



Gaps in Stillbirth Bereavement Care: A Cross-Sectional Survey of U.S. Hospitals by Birth Volume

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Abstract

Objectives The quality and scope of perinatal bereavement care in the United States has been evaluated by surveying bereaved parents, but little is known about how care varies across hospitals. We sought to survey clinicians about stillbirth bereavement care practices at U.S. hospitals and to evaluate care by hospital birth volume.

Methods Using American Hospital Association data, we employed stratified random sampling to select 300 hospitals from all centers with at least 100 annual deliveries. Within each state, we divided all hospitals into size quartiles and randomly selected from each until we reached the goal number per state. We then identified a staff member knowledgeable about typical bereavement care on labor and delivery at each hospital and sent an on-line survey about care. We linked survey data with hospital characteristics and used summary statistics, Chi squared, and Fisher's Exact test to compare care by hospital birth volume.

Results We reached an eligible respondent at 429/551 hospitals and 396 of the 429 (73%) agreed to participate. We received 289 usable surveys for an overall response rate of 67%. Only one third of hospitals (n=96, 33%) reported staff protected time for perinatal bereavement care. Of 17 bereavement topics, just six were routinely offered by at least two-thirds of the hospitals. Financial limitations and staff shortages were the most commonly identified barriers to care and were most pronounced at small-volume hospitals.

Conclusions for Practice This study offers a snapshot in bereavement care and identified important gaps for both large and small hospitals.

Significance

What is already known on this subject? While there have been efforts to improve hospital bereavement care for families after stillbirth, no researchers have surveyed U.S. hospital practices to assess current bereavement practices or how these practices vary across hospitals.

What this study adds? This study systematically sampled hospitals in all U.S. states to assess stillbirth bereavement care including memory-making, parental education, and barriers to optimal care and analyzed differences by hospital birth volume. The study found significant gaps including limited bereavement education about normal grief, mental health, impact on relationships, return to work, and the father's experience.

Keywords Stillbirth · Fetal death · Bereavement · Grief · Perinatal loss · Hospital volume

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Introduction

For each 170 live births in the United States, there is one stillbirth after 20 weeks gestation. (Centers for Disease Control and Prevention, 2020) Such losses are often traumatic for families and staff. While perinatal loss (stillbirth after 20 weeks gestation and early infant death in the first month of life) significantly increases risk of maternal mental health disorders, (Gold et al., 2014; Gold et al., 2016) the quality of hospital and bereavement care at the time of delivery/death can impact the parents' experience in both positive and negative ways. (Berry et al., 2021; Ellis et al., 2016; Heazell et al., 2016).

Hospitals have improved perinatal bereavement care for families over the years, but there are substantial gaps in care. (Atkins et al., 2022) Bereavement care includes communication, recognition of cultural beliefs, shared decision-making, acknowledgement of parenthood, aftercare for the family and infant, emotional support, and staff support. (American College of Obstetricians and Gynecologists, 2020) Bereaved parents still describe significant concerns about lack of communication, information, and follow-up at hospital discharge. (Atkins et al., 2022; Farrales et al., 2020; Helps et al., 2020; Watson et al., 2019) The death of a baby is stigmatized, and parents may find friends and family are uncomfortable talking about loss which makes sensitive care by health professionals even more critical (Keeble et al., 2018; Pollock et al., 2020). Bereaved women describe intense social exclusion and isolation, "disenfranchised" grief, and guilt. (Burden et al., 2016; Heazell et al., 2016; Leon, 2009; Pollock et al., 2020).

Recommendations for care after perinatal loss exist, but the United States is one of many countries that does not have national guidelines (de Graaff et al., 2023), and few of the recommendations specifically address care at hospital discharge. While prior research studies surveyed parents about stillbirth care at diagnosis and delivery, (Atkins et al., 2022) few have surveyed hospital staff to assess prevalence of different practices.

In the U.S., hospitals vary widely by geographic region, teaching status, and delivery volume. Larger hospitals attract medically-complex obstetrical patients and see the greatest volume of perinatal deaths. But the rate of perinatal mortality is higher at low-volume hospitals, both for high-risk and low-risk births, (Walther et al., 2021; Walther et al., 2020) suggesting limited resources, care quality, staff experience, and/or clinical expertise. We sought to assess care after stillbirth across hospitals of different sizes, since this has important implications for national priorities in bereavement care.

We conducted a national survey using random sampling stratified by state and hospital birth volume to identify

hospitals and surveyed individual bereavement coordinators at these hospitals. We analyzed bereavement education, memory making, and barriers to care by hospital birth volume.

Methods

Sample

We extracted data from the Annual Survey of American Hospital Association (AHA) dataset in 2014 to identify hospitals providing at least 100 annual obstetrical deliveries. (Society for General Internal Medicine, 2020) We excluded hospitals with < 100 deliveries yearly ($n = 238$) as stillbirth would rarely be encountered. As 2873 hospitals met criteria, we chose to sample 300 (balancing representation with limited study resources). A formal power analysis was not performed as we were primarily interested in descriptive statistics by hospital volume.

We multiplied each state's proportion of U.S. births by 300 hospitals to identify sample size for each state, with a minimum of one hospital per state. A state delivering 1% of U.S. births would have 1% of 300 hospitals ($n = 3$) sampled while a state with 5% of U.S. births would have 5% of 300 hospitals ($n = 15$) sampled; in short, we surveyed more hospitals in states with higher delivery volumes. Within each state, we stratified hospitals into quartiles by the annual number of births and randomly sampled one hospital from each quartile (largest thru smallest) until we had reached the goal sample size for that state. This approach meant states with more births had more hospitals in the study, but within a state, we tried to survey hospitals of all different sizes.

Recruitment

From December 2017 to March 2020, we contacted selected hospitals via phone and asked to speak to a staff member knowledgeable about bereavement care on labor and delivery. If the correct staff person was identified but not available, we made up to 5 additional calls over several weeks or months to reach them. Individuals agreeing to participate were sent a survey link by email and re-sent up to five times for non-responders. If the respondent was not reachable or declined, we randomly chose a replacement hospital from the same state and size quartile. The survey included a code which linked staff answers to AHA hospital descriptors. We did not record the name of the person completing the survey and only asked basic demographics to ensure anonymity of respondents. We excluded hospitals which had closed their labor and delivery units or those without an English-speaking representative (Puerto Rico only). Participants could

register for a drawing for one of six \$50 gift cards. The study was conducted in accord with prevailing ethical principles and deemed exempt by our institution’s Institutional Review Board. Purpose, risks, benefits, primary investigator, data security, and duration were described to participants in the survey materials. Submission of a completed survey was considered documentation of consent.

Measures

There are no validated instruments to assess stillbirth care, so our team developed a 37-question instrument by collating international literature on bereavement care and piloting and revising with input from six experts in stillbirth (including bereaved parents). Appendix A. We queried respondent role, training, age, gender, and protected time. We asked whether the hospital routinely provided mementoes (yes/no), frequency of oral or written education (5-point Likert scale or “unsure”), and potential barriers to care (4-point Likert scale). We included additional topics beyond the scope of this manuscript, such as community resources, staff communication and training, and patient outreach. Questions were multiple choice, Likert-style, or open-ended text. Surveys had a single format and question order and did not utilize adaptive questioning. We purposefully omitted a “not-applicable” response to force choice, although participants could leave a question blank.

Data Analysis

We sampled hospitals from the AHA database using R (<https://www.r-project.org/>, v3.3.0) and downloaded data into Stata (version 13.1, College Station, TX). Data were analyzed by summary statistics. Comparisons of responses by hospital volume used Chi-squared or Fisher’s Exact test for cell sizes ≤ 5. We compared outcomes using completed

data across hospital quartiles including the difference between the smallest (Q1) and largest (Q4) quartiles assuming an alpha level of 0.05. Missingness ranged from 16 to 18% (demographic variables), 1–11% (hospital descriptors), 5–6% (memory items), 5–15% (educational content), and 17% (barriers to care). We used The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004, 2012) and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (STROBE checklist for cohort, case-control, and cross-sectional studies, 2007) to report findings.

Results

Demographics

Using rolling recruitment, we reached out to 551 hospitals. (Fig. 1) We excluded 35 without an active obstetrics unit, one reporting < 100 annual births, and 86 where no contact person was reached. Among eligible participants at 429 institutions, 33 declined. Staff at 396 hospitals agreed to participate and were emailed a link to the survey. We received 299 responses. During analysis we identified duplicate surveys for 10 hospitals and retained only the first submission for each. This resulted in usable surveys from 289 hospitals (67.4% of 429 hospitals where we reached staff, and 72.9% of 396 individuals sent a survey). Surveys were matched to AHA hospital data in all but 17 cases where the hospital code was erroneously omitted from the survey link.

Among respondents providing demographic information (Table 1), most self-reported as female (234/244, 95.9%), White (226/241, 93.4%), non-Hispanic (224/241, 93.3%) and worked as a nurse (n = 215/244, 88.1%) or social worker (n = 12, 4.9%). Median age was 45 (range 24–72). Completed surveys represented 48 states, Guam, and the District of Columbia. Among 270 hospitals providing regional data, more came from the South (n = 104, 38.5%) and West (n = 72, 26.7%) versus the Midwest (n = 54, 20.0%) or Northeast (n = 40, 14.8%). Forty institutions (15%) were for-profit hospitals, and this did not vary by quartile.

Median births in Quartiles 1, 2, 3, and 4 were 318, 622, 1368, and 2904, respectively. (Table 1) The largest quartile (Q4) was significantly more likely than other quartiles to represent urban hospitals, teach medical students or residents, provide protected job time for stillbirth bereavement care, and have a formal bereavement team.

Memory Items

Most hospitals provide tangible memorabilia after a loss. (Table 2) These included a birth or delivery certificate

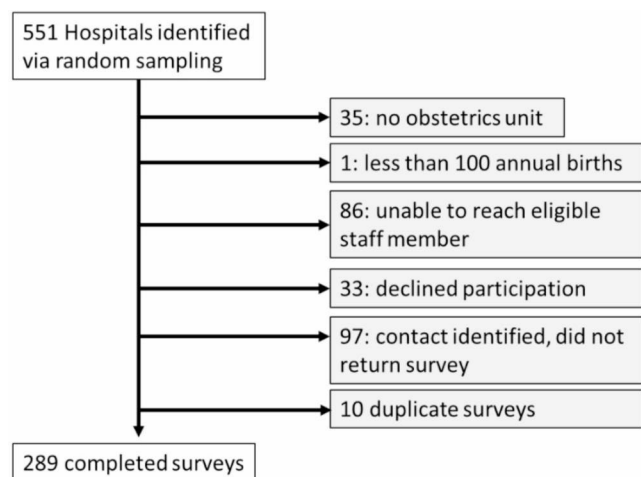


Fig. 1 Hospital recruitment

Table 1 Hospital descriptors by delivery volume (quartiles)

	All hospitals n (%)	Hospital Quartiles				Overall p value	Q1 vs. Q4 p value
		Smallest: Q1 n=49 (%)	Q2 n=66 (%)	Q3 n=61 (%)	Largest: Q4 n=94 (%)		
Median Annual Births (n=270)	1191.0	318.0	621.5	1368.0	2903.5	n/a	n/a
Rural location (n=256)	20 (7.8)	11 (23.4)	6 (9.7)	3 (5.2)	0 (0)	< 0.001*	< 0.001*
Teaching hospital (n=270)	149 (55.2)	13 (26.5)	23 (34.9)	35 (57.4)	78 (83.0)	< 0.001*	< 0.001*
Any staff with protected time for bereavement work (n=289)	96 (33.2)	9 (18.4)	20 (30.3)	20 (32.8)	40 (42.6)	0.031*	0.004*
Hospital has formal bereavement team (n=286)	106 (37.2)	9 (18.8)	17 (26.2)	24 (40.0)	48 (51.6)	< 0.001*	< 0.001*

* $p < .05$. All hospitals with survey data = 289. Quartiles, median births, rural location, and teaching hospital based on 270 hospitals with linked survey and AHA data. Median births in Quartiles 1, 2, 3, and 4 were 318, 622, 1368, and 2904, respectively

Table 2 Hospital provision of memory items for parents by hospital

	All hospitals n=275 (%)	Hospital Quartiles				Overall p value	Q1 vs. Q4 p value
		Smallest: Q1 n=49 (%)	Q2 n=66 (%)	Q3 n=61 (%)	Largest: Q4 n=94 (%)		
Birth or delivery certificate	220 (80.0)	37 (78.7)	49 (79.0)	50 (86.2)	70 (77.8)	0.623	0.899
Death certificate	126 (45.8)	17 (36.2)	24 (38.7)	29 (50.0)	48 (53.3)	0.140	0.056
Baptism certificate	114 (41.5)	17 (36.2)	19 (30.7)	26 (44.8)	46 (51.1)	0.066	0.096
Memory box	264 (96.0)	43 (91.5)	60 (96.8)	55 (94.8)	88 (97.8)	0.351	0.181
Handprints or footprints	273 (99.3)	47 (100)	61 (98.4)	58 (100)	89 (98.9)	1.000	1.000
Plaster molds of infant's hands or feet	172 (62.6)	20 (42.6)	35 (56.5)	34 (58.6)	70 (77.8)	< 0.001*	< 0.001*
Card or sheet with infant's birth data	270 (98.2)	44 (93.6)	60 (96.8)	58 (100)	90 (100)	0.020*	0.039*
Hospital ID bracelet †	238 (87.2)	39 (83.0)	55 (90.2)	51 (87.9)	77 (86.5)	0.734	0.580
Commemorative jewelry †	120 (44.0)	13 (27.7)	20 (32.8)	26 (44.8)	54 (60.7)	< 0.001*	< 0.001*
Photos †	256 (93.8)	41 (87.2)	56 (91.8)	53 (91.4)	88 (98.9)	0.022*	0.007*
Lock of hair †	239 (87.6)	36 (76.6)	56 (91.8)	52 (89.7)	79 (88.8)	0.090	0.062
Clothes worn by infant †	252 (92.3)	40 (85.1)	58 (95.1)	52 (89.7)	86 (96.6)	0.063	0.032*
Baby blanket †	257 (94.1)	45 (95.7)	58 (95.1)	53 (91.4)	83 (93.3)	0.803	0.714
Stuffed animal †	165 (60.4)	25 (53.2)	40 (65.6)	29 (50.0)	59 (66.3)	0.134	0.135

* $p < .05$. Hospitals responding to these question n=275 unless marked by †n=273. Quartiles based on 270 hospitals with linked survey and AHA data

(80.0% of hospitals), a memory box (96.0%), handprints or footprints (99.3%), a card or sheet with newborn weight (98.2%), photographs (93.8%), or a baby blanket (94.1%). Certain items were significantly more common at the largest hospitals versus the smallest, including plaster molds of the hands or feet (77.8% of the largest hospitals versus 42.6% of the smallest, $p < .001$), a card with the infant's information (100% versus 93.6%, $p = .039$), commemorative jewelry (60.7% versus 27.7%, $p < .001$), and photos (98.9% versus 87.2%, $p = .007$).

Parent Education

We asked about oral and written information offered to parents during hospitalization or discharge. (Table 3) Three

quarters (74.7%) of hospitals reported routinely providing education about the normal grief process (83.0% of the largest Q4 hospitals versus 59.2% of the smallest Q1, $p = .002$). Two-thirds (68.9%) offered families a hospital contact for follow-up (79.8% versus 57.1%, $p = .004$). Half addressed risks for mental health or substance use (48.4%), grief of fathers or partners (54.7%), or the impact of loss on marriage or relationships (46.4%). A third routinely offered education on sex and intimacy after loss (37.0%) or issues related to returning to work (31.1%). 56% (56.4%) offered parents resources to connect with other families and 49.5% provided online support resources. The largest volume hospitals were more likely than the smallest volume to offer education on every topic, but only 6 of the 17 bereavement

Table 3 Hospitals reporting oral or written information “always” or “almost always” provided to bereaved families

	All hospitals n=289 (%)	Hospital Quartiles				Overall p value	Q1 vs. Q4 p value
		Smallest: Q1 n=49 (%)	Q2 n=66 (%)	Q3 n=61(%)	Largest: Q4 n=94 (%)		
Normal grieving	216 (74.7)	29 (59.2)	49 (74.2)	43 (70.5)	78 (83.0)	0.020*	0.002*
Risks for mental health or substance use	140 (48.4)	18 (36.7)	30 (45.5)	24 (39.3)	56 (59.6)	0.023*	0.009*
Impact of loss on marriage/ relationship	134 (46.4)	17 (34.7)	29 (43.9)	26 (42.6)	49 (52.1)	0.241	0.047*
Impact of loss on fathers	158 (54.7)	21 (42.9)	35 (53.0)	32 (52.5)	59 (62.8)	0.143	0.023*
Sex and intimacy after loss	107 (37.0)	10 (20.4)	23 (34.9)	22 (36.1)	40 (42.6)	0.073	0.008*
How to discuss loss with older siblings	160 (55.4)	17 (34.7)	29 (44.0)	37 (60.7)	65 (69.2)	< 0.001*	< 0.001*
Physical changes for mom after discharge	226 (78.2)	34 (69.4)	49 (74.2)	46 (75.4)	84 (89.4)	0.017*	0.003*
Managing lactation	226 (78.2)	34 (69.4)	49 (74.2)	45 (73.8)	83 (88.3)	0.027*	0.005*
When it is safe for next pregnancy	184 (63.7)	26 (53.1)	49 (74.2)	34 (55.7)	60 (63.8)	0.072	0.212
Options for funeral or memorial services	257 (88.9)	43 (87.8)	54 (81.8)	56 (91.8)	87 (92.6)	0.170	0.344
Ideas to memorialize the infant	214 (74.1)	34 (69.4)	44 (66.7)	46 (75.4)	77 (81.9)	0.136	0.088
Suggested books about perinatal loss	183 (63.3)	26 (53.1)	34 (51.5)	42 (68.9)	70 (74.5)	0.007*	0.010*
Connecting to other families with loss	163 (56.4)	18(36.7)	33 (50.0)	30 (49.2)	68(72.3)	< 0.001*	< 0.001*
Options for internet support sites for loss	143 (49.5)	16 (32.7)	30 (45.5)	26 (42.6)	61 (64.9)	0.001*	< 0.001*
Who to contact at hospital for follow-up	199 (68.9)	28 (57.1)	41 (62.1)	39 (63.9)	75 (79.8)	0.018*	0.004*
Issues related to returning to work	90 (31.1)	8 (16.3)	18 (27.3)	19 (31.2)	35 (37.2)	0.072	0.010*
Cause of death	125 (43.3)	19 (38.8)	34 (51.5)	19 (31.2)	48 (51.1)	0.046*	0.162

* *p* < .05. All hospitals with survey data = 289. Quartiles based on 270 hospitals with linked survey and AHA data

Table 4 Bereavement care barriers by hospital quartile (by annual number of births). Data represents respondents who “agree” or “strongly agree.”

	All Hospitals n=240 (%)	Hospital Quartiles				Overall p value	Q1 vs. Q4 p value
		Smallest:Q1 n (%)	Q2 n (%)	Q3 n (%)	Largest:Q4 n (%)		
Financial limitations	155 (64.6)	33 (76.7)	31 (57.4)	36 (67.9)	47 (59.5)	0.164	0.055
Lack of staff	106 (44.2)	25 (59.2)	23 (42.6)	21 (39.6)	32 (40.5)	0.176	0.046*
Lack of education†	146 (60.3)	32 (74.4)	35 (63.6)	34 (64.2)	40 (50.6)	0.065	0.011*
Limited time	131 (54.6)	18 (42.9)	29 (53.7)	35 (66.0)	43 (54.4)	0.161	0.225
Lack of support from department/unit††	56 (23.2)	10 (23.8)	9 (16.4)	13 (24.5)	22 (27.9)	0.491	0.632
Lack of support from hospital administration	91 (37.9)	18 (42.9)	18 (32.7)	23 (43.4)	29 (36.7)	0.625	0.509
Emotional strain on staff††	138 (57.3)	24 (57.1)	29 (52.7)	31 (58.5)	47 (59.5)	0.884	0.803
Lack of community bereavement resources	132 (55.0)	32 (74.4)	35 (63.6)	31 (60.8)	32 (40.5)	0.002*	< 0.001*
Lack of awareness	133 (55.4)	29 (70.7)	36 (65.5)	24 (45.3)	38 (48.1)	0.018*	0.018*

**p* < .05. All hospitals with survey responses to these questions = 240 unless otherwise indicated. Quartiles based on 270 hospitals with linked survey and AHA data

†n = 242 ††n = 241

topics we assessed were routinely offered by at least two-thirds of hospitals.

Barriers to Bereavement Care

Financial limitations and lack of staff education were the most common barriers to bereavement care for all hospitals. (Table 4) The largest quartile was less likely than the smallest to report limited staff (40.5% of Q4 versus 59.2% of Q1, *p* = .046), staff education (50.6% versus 74.4%, *p* = .011), community bereavement resources (40.5% versus 74.5%, *p* < .002), or community awareness of stillbirth (48.1% versus 70.7%, *p* = .018).

Discussion

Principal Findings

This study systematically sampled U.S. hospitals to assess bereavement practices after stillbirth and found widespread gaps. A quarter of hospitals reported not routinely offering grieving parents oral or written education about normal grief, giving a hospital contact for follow-up, or addressing grief of fathers or partners, despite these being fundamental components of bereavement care.

Results in the Context of What is Known

The American College of Obstetricians and Gynecologists/Society for Maternal Fetal Medicine published 2020 guidelines on medical care after stillbirth including some recommendations for bereavement care, (American College of Obstetricians and Gynecologists, 2020) but there is limited data on actual practice. Bereavement experts recommend memory-making, follow-up, parent education, and referrals for counseling and support groups, among other components, (Bakbakhi et al., 2017; Boyle et al., 2020; Donovan et al., 2015; Thornton et al., 2019) Addressing partner grief is recommended by national and international guidelines as lack of acknowledgement can worsen stigma and isolation. (American College of Obstetricians and Gynecologists, 2020; Obst et al., 2020; Obst et al., 2021; Shakespeare et al., 2020) Families highly value memorial items and preservation of limited birth memories, (Fenstermacher & Hupcey, 2019; Gold et al., 2007) and these help create continuing bonds. (Leon, 2009; Thornton et al., 2019) Stillbirth parents in the U.S. were less likely than parents in other high income countries to report the hospital offered follow-up calls/visits or autopsy information, (Horey et al., 2021) and an international survey of parents found only half of U.S. parents felt they received the information they needed after their stillbirth. (Flenady et al., 2016).

The smallest hospitals in this study understandably report more barriers to optimal care. While care and education suffer from lack of funding and limited protected time at most institutions, the intense and traumatic nature of stillbirth make it essential that parents are cared for by sensitive and well-trained staff during their delivery stay. Low quality bereavement care can impact parents for decades to come and high-quality care may improve outcomes. (Ellis et al., 2016; Peters et al., 2015) We encourage high-volume hospitals to partner with smaller hospitals in their state or community to share bereavement training and resources. On-line support may offer a lifeline to families delivering in rural communities which lack access to specialized support groups or bereavement counselors (Domogalla et al., 2022). Smaller hospitals could also benefit from on-line perinatal loss support materials.

Clinical Implications

All hospitals providing obstetrical services should be prepared to care for families with stillbirth, even though loss may be relatively infrequent at any single hospital. (American College of Obstetricians and Gynecologists, 2020; Shakespeare et al., 2020) Parent education and memory items are typically low-cost interventions which can significantly address parent needs at hospital discharge.

Strengths and Limitations

Sampling methodology was developed to represent care at both small and large hospitals within each state. We sampled about 10% of our total which we felt would be representative of hospitals of various sizes, given our random, stratified sampling process. The use of a national dataset gave us reliable data about hospital size and type, and we had a relatively high survey response rate. Most respondents were nurses, emphasizing the importance of training and skills among obstetric nurses and the need for nurse leadership to actively support bedside staff and advocate for strong bereavement programs.

Study limitations include the risk for response and recollection bias. We surveyed bereavement coordinators, but one individual may not know how all losses are handled. We excluded hospitals with < 100 deliveries as we anticipated staff would have very limited experience with stillbirth. Identifying eligible hospital staff, connecting by phone, and obtaining a completed survey was intensely time-consuming and extended over 2.5 years. However, we are aware of no significant changes in bereavement care during this time. Due to survey space limitations, we did not ask about all care for bereaved parents, so can only present findings on a subset of practices, and not all of the topics we assessed can be included in a single manuscript. While we compared hospitals by size, we noted that larger hospital were more likely to be urban and teaching hospitals and have bereavement teams, so size may be a proxy for available resources. We identified two minor technical errors early in the study (not linking the hospital ID and survey and getting duplicate surveys from a small number of participants who responded to more than one reminder email) which required tightening of the research protocol. The study was conducted just prior to the COVID-19 pandemic so current approaches to care may differ. We surveyed approximately 10% of hospitals which we believe makes our findings more generalizable, particularly given our focus on sampling by hospital birth volume.

Conclusions

This study systematically evaluated stillbirth bereavement care across the country and by hospital birth volume, merging objective institutional data with subjective data about care. The resulting snapshot highlights substantial differences in post-loss care and major opportunities to optimize bereavement support after stillbirth in the U.S.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10995-023-03861-8>.

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Data Availability Not applicable.

Code Availability Not applicable.

Declarations

Ethics Approval The study was reviewed and deemed exempt by our Institutional Review Board.

Consent to Participate Described in the manuscript.

Consent for Publication Not applicable.

Conflict of Interest No author has any financial disclosures or conflicts of interest to disclose.

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