ARTICLE

Holding a baby after stillbirth: the impact of fetal congenital and structural abnormalities

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OBJECTIVE: Stillbirth can result in numerous adverse psychosocial sequelae. Recommendations vary with regard to holding the baby after a stillbirth. Few studies have addressed the impact of fetal abnormalities on these outcomes.
STUDY DESIGN: Analyses of singleton stillbirths within the Stillbirth Collaborative Research Network were conducted. Patient and stillbirth characteristics were compared between those who did and did not hold their baby. Results from psychometric surveys were compared between cases with and without visible fetal anomalies.
RESULT: There were no significant differences between those who held and those who did not hold in any patient or stillborn characteristics. Visible fetal abnormalities were not associated with adverse psychological outcomes.
CONCLUSION: Fetal abnormalities, including congenital and post-demise changes, do not differ between those who held and did not hold their baby after stillbirth. This suggests that patients should not be discouraged from holding their stillborn infant in the presence of visible abnormalities.

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INTRODUCTION

Stillbirth is a devastating pregnancy outcome that affects approximately 1 in 160 pregnancies in the United States each year, with rates increasing in some areas as a result of the COVID-19 pandemic [1–4]. The experience of stillbirth is associated with adverse psychosocial outcomes including post-traumatic stress disorder (PTSD), depression, and partnership breakdown [5, 6]. These effects are not self-limited, with patients reporting lasting symptoms years after the experience and in subsequent pregnancies, including worsening emotional stress, postpartum depression, and even disorganized attachment behavior with subsequent liveborn children [6–8]. Furthermore, patients endorse feelings of isolation and misunderstanding from doctors, family, friends, and other pregnant patients, which may exacerbate their psychosocial distress and lessen the level of respective maternity care these patients receive [6, 9–12]. Guidelines differ regarding the appropriate management of patients after stillbirth, with varying recommendations for lactation suppression, future pregnancy management, and bereavement support [13–15].

Evidence varies regarding the positive and negative effects of patients holding their baby after stillbirth. Some studies have identified behaviors aimed at promoting contact with the stillborn infant as causing worse outcomes, including depression, anxiety, and PTSD, in both patients and partners [13, 16, 17]. However, other studies suggest that seeing and holding the baby is associated with lower levels of anxiety and depression and fewer symptoms of PTSD [18–23]. Patients in these situations express appreciation for being able to create memories with their baby and for physicians who presented holding their infant as a natural part of their delivery, regardless of the outcome [14, 19–22, 24–28].

Fetal abnormalities are present at higher rates among stillbirths, but few of these studies have thoroughly investigated the impact of these abnormalities on the decision to hold an infant after stillbirth [29]. One study identified that congenital abnormalities did not impact the decision to hold; others have reported patients feeling fear and discomfort while holding their baby, as well as apprehension regarding their appearance [13, 19, 26]. In this study, we sought to further characterize the relationship between fetal appearance and abnormalities and the decision to hold a baby after stillbirth. We further sought to elucidate the postpartum psychological impacts of holding a baby, particularly one with abnormalities. This information will be of utility for clinicians and counselors in deciding how best to approach individuals who have given birth to a stillborn infant.

METHODS

Data

Data were derived from the Stillbirth Collaborative Research Network (SCRN), a multi-center longitudinal study that enrolled patients at 59 hospitals in five geographic regions (RI and Bristol County, MA; DeKalb County, GA; Galveston & Brazoria Counties and Bexar County, TX; and Salt Lake City County, UT), representing both stillbirths (cases) and live births (controls) from 2006 through 2009. Data collection and inclusion/exclusion criteria within the larger SCRN study have been described previously; all study procedures were approved by each center's Institutional Review Board and by the Data Coordinating and Analysis Center, and patients gave written informed consent to participate [30].

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Patients included in these analyses met the following criteria: (1) gave birth to a single, non-living fetus (i.e., multiple births were not included); (2) chose to hold their baby, see their baby, or do neither after the birth; and (3) completed a follow-up interview after delivery.

Measures

Demographic information was collected at enrollment, as well as age of the biological father of the baby. Patients were also queried regarding obstetric history, general medical history, mental health history, and substance use during pregnancy. Additionally, patients were asked about their and their partner's planning for this pregnancy and a 13-item questionnaire of stressful events in the 12 months before pregnancy [31].

At the SCRN follow-up interview (occurring within 6 to 36 months from index delivery, completed as a continuation of the original SCRN study), patients were asked about their decision to hold the baby after their stillbirth as well as if they would recommend that future patients do so [30]. Patients were also queried regarding their thoughts during the pregnancy, support structures utilized within the 2 months following delivery, professional services obtained, most stressful event of their lives up to that point, and current/subsequent pregnancies and children. Patients were also administered the following surveys: the Perinatal Grief Scale short version (PGS), the Edinburg Postnatal Depression Scale (EPDS), the Impact of Event Scale (IES), and the Post-traumatic Growth Inventory (PTGI) [32–35].

The PGS assesses grieving after reproductive loss, with scores ranging from 33 to 165; higher scores reflect more intense grief [32]. The EPDS assesses psychiatric symptoms; scores range from 0 to 30 (higher scores indicate more depressive symptoms), and an aggregate result greater than 10 indicates possible depression [33]. The IES measures subjective stress following an index event; scores range from 0 to 88 with higher scores indicating more stress and scores above 24 indicating possible PTSD [34]. The PTGI measures positive growth following trauma; scores range from 0 to 105, with higher scores indicating more positive growth following trauma [35].

Stillborn examination

All patients were asked for consent for fetal postmortem examination, as previously described [36]. Consent was also obtained for karyotype analysis, and placental and umbilical tissue were also examined [37]. Cause of death was designated by a multidisciplinary team using the initial causes of fetal death (INCODE) instrument [38, 39]. Fetal birthweight in grams was stratified according to percentile for gestational age, with particular attention to weight below the 5th percentile for gestational age [40]. A composite measure representing any visibly dysmorphic fetal features (Supplementary Table 1) was created by combining visible structural abnormality, severe degree of maceration (IV–V), karyotype significant for trisomy, and weight below the 5th percentile for gestational age.

Statistical analysis

All analyses were performed using R Studio software version 1.2.5 (R version 4.2, code available upon request). Data were sorted into two categories for the purposes of analysis: "held" or "did not hold"; the latter included both those who saw but did not hold their baby and those who did not see or hold their baby. Characteristics were compared between these two groups using Chi-Square or Fisher Exact tests for categorical variables and Mann–Whitney tests for continuous variables. Psychometric and follow-up measures were also compared between those cases who had any of the visible features making up our composite measure using similar analyses. A Bonferroni correction for multiple comparisons was used for each set of analyses.

Stillbirth characteristics were entered into multivariate logistic regression to assess odds of holding the baby after stillbirth; variable importance was determined as an odds ratio (OR) and overall area under receiver operating characteristic (AUROC) was reported.

RESULTS

Data and population characteristics

Data derived from the SCRN contained 663 stillbirth cases [30]. Of these, 272 participants completed follow-up and had data available regarding holding or seeing their baby after stillbirth, representing 41.0% of all stillbirths. Average maternal age was 28.4 ± 6.5 years; 31.3% identified as minority race, 30.1% were Hispanic, and 56.6% were married. 8.5% of patients had a previous stillbirth, and 12.1% had history of a mental health condition prior to pregnancy. See Table 1 for further sample characteristics.

Holding the baby

196 individuals held their baby after stillbirth (72.1%). Of the 76 (27.9%) who did not hold their baby, 56 (73.7%) saw their baby but did not hold it. Significantly more of those who held recommended holding the baby after stillbirth compared to those who did not hold, though the majority of both groups recommended holding (94.4% of held versus 80.3% of did not hold, Fisher Exact test $p = 0.00431$). A similar result was found when patients were queried regarding their recommendation to see the baby after stillbirth (94.9% of held versus 72.4% of did not hold, Chi-Square difference test $p < 0.001$). There was no significant difference between these groups in the number of patients given a memory box (95.4% of held versus 92.1% of did not hold, Fisher Exact test $p = 0.37$) or who held a memorial service for their baby (64.3% of held versus 60.5% of did not hold, Chi-square difference test $p = 0.76$).

There were no significant differences among demographic, pregnancy history, pre-pregnancy medical history, or substance use.

Stillbirth characteristics

Significantly fewer individuals who held their baby after stillbirth consented to full autopsy than those who did not hold (62.2% of held versus 78.9% of did not hold, Chi-square difference test $p = 0.0149$). The mean stillbirth gestational age at birth was 28.1 ± 6.8 weeks; 19.1% were below the 5th percentile in weight for gestational age, 16.5% had at least one structural abnormality present, and 6.6% had an abnormal karyotype. Cause of death was at least partially attributed to a placental disorder in 45.2%, infection in 27.2%, genetic disorder in 20.6%, medical complication in 26.1%, hypertensive disorder in 12.1%, cord abnormality in 15.1%, obstetric complication in 30.5%, and other cause in 3.7%. See Table 2 for all stillbirth characteristics.

There were no significant differences in any stillbirth characteristics between those who held and did not hold their baby after stillbirth. A marginal difference was found in cause of death attributed to obstetric complications, with 25.5% of held and 43.4% of did not hold, but this difference ($p = 0.038$) was not significant when corrected for multiple comparisons. In patients with stillbirths that showed visible abnormalities, there was also no significant difference in whether they advised future patients to hold their baby (28 advised to hold and 5 advised to not hold, Fisher exact test $p = 0.38$). A total of 84 cases involved a visible dysmorphic abnormality; there was no significant difference in those who held or did not hold in this composite (Chi-Square $p = 0.38$).

Stillbirth characteristics were not associated with higher odds of holding the baby, with AUROC = 0.552 (representative of 55.2% accuracy). No odds ratios were significant in this prediction ($p > 0.05$).

Follow-up interview

At follow-up interview, 30.5% met criteria on the EPDS for depression, and 57.0% identified their stillbirth experience as the most stressful event of their lifetime. A majority of follow-up measures were not significant between those who held and did not hold their baby after stillbirth. Significantly more individuals who held their baby after stillbirth identified it as the most stressful event of their lifetime (63.8% of held versus 39.5% of did not hold, Chi-square difference test $p = 0.00056$). This difference was not reflected in results of the IES (33.2 ± 9.3 in held versus 31.6 ± 9.6 in did not hold, Mann–Whitney test $p = 0.51$) or PTGI (90.3 ± 22.3 in held versus 90.8 ± 22.4 in did not hold,

Table 1. Sample characteristics.

		Whole sample ($n = 272$)	Held[a] ($n = 196$)	Did not hold[b] ($n = 76$)	p Value[c]
Maternal demographics[d]	Patient age (years)	28.4 ± 6.5	28.1 ± 6.5	29.1 ± 6.5	0.32
	Race—minority	85 (31.3)	64 (3.27)	21 (27.6)	0.50
	Ethnicity—Hispanic	82 (30.1)	59 (30.1)	23 (30.3)	1.00
	Years of education	13.6 ± 2.6	13.5 ± 2.5	14.0 ± 2.8	0.14
	Age of biological father of the baby	30.1 ± 7.1	29.9 ± 7.2	30.6 ± 6.7	0.50
Pregnancy history	Number of pregnancies	2.8 ± 1.9	2.1 ± 1.8	2.0 ± 2.0	0.33
	Past intrauterine fetal demise	23 (8.5)	16 (8.2)	7 (9.2)	0.97
	Patient planned this pregnancy	161 (59.2)	114 (58.2)	47 (61.8)	0.95
	Partner planned this pregnancy	189 (69.5)	134 (68.4)	55 (72.4)	1.00
Pre-pregnancy medical history	Obesity (BMI ≥ 30)	79 (29.0)	52 (26.5)	27 (35.5)	0.19
	Hypertension	35 (12.9)	26 (13.3)	9 (11.8)	0.85
	Diabetes	13 (4.8)	11 (5.6)	2 (2.6)	0.36
	Any sexually transmitted infection (STI)	35 (12.9)	25 (12.8)	10 (13.2)	1.00
	Mental health condition	33 (12.1)	24 (12.2)	9 (11.8)	1.00
	Any illicit drug use	79 (29.0)	56 (28.6)	23 (30.3)	1.00
Substances in pregnancy	Alcohol	4 (1.5)	4 (2.0)	0 (0.0)	0.58
	Cigarette smoking	20 (7.4)	13 (6.6)	7 (9.2)	0.63

All values represented as mean ± standard deviation for continuous variables and number (percentage) for categorical variables.
[a]Held: held baby after stillbirth.
[b]Did not hold: saw baby but did not hold, or did not hold or see.
[c]Result of Mann–Whitney–Wilcoxan rank test, Chi-Square difference test, or Fisher exact test. P values < 0.0013 are considered significant based on a Bonferroni correction for multiple comparisons.
[d]Non-significantly different variables include: marital status (married), living with a partner, living in public housing, moved during pregnancy, income assistance during pregnancy, total significant events 1 year pre-pregnancy.

Table 2. Stillbirth characteristics.

	Whole sample ($n = 272$)	Held[a] ($n = 196$)	Did not hold[b] ($n = 76$)	p Value[c]
Gestational age at birth	28.1 ± 6.8	28.2 ± 6.7	28.0 ± 7.2	0.64
Sex—female	111 (40.8)	73 (37.2)	38 (50.0)	0.18
Weight (g)	1295.0 ± 1177.9	1306.4 ± 1164.3	1264.5 ± 1221.2	0.53
Weight <5th percentile for gestational age	52 (19.1)	38 (19.4)	14 (18.4)	0.90
Maceration degree IV–V	18 (6.6)	11 (5.6)	7 (9.2)	0.55
Visible structural abnormality present	33 (12.1)	20 (10.2)	13 (17.1)	0.17
Any structural abnormality present	45 (16.5)	31 (15.8)	14 (18.4)	0.49
Total number of structural abnormalities	0.3 ± 0.8	0.3 ± 0.7	0.4 ± 1.0	0.53
Abnormal karyotype	18 (6.6)	13 (6.6)	5 (6.6)	1.00
Trisomy present	6 (2.2)	4 (2.0)	2 (2.6)	0.67
Cause of death				
Placental disorder	123 (45.2)	84 (42.9)	39 (51.3)	0.88
Infection	74 (27.2)	52 (26.5)	22 (28.9)	0.91
Genetic disorder	56 (20.6)	41 (20.9)	15 (19.7)	0.55
Medical complication	71 (26.1)	50 (25.5)	21 (27.6)	0.89
Hypertensive disorder	33 (12.1)	27 (13.8)	6 (7.9)	0.13
Cord abnormality	41 (15.1)	31 (15.8)	10 (13.2)	0.42
Obstetric complication	83 (30.5)	50 (25.5)	33 (43.4)	0.038
Other	10 (3.7)	7 (3.6)	3 (3.9)	1.00
Composite: any visible abnormality[d]	84 (30.9)	57 (29.1)	27 (35.5)	0.38

All values represented as mean ± standard deviation for continuous variables and number (percentage) for categorical variables.
[a]Held: held baby after stillbirth.
[b]Did not hold: saw baby but did not hold, or did not hold or see.
[c]Result of Mann–Whitney–Wilcoxan rank test, Chi-Square difference test, or Fisher exact test. P values < 0.0028 are considered significant based on a Bonferroni correction for multiple comparisons.
[d]Composite outcome: visible structural abnormality, maceration degree IV–V, weight <5th percentile for gestational age, or trisomy present.

Table 3. Follow-up interview and psychometric assessments.

		Whole sample ($n = 272$)	Comparison groups					
			Holding the baby			Visible abnormalities		
			Held[a] ($n = 196$)	Did not hold[b] ($n = 76$)	p Value[c]	Any visible abnormality[d] ($n = 84$)	No visible abnormality ($n = 188$)	p Value[c]
Years to follow-up		2.0 ± 0.6	2.0 ± 0.6	2.1 ± 0.6	0.11	2.1 ± 0.6	2.1 ± 0.7	0.99
"Was there a time during pregnancy when you thought it was not going as planned?"		136 (50.0)	100 (51.0)	36 (47.4)	0.66	49 (58.3)	87 (46.3)	0.10
Support following stillbirth	Emotional support in 2 months following stillbirth	242 (88.9)	172 (87.8)	70 (92.1)	0.69	71 (84.5)	171 (91.0)	0.03
	Professional support following stillbirth	56 (20.6)	41 (20.9)	15 (19.7)	0.91	17 (20.2)	39 (20.7)	1.00
	Psychiatric medication use following stillbirth	83 (30.5)	63 (32.1)	20 (26.3)	0.39	30 (35.7)	53 (28.2)	0.60
Subsequent children	Currently pregnant	36 (13.2)	25 (12.8)	11 (14.5)	0.67	11 (13.1)	25 (13.3)	1.00
	Adopted after stillbirth	7 (2.6)	6 (3.1)	1 (1.3)	0.68	0 (0.0)	7 (3.7)	1.00
Surveys	Perinatal Grief Scale (PGS)	96.3 ± 15.0	97.0 ± 15.0	94.4 ± 14.8	0.26	96.8 ± 14.6	96.1 ± 15.2	0.65
	Edinburgh Postnatal Depression Scale (EPDS) total	7.3 ± 5.1	7.0 ± 5.0	7.9 ± 5.3	0.20	7.6 ± 5.7	7.1 ± 4.8	0.57
	Meets criteria for depression on EPDS	83 (30.5)	54 (27.6)	29 (38.2)	0.099	28 (33.3)	55 (29.3)	0.61
	Impact of events scale (IES)	33.3 ± 10.1	33.2 ± 10.0	33.6 ± 10.4	0.88	33.1 ± 10.2	33.4 ± 10.1	0.80
	Post-traumatic growth inventory (PTGI)	91.3 ± 21.5	90.9 ± 22.1	92.2 ± 20.1	0.73	93.8 ± 18.6	90.2 ± 22.6	0.40
	Most stressful event during lifetime—stillbirth	155 (57.0)	125 (63.8)	30 (39.5)	**0.0005**	47 (56.0)	108 (57.4)	0.87

All values represented as mean ± standard deviation for continuous variables and number (percentage) for categorical variables.
[a]Held: held baby after stillbirth.
[b]Did not hold: saw baby but did not hold, or did not hold or see.
[c]Result of Mann–Whitney–Wilcoxan rank test, Chi-Square difference test, or Fisher exact test. *P* values < 0.0038 are considered significant (in bold) based on a Bonferroni correction for multiple comparisons.
[d]Composite outcome: visible structural abnormality, maceration degree IV–V, weight <5th percentile for gestational age, or trisomy present.

Mann–Whitney test $p = 0.83$) when compared in only those who selected stillbirth as the most stressful event of their lifetime. There were no significant differences in any follow-up measure between those cases with a visible fetal abnormality (composite) and those without. See Table 3 for all follow-up measures.

DISCUSSION

Fetal abnormalities are a source of potential concern for patients in seeing and holding their baby after stillbirth. Nonetheless, we found that the presence or absence of such abnormalities does not appear to impact patients' decisions [25, 26]. Any visible structural abnormality, abnormal fetal karyotype, trisomy, severe degree of maceration, or marked fetal weight disparity for gestational age (<5th percentile) did not appear to affect the decision to hold or not to hold a stillborn baby. There were also no differences in psychometric survey results between those cases associated with any visible abnormality (composite) and those not associated with visible abnormality, suggesting that the presence of visible fetal abnormalities is not associated with adverse psychological outcomes, including depression and PTSD. Though over half of participants who held their baby cited this experience as the most stressful of their lifetime, they did not experience a higher rate of adverse psychological outcomes. The majority of previous studies suggest that holding the baby after stillbirth is a positive event and should be encouraged, and we confirm that holding a baby with abnormalities is not associated with adverse mental health sequelae up to 36 months after delivery.

These results support the previous literature on this topic; the consensus appears to suggest that all individuals to be offered the opportunity to hold their infant after stillbirth regardless of fetal abnormalities. Many studies have reported patients' fears and apprehensions regarding the appearance of their infant and felt as though physician preparation was helpful in assuaging such fears [25, 26, 28]. Patients have also reported that engaging in "assumptive bonding," whereby they were offered their infant as a normal part of birth, helped to also make them less frightened by the experience [20]. Though patient choice is ultimately at the center of this experience, provider comfort in presenting a stillborn baby to a patient may indeed lessen those fears that patients have regarding their infant's appearance. We agree with previous authors that providers should be offered education in navigating this experience with their patients as to ease this situation for patients as much as can be possible and also reduce provider trauma [13, 14].

Of note in our results was the discrepancy in consent to autopsy between individuals who chose to hold versus those who did not; more individuals who chose to not hold their baby consented to full autopsy. This distinction is of interest to perinatal pathologists, as the rate of perinatal autopsy has declined in past decades largely due to refusal of consent [41]. While less invasive approaches offer other options to patients who may be reluctant to have their infant undergo postmortem examinations, vital information with implications for future pregnancy planning may be lost without the traditional autopsy [42, 43]. Patients report consenting to fetal autopsy to decrease self-blame and to make decisions for future pregnancies and more often do not regret their decision to consent. We are uncertain why those with more points of contact with their infant were less likely to consent to autopsy [44, 45]. It may be that those who choose to hold their infant have more of a sense of closure and do not feel as though they require an autopsy to obtain answers or future guidance. It may also be possible that patients who held their infant may have had trepidations regarding that baby undergoing an invasive autopsy and may be concerned about the physical process of autopsy for their deceased infant. Regardless, it is vital for physicians, midwives, and nurses to relate the importance of perinatal autopsy to patients in the complex counseling that follows a stillbirth [46]. We will continue to investigate this finding in future work.

Our results should be interpreted in the context of several limitations. Our data was collected from 2006 to 2009; though practice recommendations have not changed since this time, societal and cultural shifts in the past 15 years may not be captured in our sample. Our sample size was low compared to the overall available data within the SCRN database, which may have limited statistical significance in some analyses. Furthermore, our sample was limited to those who had completed a follow-up interval, which may have inadvertently excluded those who had had a more or less traumatic experience and did not wish to seek out additional support or medical contact. Finally, though the SCRN enrolled a diverse population of individuals, our sample has limited generalizability, with only 31.3% of self-identified minority race [39]. Such disparities in our sample may underestimate the various racial, ethnic, socioeconomic, and cultural differences in the choice to hold a baby after stillbirth [47, 48]. Such differences should continue to be assessed in future studies.

The question to hold or not to hold a baby after a stillbirth is widely debated, with intense consideration of the psychological effects of such an experience on the patients for years to come. We sought to understand the relationship between this choice and fetal abnormalities; our results showed that, regardless of the type of abnormality or visible change in the infant's appearance, there was no difference in the number of patients who chose to hold versus not to hold. Furthermore, the presence of visible fetal abnormalities does not appear to contribute to adverse psychological outcomes. This emphasizes that the decision to hold their stillborn baby should be offered to patients regardless of the degree of fetal abnormality. Further prospective studies may further characterize the psychological outcomes of this decision as well as the role of providers in counseling patients regarding this choice, as well as the discrepancies observed between a patient's choice to not hold a baby but to recommend that others do so.

DATA AVAILABILITY

Data from the Stillbirth Collaborative Research Network is available upon request and Institutional Review Board approval.

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AUTHOR CONTRIBUTIONS

TEKC was involved in data curation, conceptualization of the project, methodology and formal analysis, and writing the paper (original draft, review and editing). RMS, DJD, GRS, and RLG were involved in conceptualization of the project and writing the paper (review and editing). HP was involved in data curation, conceptualization of the project, methodology, and writing the paper (original draft, review and editing).

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COMPETING INTERESTS

The authors declare no competing interests.

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