductive health, hospital care during loss, and subsequent pregnancy outcomes over time. This manuscript reports on results from the first wave of the survey sent at 6 months post-delivery.

## Recruitment

We collaborated with the Michigan Department of Community Health (MDCH) to survey a representative sample of mothers in Michigan. Using information from birth certificates as well as fetal and infant death certificates, MDCH sent mailings to 900 consecutive mothers bereaved by perinatal death and 500 control mothers who had a live birth in the same time period. Inclusion criteria were age 18 or above, able to complete an English-language questionnaire, residents of Michigan, and mothers with a baby not given up for adoption (for mothers with a live birth). To preserve confidentiality of mothers, we provided MDCH with blank survey packets, and they used vital records data to mail the first package at approximately 6 months after delivery without providing any maternal identifiers to the study team. Non-responders were sent up to three identical mailings and a reminder postcard over several months to encourage response. The first mailing included a \$10 cash incentive.

The top page of the survey was a written consent form providing informed consent to participate in the study and permission to view variables from the baby's birth, fetal death, or infant death certificate from MDCH. Participating mothers returned the consent form, a completed survey, and name and contact information to the study team in a pre-stamped envelope. Mothers who did not wish to participate could simply not respond or could return a card with an anonymous study ID; MDCH then removed that mother from their mailing list. Since all participating mothers provided contact information to the study team, mailings for subsequent waves of the broader study at 14 and 24 months after delivery were sent directly by the team without involving MDCH and were only sent to those mothers who had responded to the 6-month mailing. At the conclusion of the study, MDCH provided the team with aggregate, de-identified demographic information about non-responders. The study was approved by the Institutional Review Board (IRB) at the University of Michigan and the IRB at the Michigan Department of Community Health.

#### Measures

To measure mental health disorders, we selected brief, validated self-report instruments. To assess Generalized Anxiety Disorder, we used the GAD-7 and used a score of 10 or higher to indicate moderate or severe anxiety which gives 89% sensitivity and 82% specificity.<sup>16</sup> For social phobia we used the MINI-SPIN and coded the test as positive for a score of 6 or above which has been shown to give a sensitivity of 89% and specificity of 90%.<sup>17</sup> Panic disorder was measured with the PRIME-MD Patient Health Questionnaire Panic Module.<sup>18</sup> We evaluated OCD using the revised version of the Obsessive Compulsive Inventory and used a cutoff of 21 and above for positive screen.<sup>19</sup>

Women were provided a list of specific mental health disorders and asked if they had "ever been told by a doctor, therapist, counselor, or medical professional" that they had each

condition and also asked about current symptoms and past and current treatment. This format mirrors questions on the National Health and Nutrition Examination Survey (NHANES) for medical conditions which ask if a "doctor or other health professional has ever told you that you have" specific diseases and then asks about current symptoms and treatment.<sup>20</sup> In our survey, a diagnosis or treatment for any of these conditions (depression, bipolar disorder, anxiety, panic disorder, phobias, post-traumatic stress disorder, OCD, hallucinations, or eating disorders) was considered past medical history of a psychiatric disorder. We asked control mothers if the problem started before the birth of their baby and asked bereaved mothers if the problem started before their baby's death. The Patient Health Questionnaire-8 was utilized to evaluate depressive symptoms, and a score of 10 or greater was considered a positive screen.<sup>21</sup> We adapted questions from the national Pregnancy Risk Assessment Monitoring System (PRAMS) to evaluate intimate partner violence from the woman's husband or partner during the pregnancy.<sup>22</sup> Social support was measured using the MOS-SSS brief version which gives a score of 5–20 with higher numbers indicating greater support.<sup>23</sup>

#### **Data Analysis**

We compared the mental health outcome for bereaved versus non-bereaved mothers in an unadjusted chi-square analysis as well as via logistic regression controlling for demographic factors which included maternal age, race, insurance type, level of education, and days between the birth/loss and completion of the survey. We also added additional covariates associated with each disorder based on prior findings from the literature. For example, for all disorders, we included a measure of current depression and a variable for prior psychiatric disorder since these have been shown to be predictive of anxiety disorders and OCD.<sup>24–27</sup> We also included variables to measure current social support and intimate partner violence during pregnancy.<sup>28–30</sup> Finally, since mothers with a loss have been noted to have increased anxiety during subsequent pregnancies, we conducted unadjusted analysis of the relationship between current pregnancy status (yes/no) and each of the mental health outcomes; these analyses were limited to bereaved mothers.

Because of the possibility of response bias between women who consented to participate in the study and those who did not, we performed an additional sensitivity analysis. We first identified demographic variables that discriminated between the two groups based on a logistic regression in which being a survey respondent was the outcome variable. A weight was calculated from this logistic regression that equaled the reciprocal of the predicted probability of being a respondent. Subsequently, a weighted logistic regression was run with each of the four mental health outcomes.

We evaluated racial differences in rates of positive screens using chi-squared test. Women were asked if they were currently being treated for any of a variety of mental health conditions; the question defined treatment as "with medication, counseling, group therapy, or other treatments." We compared treatment rates among different subgroups using both chi-squared test and Fisher's Exact tests due to small cell size for some outcomes.

Level of significance for all analyses was set at p=0.05. We used the Hosemer-Lemeshow test to test goodness of fit. We calculated the area under the receiver operating characteristic

(AUROC) for each logistic regression analysis to assess the predictive discrimination of the

#### Results

model.

Of 1400 initial mailings we received a total of 609 completed and eligible surveys (44% overall response rate); 232 (46%) were returned by mothers with a live birth and surviving child and 377 (42%) by mothers with a perinatal death.

Respondents were on average 29 years old at the time of their delivery and completed their survey a median of 9 months after the index birth or loss; these variables did not differ between bereaved and non-bereaved mothers. 483 mothers (79%) were Caucasian race, 92 (15%) were African-American. (Table 1) More than half of women had private health insurance at the time of delivery and the rest had public insurance or no insurance. 73 women (12%) had less than a high school education, 139 (23%) were high school graduates or had a GED, and the rest (397 or 65%) had more than a high school education.

There were also differences among women who responded to the survey compared with those who did not. Respondents were more likely to be well educated, Caucasian, non-Hispanic, and to have private health insurance at delivery compared to non-respondents. There were no differences in average maternal age or smoking status at time of delivery between both groups. Given baseline differences between responders and non-responders, we controlled for responder status in sub-analyses to assess this effect.

#### **Demographic Differences by Bereavement Status**

Among study participants, bereaved mothers were significantly more likely than nonbereaved mothers to have public or no health insurance (51 versus 39%, p=0.003), and to be African-American race (19 versus 8%, p=0.001). Other demographic variables were not significantly different. Mothers with a loss were more likely than non-bereaved mothers to report that they had ever been told that they had a psychiatric disorder (58% vs. 45%, p=0.002). Seventy per cent of the bereaved mothers indicated that they had been given this psychiatric diagnosis prior to their baby's death. Bereaved mothers had higher odds for positive depression screens at the time of the survey (23% vs. 8%, p<0.0005), and were more likely to report prior history of anxiety (32% vs. 21%, p=0.002) and panic disorder (17% vs. 8%, p=0.002) but not OCD (5% vs. 3%, p=0.138). There were no differences between bereaved and non-bereaved mothers in odds of intimate partner violence during the pregnancy or levels of current social support.

Among the bereaved mothers, 70 women (19%) had a positive screen for moderate or severe GAD, 164 (44%) for social phobia, 47 (12%) for panic disorder, and 35 (9%) for OCD. Numbers were lower for non-bereaved mothers with just 17 (7%) having a positive screen for moderate or severe GAD, 52 (22%) for social phobia, 14 (6%) for panic disorder, and 7 (3%) for OCD.

#### Association of Anxiety Disorders with Bereavement Status

In unadjusted analysis, bereaved mothers were significantly more likely than non-bereaved mothers to have a positive screen for the anxiety disorders.(Table 2) In multivariable analysis, bereaved women continued to have more than twice the odds for GAD (p=0.03) and social phobia (p < .0005) compared to non-bereaved women even when controlling for other significant predictors. For panic disorder, bereavement status was not significant in multivariable analysis, and only current depression and past psychiatric diagnoses significantly predicted outcome.

For OCD, in unadjusted analysis, bereaved women had significantly higher odds of the disorder (odds ratio: 3.19, confidence interval: 1.38–7.33, p=0.006). However, once we added the covariates, the higher odds were no longer significant (odds ratio: 2.20, confidence interval: 0.83–5.83, p=0.112). In fact, only current depression, past psychiatric disorder, and IPV were significant predictors in the final model.

The c-statistic demonstrated that most of our models explained a large amount of the variation in our results; AUROC for moderate/severe GAD was 0.91, for social phobia 0.76, for panic disorder 0.83, and for OCD 0.86. The Hosemer-Lemeshow statistic was not significant for any model which indicated adequate fit of the model.

In unadjusted analysis limited to the subset of bereaved mothers, we found there was no significant association between whether the mother was currently pregnant and current anxiety disorder or OCD. Finally, we conducted analyses to compare rates of anxiety disorders among bereaved and non-bereaved as function of race and found no association for outcomes with race.

We carried out a number of subgroup analyses for prevalence of current treatment. Treatment prevalence did not differ between bereaved and non-bereaved women with positive screen. Among bereaved women with positive screens for any of the anxiety disorders, 54 (28%) reported current psychiatric treatment for any these disorders, while among non-bereaved mothers with positive screen 12 (20%) reported current treatment, a nonsignificant difference. Caucasian women (n=141) with a positive screen for any of the four disorders were more likely to currently be in treatment compared to African-American women (n=34) with a positive screen, but this did not meet the level of significance (32% versus 15%, p=0.057).

We also evaluated the potential for response bias using the respondent-weighting-variable. However, adding the weighting variable into the regression calculations did not significantly change any outcomes, indicating that response bias did not impact the mental health findings.

## Discussion

We found that an average of nine months after loss, bereaved mothers have more than twice the odds of GAD and social phobia when compared to their non-bereaved peers, even when controlling for demographic factors, prior psychiatric disorders, current depression, social

support, and intimate partner violence. Bereaved mothers also have higher odds of panic disorder and OCD but these differences are not significant in multivariate analysis.

To our knowledge, our study is the first to report on symptoms of GAD, social phobia, panic disorder, and OCD among perinatally-bereaved mothers. Prior work has described a high symptom burden for anxiety but has not evaluated for specific disorders. Being able to discriminate general symptoms from clinically-significant mental health disorders allows the development of appropriate mental health interventions to support bereaved mothers.

In one of the pioneering studies on mental health after loss from nearly three decades ago, Australian researchers reported that up to 30 months after loss, bereaved mothers had higher rates of anxiety symptoms than control mothers with surviving children; however this study focused on married women and controlled for only few potential confounders.<sup>15,31</sup> A Norwegian study from the 1980s reported a quarter of women with stillbirth and 40% of those with early infant death reported high levels of anxiety—figures roughly three times that of non-bereaved mothers; lower social support at the time of birth and older age predicted higher anxiety.<sup>4</sup> A large convenience sample of bereaved mothers recruited from the internet has also noted high levels of anxiety.<sup>32</sup> While such research paints a broad picture of distress among bereaved mothers, the limitations of not controlling for important confounders such as demographic factors, prior mental health problems, social support, and intimate partner violence; convenience sampling; and small sample sizes may lead to skewed results or findings which are not representative of the broader population with loss.

Bereaved women in this study had higher rates of positive screens for these anxiety disorders and OCD than would be expected among the general population. The 12-month prevalence in the general population are at 3% for GAD, 7% for social phobia, 3% for panic disorder, and 1% for OCD.<sup>33</sup> While there is limited data about the natural course of these anxiety disorders and OCD during pregnancy and postpartum, prevalence rates in the perinatal timeframe appear to be fairly low. For example, a systematic review noted 9–11% incidence of panic disorder within the first 6 months postpartum.<sup>27</sup> A small study assessing GAD reported just 4% incidence at eight weeks postpartum.<sup>34</sup> A systematic review found OCD incidence in four studies to range from 0–30% in the postpartum period, though the largest study only included 46 patients.<sup>27</sup>

It was notable that we found a higher reported rate of pre-existing mental health diagnoses among the bereaved cohort in our population. A growing body of literature suggests existing maternal mental illness itself is an independent risk factor for perinatal death as well as other adverse birth outcomes.<sup>35–38</sup> Not only may women with pre-existing mental health complications be at increased risk for poor pregnancy outcomes but they may also represent a group with particularly vulnerability following a devastating loss like perinatal death. Additional work is needed to understand the mechanisms which place this group at high risk and how best to address their mental health needs. Just 28% of bereaved women who screened positive for an anxiety disorder in this study reported current mental health treatment. While only a small portion of women with postpartum depression seek treatment, little is known about treatment rates for postpartum anxiety disorders so it is not possible to compare these rates to other perinatal populations.<sup>39,40</sup>

Mothers often have high levels of maternal anxiety in pregnancies following perinatal loss; this appears to be an adaptive response to the uncertainty and loss of control which accompany pregnancy and typically resolves after the birth of a healthy baby.<sup>4,10,15</sup> In our analyses pregnancy status did not increase odds for anxiety disorders in bereaved mothers and bereaved mothers actually had lower mean scores on the measures. Prior research on anxiety in a next pregnancy has reported on a homogenous, primarily Caucasian population and general symptomatology rather than discrete disorders.

It is possible that many women may have more anxiety symptoms specific to pregnancy but that these do not meet specific DSM-V criteria for a psychiatric disorder. It is important to emphasize that grief is a normal human experience, and not a disease or disorder. There is some overlap between psychiatric symptoms and grief; however, many researchers have shown that even in the midst of grief, individuals can experience psychiatric disorders which may benefit from specific mental health care.<sup>41,42</sup> To identify which treatments can help bereaved mothers, it is critical to clarify the nature of their psychiatric symptoms. Diagnosing specific disorders can be reassuring for patients who may feel overwhelmed by their symptoms, and a diagnosis also offers hope for improvement.

Our study is not without some limitations. Being a retrospective study we had to rely on self-report of symptoms. Our instruments are screens for mental health disorders, but are not diagnostic interviews which may provide more accurate estimations of prevalence. Screens will over-identify some disorders and miss others so can only give us estimates of a problem and not diagnostic certainty. We also encountered a response bias in our survey, although we controlled for this statistically and got unchanged results. While we believe that we captured the most relevant predictors described in the literature for model testing, we cannot rule out an unmeasured variable which may further explain variance in the model. These limitations are balanced by substantial study strengths including: a large sample size, population-based sampling strategy, inclusion of a control group, and measures of multiple covariates, all of which put this study in methodological rigor above previous work.

## Conclusion

In conclusion, our work demonstrates that despite high levels of distress meeting criteria for clinically-significant anxiety disorders, only about a quarter of perinatally-bereaved women with a positive screen for such disorders are actively receiving any type of mental health treatment. This finding is highly concerning from a public health perspective as it adversely impacts women's current mental health as well as their health in subsequent pregnancies. Further longitudinal research tracking of the natural unfolding of mental health symptoms among bereaved women is needed in order to learn about modifiers of illness trajectory, and to be able to develop targeted interventions that can ameliorate illness course in this population.

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## Table 1

## Demographics and Descriptive Variables

Variable	Bereaved Mothers (n=377)	Non-Bereaved Mothers (n=232)	Full Cohort (n=609)
Maternal Age at Delivery (mean, SD, in years)	29 (+/-6)	29 (+/-6)	29 (+/-6)
Education			
Less than high school	51 (14%)	22 (9%)	73 (12%)
High school degree or GED	88 (23%)	51 (22%)	139 (23%)
Some college but less	135 (36%)	79 (34%)	214 (35%)
Bachelor's degree or	103 (27%)	80 (35%)	183 (30%)
Race*			
Caucasian	285 (76%)	198 (85%)	483 (79%)
African American	73 (19%)	19 (8%)	92 (15%)
Other	19 (5%)	15 (6%)	34 (6%)
Insurance Type <sup>*</sup>			
Private	184 (49%)	142 (61%)	326 (54%)
Public or None	193 (51%)	90 (39%)	283 (46%)
Past Medical History Any Psychiatric Disorder*	218 (58%)	104 (45%)	322 (53%)
Intimate Partner Violence During Pregnancy	44 (12%)	26 (11%)	70 (11%)
Current Depression*	19 (8%)	86 (23%)	105 (18%)
Social Support (Mean score, SD)	16 (+/-4)	16 (+/-4)	16 (+/-4)

\*p<0.05

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Odds ratio and confidence intervals for anxiety disorders in perinatally bereaved versus nonbereaved mothers

	GAD (n=58	(8)	Social Phobia (	(n=593)	Panic Disorder	(n=593)
	Unadjusted	p-value	Unadjusted	p-value	Unadjusted	p-value
Bereaved Mothers	3.09* (1.74–5.47)	p<0.0005	2.64* (1.82–3.83)	p<0.0005	2.24* (1.20-4.17)	p=0.011
	Adjusted	p-value	Adjusted	p-value	Adjusted	p-value
Bereaved Mothers	2.39* (1.10–5.18)	0.028	2.32* (1.52–3.54)	p<0.0005	1.55 (0.78–3.10)	p=0.214
Age	0.99 (0.93–1.05)	0.671	0.99 (0.95–1.02)	p=0.454	0.96 (0.91–1.02)	p=0.171
Race						
Caucasian	1.0	1	1.0	1	1.0	1
Black	0.84 (0.35–2.04)	0.699	0.72 (0.41–1.26)	p=0.249	0.55 (0.20–1.49)	p=0.241
Other/multiple	4.31* (1.39–13.3)	0.011	1.96 (0.87–4.45)	p=0.105	0.65 (0.17–2.53)	p=0.536
Insurance						
Public	1.0	1	1.0	1	1.0	1
Private	0.52* (0.28–0.97)	0.039	0.70 (0.48–1.03)	p=0.072	1.36 (0.75–2.48)	p=0.316
Education						
High school or less	1.0	1	1.0	1	1.0	1
More than high school	0.72 (0.36–1.41)	0.333	$0.58^{*} \ (0.38-0.90)$	p=0.014	1.57 (0.78–3.16)	p=0.205
Days from death to survey	1.00 (1.00–1.01)	0.621	1.00 (1.00–1.01)	p=0.026	1.00 (1.00–1.01)	p=0.772
Current depression	15.0 * (7.97–28.36)	p<0.0005	4.09* (2.43–6.89)	p<0.0005	4.29 (2.19–8.40)	p<0.0005
Past psychiatric disorder	4.55* (2.09–9.88)	p<0.0005	$1.63^{*}(1.10-2.41)$	p=0.015	4.29 (2.19–8.40)	p<0.0005
More social support	$0.91^{*} (0.84 - 0.97)$	p=0.008	0.97 (0.93–1.02)	p=0.253	0.99 (0.92–1.07)	p=0.859
Intimate Partner Violence	1.21 (0.54–2.73)	p=0.649	1.57 (0.86–2.86)	p=0.143	1.19 (0.54–2.62)	p=0.674