



Genomic Bereavement Care for Pregnancy Loss: A modified Delphi study

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Introduction

25% of pregnancies end in loss and it is thought that 50% of early losses are due to aneuploidy, with a proportion of others being due to genetic changes. Bereavement care is a cornerstone to obstetric and midwifery practice and as the new genomic era approaches, how should patients and families be best supported when they suffer a pregnancy loss with a likely genomic cause.

Objectives and Design

To generate consensus on the care offered to families who suffer pregnancy loss where there is a likely underlying genetic cause.

Methodology chosen to provide anonymity to participants as well as reduce bias from group interaction..

The outcome measure was >80% agreement for a statement to meet consensus.

Results

Participants in each round

	Clinician (FM, CG, PP)	Laboratory Scientist	Bereavement Midwife
Enrolled	29	6	20
Round 1	23	6	18
Round 2	16	5	11
Round 3	13	5	6

Results from each survey round

Round	Total statements	Met consensus	Further round	Remove
1	198	52	68	69
2	86	21	33	32
3	40	30	0	10

Results were grouped in 5 areas, depending on the stage of the patient's journey; diagnosis, delivery, laboratory investigations, postnatal care and care in future pregnancies

Consensus was met in areas such as the role of genomics and bereavement midwives, timing and types of post mortem and testing, availability of testing, referral pathways and follow-up. A particular focus was on the availability of staff trained to consent for post mortem and further testing.

It was difficult to establish consensus on follow up protocols for future pregnancies. Consensus was met for some major anomalies as well as for families at increased risk of recurrence in future pregnancies whilst consensus was not met for anomalies that are not thought to have a genetic cause.

Methodology

A modified Delphi was completed using the opinions of healthcare experts from the fields of Fetal Medicine, Clinical Genetics, Perinatal Pathology, Laboratory Science and Bereavement midwifery as the 5 stakeholder groups.

Participants were invited from all 7 GMSAs across England with stakeholder groups having representation from at least 5 GMSAs in the first round of responses.

Initial consensus statements were drafted by a steering group comprising 2 obstetricians, a clinical geneticist, a perinatal pathologist, 2 laboratory scientists and 2 midwives. Patient groups were asked about areas they felt were important to address to be included in statements.

3 rounds of surveys were completed with respondents answering on a 5-point Likert scale. Statements with >80% of responses of "agree" or "strongly agree" were said to meet consensus. Those with <60% were removed from the survey and those with 60-80% were reviewed and included in the subsequent round.

Following completion of the 3 round of surveys, final approval of statements was completed by the steering group.

Conclusions and next steps

86 statements met consensus by the end of the 3rd round.

- Publication of methodology and statements that met consensus
- Complete a round table discussion to draft best practice guidance
- Involvement of PPV groups and charities in this area to provide patient perspective
- Discussion around further training needs for staff working in this area