

Experiences of pregnancy with fatal fetal anomaly



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A universal term, definition and review of the legislation around termination of pregnancy is needed to permit appropriate care for women with complex antenatal diagnosis that will ultimately result in a perinatal death. A universal database is necessary to collect essential epidemiologic information on congenital anomalies within the Republic of Ireland which can support healthcare professionals in their counselling of parents following a diagnosis of fatal fetal anomaly. Removal of criminal liability attached to the legislation is needed to prevent conservative interpretations. Legislators should listen and trust those working in abortion care and their expert management of pregnancies affected by fatal fetal anomaly.

What is a fatal fetal anomaly?

Internationally, approximately 2-3% of pregnancies receive a diagnosis of a major congenital anomaly.¹ Despite their low incidence, congenital anomalies are one of the leading causes of fetal and infant mortality.²

Fatal fetal anomaly (FFA) is not a medical term; however, it has gained popularity within Ireland, following its use by political parties in attempt to amend the Eighth amendment with the Protection of Life During Pregnancy (Amendment) (Fatal Foetal Abnormalities) Bill 2013 and Bill 2015. There is debate as to what this term means.

The Health (Regulation of Termination of Pregnancy (TOP)) Act 2018³ legally permits a TOP for FFA if two medical practitioners (one being an Obstetrician) diagnoses a pregnancy with a **condition 'likely to lead to death of fetus' in utero or within the first 28 days of birth**. The term FFA is widely used in Ireland despite its absence within the Irish abortion legislation.

There is no universal agreed list of conditions that belong to the term FFA as death in utero or within 28 days of birth is not guaranteed for many of the fetal conditions associated with this term.

The rapid introduction of the legislation presented many challenges for the 19 maternity units

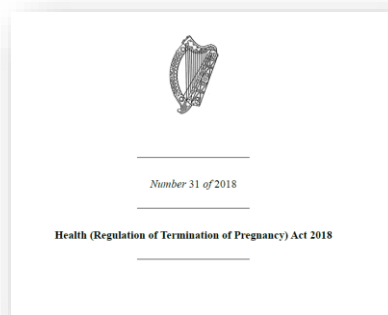
- **28 May 2018:** Repeal of the Eight Amendment
- **20 December 2018:** Ireland legislates for TOP in the Health (Regulation of Termination of Pregnancy) Act 2018
- **01 January 2019:** Ireland enacts the Health (Regulation of TOP) Act 2018; Clinical guidelines for service delivery published; services commenced.

What do we already know?

Parents attend their antenatal visits anticipating confirmation of a healthy baby and the discovery of a fetal anomaly generates fear and anxiety, often exacerbated by diagnostic and prognostic uncertainty.^{4,5,6}



A diagnosis of FFA can result in an intense grief reaction for parents which can be exacerbated by inadequate care and support.^{7,8} Parents are faced with difficult and complex decisions including whether to continue the pregnancy and prepare for the birth of an affected baby or to terminate the pregnancy.



Our study explored the experiences of parents, both those who continue and terminate a pregnancy, following a FFA diagnosis, and the experiences of those who support and care for them

What did we do?

- Identified the incidence of FFA associated with perinatal mortality in Ireland⁹
- Assessed the general public's knowledge of FFA during the referendum to repeal the Eighth Amendment¹⁰
- Undertook a critical discourse analysis on the influence of media commentary on FFA¹¹
- Conducted a Delphi survey to identify the educational needs of volunteers who provide support to bereaved parents¹²
- Explored Volunteers and Fetal Medicine Specialists (FMS) experiences of providing care and support, and Parents experiences of receiving care following a FFA diagnosis, during the implementation of a new service of TOP for FFA^{13,14,15}

What did we find?

There was a **lack of accurate knowledge** on its classification, diagnosis and chance of survival, as well as the supports available following a diagnosis of FFA¹⁰. This is unsurprising as the presentation of FFA and supports and services available to women following a diagnosis was identified to be **misrepresented within the media** from 2012 to 2017, the years preceding the referendum¹¹.

The language used to describe fetal anomalies that result in perinatal death and the **lack of a universal agreement of what constitutes a FFA** or a list of conditions associated with this term compounds the complexity associated with FFA. Terms used in clinical practice, such as fatal and lethal, do not accurately describe many of the conditions associated with this term, as known survivors are linked to many of the conditions. Our secondary data analysis of data pertaining to perinatal deaths, found **only 42% of these deaths could be classified a FFA in accordance with criteria outlined in the Irish legislation**. This is despite all conditions resulting in a perinatal death.⁹

Due to the potential for survivors and the ambiguous and restrictive legislation, the complex nature of FFA created many difficulties for both FMS¹⁴ and Volunteers¹³. As a result, **FMS expressed their fears of criminal prosecution and the subsequent media scrutiny if there was a disagreement with a diagnosis of a FFA made due to the lack of universal agreement of a definition of a FFA**. The retained criminalisation resulted in **conservative practices and inconsistencies** as was experienced by Volunteers. This was evident from Volunteers' observations of a **lack of standardised care** from those they provide support to, whose care options offered depended not on the fetal diagnosis but on the clinician caring for them.

“ People are nervous about being that first person who might be prosecuted... when people have to put their name on something or their head is on the line there is a fear for sure (FMS)

Week one of the new legislation, it was fetal medicine reports on the front page of the newspaper being read out in the Dáil, that is at the back of your mind (FMS)

I think that my biggest challenge is the understanding of what is covered under the legislation. I think that it is more what is covered and I think people thought that if we had termination of pregnancy introduced in Ireland that nobody would ever have to travel to the UK for termination of pregnancy again. And that is not the case (FMS)

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The **ambiguous legislation and complexity of FFA generated conflict and opposition between FMS and colleagues when attempting to agree on the qualification of congenital anomalies as FFA.** Additionally, the rapid introduction and the **lack of preparation time, the lack of institutional support** and the expectation of delivering a new service with an increased workload with no new colleagues created difficulties for FMS. Feticide also generated **internal conflict for FMS as they battled with their own moral and ethical beliefs yet were motivated by parents in their care, to provide and develop these services.**

When feticide was not undertaken, FMS faced **challenges with obtaining support to provide palliative care** in the event of a live birth. Frustration was also identified when **FMS faced delays in care due to conscientious objectors and a lack of institutional support for FMS for the provision of TOP services.** A need for collegial and **institutional support** due to the psychological impact of working with perinatal death experienced by FMS was identified. Similarly, Volunteers identified the need for **peer-to-peer support** to facilitate wellbeing while acting as a volunteer. The need for **educational opportunities** was recognised for both FMS and Volunteers for them to provide parents with accurate information on all aspects of care following a FFA diagnosis.



“You're on a different world, there's no place for you in the pregnancy world..... I went through the book [booklet on pregnancy received from the hospital] and like I don't know how many pages there was, but it was like one page that addressed miscarriage and stillbirth, like one page..... it's like do they think it's contagious? You know, I don't think there's a lot talked about it (Parent) ”

Parents¹⁵ shared the different approaches and level of attachment to their baby that supported their coping. **Those who continued the pregnancy shared the news with family and friends and found creating a journey and identity for the baby gave a sense of meaning.** In contrast, **those who terminated experienced a silence around the diagnosis and subsequent termination** and disclosed that continuing a bond with the baby was too agonising and painful.

Regardless of the level of attachment many **parents benefited from the acts of remembrance.** Regardless of choice of care, **parents expressed how they no longer felt they belonged in the 'pregnancy world'** and did not want to be around other pregnant women and felt a distinct differentiation with other types of pregnancy loss. They described a **need for healthcare professionals to recognise their loss and create a safe and supportive environment in which they could share their grief.** Despite this, parents accounts highlighted variations and inconsistencies in care and service provision.

This **lack of continuity of care** was felt in varying degrees by the parents, with those who continued the pregnancy reporting a more positive experience than those who terminated. Parents indicated that **clear and empathetic communication facilitated trust** between them and the healthcare professional, whereas failings in communication by the healthcare professional created a disconnect.

“The person that should have been the kindest to us, was the complete opposite; the bereavement midwife. And she came in, and her first question to us was like, "why did you come here? You know, they've been up those consultants, late every night for the last three or four nights, trying to sort you out, you realise, how lucky you are....Have you considered how lucky you are for the hard work that they've done in the background to help you out" I was like, what ??...grateful?...for like, for what? For this? For the position that I'm in? I don't see anything to be grateful for in that situation at all (Parent) ”

What are the implications of this work?

- **Improved antenatal education and public health campaigns** to enhance health information about FFA to facilitate informed decision making following a FFA diagnosis.
- **Improved knowledge** on the complexity relating to the presentation of infants with a FFA that leads them to being fatal. Universal term and definition that describes conditions causing perinatal death.
- **Universal database** to collect essential epidemiologic information on congenital fetal anomalies within the Republic of Ireland which can support healthcare professionals in their counselling of parents following a diagnosis of FFA.
- **Review of the legislation** to permit FMS to appropriately care for women with a complex antenatal diagnosis that will ultimately result in a perinatal death. **Abolish criminal liability** attached to the legislation to prevent conservative interpretations.
- **Delivery of a standard of care that is sensitive, patient centred and responsive to parents**, who receive a diagnosis of a FFA, needs; a perinatal palliative care approach that is individual to the parents and supports them to cope with the loss of their baby.
- **Volunteers and Fetal Medicine Specialists' to be supported** in their role and their peer-to-peer support and **holistic care be acknowledged**.

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I just knew that I delivered it, and on my own, and I think that's something, that someone, I know they're really busy, but I felt like someone could have been there,.....I felt like, I could have been just an inpatient for, I don't know, something very minor (Parent)


You know, it helped [encouragement from HCPs in engaging with acts of remembrance], I suppose to guide us through it in terms of, you know, ultimately, it could have been a healthy baby. So, you know, put a name on it and, you know, go through that process of you know, of, you know, holding it..... it was helpful for the process (Parent)

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A perinatal palliative care approach is appropriate for Parents who continue their pregnancy after antenatal diagnosis of fatal fetal anomalies (FFA) / life-limiting conditions (LLC) as well as for those who opt for termination of pregnancy (Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland)¹⁵

Further information

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References

1. World Health Organization. Birth defects. Report by Secretariat, Sixty-third World Health Assembly Provisional Agenda item 11.7. A63/10, 1 April 2010.
2. Lanzoni M et al. European Monitoring of Congenital Anomalies: JRC-EUROCAT Report on Statistical Monitoring of Congenital Anomalies (2006 – 2015). Ispra: European Commission; 2017.
3. Government of Ireland. Health (Regulation of Termination of Pregnancy) Act 2018 (2018). Dublin: The Stationery Office
4. Benute GRG et al. Feelings of women regarding end-of-life decision making after ultrasound diagnosis of a lethal fetal malformation. *Midwifery*. 2012;28:472-475.
5. Webb NR. When joy turns to anxiety: parental experience with counselling after prenatal diagnosis of congenital anomaly. *BJU International*. 2017;119(4):E8-E8.
6. Fleming V et al. Dying at life's beginning: Experiences of parents and health professionals in Switzerland when an 'in utero' diagnosis incompatible with life is made. *Midwifery*. 2016;34:23-29.
7. Finnemore P. Future Imperfect: Coping and Communication in Continuing Pregnancy after Diagnosis of Fetal Abnormality. London, UK: University of Middlesex; 2000.
8. Lalor JG, Devane D, Begley CM. Unexpected diagnosis of fetal abnormality: Women's encounters with caregivers. *Birth*. 2007;(34): 80-88.
9. Power S, Meaney S, O'Donoghue K. The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland. *Prenatal Diagnosis*. 2020;40: 549-556.
10. Power S, Meaney S, O'Donoghue K. An assessment of the general public's knowledge of fatal fetal anomalies. *Prenatal Diagnosis*. 2018;38:883-890.
11. Power S, O'Donoghue K, Meaney S. Critical discourse analysis on the influence of media commentary on fatal fetal anomaly in Ireland. *Health*. May 2021.
12. Power S, Meaney S, Cotter R, O'Donoghue K. Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey. *International Journal of Palliative Nursing*. 2020;26(4):156-166.
13. Power S, O'Donoghue K, Meaney S. Experiences of volunteers supporting parents following a fatal fetal anomaly diagnosis. *Qualitative Health Research*. 2021;31(5):835-846.
14. Power S, Meaney S, O'Donoghue K. Fetal medicine specialist' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: a qualitative study. *British Journal of Obstetrics and Gynaecology*. 2021;128: 676-684. Jackson P, Power Walsh S, Dennehy R, O'Donoghue K. Fatal fetal anomaly: Experiences of women and their partners. *Prenatal Diagnosis*. Under Review.
15. O'Donoghue K. Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy - Termination of Pregnancy. Version 2.0. The Institute of Obstetricians and Gynaecologists. December 2020.