Atkins Bethany Ann (Orcid ID: 0000-0003-1445-3820)
Boyle Fran (Orcid ID: 0000-0003-1665-2137)

Is care of stillborn babies and their parents respectful? Results from an international online survey

Shortened running title: Respectful care of stillborn babies and their parents

Bethany Atkins[1]
Hannah Blencowe[2]
Frances M Boyle[3,4]
Emma Sacks[5]
Dell Horey[4, 6]
Vicki Flenady[4]

Corresponding author:
Bethany Atkins
Bethany.atkins@nhs.net
07999563181
Address: EGA Institute for Women's Health, University College London,

Affiliations:
1. EGA Institute for Women's Health, University College London
2. MARCH Centre, London School of Hygiene and Tropical Medicine
3. Institute for Social Science Research, The University of Queensland, Australia
4. NHMRC Centre of Research Excellence, Mater Research Institute-The University of Queensland, Australia
5. Department of International Health, Johns Hopkins School of Public Health, Baltimore, MD, USA, 21025
6. Department of Psychology and Public Health, La Trobe University, Australia

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/1471-0528.17138

Abstract

Objective

To quantify parents' experiences of respectful care around stillbirth globally.

Design

Multi-country, online, cross-sectional survey.

Setting and Population

Self-identified bereaved parents (n=3769) of stillborn babies from 44 high- and middle-income countries.

Methods

Parents' perspectives of 7 aspects of care quality, factors associated with respectful care, and 7 bereavement care practices were compared across geographical regions using descriptive statistics. Respectful care was compared between country income groups using multivariable logistic regression.

Main Outcome Measures

Self-reported experience of care around the time of stillbirth

Results

A quarter (25.4%) of 3769 respondents reported disrespectful care after stillbirth and 23.5% reported disrespectful care of their baby. Gestation <30 weeks, and primiparity were associated with disrespect. Reported respectful care was lower in middle-income countries (MICs) than in high-income countries (HICs) (aOR=0.35,

95%CI (0.29-0.42), p <0.01). In many countries, aspects of care quality need improvement, such as ensuring families have enough time with providers. Participating respondents from Latin America and Southern Europe reported lower satisfaction across all aspects of care quality compared to Northern Europe. Unmet need for memory-making activities in MICs is high.

Conclusions

Many parents experience disrespectful care around stillbirth. Provider training, and system-level support to address practical barriers are urgently needed. However, some practices (which are important to parents) can be readily implemented such as memory-making activities and referring to the baby by name.

Keywords

Stillbirth, quality of care, respectful care, experience of care, bereavement, survey, global

Tweetable abstract

1in4 experience disrespectful care after stillbirth. Parents want more time with providers & their babies to talk & memory-make.

Introduction

The World Health Organization (WHO) envisages a world where "every pregnant woman and newborn receives quality care."[1] The past decade has seen some reductions in stillbirth rates globally,[2] but many countries lag behind the Every Newborn Action Plan (ENAP) target of 12 or fewer stillbirths per 1000 births by 2030[3]. Ensuring provision of high-quality, respectful maternity care where women feel safe and motivated to attend[4] is one mechanism for achieving this goal.[5] Facility-based care attendance can be compromised by disrespect; women are dissuaded and may dissuade others from seeking essential care.[6]

Ethically, all women and their families have a right to be treated with respect and dignity while accessing healthcare.[7] Respectful care[8] is defined by the WHO as care provided "*in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labour and childbirth".* Identifying objective measures of dignity and respect is challenging; respectful care requires adaptation to cultural norms and individual preferences and is based on expectations and awareness of rights.[9]

Stillbirth is a catastrophic event, potentially causing long-term negative consequences for parents, siblings, wider family and communities; psychological symptoms, isolation, substance misuse, chronic pain, employment difficulties and financial debt.[10] These adverse outcomes are magnified in parents unsupported by health professionals and their community, and whose grief is exacerbated by stigma.

Two systematic reviews have sought to examine respectful care around stillbirth.[11,12] The RESPECT study built on these two reviews and, through consensus of expert and healthcare providers, identified 8 fundamental principles of high-quality perinatal

bereavement care including to "provide respectful maternity care to bereaved women, their families, and their babies".[13]

Providing parents opportunities to engage with their stillborn baby and to create memories, for example holding their baby, introducing to family members, taking photographs, and commemorative services, are central to high-quality bereavement care.[10,14] These care practices have been associated with a range of improved longer term psychosocial outcomes and a more adaptive grieving process.[10,14,15]

This study aims to quantify parents' perceptions of respectful care of themselves and their stillborn baby, comparing geographical regions and identifying factors associated with reporting respectful care. This study also compares care quality during pregnancy and after stillbirth, including bereavement care practices parents wanted and what they were offered after their baby was stillborn.

Methods

Data collection

Data were collected through a global, anonymous, voluntary, web-based survey of self-identified parents bereaved by stillbirth, distributed by member organisations of the International Stillbirth Alliance.[16] Relevant sections of the survey are available in Appendix S1.

The data were analysed using STATA 16. The strategy for data analysis was determined prior to any data access.

Other analyses of these data have been published; one which triangulated the perspectives of parents, care providers, and community members[17]; and one which explored parents' experiences in subsequent pregnancies[18]. These data have also been used in analyses that compare high-income and middle-income countries[10,19]. These show the variability in parents' experiences after stillbirth and describe where bereavement care practices are offered to parents. However none of these previous analyses have focused specifically on the experience of respectful care or unmet need for bereavement care practices.

Definitions

The WHO definition of stillbirth for international comparison (a baby born without signs of life at ≥1000g birth weight, ≥28 weeks gestation, or ≥35cm body length[20]) is applied inconsistently throughout the world. Therefore, the lowest measure used in high income countries of 20 weeks gestation was utilized;[21] participants were excluded if the reported gestational age at stillbirth was below this. A flowchart of participant selection can be found in Appendix S2.

Respectful care was defined subjectively, and on the principle that low quality care is not respectful. Parents were asked if they felt their care was respectful during pregnancy and after stillbirth, and asked about 7 aspects of care quality, derived from a review of what women want from maternity care.[17]

Small *et al*[22] had previously associated 7 aspects of care with quality (Box 1). An additional question was asked regarding care after birth; "Was your baby treated with kindness and respect?" Each item was rated using a 4-point categorical response scale ('always'/'most of the time'/'sometimes'/'never').

Box 1. Key aspects of quality maternity care as described by Small et al.[22]

1. Information provision
2. Time with care providers
3. Involvement in decision making
4. Understandable communication
5. Being listened to
6. Concerns taken seriously
7. Being treated with kindness and respect

Parental access to 7 bereavement care practices was explored; whether they had the opportunity to have a funeral, take their baby home, name their baby, create memories and mementoes (for example photos), see and hold their baby, spend time with their baby and allow friends or family to meet their baby. These 7 practices were explored using the options: (A) "desired and offered", (B) "desired but not offered", (C) "not desired but offered", (D) "not desired and not offered". Responses A or C were collapsed and categorized as "received (the care practice)", A or B as "desired", and option B as having "unmet need".

Coverage of respectful care of parents and their stillborn baby

Each aspect of care quality was converted to binary variables: “most of the time” or “always” were categorized as a positive response; “some of the time” or “never” as a negative response.

The associations between respectful care and the following variables were explored: parental age, education status, employment status, time elapsed since stillbirth, gestational age at the time of stillbirth, respondent type (mother or father), and if they had other children prior to their stillbirth.

Respondents were grouped into either high- (HIC) or middle-income Countries (MIC), using the 2020 United Nations Geographic Regions Classification. The confounding effect of variables on the association between income grouping of country of residence[23] (MIC vs. HIC) and respectful care was explored using multivariate logistic regression in a forward stepwise approach (Appendix S3).

Respondent-reported care quality was compared during pregnancy and after stillbirth.

The frequency of positively reporting each aspect of quality care after stillbirth was reported, stratified by the United Nations’ geographical regions and compared with Northern Europe as the reference group [24]. Northern Europe was the reference group as it was the region with the highest reported quality of care in 5 of 7 aspects.

Care practices parents wanted and were offered after their baby was stillborn

Descriptive statistics were presented for: desire for, access to, and unmet need for each care practice in HICs and MICs. Unmet needs were compared between HICs and MICs.

Results were reported according to the EQUATOR STROBE guidelines for observational studies. Characteristics of the study population and coverage of respectful care practices were reported using descriptive statistics, and associations assessed using odds ratios and McNemar's chi-squared test of association. Analysis was completed using STATA version 16.

Ethical considerations

No identifiable information was collected. Participation was fully voluntary and respondents could exit the survey at any time. Parents were informed of available support services, due to the potential for distress in recalling and relating events.

Ethical approval for the survey was granted by the Mater Health Services Human Research Ethics Committee (reference no. HREC/13/MHS/121).

Results

There were 3769 survey respondents: 3639 mothers and 130 fathers (Table 1) from 44 countries, including 27 HICs (3150 respondents) and 17 MICs (619 respondents) (Appendix S4). Respondents' mean age was 35 years at survey completion. Almost all respondents had completed secondary school; only 67 (1.8%) had not.

Most respondents' babies (71.9%) were stillborn within the preceding 5 years. Non-response to questions varied between 0 – 1.6% and was considered non-important for study findings.

Parents' perceptions of respectful care

Overall, 25.4% of parents did not find their care after stillbirth respectful, and 23.5% felt their baby did not consistently receive respectful care. For both, just over half reported that care was "always" kind and respectful (52.9% and 57.7% respectively).

There was no difference in the reporting of respectful care between parents without education beyond secondary school and parents with undergraduate or vocational training (Table 1). However, parents with a postgraduate degree were more likely to report respectful care (OR 1.74, 95% CI 1.37 – 2.21) compared to parents without education beyond secondary school.

Parents of stillborn infants with gestational ages over 30 weeks were more likely to report respectful care compared to those born below 30 weeks (30-37 weeks OR 1.45, 95% CI 1.21-1.74; ≥38 weeks OR 1.43, 95% CI 1.20-1.70).

The association between parental age and likelihood of reporting respectful care was non-linear, but potentially suggests less respectful care at each extreme of age. 76.7% of parents aged 30-44 years reported respectful care, compared with 69.5% of respondents under 29 years, and 69.9% over 45. Parents whose baby was

stillborn 5 or more years prior to the survey were less likely to report respectful care than parents whose baby was stillborn more recently (69.0% vs. 77%, OR 0.67, 95% CI 0.57-0.79).

Parents were also less likely to report respectful care when this stillbirth was not their first pregnancy. This decreased likelihood was consistent across both parents with living children and parents whose child had died (including previous miscarriage or stillbirth). No difference in reporting respectful care was detected between mothers and fathers.

Compared with parents from HICs, reported respectful care was lower for parents from MICs (OR 0.37, 95% CI 0.30 – 0.44). None of the variables were found to have a confounding effect on the association between MIC/HIC and respectful care (detail in Appendix S3). However, the time elapsed since the stillbirth and parental age at survey completion both caused effect modification. Parents from MICs were less likely to report respectful care compared to HICs, and this association was stronger among parents whose baby was born within the last 5 years (stillbirth <5 years ago, stratified OR 0.31, 95% CI 0.26-0.39; stillbirth >5 years ago, stratified OR 0.53, 95% CI 0.35 – 0.81, p-value for test of homogeneity 0.03). Whilst the effect of parental age on the association between respectful care and MICs/HICs was non-linear, the gap between MICs and HICs tended to be greater among younger parents and reduced with increasing age.

Assessments of care in pregnancy and after stillbirth

Positive responses regarding each of the 7 aspects of quality care ranged from 55.1% to 78.1% during pregnancy and 52.7% to 74.7% after stillbirth (Table 2). Only 55.1% of parents felt their concerns were taken seriously during pregnancy, which was the most negatively reported aspect of quality pregnancy care. Even for the

most positively reported care aspect during pregnancy, 1 in 5 parents reported that providers did not talk in an understandable way.

Parents' responses were less positive regarding their care after stillbirth than their care during pregnancy for 4 of the 7 aspects of care quality. However, there was no detectable difference in the proportion of parents reporting that they were treated with kindness and respect (OR 0.88, 95% CI 0.76–1.03), or whether they felt providers listened to them (OR 0.91, 95% CI 0.81–1.03) after stillbirth. Only one of the seven aspects of care quality was reported more positively after stillbirth, which was whether parents felt their concerns were taken seriously (OR 1.39, 95% CI 1.22-1.58) but this aspect was also rated less positively during pregnancy than the other aspects of care quality.

Comparing parents' reports of care after stillbirth in different geographical regions, Latin America and the Caribbean had the lowest proportion of positive responses across the 7 aspects of care quality, followed by Southern Europe (Figure 1) (numerical data in Appendix S5). There was wide variation between these regions and Northern Europe, across all care aspects (lowest OR 0.15, 95% CI 0.10-0.23, highest OR 0.31, 95% CI 0.23-0.41).

In most geographical regions, parents reported most positively regarding whether their care was kind and respectful, and least positively regarding whether providers spent enough time with them or gave them adequate information.

Care practices parents wanted and were offered after their baby was stillborn

Figure 2 illustrates care practices offered and accepted by parents after their baby was stillborn (numerical data in Appendix S6). Overall, baby naming was the most desired care practice (97.2% of respondents) and the one most frequently undertaken (85.6%). The proportion of parents who reported that they were offered

and accepted other care practices varied from 65% to 77%, with the exception of taking their baby home, which was reported by only 11.4%. This care practice had the largest unmet need overall, with one in three parents (35.3%) reporting that they would have liked to have been offered this.

The second largest unmet care need was the opportunity to create memories and keepsakes, which 27.2% of parents reported they wanted but were not offered.

The proportion of parents reporting unmet needs was far higher in MICs than in HICs and was prevalent for every care practice. The likelihood of unmet need in MICs was more than twice that in HIC for being able to take their baby home (OR 2.35, 95% CI 1.95-2.82, $p<0.01$) and more than seven times higher for seeing and holding their baby (OR 7.18, 95% CI 5.77-8.93, $p<0.01$) (Appendix S6).

Discussion

This is the first known study to quantify respectful care around stillbirth on a global scale. While the majority of parents reported that care was kind and respectful both during pregnancy and after their baby was born, around one in four did not.

Parents in MICs were less likely to report respectful care than those in HICs. This gap reduced with increasing age, correlating with studies suggesting greater respect for older mothers in some LMICs (low- and middle- income countries).[25–27] Additionally gaps between respectful care in MICs and HICs were wider among parents whose baby was stillborn more recently, suggesting possible improvements in HICs unmatched by MICs.[4]

Previous assessments of respectful maternity care, not specific to stillbirth, estimate 15-98% of women in LMICs experience disrespect and abuse.[28] Despite difficulties with comparison due to study designs, locations, populations and highly diverse results, estimates of disrespectful care from this study are higher than some estimates of RMC not specific to stillbirth.

Several other factors were associated with reported respectful care: attainment of postgraduate degree, gestational age >30 weeks, stillbirth occurring within 5 years, and primiparity. Parents with postgraduate degrees reported more respectful care than those in other educational groups. This could be attributable to differential treatment of less well-educated parents,[29] or to highly educated parents with high health literacy accessing different service providers or expecting, and demanding, better care.

Parents of very preterm babies reported less respectful care. A similar association between gestational age and disrespect has been seen for small and sick neonates.[30] In previous studies, this lack of respect was attributed to providers

fatalism and feelings of incapability. In the context of stillbirth, different stillbirth causes and care options at lower gestational ages may compound this.[31]

Parents who experienced stillbirth more than 5 years before the survey reported less respectful care than those with recent stillbirths, which may imply improvements. However, selection bias necessitates cautious interpretation. Parents were recruited through the ISA network and ongoing engagement may be due to particularly negative experiences, inspiring involvement with support and advocacy work.

Regarding provision of the 7 aspects of care quality, parents were least satisfied with feeling that their concerns were taken seriously during pregnancy, being given adequate information, and having sufficient time with providers after birth. Providers may feel unprepared to broach information around stillbirth, as described with other instances of discussing difficult topics with patients.[32–34] Difficulties with ensuring sufficient contact time were reflected in a 2016 qualitative evidence synthesis which found parents valued “privacy not abandonment” and care providers recognized their availability as a challenge in providing high-quality care.[11]

For most aspects of care quality, parents were less satisfied with their care after their baby was born than during pregnancy. However, as responses were gathered retrospectively, this difference may be influenced by changes in emotions or expectations.

Parents in Latin America, the Caribbean, and Southern Europe reported lower care quality than those in other geographical regions. Limited resources may have influenced lower care quality, but is unlikely to account fully for the differences reported. More research is needed to understand how parents’, healthcare providers’ and community members’ cultural perceptions of stillbirth relate to specific respectful care practices.

Care practices around stillbirth

The importance and potential positive impacts for parents supported to engage with their baby after stillbirth through various care practices has been well documented.[10,14,15,35]

In this study, unmet need for most care practices was reported by more than 10% of parents. Parental desire for each practice was similar between country income groups, but unmet need was consistently much higher in MICs.

While provision of memory-making activities (for example photography) was high in HICs, this was the largest unmet need in MICs. Whilst some difference can be attributed to financial barriers, other practices (such as creating footprints) are relatively low-cost and lack of access suggests other barriers, such as lack of awareness or limited training of health-care workers or hospital administrators.

Most parents were not offered the opportunity to take their baby home, but many reported they would have liked to. This may reflect strongly embedded cultural and religious beliefs and practices and barriers, such as availability of cold cots, legal restrictions, attitudinal barriers and stigma. More research is needed in this area.

Strengths and limitations

This study's predominant strength was data collection via online survey, allowing sampling of large numbers of parents from diverse geographical contexts in an anonymous format but those with fewer resources were more likely to be excluded. Parents from MICs were underrepresented and parent participation in MICs is likely to be skewed towards more advantaged groups whose experiences of care may differ from less advantaged groups. Similarly, the broad array of issues included the survey reflect the cultural perspectives of the researchers and also gave limited opportunity to explore respectful care in more detail.

Recruitment through the ISA network may have meant parents with particularly negative experiences are over-represented. The study population was highly educated; 71.7% of respondents completed tertiary education, compared with 34.6% of adults aged 25-54 in Europe.[36] Conversely, since our study found that parents with higher education reported more respectful care, we may have underestimated the proportion of parents experiencing disrespectful care. Currently, in this under-researched area, no reliable measures of clinician behaviour exist, so studies are dependent on parents' perceptions and associated challenges with participation. Nevertheless, the survey questions were derived from the literature, there was a large multi-country sample, and a high degree of consistency in the findings.

Fathers were included, but represented a small portion of respondents, limiting subgroup analyses. It is possible that parents may have influenced each other's responses. The survey also did not solicit perspectives from other family members. As parents could decline any question, there were variable levels of missing data across questions, however limited to <10% throughout.

Recommendations

This study represents a preliminary analysis of respectful care during pregnancy and after stillbirth. By demonstrating high unmet needs, some actions can be taken immediately, while further research is ongoing. There is a clear need for urgent action to eliminate disrespectful care of parents globally and raise awareness of stigma, bias, and disrespect around stillbirth. Actions such as offering simple memory-making activities (for example creating footprints) and ensuring babies are consistently called by their chosen name can be implemented immediately.

System-level changes are required to ensure providers can spend sufficient time with parents. Provider training must be developed and implemented, particularly focused

on communication; for example, balancing reassurance with taking concerns seriously, and ensuring adequate support and information is provided to parents.

This study identifies a clear gap between parents' experiences in care quality and memory-making activities in MICs and HICs, and further qualitative research is essential to understanding practical, cultural, and attitudinal causes and how these can be overcome.

Conclusion

Disrespectful care was reported by 25% of parents. Higher levels of disrespectful care and unmet need was reported by parents in some geographical areas, including Southern Europe, suggesting potential systematic differences in care practices and attitudes. While the desire for memory-making activities in MICs was similar to HICs, the unmet need was far higher, including activities with little or no associated cost.

Provider training, and system-level support to address practical barriers must be undertaken to ensure that globally, all parents and all stillborn infants, receive high-quality, compassionate, and respectful care.

Acronyms

ANC	Antenatal care
aOR	Adjusted odds ratio
CI	Confidence interval
ENAP	Every Newborn Action Plan
HIC	High-income country
ISA	International Stillbirth Alliance
LMIC	Low- or middle-income country
MIC	Middle-income country
OR	Odds ratio
RMC	Respectful Maternity Care
WHO	World Health Organization

Acknowledgements

We would like to thank the International Stillbirth Alliance for their assistance with survey design and distribution, and Professor Robin Bailey for his encouragement and advice.

Disclosure of Interests

The authors declare no competing interests.

Contribution to authorship

The survey design and data collection were completed separately to this analysis. This study design was planned by BA, with input from HB, FB, ES, DH and VF. The data analysis was undertaken by BA with guidance from HB. The first draft was written by BA, with comments and editing from all co-authors. All authors reviewed and approved the final version.

Details of ethics approval

Ethical approval for the survey was granted by the Mater Health Services Human Research Ethics Committee (reference no. HREC/13/MHS/121).

Funding

Funding was through the Centre of Research Excellence in Stillbirth (Stillbirth CRE) at the Mater Research Institute, The University of Queensland, Australia. Core funding to support the Stillbirth CRE is provided by the National Health and Medical Research Council (NHMRC).

References

1. Tunçalp, Were WM, Maclennan C, Oladapo OT, Gülmezoglu AM, Bahl R, et al. Quality of care for pregnant women and newborns - The WHO vision. BJOG An Int J Obstet Gynaecol [Internet]. 2015 Jul 1 [cited 2020 Sep 7];122(8):1045–9. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5029576/

2. You D, Hug L, Mishra A, Blencowe H, Moran A. A Neglected Tragedy The global burden of stillbirths Report of the UN Inter-agency Group for Child Mortality Estimation, 2020 [Internet]. New York ; 2020 Oct [cited 2021 Mar 26]. Available from: https://www.unicef.org/media/84851/file/UN-IGME-the-global-burden-of-stillbirths-2020.pdf

3. 2018 Progress Report: Reaching Every Newborn National 2020 Milestones [Internet]. 2018 Mar [cited 2020 Sep 1]. Available from: https://www.healthynewbornnetwork.org/hnn-content/uploads/Final-Country-Progress-Report-v9-low-res.pdf

4. Frederik Frøen J, Friberg IK, Lawn JE, Bhutta ZA, Pattinson RC, Allanson ER, et al. Stillbirths: Progress and unfinished business [Internet]. Vol. 387, The Lancet. Lancet Publishing Group; 2016 [cited 2020 Sep 1]. p. 574–86. Available from: http://livessavedtool.org

5. Lawn JE, Blencowe H, Waiswa P, Amouzou A, Mathers C, Hogan D, et al. Stillbirths: Rates, risk factors, and acceleration towards 2030 [Internet]. Vol. 387, The Lancet. Lancet Publishing Group; 2016 [cited 2020 Aug 24]. p. 587–603. Available from: http://dx.doi.org/10.1016/

6. Shakibazadeh E, Namadian M, Bohren M, Vogel J, Rashidian A, Nogueira Pileggi V, et al. Respectful care during childbirth in health facilities globally: a

qualitative evidence synthesis. BJOG An Int J Obstet Gynaecol [Internet]. 2018 Jul 1 [cited 2020 Jun 17];125(8):932–42. Available from: http://doi.wiley.com/10.1111/1471-0528.15015

7. Respectful Maternity Care Charter: The Universal Rights of Women & Newborns, Respectful Maternity Care [Internet]. 2019 [cited 2020 Jun 17]. Available from: https://www.whiteribbonalliance.org/wp-content/uploads/2019/10/WRA_RMC_Charter_FINAL.pdf?eType=EmailBlastContent&eId=44444444-4444-4444-4444-444444444444

8. WHO recommendation on respectful maternity care during labour and childbirth | RHL [Internet]. 2018 Feb [cited 2020 Sep 1]. Available from: https://extranet.who.int/rhl/topics/preconception-pregnancy-childbirth-and-postpartum-care/care-during-childbirth/who-recommendation-respectful-maternity-care-during-labour-and-childbirth

9. Afulani PA, Buback L, McNally B, Mbuyita S, Mwanyika-Sando M, Peca E. A rapid review of available evidence to inform indicators for routine monitoring and evaluation of respectful maternity care. Vol. 8, Global Health Science and Practice. Johns Hopkins University Press; 2020. p. 125–35.

10. Heazell AEP, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. Stillbirths: Economic and psychosocial consequences [Internet]. Vol. 387, The Lancet. Lancet Publishing Group; 2016 [cited 2020 Sep 1]. p. 604–16. Available from: http://dx.doi.org/10.1016/

11. Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, et al. Systematic review to understand and improve care after stillbirth: A review of parents' and healthcare professionals' experiences. BMC Pregnancy Childbirth [Internet]. 2016 Jan 25 [cited 2020 Apr 20];16(1):16. Available from:

http://www.biomedcentral.com/1471-2393/16/16

12. Shakespeare C, Merriel A, Bakhbakhi D, Baneszova R, Barnard K, Lynch M, et al. Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary. BJOG An Int J Obstet Gynaecol [Internet]. 2019 Jan 17 [cited 2020 Apr 13];126(1):12–21. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1111/1471-0528.15430

13. Shakespeare C, Merriel A, Bakhbakhi D, Blencowe H, Boyle FM, Flenady V, et al. The RESPECT Study for consensus on global bereavement care after stillbirth. Int J Gynecol Obstet [Internet]. 2020 May 26 [cited 2020 Sep 1];149(2):137–47. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/ijgo.13110

14. Furtado-Eraso S, Escalada-Hernández P, Marín-Fernández B. Integrative Review of Emotional Care Following Perinatal Loss: https://doi.org/101177/0193945920954448 [Internet]. 2020 Sep 4 [cited 2021 Oct 14];43(5):489–504. Available from: https://journals.sagepub.com/doi/abs/10.1177/0193945920954448

15. Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelöv E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. Midwifery. 2009 Aug 1;25(4):422–9.

16. Member Organizations - International Stillbirth Alliance [Internet]. [cited 2020 Sep 14]. Available from: https://www.stillbirthalliance.org/member-organizations/

17. Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al. Stillbirths: recall to action in high-income countries. Lancet [Internet]. 2016

[cited 2020 Apr 21];387:691. Available from: http://dx.doi.org/10.1016/

18. Wojcieszek AM, Boyle FM, Belizán JM, Cassidy J, Cassidy P, Erwich JJHM, et al. Care in subsequent pregnancies following stillbirth: an international survey of parents. BJOG An Int J Obstet Gynaecol. 2018 Jan 1;125(2):193–201.

19. Horey D, Boyle F, Cassidy J, Cassidy P, Erwich J, Gold K, et al. Parents' experiences of care offered after stillbirth: An international online survey of high and middle-income countries. Birth [Internet]. 2021 Sep 1 [cited 2021 Aug 30];48(3):366–74. Available from: https://pubmed.ncbi.nlm.nih.gov/33738843/

20. Making every baby count: Audit and review of stillbirths and neonatal deaths [Internet]. Geneva; 2016 Sep [cited 2020 Sep 14]. Available from: https://www.who.int/publications/i/item/9789241511223

21. Hoyert DL, Gregory ECW. National Vital Statistics Reports Volume 65, Number 7 October 31, 2016 Cause of Fetal Death: Data From the Fetal Death Report, 2014. Vol. 65, National Vital Statistics Reports. 2014.

22. Small R, Roth C, Raval M, Shafiei T, Korfker D, Heaman M, et al. Immigrant and non-immigrant women's experiences of maternity care: A systematic and comparative review of studies in five countries. BMC Pregnancy Childbirth [Internet]. 2014 Apr 29 [cited 2020 Jul 2];14(1):152. Available from: http://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-14-152

23. World Bank Country and Lending Groups – World Bank Data Help Desk [Internet]. The World Bank. 2020 [cited 2020 Sep 1]. Available from: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519

24. Standard country or area codes for statistical use (M49) [Internet]. United

Nations, Department of Economic and Social Affairs, Statistics Division. 2020 [cited 2020 Sep 1]. Available from: https://unstats.un.org/unsd/methodology/m49/

25. Bohren MA, Mehrtash H, Fawole B, Maung TM, Balde MD, Maya E, et al. How women are treated during facility-based childbirth in four countries: a cross-sectional study with labour observations and community-based surveys. Lancet [Internet]. 2019 Nov 9 [cited 2020 Sep 4];394(10210):1750–63. Available from: https://doi.org/10.1016/

26. Pathak P, Ghimire B. Perception of Women regarding Respectful Maternity Care during Facility-Based Childbirth. Obstet Gynecol Int. 2020;2020.

27. Kabo JW, Holroyd E, Edwards G, Sarki AM. Sociodemographic factors associated with mothers' experiences of psychosocial care and communication by midwives during childbirth in Nairobi, Kenya. Int J Africa Nurs Sci. 2019 Jan 1;11:100164.

28. Sando D, Abuya T, Asefa A, Banks KP, Freedman LP, Kujawski S, et al. Methods used in prevalence studies of disrespect and abuse during facility based childbirth: Lessons learned Prof. Suellen Miller [Internet]. Vol. 14, Reproductive Health. BioMed Central Ltd.; 2017 [cited 2020 Sep 23]. p. 127. Available from: https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-017-0389-z

29. Blanchard J, Lurie N. R-E-S-P-E-C-T: Patient reports of disrespect in the health care setting and its impact on care. J Fam Pract. 2004 Sep;53(9).

30. Waiswa P, Nyanzi S, Namusoko-Kalungi S, Peterson S, Tomson G, Pariyo GW. I never thought that this baby would survive; I thought that it would die any time: Perceptions and care for preterm babies in eastern Uganda. Trop

Med Int Heal [Internet]. 2010 Oct [cited 2020 Sep 4];15(10):1140–7. Available from: https://pubmed.ncbi.nlm.nih.gov/20723185/

31. Stormdal Bring H, Hulthén Varli I, Kublickas M, Papadogiannakis N, Pettersson K. Causes of stillbirth at different gestational ages in singleton pregnancies. Acta Obstet Gynecol Scand [Internet]. 2014 Jan [cited 2021 Oct 25];93(1):86–92. Available from: https://pubmed.ncbi.nlm.nih.gov/24117104/

32. Luz R, George A, Spitz E, Vieux R. Breaking bad news in prenatal medicine: a literature review. Vol. 35, Journal of Reproductive and Infant Psychology. Routledge; 2017. p. 14–31.

33. Gold KJ. Navigating care after a baby dies: A systematic review of parent experiences with health providers [Internet]. Vol. 27, Journal of Perinatology. Nature Publishing Group; 2007 [cited 2020 Aug 21]. p. 230–7. Available from: www.nature.com/jp

34. Warland J, Glover P. Talking to pregnant women about stillbirth. BMC Pregnancy Childbirth [Internet]. 2015 Dec 15 [cited 2020 Sep 18];15(S1):12. Available from: http://www.biomedcentral.com/1471-2393/15/S1/A12

35. Erlandsson K, Warland J, Cacciatore J, Rådestad I. Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth—Findings from an online questionnaire. Midwifery. 2013 Mar 1;29(3):246–50.

36. Eurostat - Data Explorer [Internet]. European Statistical Office of the European Union. 2020 [cited 2020 Sep 1]. Available from: https://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do

Table S1. Association between individual variables and likelihood of parents reporting respectful care after stillbirth

		Number of parents (%)	Number reporting respectful care (%)*	Likelihood of reporting respectful care (OR, 95% CI)	P-value**
Overall N=3769		3769	2813 (74.6)		
Age at survey completion (years) N=3769	Less than 24	220 (5.2)	142 (64.6)	1.0 (reference)	<0.01
	25-29	564 (15.0)	403 (71.5)	1.37 (0.97 – 1.92)	
	30-34	1056 (28.1)	830 (78.6)	2.01 (1.47 – 2.77)	
	35-39	1005 (26.7)	765 (76.1)	1.75 (1.28 – 2.40)	
	40-44	581 (15.4)	432 (74.4)	1.59 (1.14 – 2.23)	
	45 years or older	339 (9.0)	237 (69.9)	1.28 (0.89 – 1.83)	
Education status N=3707	Secondary school or lower	1051 (28.4)	750 (71.4)	1.0 (reference)	<0.01
	Undergraduate or college degree	1763 (47.6)	1309 (64.3)	1.16 (0.98 – 1.37)	
	Postgraduate degree	646 (17.4)	525 (81.3)	1.74 (1.37 – 2.21)	
	Vocational training	247 (6.7)	189 (76.5)	1.31 (0.95 – 1.81)	
Time since stillbirth N=3764	<5 years	2708 (71.9)	2081 (76.9)	1.0 (reference)	<0.01
	≥5 years	1056 (28.1)	729 (69.0)	0.67 (0.57 – 0.79)	
Gestational age at time of stillbirth N=3769	20-29 weeks	1355 (36.0)	950 (70.1)	1.0 (reference)	<0.01
	30-37 weeks	1140 (30.3)	881 (77.3)	1.45 (1.21 – 1.74)	
	≥38 weeks	1274 (33.8)	982 (77.1)	1.43 (1.20-1.70)	
Relationship to baby N=3769	Mother	3639 (96.6)	2714 (74.6)	1.0 (reference)	0.69
	Father	130 (3.5)	99 (76.2)	1.09 (0.72 – 1.64)	
Previous death of a child (includes miscarriage or stillbirth) N=3754	No prior children	762 (20.3)	606 (79.7)	1.0 (reference)	<0.01
	Prior children, no child death	2244 (59.8)	1643 (73.2)	0.70 (0.58-0.86)	
	Prior children, prior child death	748 (19.9)	555 (74.2)	0.74 (0.58-0.94)	
Attended bereavement support group? N= 3734	No	2385 (63.9)	1763 (73.9)	1.0 (reference)	0.14
	Yes	1349 (36.1)	1027 (76.1)	1.12 (0.96-1.31)	

*Parents who reported that care was "kind and respectful" always or most of the time after their baby was stillborn **Chi-squared test of homogeneity of odds ratios

Table 2. Parents' perspectives of the quality of care before and after their baby was stillborn (all respondents)

	Time period	Quality care provided* (n, %)	Likelihood of reporting high-quality care (OR, 95% CI)	P-value**
1. Providers gave adequate information N= 3751	During pregnancy	**2478 (66.1)**	**1.0**	**<0.01**
	After stillbirth	**2041 (54.4)**	**0.47 (0.41-0.53)**	
2. Providers spent enough time with parents N= 3746	During pregnancy	**2177 (58.1)**	**1.0**	**<0.01**
	After stillbirth	**1974 (52.7)**	**0.70 (0.62-0.79)**	
3. Parents felt involved in decision-making N=3740	During pregnancy	**2444 (65.4)**	**1.0**	**<0.01**
	After stillbirth	**2177 (58.2)**	**0.62 (0.55-0.70)**	
4. Providers talked to parents in an understandable way N=3742	During pregnancy	**2924 (78.1)**	**1.0**	**<0.01**
	After stillbirth	**2537 (67.8)**	**0.37 (0.32–0.44)**	
5. Providers listened to parents N= 3740	During pregnancy	**2299 (61.5)**	**1.0**	**0.15**
	After stillbirth	**2251 (60.2)**	**0.91 (0.81–1.03)**	
6. Parents concerns were taken seriously by providers N= 3729	During pregnancy	**2055 (55.1)**	**1.0**	**<0.01**
	After stillbirth	**2221 (59.6)**	**1.39 (1.22- 1.58)**	
7. Parents were treated with kindness and respect	During pregnancy	**2832 (75.8)**	**1.0**	**0.11**
	After stillbirth	**2789 (74.7)**	**0.88 (0.76– 1.03)**	

N=3736	

*Provided “always” or “most of the time” **McNemar’s chi-square test

Figure S1. Parents' experiences of 7 aspects of care quality after stillbirth, by geographical region

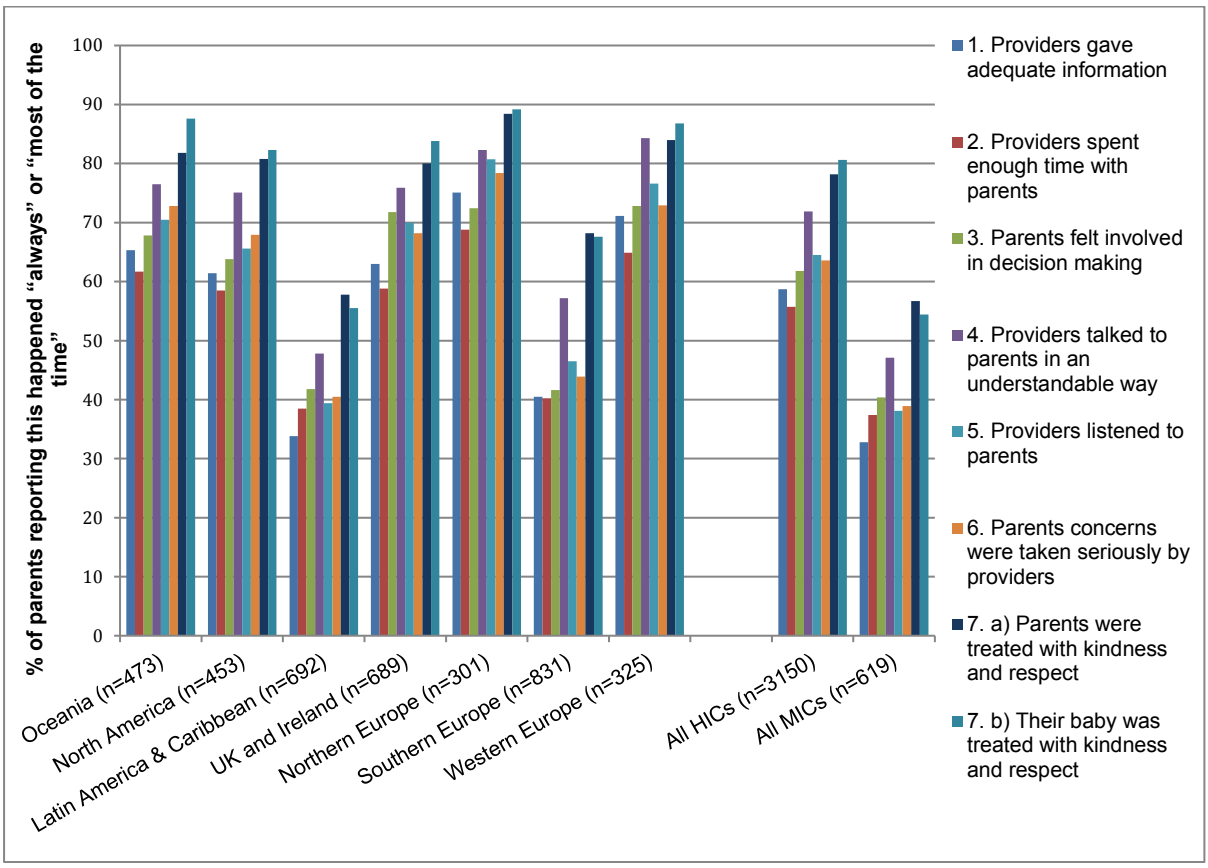

Figure 2. Care practices after stillbirth: parents' desires and unmet needs.