Death Before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination and stillbirth

Background

This project engages with an important and large-scale social issue: it is estimated that approximately 1 in 5 known pregnancies end in miscarriage, 1 in every 200 births is a stillbirth, and 2,000 terminations for reasons of fetal anomaly are performed in the UK each year. Yet many of those affected experience uncertainty, ambiguity and silence in the face of pregnancy loss. Often unexpected and unexplained, pregnancy loss engenders complex emotions that are difficult to articulate, even to those in supportive roles.

Research

English law is not straightforward when it comes to treatment of miscarriage, termination, and stillbirth. Our research examines questions ranging from the status of fetal material to an examination of how law can legitimise or stigmatise certain forms of pregnancy loss and bereavement. Through a detailed analysis of interviews with a range of stakeholders and bereaved individuals we explored the ways in which law shapes experiences of pregnancy loss and bereavement.

Our work with bereaved parents has identified the use of metaphor as a tool to understand, communicate and make sense of such difficult feelings. Studying the metaphors that the bereaved parents use when talking about this emotionally-complex, potentially isolating experience and the decision-making processes that accompanied it has provided a powerful way of gaining insights into their thinking processes and of opening up additional lines of communication with support agencies. Through an analysis of interviews conducted with bereaved families and support agencies, we have found that:

- There is considerable variation across England in terms of the information and support received by people who have experienced pregnancy loss.
- Often women are not fully informed about what they may experience during miscarriage, still birth, or termination for fetal anomaly.
- The experience of pregnancy loss appears to shape the ways in which people view the world through metaphor
- Some of the ways in which it does this resemble responses that people have to bereavement more generally, but in other cases, the metaphorical thinking that takes place appears to be unique to this experience

Working with our partner organisations – the Human Tissue Authority, Miscarriage Association, Stillbirth and Neonatal Death Charity (SANDS), Antenatal Results and Choices (ARC) – we are identifying the best ways of using our findings to inform training for supporters, to provide an evidence base for formal guidance produced by the Royal Colleges (e.g. RCN, RCOG), and to contribute to public awareness about pregnancy loss.

BEAR has been useful for us as we have had large quantities of confidential interview data that we have needed to store securely.

https://deathbeforebirthproject.org/

Case study

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BEAR Research Data Store (RDS)

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