

Care in subsequent pregnancies following stillbirth: An international survey of parents

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Running title: Subsequent pregnancies following stillbirth

Abstract

Objective: To assess the frequency of additional care, and parents' perceptions of quality, respectful care in pregnancies subsequent to stillbirth.

Design: Multi-language web-based survey

Setting: International

Population: 2,716 parents, from 40 high- and middle-income countries

Methods: Data were obtained from a broader survey of parents' experiences of stillbirth. Data were analyzed using descriptive statistics and stratified by geographical region. Subgroup analyses explored variation in additional care by gestational age at index stillbirth.

Main outcome measures: Frequency of additional care, and perceptions of quality, respectful care.

Results: The majority (66%) of parents conceived their subsequent pregnancy within one year of stillbirth. Additional antenatal care visits and ultrasound scans were provided for 67% and 70% of all parents, respectively, although there was wide variation across geographical regions. Care addressing psychosocial needs was less frequently provided, such as visits to a bereavement counsellor (10%) and access to named care provider's phone number (27%). Compared to parents whose stillbirth occurred at 29 weeks' gestation or less, parents whose stillbirth occurred at 30 weeks' gestation or greater were more likely to receive various forms of additional care, particularly the option for early delivery after 37 weeks. Around half (47-63%) of all parents felt that elements of quality, respectful care were consistently applied, such as spending enough time with parents and involving parents in decision-making.

Conclusions: Greater attention is required to providing thoughtful, empathic, and collaborative care in all pregnancies following stillbirth, irrespective of gestational age. Specific education and training for health professionals is needed.

Keywords: Stillbirth; subsequent pregnancy; management; recurrence; psychosocial/psychology; epidemiology

Tweetable abstract: More support for providing quality care in pregnancies after stillbirth is needed.

Introduction

Globally, around 2.6 million third-trimester stillbirths occur every year (1). These deaths are associated with enduring psychosocial and economic consequences (2-4). The risk of stillbirth and other related pregnancy complications (5) is increased for parents who have had a previous stillbirth; a recent systematic review including over three million women showed an almost five-fold increased risk of stillbirth among women in high-income countries with a previous stillbirth from any cause (6).

There is currently little evidence to guide clinical management of pregnancies subsequent to stillbirth (7-10). Women often want increased antepartum surveillance and early birth in these pregnancies (11), but in most cases the medical benefits of such practices remain uncertain. In addition to recurrent stillbirth, previous stillbirth is associated with various adverse pregnancy outcomes (5, 12, 13), some of which may be iatrogenic (14). In one study, increased surveillance and early birth were commonly recommended by obstetricians for pregnancies subsequent to unexplained stillbirth, regardless of the presence or absence of (other) obstetric risk factors (14). The Royal College of Obstetricians and Gynecologists recommends that decisions for scheduled birth following unexplained stillbirth consider the gestational age of the previous stillbirth, previous intrapartum history, and the safety of induction of labor (15). Similarly, the American College of Obstetricians and Gynecologists encourages clinicians to balance the benefits of early delivery with its potential risks to mothers and babies (10).

In addition to specialized clinical care subsequent to stillbirth, it is critical to address parents' unique psychosocial needs. Pregnancies subsequent to perinatal death are often characterized by intense anxiety, fear, and other complex emotional responses (2, 4, 16). Many women doubt their capacity to maintain a healthy pregnancy, and some may refrain from attachment to their baby as a coping mechanism (2, 4, 16). Indeed, disorganized attachment is more common among infants born subsequent to stillbirth (17), and this may have extended adverse consequences for families.

It is clear that, in pregnancies after stillbirth, expectant parents require specialized clinical care and emotional support. The aim of this study was to assess the frequency with which additional clinical care and psychosocial support was provided in pregnancies subsequent to stillbirth, and to assess parents' perceptions of the extent to which they received quality, respectful care. We also explored whether provision of additional care in subsequent pregnancies differed depending on the gestation of the previous (hereafter 'index') stillbirth.

Methods

Data collection involved a large-scale, multi-language web-based survey of bereaved parents developed as part of *The Lancet* series on Ending Preventable Stillbirths (see Flenady et al. (18) for detailed methods). A section of the survey was devoted to care during pregnancies subsequent to stillbirth, which was made available to parents who responded 'Yes' to '*Have you had another pregnancy since your baby was stillborn?*' Categorical items assessed obstetric characteristics of the subsequent pregnancy, provision of additional care in the subsequent pregnancy, and perceptions of quality, respectful care in pregnancies subsequent to stillbirth (see subheadings below). Additional open-ended items assessed parents' perceptions on the most important aspects of care in their subsequent pregnancy and how their care could have been improved (not reported in this manuscript). Parents who had had more than one subsequent pregnancy after stillbirth were asked to answer questions with regard to their first subsequent pregnancy. Because of the recruitment method adopted in this study, we could not determine the total number of parents who received a survey invitation (the denominator), and therefore the overall response rate.

Provision of additional care

Parents were asked via one categorical item whether they received any additional care (beyond standard antenatal care in their setting) in their subsequent pregnancy. Response options included additional antenatal care (ANC) visits; additional ultrasound scans (USS); the option for early (scheduled) delivery after 37 weeks' gestation; emergency room visits; visits to a bereavement

counsellor; provision of a named care provider's phone number; and specialist antenatal classes for bereaved parents. Parents could select all options that applied, along with an 'other' option with space for free-text. 'Unsure' and 'I prefer not to answer' response options also were provided. Google Translate software was used to translate non-English responses to the 'other' additional care response option, and translations were checked for accuracy and edited where required by co-authors or other volunteers. Responses were coded in SPSS V22 (Version 22, IBM, NY, USA).

Provision of quality, respectful care

Seven items measuring quality, respectful care were developed with reference to criteria defined by Small and colleagues (19). Items were measured on a four-point categorical scale ('Never' / 'Some of the time' / 'Most of the time' / 'Always'). An 'I prefer not to answer' response option was also provided.

Statistical analyses

Demographic data, provision of additional care, and perceptions of quality, respectful care were assessed using descriptive statistics expressed as frequencies and proportions. To explore trends in care according to geographical location, outcome data were stratified by geographical region. Subgroup differences in provision of additional care by gestation at index stillbirth were assessed across the study sample using chi-square tests with 2x2 contingency tables. Gestation at index stillbirth was dichotomized into 29 weeks' gestation or less versus 30 weeks' gestation or more. This cut-off was chosen to approximate the distinction between early and late/third-trimester stillbirth. We report the corresponding Pearson chi-square value with continuity correction for 2x2 tables and statistical significance set at $p < 0.05$. Effect sizes for significant results were reported using the Phi coefficient. Magnitude of effect sizes were described according to the conventions in Pallant (2013) (20). All analyses were performed in SPSS V22 (Version 22, IBM, NY, USA).

Results

Characteristics of parents

Of the 4,182 parents included in the broader survey, 2,716 parents indicated that they had had a subsequent pregnancy (female = 2,507; male = 204; gender not stated = 5).¹ Table 1 presents demographic characteristics of these 2,716 parents. A breakdown of responses by geographical region and country is presented in Table S1. Parents were most commonly aged 30-39 years (55%), had an undergraduate/college degree (45%), and were employed full-time (44%). For the majority of parents, the index stillbirth occurred in the antepartum period (74%) and within three or more years of survey completion (65%). Index stillbirths occurred most commonly at 35-40 weeks' gestation. Around half of parents (55%) reported that an autopsy/post-mortem examination was performed on their stillborn baby. Of these 1,504 parents, half reported having received some kind of information about the examination results (data not shown), though the survey did not probe further as to what information was received.

Most (66%) parents conceived their subsequent pregnancy within one year following stillbirth. The most common outcome of subsequent pregnancies was a live birth (67%), followed by miscarriage (16%). Around 12% of all parents were still pregnant at the time of survey completion.

Approximately 3% of parents had a recurrent stillbirth. The majority (88%) of parents resided in high-income countries, with the remainder residing in middle-income countries (Table S1). The majority of middle-income countries were represented in the Latin America regional grouping (Table S1).

[Insert Table 1]

Provision of additional care

Table 2 shows provision of additional care in subsequent pregnancies overall and by geographical region. The majority (67%) of all parents had additional ANC visits, ranging from 54% in Southern Europe to 78% in the UK and Ireland. The majority (70%) also had additional USS, ranging from 51%

¹ For detail on responses received for the broader survey of parents, see Flenady et al. (18)

in Southern Europe to 90% in Northern Europe. Around 37% of parents were offered early delivery after 37 weeks' gestation, ranging from 16% in Latin America to 59% in Northern Europe. The provision of additional visits to a bereavement counsellor ranged from 6-22%, while the provision of a named care provider's phone number ranged from 18-36%. Specialist antenatal classes for bereaved parents were uncommon in all regions (1-8%), and particularly Western Europe (1%). No additional care was provided to 15% of parents overall, most frequently in Southern Europe (24%). Overall, 6% of parents reported receiving 'other' additional care, including delivery at or before 37 weeks, additional testing or monitoring, and specialist referrals (see Table 2). Provision of these 'other' forms of care ranged from 2% in Latin America to 13% in North America. Two respondents used the 'other' additional care item to indicate that while they did not want any additional care, it had been made available to them (e.g. additional USS).

[Insert Table 2]

Subgroup analyses of additional care by gestation at index stillbirth

Six parents did not provide data on gestation at index stillbirth, resulting in a sample size of 2,710 for subgroup analyses. Table 3 presents chi-square and p values with corresponding effect sizes for each analysis. Compared to parents whose index stillbirth occurred at 29 weeks' gestation or less, additional ANC visits and USS were significantly more frequent among parents whose index stillbirth occurred at 30 weeks' gestation or greater ($p < .001$). Both results showed small to medium effect sizes (see Table 3). Additional visits to a bereavement counsellor, provision of a named care provider's phone number, and specialist antenatal classes were also more frequent among parents whose index stillbirth occurred at 30 weeks' gestation or greater compared to 29 weeks' gestation or less, showing small effect sizes. The option for early delivery after 37 weeks' gestation was more likely when the index stillbirth occurred at 30 weeks' gestation or greater compared to 29 weeks' gestation or less ($p < .001$), showing a medium to large effect size. Lack of additional care was more likely when the index stillbirth occurred at 29 weeks or less, showing a small to medium effect size.

There was no difference in visits to the emergency room according to gestation at index stillbirth ($p = .225$).

[Insert Table 3]

Provision of quality, respectful care

Across the study sample, elements of quality, respectful care most consistently carried out were treating parents with kindness and respect, and talking to parents in a way they could understand, both reported to have ‘always’ occurred by 63% and 60% of parents, respectively (see Table 4). Around 53% of all parents ‘always’ felt listened to, ranging from 43% in Southern Europe to 69% in North America, while 53% felt their concerns were ‘always’ taken seriously, ranging from 42% in Southern Europe to 65% in North America. Just over half (51%) of parents felt they were ‘always’ involved in decision-making about their care, most commonly in North America (66%) and least commonly in Southern Europe (41%). Around half (48%) of parents were ‘always’ given the information they needed, ranging from 41% in Southern Europe to 61% in North America. Spending enough time with parents was the least consistently applied aspect, which ‘always’ occurred according to 47% of all parents.

[Insert Table 4]

Discussion

Main findings

The majority of parents conceived their subsequent pregnancy within one year following stillbirth. Increased antepartum surveillance in subsequent pregnancies, particularly additional USS, was common, although there was variation across geographical regions. Care specifically addressing psychosocial needs was less common across all regions. Compared to parents whose index stillbirth occurred at 29 weeks’ gestation or less, parents whose index stillbirth occurred at 30 weeks’ gestation or greater were more likely to have various forms of additional care, particularly the option for early delivery after 37 weeks. Only roughly half of all parents felt that elements of quality,

respectful care were applied consistently. The greatest opportunities for improvement across all regions related to listening to and spending time with parents, providing information, involving parents in decision-making, and taking parents' concerns seriously.

Strengths and limitations

This study is strengthened by the large international sample, allowing capture of data from multiple geographical regions. The use of a multi-language survey further enhanced our capacity to gain an "international picture" of care. However, participating parents were largely recruited through charity and support groups in high-income countries. Our sample consequently over-represented highly-educated men and women, those with the means and willingness to respond to a web-based survey. It is possible that the findings over-estimate the level of compassionate care received by the broader population of parents, which would only reinforce the need for improvements in care. The survey sought to gain a comprehensive picture of parents' experiences while minimizing the burden placed on respondents and optimizing the quality of data obtained. For this reason, information was not collected about potentially important aspects of parents' experiences, including specific procedures performed, screening for depression, or cause of death for the index stillbirth, all of which might be expected to influence clinical care. Finally, our study is confined to the care experiences of those parents who had a subsequent pregnancy and did not identify or address the care of those who may have attempted but not achieved a new pregnancy.

Interpretation

The risk of stillbirth recurrence in the current study was 2.9%, which is similar to that reported in Lamont and colleagues' systematic review of stillbirth recurrence in high-income countries (2.5%) (6). Our findings around increased antepartum surveillance are also consistent with previous research (11, 14, 16, 21, 22), and are likely to reflect increased vigilance of both parents and care providers in pregnancies subsequent to stillbirth. However, while most parents received additional ANC visits and USS, far fewer received additional care specifically addressing psychosocial needs.

Specialist antenatal classes for bereaved parents were rarely provided, despite the benefits of group-based/peer antenatal support and education programs for parents who have experienced loss (16, 23). Unavailability of the necessary infrastructure, staff, and expertise, as well as competing demands on resources, may explain the relative rarity of these psychosocial aspects of care.

Dedicated clinical guidelines around care in pregnancies after stillbirth appear to be rare, as found in a recent survey of UK practice (22). According to the study, availability of such guidelines was limited and, where guidelines were available, these tended to concentrate on the prevention of stillbirth recurrence through antepartum surveillance rather than on parents' psychosocial wellbeing (22). In the RCOG stillbirth guideline psychosocial care is mentioned, albeit briefly (15). Clearly, more evidence had been needed as to how to provide quality, respectful care.

In our study, the greatest opportunities for improvement in providing quality, respectful care related to parents' perceptions of whether care providers listened to and spent enough time with them, provided information, involved them in decision-making, and took their concerns seriously. These aspects of care mirror those that enhance parents' emotional wellbeing in pregnancies subsequent to stillbirth or neonatal death (16). Active involvement in care and shared decision-making (24) are particularly valued, and may aid coping in these anxiety-laden pregnancies by enhancing self-confidence and feelings of control (25, 26). These elements of care also reflect good practice in bereavement care, where similar deficiencies in quality have been identified (2, 18, 27). Lack of time, lack of confidence, embarrassment, and lack of understanding of stillbirth among care providers are major barriers to providing quality bereavement care (27). These same barriers likely impact care in pregnancies after stillbirth. Therefore, as for bereavement care, training in communication skills and providing thoughtful, empathic, and collaborative care is undoubtedly needed for those providing care in subsequent pregnancies following stillbirth.

The majority of parents conceived their subsequent pregnancy within one year following stillbirth, and over one-third within five months. These data are consistent with previous studies (28-30), and may be explained by the overwhelming desire among many women to fulfil their reproductive

aspirations and expectations (4, 30). An interpregnancy interval of 15-24 months has been recommended (31) following stillbirth to reduce the risk of adverse outcomes, although evidence to support this recommendation is limited (31). Regardless of obstetric risks, women who conceive within one year of a stillbirth may have a higher risk of depression and anxiety in the subsequent pregnancy, whereas women who delay conception for one year may be at no higher risk than the general population (29). Conversely, delaying conception may bring added psychological burden to women struggling with feelings of 'emptiness' or having 'failed' (30, 32), while intensifying potential fears about age-related fertility decline (30, 33). Future research assessing the emotional impact of unwanted delays in conception will inform counselling efforts and assist care providers to offer balanced information to parents.

The current study showed that the option for early delivery after 37 weeks was significantly more common among parents whose index stillbirth occurred later in pregnancy compared to earlier in pregnancy. The inclination towards early delivery may be heightened at near term gestational ages (37-39 weeks) when the risk:benefit ratio becomes more favorable (34), and when approaching the gestational age at which the index stillbirth occurred. However, although of potential emotional benefit, the medical efficacy of early delivery remains unproven. Additional ANC visits and USS, additional visits to a bereavement counsellor, provision of care provider's phone number and specialist antenatal classes for bereaved parents were also more likely when the index stillbirth occurred at later gestations. It is therefore possible that both the impact of the previous loss and its perceived preventability, which may be thought by some to be greater for later gestation stillbirths, alters care pathways in subsequent pregnancies. Stillbirths occurring at earlier gestations are often associated with complications such as spontaneous preterm birth (35), which carry a substantial recurrence risk, but are difficult to prevent (36). Nonetheless, since stillbirth recurrence risk (35, 37) and parents' emotional needs in subsequent pregnancies are no less important for those who experienced stillbirth at lower gestations, such differential allocation of services does not seem

justified. Future research in care in subsequent pregnancies may shed more light on these findings and has been prioritized by bereaved parents and care providers (18, 38).

Conclusion

Greater attention is required to providing thoughtful, empathic, and collaborative care in all pregnancies following stillbirth, and irrespective of the gestational age of the previous stillborn baby. Formal training and clinical practice guidance for providing care in pregnancies subsequent to stillbirth is urgently needed, emphasizing emotional and psychological aspects of care in addition to obstetric management, and including education around recurrence risk according to gestational age at index stillbirth. The roles of specialist staff for providing care in pregnancies after stillbirth should be further explored.

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Disclosure of interests

To be completed

Contribution to authorship

AMW led the development and writing of the manuscript. AMW conducted data analyses. VF led the development of the survey instrument and methodology with AMW, FMB, JB, JC, PC, JJE, LF, MMG, AEPH, SHL, KP, CR, JR, DS, RMS, CS, AV, PM and DE. AMW coordinated the dissemination of the survey with contributions from FMB, JB, JC, PC, JJE, LF, MMG, AEPH, SHL, MM, KP, CR, JR, DS, RMS, CS and AV. AMW and SHL coordinated translations of the survey instrument with contributions from JB, JC, PC, JJE, MMG, CR and AV. PC, JC, JJE, MMG, CR and AV completed checking of translations for the 'other' additional care responses. TM contributed to the interpretation of findings. All authors reviewed and added input to the manuscript.

Details of ethics approval

This study was approved by the Mater Health Services Human Research Ethics Committee on 29th November 2013 (Ref #HREC/13/MHS/121), within the guidelines of the Australian National Statement on Ethical Conduct in Human Research, and by the University of British Columbia Office of

Research Services, Behavioral Research Ethics Board on 22nd December 2014 (Ref #H14-02784)
(Vancouver, Canada).

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