

ORIGINAL ARTICLE

Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome[†]

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ABSTRACT

Objective The aim of the article is to examine the psychological impact, specifically symptoms of grief, post-traumatic stress and depression, in women and men who either terminated or continued a pregnancy following prenatal diagnosis of a lethal fetal defect.

Method This project investigated a diagnostically homogeneous group composed of 158 women and 109 men who lost a pregnancy to anencephaly, a lethal neural tube defect. Participants completed the Perinatal Grief Scale, Impact of Event Scale – Revised and Beck Depression Inventory-II, which measure symptoms of grief, post-traumatic stress and depression, respectively. Demographics, religiosity and pregnancy choices were also collected. Gender-specific analysis of variance was performed for instrument total scores and subscales.

Results Women who terminated reported significantly more despair ($p=0.02$), avoidance ($p=0.008$) and depression ($p=0.04$) than women who continued the pregnancy. Organizational religious activity was associated with a reduction in grief (Perinatal Grief Scale subscales) in both women ($p=0.02$, $p=0.04$ and $p=0.03$) and men ($p=0.047$).

Conclusion There appears to be a psychological benefit to women to continue the pregnancy following a lethal fetal diagnosis. Following a lethal fetal diagnosis, the risks and benefits, including psychological effects, of termination and continuation of pregnancy should be discussed in detail with an effort to be as nondirective as possible. © 2015 John Wiley & Sons, Ltd.

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INTRODUCTION

It is well understood that pregnancy loss due to fetal anomalies commonly results in psychiatric symptoms including depression, grief and post-traumatic stress, which can last for months and sometimes years. However, prior studies of psychological outcome have primarily focused on pregnancy loss via termination and included heterogeneous study groups with fetal anomalies ranging from mild to severe.^{1–13} While a fetal diagnosis of any type can be devastating, lethal fetal diagnoses are distinct from those compatible with survival. In these instances, health care providers tend to be directive regarding pregnancy management.¹⁴ Additionally, pregnancy management decisions do not affect the ultimate fetal outcome, as a lethal fetal diagnosis will result in the loss of a pregnancy or baby regardless of the decision to terminate or continue. This

distinction may ease the decision to terminate and mitigate parental guilt following termination.

Lethal fetal diagnoses account for approximately 7% to 15% of anomalies detected on prenatal ultrasound.^{15,16} While the majority of prenatally diagnosed lethal fetal defects end in pregnancy termination, a significant number of patients continue the pregnancy.¹⁷ Yet a paucity of research exists on the psychological impact of continuing, rather than terminating, a pregnancy following a serious fetal diagnosis.¹⁸

Another understudied aspect of pregnancy loss due to fetal anomalies is the psychological impact on men. The majority of previous psychological outcome research has focused solely on women with significantly less attention paid to men. Descriptive studies of men have reported that men struggle with grief, anger and helplessness following the loss and often feel forgotten by health care providers and society.^{19–22} While

prior quantitative research of men on the impact of pregnancy loss due to fetal anomalies is minimal, the few published studies indicate that men also experience grief, depression and post-traumatic stress, although perhaps to a lesser degree and for a shorter period.^{8,11,12}

Additional pregnancy management variables, such as method of termination and gestational age at termination, may influence psychological outcome. While it has been hypothesized that surgical termination may be emotionally easier than induction of labor due to elimination of fetal contact, prior quantitative research suggests that method of termination does not significantly impact psychological outcome.^{2,13,23} Termination at an earlier gestational age is also thought to result in less psychiatric symptomatology as less time has passed to bond with the fetus. However, prior studies of the impact of gestational age at termination have resulted in conflicting findings. While some studies have shown that women who terminate later in pregnancy experience higher levels of grief and post-traumatic stress, other studies have found no relationship between gestational age and psychological outcome.^{1,3,9,13,24,25}

The purpose of this project was to examine the psychological impact, specifically symptoms of grief, post-traumatic stress and depression, in women and men who either terminated or continued a pregnancy following prenatal diagnosis of a lethal fetal defect.

METHODS

Participants

Participants were recruited between March and October 2013 from two sources: the Hereditary Basis of Neural Tube Defects study conducted at Duke University Medical Center (Duke NTD study) and through social media. Participants in the Duke NTD study were ascertained across the United States from 1994 to 2013 from a variety of sources including referrals from health care providers, NTD support groups and self-referral in response to advertisements.²⁶ Families with at least one individual with any type of NTD qualified to participate. Women who experienced an anencephalic pregnancy and their male partners were re-contacted for participation in this study. From a pool of over 5000 participants, 340 women and 295 men were eligible to participate in this study. Questionnaires were mailed to 133 women (39%) and 117 men (40%), who responded to the study advertisement. Ultimately, 103 women (30%) and 75 men (25%) from the Duke NTD study completed and returned the questionnaires.

Social media participants were recruited through study advertisements posted on several anencephaly Facebook groups. Eligible participants were women and men who previously lost a pregnancy to anencephaly. Participants were included if the pregnancy had already ended, irrespective of how long ago the pregnancy occurred. Questionnaires were mailed to 78 women and 57 men, who responded to study advertisements. Ultimately, 55 women and 34 men ascertained through social media completed and returned the questionnaires.

Analyses were performed to determine what, if any, differences existed between participants from the two recruitment sources.

Age at the time of pregnancy, education and pregnancy decision did not differ significantly between the two groups. Time since the pregnancy ended was longer in the social media group ($p=0.04$). In addition, mean instrument total and subscale scores were significantly higher in the social media group, indicating more psychological distress in this group. Therefore, recruitment source was used as a covariate in all subsequent analyses.

Combining participants from both recruitment sources, a total of 158 women and 109 men was available for analysis. All 109 men participated along with the mother of the pregnancy. Therefore, the study group consisted of 109 parent pairs and 49 women who participated without the father of the pregnancy. Participants experienced a total of 173 anencephalic pregnancies. Those who experienced more than one anencephalic pregnancy ($n=22$, 8%) were asked to answer questions only about their most recent affected pregnancy. Therefore, pregnancy outcome information was collected on a total of 158 unrelated anencephalic cases. Enrolled participants primarily resided in the United States, with 15 participants residing outside the United States (UK, Canada or Australia). Approval to conduct this study was obtained from the Institutional Review Board at Duke University Medical Center. All participants provided written informed consent.

Measures

Participants self-administered three standardized instruments commonly used in pregnancy loss research: the Perinatal Grief Scale (PGS), Impact of Event Scale – Revised (IES-R) and Beck Depression Inventory-II (BDI-II), which measure symptoms of grief, post-traumatic stress and depression, respectively.^{27–29} Participants were instructed to complete the instruments based on their current feelings, not to recall feelings at the time of the pregnancy. The PGS consists of 33 items rated along a five-point scale from 1 (strongly disagree) to 5 (strongly agree) divided into three subscales: active grief, difficulty coping and despair. A total score of 92 or above and subscale scores of 34 (active grief), 30 (difficulty coping) and 27 (despair) or above are considered to reflect a high degree of grief. The IES-R consists of 22 items rated along a five-point scale from 0 (not at all) to 4 (extremely) divided into three subscales: avoidance, intrusions and hyperarousal. A total score of 33 or above is used to indicate significant post-traumatic stress. The BDI-II consists of 21 items rated along a four-point scale from 0 to 3 with scores of 14 or above indicating some degree of depression.

Participants also completed two items from the Duke University Religion Index (DUREL): organizational religious activity (ORA), such as attending church or other religious meetings, rated along a six-point scale from 1 (never) to 6 (more than once a week), and non-ORA (NORA), such as prayer, meditation or Bible study, rated along a six-point scale from 1 (never) to 6 (more than once a day).³⁰ Finally, participants completed the Pregnancy History and Choices Questionnaires (PHCQ), developed specifically for this project to collect relevant information about demographics, pregnancy outcome and pregnancy management choices. Pregnancy outcome was self-report and not confirmed via medical records.

Statistical methods

The IES-R, PGS and BDI-II total scores and subscales, if applicable, were calculated using standard algorithms. Total and subscale scores were then correlated with items on the DUREL and PHCQ. All analyses were conducted using SAS version 9.4 (SAS Systems, Cary, NC). Because of the potential correlation among each parent pair, generalized estimating equations were utilized in PROC GENMOD to control for within-family dependencies. When investigating associations using only one person from each parent pair (gender-specific analyses), PROC GLM was used to perform standard analysis of variance for total scores and subscales, while PROC LOGISTIC was used to perform ordinal logistic regression for item level variables. All total scores and subscales were log-transformed prior to analysis in order to achieve approximate normality. Univariate analyses were performed first to investigate associations between demographic factors (gender, parental age at pregnancy, education, time since pregnancy ended and recruitment source) and instrument total and subscale scores. Three factors, gender, time since pregnancy ended and recruitment source were significantly associated with instrument scores (parental age at pregnancy and education were not). Therefore, gender-specific models to investigate associations between pregnancy management decisions and instrument scores included time since pregnancy and recruitment source as covariates. ORA was used as an additional covariate in analyses comparing pregnancy decision (continued vs terminated). Participants were categorized into pathogenic or non-pathogenic groups for each instrument score by gender, and chi-squared tests (or Fisher's exact tests for cell counts <5) were used to determine whether scoring in the pathogenic range on a specific instrument was associated with pregnancy decision. Untransformed means are presented for interpretability. A *p*-value of <0.05 was used to determine statistical significance for all data analyzed.

RESULTS

Demographics

Demographics of the study group are summarized in Table 1. Participants were primarily non-Hispanic Caucasians between the ages of 17 and 42 years at the time of the anencephalic pregnancy with a median age of 30 years. Pregnancies had ended between 1 month and 32 years prior to participation with a median of 3 years prior. More participants chose to continue the pregnancy than terminate. A small number of participants (labeled as 'no choice' in Table 1) received the diagnosis of anencephaly either shortly before or at delivery and therefore were never offered termination. These individuals were not included in subsequent psychological outcome analyses.

Pregnancy outcome for the study group is summarized in Table 2. The majority of terminations took place in the second trimester. There were a wide range of pregnancy outcomes for those who continued with the greatest number vaginally delivering a live-born, full-term baby. C-section deliveries were 8.6 times more likely than vaginal deliveries to result in a live

Table 1 Study participant demographics (*N*=267; 158 women, 109 men)

	Women (<i>n</i>)	Women (%)	Men (<i>n</i>)	Men (%)
Ethnicity/race				
Non-Hispanic Caucasian	150	95	98	90
Hispanic	2	1	5	5
Asian	2	1	3	2.5
Mixed race	4	3	3	2.5
Age at pregnancy				
Teen (17–19 years)	3	2	0	0
Young adult (20–25 years)	31	20	13	12
Adult (26–34 years)	105	66	72	66
Older adult (35–42 years)	19	12	24	22
Time since pregnancy ended				
<1 year	23	15	22	20
1–2 years	45	28	29	27
3–5 years	43	27	37	34
6–9 years	24	15	11	10
10+ years	23	15	10	9
Organizational religious activity				
Never	38	24	34	31
Once a year or less	5	3	6	6
A few times a year	22	14	12	11
A few times a month	20	13	12	11
Once a week	41	26	32	29
More than once a week	32	20	13	12
Pregnancy decision				
Terminate	65	41	47	43
Continue	90	57	59	54
No choice	3	2	3	3

birth (*p*=0.001) with 89% of babies delivered via C-section being live born versus 49% following a vaginal delivery. The vast majority of live-born babies passed away within 1 day.

Psychological outcome

There was tremendous individual variability in psychological outcome. Women's scores on the PGS ranged from 36 to 134, and men's scores ranged from 37 to 120 with 24% of women and 11% of men scoring in the pathogenic range for grief. Women's scores on the IES-R ranged from 0 to 67, and men's scores ranged from 0 to 55 with 20% of women and 13% of men scoring in the pathogenic range for post-traumatic stress. On the BDI-II, women's scores ranged from 0 to 38, and men's scores ranged from 0 to 39 with 34% of women and 19% of men within the range for depression. Gender and time since pregnancy were significantly associated with scores on all three instruments with women and those with more recent losses scoring higher.

While ORA and NORA were associated with pregnancy continuation, only ORA was associated with psychological

Table 2 Outcome of anencephaly pregnancy (N= 158)

	n	%
Terminated	65	41
Multiple gestation		
Yes	1	2
No	64	98
Method of termination		
Surgical	32	49
Induction of labor	33	51
Gestational age at termination		
12–13 weeks	13	20
14–19 weeks	24	37
20–26 weeks	28	43
Continued (includes no choice)	93	59
Multiple gestation		
Yes	13	14
No	80	86
Method of delivery		
Vaginal	65	70
Medically necessary C-section	13	14
Elective C-section	15	16
Timing of delivery		
Extremely preterm (<28 weeks)	3	3
Very preterm (28–31 weeks)	7	8
Moderate to late preterm (32–36 weeks)	29	31
Full term (37–40 weeks)	49	53
Post term (41–42 weeks)	5	5
Outcome at delivery		
Stillbirth	36	39
Live birth	57	61
Survival after delivery		
≤1 h	18	32
Day 1 (>1 h)	28	49
Days 2–3	7	12
Days 5–7	3	5
Day 10	1	2

outcome. ORA was inversely associated with total and subscale scores on the PGS in women and with the PGS despair subscale in men (Table 3). Meaning, as ORA increased, reported amounts of grief decreased. ORA did not significantly impact reported amounts of post-traumatic stress or depression.

Instrument total and subscale mean scores for participants who either terminated or continued the pregnancy are presented in Table 4. *P*-values have been adjusted for the effects of recruitment source, time since the pregnancy ended and ORA. Women who terminated the pregnancy were significantly more likely to report feelings of despair ($p=0.02$), avoidance ($p=0.008$) and depression ($p=0.046$) than women who continued the pregnancy. In addition, women who terminated were significantly more likely to

Table 3 Association between frequency of organizational religious activity and instrument scores

	Women		Men	
	Beta	<i>p</i>	Beta	<i>p</i>
PGS				
Total	−0.029	0.02	−0.023	0.18
Active grief	−0.023	0.04	−0.001	0.93
Difficulty coping	−0.031	0.06	−0.040	0.06
Despair	−0.033	0.03	−0.040	0.047
IES-R				
Total	−0.039	0.45	−0.040	0.62
Avoidance	−0.046	0.40	−0.074	0.36
Intrusions	−0.026	0.56	−0.006	0.92
Hyperarousal	−0.051	0.37	−0.046	0.52
BDHI				
Total	−0.007	0.89	−0.099	0.29

PGS, Perinatal Grief Scale; IES-R, Impact of Event Scale – Revised; BDHI, Beck Depression Inventory-II.

Bold values are significant.

score in the pathogenic range on the active grief subscale of the PGS (52% vs 33%, $p=0.01$) and on the BDI-II (43% vs 27%, $p=0.04$) than women who continued. In contrast, men whose partner continued the pregnancy were significantly more likely to report difficulty coping ($p=0.04$) than men whose partner terminated. There were no significant differences on any instrument in the percentages scoring in the pathogenic range between men whose partner continued or terminated.

To look at the association between pregnancy decision and psychological outcome in finer detail, instrument item level analyses were performed. These analyses revealed several items significantly associated with termination of pregnancy in women and one item in men (Table 5). Items related to guilt and avoidance were endorsed significantly more often by women who terminated. No items were more likely to be endorsed by women who continued compared with women who terminated. In contrast, several items were more likely to be endorsed by men whose partner continued compared with men whose partner terminated. One item, 'It feels great to be alive', indicated a positive outcome in men whose partner continued. However, the other items indicated certain aspects of psychological distress that were increased in men whose partner continued, with the most significant being, 'Pictures about it popped into my mind'.

Method of termination did not significantly impact psychological outcome in women or men (Table 4). However, men whose partner terminated in the second trimester reported significantly higher active grief ($p=0.03$), post-traumatic stress ($p=0.009$), intrusions ($p=0.0005$) and depression ($p=0.03$) than men whose partner terminated in the first trimester. *P*-values have been adjusted for the effects of recruitment source and time since the pregnancy ended. Women who terminated in the second trimester also tended to report higher post-traumatic stress, although this was not a statistically significant association.

Table 4 Association between pregnancy management variables and mean instrument scores

	TAB	C	<i>p</i>	IOL	D&E	<i>p</i>	1st	2nd	<i>p</i>
Women									
	Pregnancy decision ^a (N = 154)			Method of termination ^b (n = 65)			Timing of termination ^b (n = 65)		
PGS									
Total	81.5 (31%)	73.7 (19%)	0.11 (0.09)	79.5	83.6	0.82	80.3	81.8	0.89
Active grief	34.1 (52%)	30.9 (33%)	0.07 (0.01)	33.3	34.9	0.84	33.3	34.3	0.99
Difficulty coping	23.7 (20%)	22.6 (22%)	0.58 (0.71)	22.9	24.6	0.87	24.2	23.6	0.57
Despair	23.6 (31%)	20.2 (18%)	0.02 (0.06)	23.2	24.1	0.78	22.9	23.8	0.76
IES-R									
Total	20.8 (23%)	16.9 (18%)	0.21 (0.44)	20.7	20.9	0.77	13.0	22.8	0.13
Avoidance	6.8	4.3	0.008	6.0	7.6	0.52	6.2	6.9	0.79
Intrusions	9.4	8.6	0.61	9.7	9.0	0.42	5.5	10.4	0.07
Hyperarousal	4.7	4.1	0.77	5.0	4.3	0.46	1.4	5.5	0.07
BDHI									
Total	12.3 (43%)	9.2 (27%)	0.046 (0.04)	12.0	12.5	0.76	8.9	13.1	0.59
Men									
	Pregnancy decision (N = 105)			Method of termination (n = 47)			Timing of termination (n = 47)		
PGS									
Total	64.5 (13%)	64.4 (9%)	0.34 (0.49)	67.2	62.4	0.28	58.8	66.0	0.13
Active grief	26.9 (15%)	27.2 (10%)	0.55 (0.48)	28.0	26.1	0.31	22.7	28.0	0.03
Difficulty coping	19.1 (15%)	20.3 (9%)	0.04 (0.32)	20.3	18.3	0.40	18.1	19.4	0.39
Despair	18.5 (9%)	16.8 (7%)	0.88 (0.99)	19.0	18.1	0.38	18.0	18.6	0.42
IES-R									
Total	13.2 (17%)	12.9 (10%)	0.65 (0.32)	14.7	12.2	0.44	7.6	14.8	0.009
Avoidance	5.9	4.2	0.79	6.2	5.7	0.61	4.3	6.4	0.29
Intrusions	5.2	6.1	0.28	5.6	4.9	0.53	2.2	6.0	0.0005
Hyperarousal	2.1	2.7	0.24	2.9	1.6	0.16	1.1	2.4	0.09
BDHI									
Total	7.0 (21%)	6.7 (17%)	0.72 (0.60)	8.8	5.8	0.80	3.6	8.0	0.03

Percent scoring in pathogenic range are shown in ().

TAB, pregnancy termination; C, pregnancy continuation; IOL, induction of labor; D&E, surgical termination; 1st, first trimester; 2nd, second trimester; PGS, Perinatal Grief Scale; IES-R, Impact of Event Scale – Revised; BDHI, Beck Depression Inventory-II.

^a*P*-values were adjusted for recruitment source, time since pregnancy ended and organizational religious activity.

^b*P*-values were adjusted for recruitment source and time since pregnancy ended.

Bold values are significant.

For participants who continued, there were no significant differences in psychological outcome between those who had a stillborn or live-born baby. There were also no significant differences between participants who had a surviving healthy twin and those who did not.

DISCUSSION

This project investigated the psychological impact of pregnancy loss due to lethal fetal defects in a diagnostically homogeneous group composed of 158 women and 109 of their male partners who lost a pregnancy or baby to anencephaly. Pregnancy loss to lethal fetal defects results in similar psychiatric symptoms to what has been previously reported in diagnostically heterogeneous populations. A significant number of women and men reported symptoms of grief, post-traumatic stress and depression within the pathogenic range. As a whole, women experienced a greater

degree of psychiatric distress than men, and psychiatric distress tended to decrease over time. However, it is important to note that there was tremendous individual variability. Some men reported significant psychiatric distress, and there were participants whose pregnancies ended over 10 years ago still scoring within the pathogenic range.

Increased participation in ORA resulted in less reported grief in both women and men but did not impact post-traumatic stress or depression. Little quantitative research has been conducted on the impact of religiosity on psychological outcome following pregnancy loss. We are aware of only two prior studies that used a standardized measure of religiosity. The first reported an inverse association between religious attendance and grief in women who had experienced spontaneous pregnancy losses.³¹ In concordance with this study, other measures of religiosity were not associated with psychological outcome, nor did

Table 5 Instrument items endorsed significantly more often by participants who terminated or continued^a

	Terminated				Continued			
	Women		Men		Women		Men	
	<i>p</i>	OR	<i>p</i>	OR	<i>p</i>	OR	<i>p</i>	OR
PGS								
It is painful to recall memories of the loss.	<0.0001	4.01	–	–	–	–	–	–
I get upset when I think about the baby.	0.0001	3.61	0.03	2.61	–	–	–	–
I cry when I think about him/her.	0.047	1.91	–	–	–	–	–	–
I feel guilty when I think about the baby.	<0.0001	3.54	–	–	–	–	–	–
I feel physically ill when I think about the baby.	0.0003	3.49	–	–	–	–	–	–
I feel as though I am just existing and not really living since he/she died.	–	–	–	–	–	–	0.04	2.89
It feels great to be alive.	–	–	–	–	–	–	0.04	2.52
IES-R								
I avoided letting myself get upset when I thought about it or was reminded of it.	0.03	2.04	–	–	–	–	–	–
I stayed away from reminders about it.	0.03	2.25	–	–	–	–	–	–
Pictures about it popped into my mind.	–	–	–	–	–	–	0.008	3.27
I tried not to think about it.	0.006	2.73	–	–	–	–	–	–
My feelings about it were kind of numb.	0.048	1.98	–	–	–	–	–	–
I tried to remove it from my memory.	0.03	3.07	–	–	–	–	–	–
I felt watchful and on guard.	–	–	–	–	–	–	0.04	3.53
I tried not to talk about it.	0.01	2.72	–	–	–	–	–	–
BDHI								
Guilty feelings	0.03	2.20	–	–	–	–	–	–
Self-dislike	0.02	2.36	–	–	–	–	–	–
Self-criticalness	0.005	2.66	–	–	–	–	–	–
Crying	–	–	–	–	–	–	0.02	3.47
Loss of interest	–	–	–	–	–	–	0.03	3.15
Concentration difficulty	0.006	2.69	–	–	–	–	–	–

OR, odds ratio; PGS, Perinatal Grief Scale; IES-R, Impact of Event Scale – Revised; BDHI, Beck Depression Inventory-II.

Only significant associations are reported. Associations that were not significant are marked with (–).

^a*P*-values were adjusted for recruitment source, time since pregnancy ended and organizational religious activity.

religious attendance impact depression. The second study reported an inverse association between the intrinsic religiosity and the despair subscale of the PGS in women who experienced a second trimester fetal demise or pregnancy termination.³² Again, no association was found between religiosity and depression or post-traumatic stress. These findings suggest that certain aspects of religiosity, specifically attending church or other religious meetings, may contribute to reduced grief following pregnancy loss. The psychosocial support provided by faith-based communities may contribute to a reduction in grief.

Pregnancy continuation was also associated with less psychiatric distress in women. As a group, women who continued reported significantly less despair, avoidance and depression than women who terminated. In contrast to the thought that lethal anomalies may avert feelings of guilt following termination, items related to guilt were significantly associated with termination in women. The active choice involved in termination does appear to

increase the likelihood that guilt will be experienced, even in the case of lethal fetal anomalies.

In contrast to women, pregnancy continuation was not associated with improved psychological outcome in men. For the most part, psychological distress reported by men whose partner continued or terminated was equivalent. However, while analyses failed to reveal clear aspects of difficulty, it does appear that pregnancy continuation may somewhat complicate psychological outcome in men.

There are several aspects of pregnancy continuation that may contribute to improved psychological outcome in women. Women who continue typically have several months between the time of diagnosis and the end of the pregnancy. This time may allow women to grieve and eventually reach acceptance with the diagnosis and impending loss prior to delivery. In contrast, women who terminate often do so shortly after the diagnosis with only hours or days to prepare for the loss. Women who continue the pregnancy may also receive more support from family and friends as the loss of a newborn is a

more visible and socially acceptable loss than termination of a pregnancy. Continuing the pregnancy also allows more opportunities to find meaning and for memory making, such as opportunities to hold and care for the baby, take photographs, create other keepsakes and perhaps participate in research, tissue or organ donation, all of which can contribute positively to the grieving process.³³

Although nondirective counseling is widely supported following prenatal diagnosis of serious fetal anomalies, health care providers often counsel in favor of pregnancy termination, especially in the presence of lethal anomalies.^{14,34} Even when a nondirective counseling style is used, comprehensive information about both termination and continuation of pregnancy is not always provided. A recent study of genetic counselors found that most mentioned termination as an option but only 37% discussed pregnancy continuation.³⁵ To facilitate a fully informed decision, the risks and benefits, including psychological effects, of termination and continuation of pregnancy should be discussed in detail.

Additional pregnancy management factors also had an impact on psychological outcome. Termination at a later gestational age was associated with greater psychiatric distress in both men and women, although this was only statistically significant in men. This may be explained by the tendency for women to form stronger emotional attachments to a pregnancy earlier in gestation than men. When termination is chosen, procedures performed earlier in gestation are certainly advantageous physically, but there may be a psychological benefit as well. More widespread acceptance of first-trimester screening, which can detect anencephaly in addition to the common trisomies, would allow greater numbers of patients the option of earlier termination. In agreement with prior studies, method of termination was not associated with psychological outcome. When it comes to the method of termination, compliance with patient choice appears to be the most important factor.²

A number of participants who continued the pregnancy elected a C-section delivery in the hopes of increasing the likelihood of a live birth. While C-section delivery did significantly increase the odds of a live birth, there was no measureable psychological benefit. Physicians and patients will obviously need to reach a mutually agreeable decision when selecting the preferred method of delivery. A recent survey of physicians found that 71% would comply with patient requests for a C-section delivery in the presence of a uniformly lethal fetal anomaly.³⁶ The American College of Obstetricians and Gynecologists also supports elective surgeries when 'based on strong support for patients' informed preferences and values'.³⁷

While we took great care to perform the analyses presented here, we acknowledge that limitations to the present study nonetheless do exist. Participants were recruited through either an NTD genetics study or social media, which may constitute a population not fully representative of the general population. Participants recruited through social media reported significantly more psychological distress. There was also considerable variability in the amount of time that had passed since the pregnancy ended. In an effort to control for these limitations, recruitment source and time since

pregnancy were used as covariates in all analyses. Additionally, anencephaly was used as the disease model; therefore, findings may not be completely transferable to other lethal fetal defects. Pregnancy outcome was self-report and not verified by medical records. The study group consisted of primarily Caucasian Americans; therefore, findings may not be representative of other ethnic groups or cultures. Finally, because we were interested in several psychological outcomes, we performed a large number of statistical tests. Although these tests were adjusted for important covariates as described, we did not adjust the *p*-values for multiple testing. Thus, replication of these associations in an independent cohort is warranted.

Anticipatory counseling regarding the psychological impact of pregnancy loss to lethal fetal defects should routinely be provided. However, because of the tremendous variability in psychological outcome, it is not possible to predict with certainty the level of psychiatric distress experienced by any one patient. Ultimately, coping with the loss of a pregnancy or baby is deeply personal and will be experienced differently by each person. While some patients will struggle more than others, it is incorrect to think that only some patients would benefit from counseling. Resources including local support groups, online groups and options for individual counseling should be provided to all patients and their partners.

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CONCLUSION

There appears to be a psychological benefit to women to continue the pregnancy following prenatal diagnosis of a lethal fetal defect. Following a lethal fetal diagnosis, the risks and benefits, including psychological effects, of termination and continuation of pregnancy should be discussed in detail with an effort to be as nondirective as possible.

WHAT'S ALREADY KNOWN ABOUT THIS TOPIC?

- Pregnancy loss due to fetal anomalies commonly results in psychiatric symptoms including depression, grief and post-traumatic stress.
- Prior studies of psychological outcome have primarily focused on women and pregnancy loss via termination and included heterogeneous study groups with fetal anomalies ranging from mild to severe.

WHAT DOES THIS STUDY ADD?

- This study examined symptoms of grief, post-traumatic stress and depression, in women and men who either terminated or continued a pregnancy following prenatal diagnosis of a lethal fetal defect.
- There appears to be a psychological benefit to women to continue the pregnancy following a lethal fetal diagnosis.
- Organizational religious activity may contribute to reduced grief in both women and men following pregnancy loss due to lethal fetal defects.

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