

Embodied experiences of prenatal diagnosis of fetal abnormality and pregnancy termination

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Abstract: *Pregnant women routinely undergo prenatal screening in Australia and this has become a common experience of motherhood. When prenatal screening or prenatal testing results in diagnosis of a serious fetal abnormality, women are presented with a decision to continue or terminate their pregnancy. Few recent studies have explored women's psychosocial experience of prenatal diagnosis and pregnancy termination for fetal abnormality, and within this small group of studies it is rare for research to consider the embodied aspect of women's experiences. This paper reports on qualitative findings from in-depth interviews with 59 women in Melbourne, Australia who received a prenatal diagnosis of a significant abnormality and decided to terminate the pregnancy. Interview transcripts were coded inductively through thematic analysis. Two themes about embodiment were generated from the interviews: transitioning embodiment, and vulnerable bodies in un/comfortable spaces. Theory of pregnant embodiment was drawn on in interpreting women's narratives. Recommendations arising from the analysis include health professionals recognising, acknowledging and accommodating the transitioning embodied state of women as they consider, prepare for, undergo and recover from pregnancy termination for fetal abnormality. Further recommendations address the connections and disconnections between this transitioning embodied state and the spaces of clinics, hospitals and home.*
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Keywords: embodiment, pregnancy termination, fetal abnormality, prenatal diagnosis and testing, environment, space

Introduction

Pregnant women routinely undergo prenatal screening in Australia and this has become a common experience of motherhood.¹ When prenatal screening or prenatal testing results in diagnosis of a serious fetal abnormality, women are presented with a decision to continue or terminate their pregnancy. While termination rates vary across countries and jurisdictions, in Victoria, Australia the majority of pregnancies diagnosed with a serious fetal abnormality are terminated.² Pregnancy termination in second trimester can be either a surgical procedure – dilation and curettage (D&C)/dilation and evacuation (D&E) – or a medical induction of labour. Few qualitative studies have explored women's psychosocial experience of pregnancy termination for fetal abnormality.³ In this

article, we provide an in-depth account of women's embodied experiences of prenatal diagnosis and termination in Melbourne, Australia and consider the implications for healthcare professionals' practice.

Termination for fetal abnormality (TFA): embodied experiences

Research reports drawing on qualitative data about psychosocial experiences of TFA have focused on women's psychological and emotional responses,^{4–6} women's decision making about terminating the pregnancy and further decisions following the termination,^{7–9} and women's coping strategies and adjustment to loss.^{10–13} Few recent reports have considered women's *embodied* experiences during and following the events of prenatal diagnosis and

subsequent termination.^{10,14} Research with three women who experienced TFA shows that the women experienced a transition from being a pregnant woman to being a woman dealing with loss, but that future research was needed with a larger participant group.¹⁰ Scarce other research has pointed to the significance of spatial or environmental aspects of women's experiences of care. A US study found that requiring women who are waiting to have TFA to share environments with women waiting to have caesarean sections can cause distress.¹⁴ A UK study found women's preferences varied regarding whether they should have TFA in a gynaecological ward or a birthing unit and that denying women choice about this can contribute to distress.¹⁵

It is not uncommon for research reports on the psychological and emotional impact of TFA to include participant quotes that suggest the embodied nature of the experience. However, researchers have tended to interpret these descriptions as indicative of grief, trauma or psychological disorder,^{16–17} rather than to explore the detail of women's experiences of embodiment and the meaning they attribute to these experiences. For example, in a report on Israeli mothers' experiences of TFA, one woman's recount of her bodily experience is interpreted as suggestive of Acute Stress Disorder and its dissociative symptoms.¹⁶ In this article, we focus on women's embodied experiences of TFA in order to add a further complementary dimension to current understanding of the psychosocial experience of prenatal diagnosis and termination.

The politicised and polarising nature of international critiques of pregnancy termination mean that the voices of women who experience TFA often remain unheard.^{3,18} These critiques include the anti-abortion movement and the disability rights critiques of prenatal diagnosis and subsequent pregnancy termination decisions.¹⁹ Societal taboo and stigma about pregnancy termination arguably curbs public discussion about the experiences and care needs of women going through TFA. Our aim in reporting on women's embodied experiences is to add detail and depth to healthcare professionals' understanding of the experience of diagnosis and TFA, and to suggest recommendations as to how care provided to women who undergo TFA could be enhanced.

Research context: TFA in Melbourne, Australia

Women's experiences of TFA are known to vary across cultural, legal and national contexts.³ Prenatal screening, diagnosis, and pregnancy termination

are offered in private and public healthcare settings in Australia; there are no previous published reports of studies of women's experiences of TFA in the Australian context. Termination methods vary between healthcare settings and practitioners, as do abortion laws in Australian states. In Victoria, an abortion may be lawfully performed by a doctor in any circumstance before 24 weeks gestation. After this gestation an abortion can be lawfully performed if two doctors agree that it is appropriate.²⁰ In Victoria, genetic counsellors often provide ongoing care for women who receive a prenatal diagnosis.

Methods

The data reported here are a subset of data from a larger mixed methods study entitled Prenatal Testing: A Longitudinal Study (PeTALS), which is exploring women's and couples' experiences of prenatal diagnosis of fetal abnormality and their support needs. Participants were eligible for the PeTALS study if: they had recently received a prenatal diagnosis of a fetal chromosomal, single gene, cardiac or other structural abnormality; were aged 18 years and over; and were fluent in English. There were three recruitment sites, selected to represent a range of experiences: two public hospitals and one private ultrasound clinic in Melbourne. Ethical approval was obtained from all sites and recruitment occurred between July 2012 and April 2015. Genetic counsellors approached all women in their care who met the eligibility criteria, gave written and verbal information about the study and invited them to provide their contact details for the researchers. Those who agreed to be contacted were subsequently telephoned by a researcher and given a full explanation of the study. Recruitment continued until no new perspectives were emerging in data analysis.

Data collection is occurring at three time-points: six weeks (time-point 1), six to nine months (time-point 2), and two years (time-point 3) after prenatal diagnosis of fetal abnormality. Time-point 1 interviews and analysis have now been completed with a total of 102 participants (women n=75; men n=27) who received a prenatal diagnosis of fetal abnormality and made a decision about termination of pregnancy. The time-point 1 interviews were performed as close as possible to six weeks after diagnosis, ensuring that women who had chosen to terminate their pregnancy had undergone the procedure at least two weeks earlier.

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