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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: Care in pregnancies subsequent to stillbirth appears inconsistent. Greater attention is required to providing thoughtful, empathic, and collaborative care in all pregnancies following stillbirth. Training for health professionals is needed.

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

Tweetable abstract: More support for providing quality, respectful care in all pregnancies after stillbirth is required.

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 (as defined by Small et al. (18)). 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. (19) 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.

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

Eight items measuring quality, respectful care were developed based on the QUICK mnemonic defined by Small and colleagues (18) (see online Appendix). This mnemonic captures components of quality care consistently identified as important to women in population studies of experiences of maternity care. 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

A total of 2,716 parents completed items about subsequent pregnancy care (female = 2507; male = 204; gender not stated = 5).[1] Table 1 presents demographic characteristics of parents. 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. Most (66%) parents conceived 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. The majority (88%) of parents resided in high-income countries, with the remainder residing in middle-income countries. The majority of middle-income countries were represented in the Latin America regional grouping.

[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% 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%). No additional care was provided to 15% of parents overall, most frequently in Southern Europe (24%). 2-13% of parents reported receiving

[1] For detail on responses received for the broader survey of parents, see Flenady et al. (19)

'other' additional care, including delivery at or before 37 weeks, additional testing or monitoring, and specialist referrals (see Table 2). 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 likely 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 likely 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, with the strongest effect seen for the option for early delivery after 37 weeks. Only roughly half of all parents felt that elements of quality, respectful care were applied consistently, with the greatest opportunities for improvement in Southern Europe. Specific areas for improvement 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, our findings are limited by the use of a convenience sample and potential for responder bias, given that parents who received poor(er) care may have been more likely to respond. Since the majority of respondents resided in high-income countries, our findings cannot be generalized to other income settings. Finally, the study is limited by a lack of data on the cause of death for the index stillbirth, which would be expected to have an impact on clinical care.

Interpretation

Our findings around increased antepartum surveillance are consistent with a recent metasynthesis on parents' experiences of care in pregnancies subsequent to perinatal loss (16), as well as research showing pregnant women with a history of perinatal loss access health services at a greater rate than women with no previous loss (21). The findings are also broadly consistent with research showing women want (11), and care providers commonly recommend (14, 15), increased antepartum surveillance in pregnancies subsequent to unexplained stillbirth. Taken together, these findings reflect increased vigilance of both parents and care providers in pregnancies subsequent to stillbirth.

While most parents had additional ANC visits and USS, far fewer had 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, 22). 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.

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, all of which consistently occurred according to only roughly half of all parents, and least often in Southern

Europe. 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 (23) are particularly valued, and may aid coping in these anxiety-laden pregnancies by enhancing self-confidence and feelings of control (24, 25). These elements of care also reflect good practice in bereavement care, where similar deficiencies in quality have been identified (2, 19, 26). Lack of time, lack of confidence, embarrassment, and lack of understanding of stillbirth among care providers are major barriers to providing quality bereavement care (26). 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. Short interpregnancy intervals have been noted elsewhere (27-29), and may be explained by the overwhelming desire among many women to fulfil their reproductive aspirations and expectations (4, 29). An interpregnancy interval of 15-24 months has been recommended (30) following stillbirth to reduce the risk of adverse outcomes, although evidence to support this recommendation is limited (30). 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 (28). Conversely, delaying conception may bring added psychological burden to women struggling with feelings of 'emptiness' or having 'failed' (29), while intensifying potential fears about age-related fertility decline (29, 31). The timing of conception after stillbirth is therefore a highly personal decision. Parents can be supported to make this decision by being offered information about the risks and benefits of delaying conception in their unique circumstances, given their values and needs (29). 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 (32), 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. These results should nonetheless be interpreted with caution due to smaller magnitudes of effect. It is 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 (33), which carry a substantial recurrence risk, but are difficult to prevent (34). Nonetheless, since stillbirth recurrence risk (35) 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 (19, 36).

Conclusion

This study suggests that while increased pregnancy surveillance is typically common in pregnancies subsequent to stillbirth, additional forms of care specifically addressing parents' psychosocial needs are less frequently provided, and there is variation across geographical regions. Greater attention is required to providing thoughtful, empathic, and collaborative care in all pregnancies following stillbirth. Care must balance the risks of stillbirth recurrence with the risks of adverse iatrogenic

outcomes for mothers and babies. Training for health professionals providing care in pregnancies subsequent to stillbirth is needed.

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Disclosure of interests

The authors declare no competing interests.

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, within the guidelines of the Australian National Statement on Ethical Conduct in Human Research, and the

University of British Columbia Office of Research Services, Behavioral Research Ethics Board. (Vancouver, Canada).

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