

PREGNANCY LOSS RESEARCH GROUP

Fatal Fetal Anomaly: Exploring Experiences of Women and their Partners

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Background

The diagnosis of a fatal fetal anomaly (FFA) can have a traumatic impact on parents, who then may be faced with the decision to continue or to terminate the pregnancy. In January 2019, the provision of termination of pregnancy for FFA was legalised for the first time in Ireland. Parents’ experiences of both continuing and terminating their pregnancy following a FFA diagnosis in this new context need to be examined, to help inform care and service delivery.

Objective

To explore the care experiences of parents whose pregnancy was diagnosed with a FFA following the legalisation of termination of pregnancy for FFA in Ireland in 2019.

Methods

Design A qualitative study using semi-structured interviews and interpretative phenomenological analysis.

Recruitment

- A purposive sampling approach was implemented
- One arm of recruitment was through relevant voluntary support organisations
- The second arm involved the pregnancy loss team in a large tertiary maternity hospital
- **Inclusion Criteria:** 18 years or older, one year post bereavement, pregnancy with a diagnosis of a FFA since December 2018

Sample

- A purposeful sample of six women and four of their partners was recruited
- These parents were cared for in four out of the six fetal medicine units in the Republic of Ireland
- Parents recruited were equally balanced between those that terminated the pregnancy and those that continued the pregnancy

Data collection and analysis

Data collection involved one-to-one semi-structured online interviews over Google Meet. Interpretative phenomenological analysis was utilised and followed the six-stage process outlined by Smith and Larkin.¹

1. Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method, Research. London: Sage; 2009.

Results

Superordinate Themes	Subtheme	Analysis
Consistency of Care	Detection	Parents described a time of shock, uncertainty and isolation, with a lack of support from carers.
	Self-advocacy	There was a requirement to advocate for further investigations, for referral to counselling, and for mementos of their baby.
	Continuity of care	A consistently well-supported, empathetic environment had a profound positive impact on parents.
Recognition	Recognition of Trauma and Loss	Acknowledgment by staff of the trauma and loss that parents were going through made them feel supported and safe. Failure to recognise the distress of the experience was deeply troubling to parents.
	“There’s no place for you in the Pregnancy World”	Women no longer felt a shared common ground with other pregnant women. Shared waiting areas in the maternity unit were particularly upsetting. Most parents went looking for others who had a shared experience that they could relate to.
	Acknowledgement of Baby’s Pain and Personhood	The wellbeing of the baby was a high priority. The baby’s experience of pain was a determining factor in the continuation or termination of pregnancies. Some parents chose to cherish and develop the identity of the baby, others detached as a form of coping.
Impact of Communication	Clear and Comprehensive Information	Parents highlighted benefits of receiving clear information throughout their care and helping them understand the process. A lack of clarity led to a few parents feeling confused about information, increasing the uncertainty they felt.
	Promoting Remembrance	Many parents expressed gratitude towards staff when they raised awareness of memory making, which was beneficial in the grieving process.
	Appropriateness	While uncommon, parents shared inappropriate interactions that made a lasting impression on them which they felt demonstrated a lack of understanding for their emotional distress.

Being frightened, and so sad, just feeling so alone and nobody...my GP wasn't aware of what was going on and nobody from the hospital contacted me (F-TOP)

There was always somebody there to answer a question, and to take the time, and to be with us and to listen (F-CONT)

She was doing a job..... I don't think she really saw the person behind the news (F-TOP)

You're kind of sitting around in the waiting room where you're looking at other people who have their bumps and stuff (F-CONT)

I don't want someone coming in taking pictures of a dead baby. I said I'll find that actually disrespectful, but once again, so glad we did (M-CONT)

To make sure that nobody was coming down the corridors. They were saying things like, yeah, clear, all clear. If somebody had said to me, listen, we do it to protect your dignity (F-TOP)

Conclusion

This study provides a unique insight into the experience of parents whose pregnancy was diagnosed with a fatal fetal anomaly, helping us to further understand their care needs at this time. The findings suggest inconsistencies across care providers and care pathways, emphasising both the impact and occurrence of good and bad bereavement care across parental experiences. Our study highlighted parents’ need for consistent, well communicated, and comprehensive care, which encourages an individualised perinatal palliative care approach to these pregnancies.