



# Fetal medicine specialist experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: a qualitative study

S Power,<sup>a,b</sup> S Meaney,<sup>b,c</sup> K O'Donoghue<sup>a,b</sup>

<sup>a</sup> The Irish Centre for Maternal and Child Health Research (INFANT), University College Cork, Cork, Ireland <sup>b</sup> Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland <sup>c</sup> National Perinatal Epidemiology Centre, University College Cork, Cork, Ireland

Correspondence: K O'Donoghue, Department of Obstetrics and Gynaecology, Cork University Maternity Hospital, Wilton, Cork, Ireland.  
Email: k.odonoghue@ucc.ie

Accepted 3 September 2020.

**Objective** To explore fetal medicine specialists' experiences of caring for parents following a diagnosis of fatal fetal anomaly (FFA) during the implementation of termination of pregnancy (TOP) for FFA for the first time.

**Design** Qualitative study.

**Setting** Fetal medicine units in the Republic of Ireland.

**Population** Ten fetal medicine specialists from five of the six fetal medicine units.

**Methods** NVIVO 12 assisted in the thematic analysis of semi-structured in-depth face-to-face interviews.

**Main outcome measures** Fetal medicine specialists' experiences of prenatal diagnosis and holistic management of pregnancies complicated by FFA.

**Results** Four themes were identified: 'not fatal enough', 'interactions with colleagues', 'supporting pregnant women' and 'internal conflict and emotional challenges'. Fetal medicine specialists feared getting an FFA diagnosis incorrect because of media scrutiny and criminal liability associated with the TOP for FFA legislation. Challenges with the ambiguous and 'restrictive'

legislation were identified that 'ostracised' severe anomalies. Teamwork was essential to facilitate opportunities for learning and peer support; however, conflict with colleagues was experienced regarding the diagnosis of FFA, the provision of feticide and palliative care to infants born alive following TOP for FFA. Participants reported challenges implementing TOP for FFA, including the absence of institutional support and 'stretched' resources. Fetal medicine specialists experienced internal conflict and a psychological burden providing TOP for FFA, but did so to 'provide full care for women'.

**Conclusions** Our study identified challenges regarding the suitability of the Irish legislation for TOP for FFA and its rapid introduction into clinical practice. It illustrates the importance of institutional and peer support, as well as the need for supportive management, in the provision of a new service.

**Keywords** Fetal medicine and surgery, maternity services, medical law, qualitative research, termination of pregnancy.

**Tweetable abstract** The implementation of termination services for fatal fetal anomaly is complex and requires institutional support.

Please cite this paper as: 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. BJOG 2020; <https://doi.org/10.1111/1471-0528.16502>.

## Introduction

Approximately 3% of pregnancies receive a diagnosis of a major congenital anomaly,<sup>1</sup> and more women now receive a diagnosis of a fetal anomaly during pregnancy as a result of advancements in prenatal testing.<sup>2</sup> Such a diagnosis creates much uncertainty regarding the fetal prognosis and

parents face many difficult decisions,<sup>3,4</sup> primarily whether to terminate or continue with the pregnancy.<sup>5</sup>

Universal access to reproductive health care and safe termination of pregnancy (TOP) has long been advocated as a woman's human right,<sup>6-8</sup> resulting in countries reforming their laws in order to facilitate and broaden TOP services.<sup>9,10</sup> The Republic of Ireland legislated for TOP for

fatal fetal anomaly (FFA) for the first time in 2018. Prior to this, Ireland held one of the most restrictive legislative positions on TOP in the world:<sup>11</sup> the Eighth Amendment of the Constitution protected ‘the right to life of the unborn’,<sup>12</sup> and ensured that TOP, including TOP for FFA, was a criminal offence.<sup>13,14</sup> On 1 January 2019, the Health (Regulation of Termination of Pregnancy) Act 2018 was enacted, permitting TOP if two medical practitioners (one being an obstetrician), ‘are of the reasonable opinion’ that the fetal diagnosis is ‘likely to lead to the death of the fetus’ during the pregnancy or in the first 28 days of life.<sup>15</sup> TOP outwith the provisions of the legislation was retained as a criminal offence. A fetal medicine specialist usually makes or confirms a diagnosis and approves the request for TOP for FFA. The Irish Interim Clinical Guideline for TOP for FFA recommends that discussions with the fetal medicine multidisciplinary team (for suggested members, see Appendix S1) regarding the diagnosis and prognosis should form a component of the assessment of fetal anomalies.<sup>16</sup>

There is little qualitative research, however, on the lived experience of the fetal medicine specialists (FMSs) who are involved in prenatal diagnosis and the counselling and care of pregnancies complicated by FFA. This study aimed to explore FMSs’ experiences in caring for women diagnosed with an FFA during a change in service provision for TOP for FFA.

## Methods

A qualitative research design was used as it facilitated the interpretation of how people make sense of their lived experience.<sup>17,18</sup> This methodology allowed the researcher to examine FMS experiences of changing practice in caring for parents who receive an FFA diagnosis following the implementation of TOP for FFA. Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ref. no. ECM 4 (gg) 12/02/19).

Purposive sampling was implemented to ensure only those currently practising as FMSs following specialist training were recruited. Members of the national Fetal Medicine Working Group were approached by KOD to facilitate communications from SP about the study. SP provided participant information leaflets to 12 FMSs and encouraged them to share study information with their FMS colleagues. The topic guide was developed by all three authors and input was sought from members of the Pregnancy Loss Research Group, which include representatives of the multidisciplinary team (MDT) and service users.<sup>19</sup> No other input was sought from patient and public representatives. Data collection occurred between November 2019 and January 2020. Ten FMSs, seven female and three male, with varying years of experience (presented in

**Table 1.** Years of experience working in fetal medicine

Participant	Years
1	4–14 years
2	4–14 years
3	4–14 years
4	15–30 years
5	15–30 years
6	4–14 years
7	15–30 years
8	15–30 years
9	15–30 years
10	4–14 years

Table 1), and all specialty trained outside Ireland, representing five of the six fetal medicine units in Ireland, participated in semi-structured face-to-face interviews. This represented over a third of the 27 FMSs practising in Ireland, with varied involvement in TOP. A topic guide was used to aid the interviews conducted by SP (Appendix S2). Interviews lasting from 36 to 71 minutes were recorded and transcribed verbatim by SP.

This study adopted a data analysis methodology based on the principles of thematic analysis.<sup>20</sup> The transcripts were read and re-read to become familiarised with the data and to identify initial codes. Further analysis facilitated the categorisation of codes through grouping the initial codes, developing them into potential themes and subthemes, and generating definitions and names for each theme. Nvivo 12 (QSR International, Chadstone, Victoria, Australia) was used to assist with the analysis of the data and enhance the trustworthiness of this study through acting as an audit trail. Data analysis was undertaken by SP, and an external check on the analytical process and a consensus discussion regarding theme development with SM was undertaken. This practice is a helpful approach to encourage reflection on assumptions that unwittingly may have been overlooked.<sup>21–23</sup> Coding is a reflexive process that bears the mark of the researcher.<sup>21</sup> Reflexivity is essential as it enables the reader to assess the validity of qualitative analysis by understanding the composition of the research team responsible for its production.<sup>24</sup> SP is a children’s nurse undertaking a PhD in major fetal anomalies and SM is a social researcher with a PhD and 15 years of experience in conducting qualitative research. SP and SM had no relationship with any research participant prior to the interview. KOD did not actively participate in data collection or analysis because of her position as an FMS but did review the finalised themes for publication to limit bias further. Reflexive thematic analysis argues that meaning is generated through interpretation, therefore inhibiting the

**Table 2.** Themes and subthemes

Theme	Subtheme
Not fatal enough	Fear of getting it wrong
	Legislation is difficult
	Not clearly fatal but clearly awful is challenging
Interactions with colleagues	Teamwork
	Conflict
	Organisational culture
Support for pregnant women	Warning shot
	Health literacy
	How much support is enough
Internal conflict and emotional challenges	Internal conflict
	Psychological impact
	Positive feelings

prediction of the number of data items or when to cease data collection.<sup>25</sup> Therefore, data were collected until no new themes were identified and inductive thematic saturation was perceived.<sup>25</sup>

## Results

Four overarching themes emerged from the data: ‘not fatal enough’, ‘interactions with colleagues’, ‘support for pregnant women’ and ‘internal conflict and emotional challenges’, all with three subthemes each, as presented in Table 2. Direct quotes to support each theme are presented in Tables 3 and 4.

### Not fatal enough

Patients’ best interest motivated FMSs to ensure that a ‘diagnosis is correct’ and that they ‘are doing everything to inform women and their partners’. FMSs identified that ‘where the default is termination is the worst outcome’ it leaves them ‘exposed’, meaning that if a TOP for FFA has been performed and the diagnosis is found to be incorrect, the FMSs feel vulnerable to prosecution and the media scrutiny that an incorrect diagnosis would create. As a result, over half of the participants shared their fear of getting the diagnosis wrong. They expressed ‘anxiety’ regarding permitting a TOP for the identified anomaly and the consequence ‘if somebody doesn’t agree’ that it is fatal.

**Table 3.** Direct quotes

#### Not fatal enough

*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*

*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*

*... the litigious environment that we work in and the medical legal aspects of working in this area have been shown... difficult cases last year and cases that have made it into the media and the cases that will go to court. And so we are not protected in our practicing in any way none of us want to be in a situation where we thought, ah sure deliver and then the baby is alive six weeks later and there’s all the issues that go with that*

*from a very kind of selfish perspective. And you’d worry about whether if I do get it wrong and what if we, you know, induce this baby at term and actually it lives for six weeks because there’s always an outlier*

*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*

*But it’s quite strict in terms of what is offered. You know, and it’s purely almost certain. And, what’s the word? in reasonable faith, So the bar is set high. So there are many patients that are still travelling to the UK*

*‘Oh I have seen a case where the baby lived’ so it is almost if somebody has seen a baby survive something, other people are afraid to appear as pro-abortion*

*Non-fatal is a whole different ball game. You have got a baby with life limiting, with a poor quality of life which may limit the duration but it is certainly going to have an impact on the parents and the other children in the family and the rest of their lives. That is a much bigger deal and I feel for those parents now, I feel they are completely and utterly abandoned really by the system*

#### Interactions with colleagues

*The midwives are very experienced and comfortable which is probably the most important thing*

*I would usually involve the bereavement midwives early and I think that is really helpful... it would really fall on the bereavement midwives a lot*

*... obviously the national and international meetings are very good on keeping up to date. And the teams here have been very supportive amongst each other*

*... so like peer support with my colleagues is very important to me and that I suppose locally. And maybe more broadly nationally, talking about these things in an informal setting because it isn’t something that is necessarily easy to talk about with certainly non-medical people... It’s actually got infinitely harder since January a year ago (when TOP for FFA was implemented)*

**Table 4.** Direct quotes**Support for pregnant women**

*I don't really like doing it if they don't have someone with them so it can be a little bit less, it is usually bare diagnosis and would you like to come back with somebody with you... I feel this is too much for one person. ... I think patients as well, they listen to that cue so when the sonographer is saying you are going to see the doctor, you need to bring someone with you. For the majority of them that is a sign.*

*And then we arrange for them then to come into the hospital and I... I actually find that, that they have time, and we may see them the next day or the following day, it is usually within 48 hours, but that they have processed and started to think about what it means for them and their baby and their pregnancy.*

*It (diagnosis) would always be in person. I never do anything over the phone... I would always bring people back in.*

*The first was to be compassionate, honest, open. You kinda judge things depending on how bright, intelligent, how supportive they are at the time.*

*We tell them there is open access, if they ring in and they have a problem they come into us. So they bypass the normal clinics after that.*

*I think ultimately it is a shit time and it is a lonely time for them and often it is them and their partner dealing with it. I honestly don't know how much support is enough. (a FMS who offers open access to parents)*

*I don't think it's (support) adequate, but I think it's adequate in what we can offer.*

*We kind of give them the option to come back for a six week check with us, sometimes they don't necessarily come back to see me, they might see one of the midwives, it just depends on if there is any complications, if they want to talk about the future... There are some couples that you do get very attached to.*

*I realising now that that's good to be a part of my role. But just to get to follow them up and meet you back afterwards. And and again, that's quite useful for them because they're at a stage where they can think about planning another pregnancy sometimes*

**Internal conflict and emotional challenges**

*To be honest, I struggled with this quite a bit. But I've seen so many women traumatised in this situation, the fatal fetal and lethal, LLCs (life-limiting conditions), that I think the right thing for that group is to offer this treatment in Ireland*

*It is always very sad and emotional, it is difficult but something that I guess I have been doing for a long time and I am aware that I am doing it for a long time. It doesn't necessarily mean it is easier, it is always very sad*

*I remember getting sick out in the corridors afterwards because I thought it (feticide) was such an awful procedure and so dreadful*

*You have to see the positive in it otherwise you would drive yourself mad*

*Ultimately you feel some degree of positivity if you get people through. And then if you see them back in another pregnancy and they've made it and so on, that's good*

Half of the FMSs expressed 'uncertainty' regarding a diagnosis being fatal as it 'depends' on an individual's 'definition' of what is fatal. Relating to prognosis, participants identified that 'there is never any certainty' when death will occur, and that there is always an 'outlier' (i.e. a baby that will live longer than expected). A couple of FMSs commented on the relief experienced when the baby dies, confirming that their diagnosis was 'right'. Their fear of getting it wrong is associated with the 'difficult' legislation, and that 'under the legislation, [they] can't have babies who survive for a long period of time', i.e. beyond the 28 days referenced within the legislation. Legislative challenges were identified by most participants, primarily ambiguity, 'understanding what the legislation allows for' and which conditions are deemed fatal and can therefore be terminated legally. Over half of the participants referenced the legislation as 'restrictive' and argued that it was forcing them to travel for a TOP for conditions that are not 'quite fatal enough but are absolutely not going to survive'.

All FMSs faced difficulty with conditions that were 'not clearly fatal but clearly awful'. They felt frustration in hearing these cases being referred to as 'severely fatal', having the potential to be fatal and TOP not being 'sanctioned' if there was ever a survivor. Half of the FMSs shared that the

distinction between fatal and severe resulted in women being 'ostracised', as only women with a fatal diagnosis can legally obtain a TOP in Ireland, whereas women with a severe diagnosis must travel for this service. These women are then open to 'societal questioning' and suggestions that they are travelling 'because it is not fatal enough, as maybe the baby could be okay'. Over half of the participants identified the 'complex' cases and the 'difficult decisions' of what conditions met the criteria within the legislation, and felt that the MDT was 'supportive' with their decision making. MDT discussions gave FMSs an opportunity to include other 'specialties' and 'experienced colleagues' to assist in their decision making; however, some FMSs expressed 'lament having to bring' discussions to the MDT as some disciplines were too 'vocal' and 'strong' with their 'anti-abortion' opinions.

**Interactions with colleagues**

Almost all FMSs identified that a good working relationship with MDT members was 'essential' to provide good quality care. Over half of the FMSs identified midwives as 'essential'; they were 'more available' and 'better' in supporting women. Teamwork benefitted the FMSs directly as local and national colleagues acted as both a source of

learning and peer support. Nearly all FMSs identified the need to 'debrief' with those who understand their challenges as being 'very important' for their self-care. Despite identifying the need for collaborative working, nearly all participants experienced 'conflict' or 'opposition' when discussing the fatality of conditions. Half of the FMSs described meetings involving 'contentious cases' as being 'divisive'. They shared that there was 'a massive uncomfatableness' and 'suspicion' with TOP. Over half of the FMSs experienced conflict with neonatologists. Participants reported frustration that these colleagues would engage in decision making for TOP for FFA but would refuse to care for the woman and her baby 'if the driving force was termination'. This generated concern for FMSs as they are 'unclear as to who will look after those babies' if a baby is born alive following TOP by induction of labour and without feticide, resulting in them 'begging people to help' them in providing palliative care.

This led to another challenge experienced by FMSs: 'dare I say the word feticide'. Over half of the FMSs experienced differences of opinion relating to feticide. Some participants expressed 'friction' with neonatologists because of an expectation for 'universal feticide' to ensure that no baby was born alive. Half of the FMSs identified a 'role for feticide', 'depending on the anomaly', whereas some expressed that feticide needed to be mandatory for late gestations because it was in the best interest of the baby to not be born alive. A couple of FMSs advocated that feticide should be a parental choice, and that the 'relatively tight definition' (Irish legislation) and 'small number of cases' dismissed it as a requirement.

Over half of the FMSs experienced opposition with conscientious objectors. Although acknowledging people's right to conscientious objection, they were frustrated with what they called 'conscientious obstruction'. Some felt that treatment was delayed at times: for example, where the provision of TOP for FFA was limited to certain days. Others described the situation as 'tense', unsure of 'how far conscientious objection extended'. Where hospital management held a position of conscientious objection, participants expressed that this 'led to a lack of support of those working in this area'. These FMSs expressed feelings of being 'undervalued' and a lack of acknowledgement for the 'difficult' tasks associated with their role. Half of the participants shared feelings of disapproval and disrespect from local, national and retired colleagues.

Nearly all of the FMSs experienced difficulties when implementing the TOP service. Half of the FMSs reported that they had to self-prepare, alongside their colleagues, in the absence of institutional support. An unsupportive environment resulted in FMSs feeling unable to 'ask for help' when 'providing a new service with no new colleagues' and with an 'increased workload'. These FMSs acknowledged

that although a small number, these cases take up 'a lot more time' and can require multiple visits. The few FMSs who had organisational support reported positive experiences with the implementation of TOP for FFA. Despite their initial challenges, it 'bedded in' and became 'normalised'.

### Support for pregnant women

Nearly all FMSs shared the need to give parents a 'warning shot that something's not okay' when diagnosing an FFA. A warning shot enabled FMSs to encourage women to have support when receiving a diagnosis of an FFA, as some participants expressed difficulties when informing women of an FFA when they were on their own. Half of the FMSs suggested that they found it beneficial to allow time between appointments following the 'warning shot', as it enables 'much more meaningful discussion' about the diagnosis at the next visit. Over half of the participants identified the need to choose language 'carefully' based on their patient's 'health literacy', in order to 'pitch' it at a level that they could understand to ensure that the diagnosis is 'clear for people'.

Nearly all participants identified the importance of follow-up care and over half provided 'open access' for parents, where, if needed, they could return to their clinic at any time. Additionally, over half provided care for the parents during their subsequent pregnancy, with a few wanting to see these women have a 'nice outcome' and get 'through' the experience of an FFA.

### Internal conflict and emotional challenges

Internal conflict was experienced by almost all FMSs as a result of caring for women with an FFA; they expressed having 'a line' that they 'do not cross', and that the condition being terminated is a 'significant abnormality'. Over half of the FMSs expressed internal conflict about the provision of feticide and the need to 'separate yourself from it completely'. They described feticide as 'brutal', 'awful' and 'emotionally difficult', referring to it as 'stabbing the baby in the heart', and held themselves responsible for the death of the baby: 'I caused the death'. Almost all of the FMSs justified providing TOP for FFA or feticide because it was a 'kindness in some cases', and they would want someone to 'step up and just be kind'. FMSs felt obliged to provide TOP for FFA as it is 'the right thing to do' and expressed the importance of being in a position to 'provide full care for women'.

Providing TOP for FFA created a 'psychological burden' for over half of the FMSs. A couple of them referred to themselves as 'doctor death', dealing with death and dying or with opinions from others that they 'are trying to terminate everything'. However, half of the participants expressed that this was their job, and that they have 'chosen' 'to support (parents)' and 'it's important to do it well'.

## Discussion

### Main findings

This study, within an Irish context where TOP for FFA is being provided for the first time, following an electoral referendum, identified the fears of FMSs working in prenatal diagnosis because of the potential for media scrutiny, and criminal liability, if a pregnancy was terminated for a fetal condition that was not deemed to be an FFA. They expressed challenges resulting from the rapid introduction of the new TOP services, such as being unprepared or unsupported by their institution, and working with difficult legislation and an increased workload. Although they recognised teamwork as essential, conflict and opposition was widespread within their practice, as a result of differences of opinion regarding what qualifies as an FFA and the practice of feticide. Internal conflict and psychological burden among FMSs providing TOP for FFA was highlighted, but FMSs identified that services needed to be provided and supporting parents motivated them to develop these services.

### Strengths and limitations

A potential limitation of this study is that the participants self-selected to be a part of this study. Thus, it is possible that those who participated were influenced by personal agendas that potentially may have influenced the content of their interviews. Nonetheless, this study is the first to explore experiences of FMSs during a significant national change in service provision for TOP for FFA.

### Interpretation

Within this study, FMSs expressed their fear of media scrutiny and being questioned on their diagnosis of an FFA. The Irish media regularly reports on adverse obstetric events, suggesting mismanagement and providing the names of the clinicians involved,<sup>19</sup> as was evident within weeks of introducing TOP services.<sup>27</sup> Such media attention can have a negative impact on healthcare professionals and parents.<sup>28,29</sup> FMSs fears stemmed from the 'difficult legislation' and the various definitions of what constitutes an FFA. Such definitions do not accurately describe many of the conditions associated as an FFA, as known survivors are linked to many of these conditions.<sup>30,31</sup> Additionally, diagnosing conditions as FFAs in accordance with Irish legislation is complex, as many anomalies in isolation may not be considered an FFA but when combined are potentially fatal.<sup>30</sup>

The FMSs within this study shared their experiences of opposition from colleagues relating to decision making on the fatality of conditions. Dommergues et al. (2010) suggest that in all countries where TOP for FFA is legalised, the interpretation of the legislation is feasible.<sup>32</sup> Where the criminal liability of clinicians exists, as it does in Ireland, the UK and throughout the USA,<sup>33</sup> there is a potential for

conservative interpretations of legislation leading to inconsistencies in service provision.<sup>34</sup> Power et al. (2020) identified the need for universal definitions, with accurate descriptions of FFAs that result in perinatal death in order to aid diagnosis, reduce subjectivity and standardise health-care provision.<sup>30</sup> Furthermore, the FMSs described Neonatologists' refusal to provide perinatal palliative care to the baby following a TOP by induction of labour and without feticide, with some of the FMSs describing experiencing pressure from Neonatologists to conduct feticide. FMSs identified these experiences as a source of tension and conflict, as they felt that in the absence of universal feticide, perinatal palliative care is warranted for these cases, but are left 'begging' for support to ensure its delivery. Unfortunately, although the majority of TOPs for FFA occur within the second trimester, before viability,<sup>35</sup> some pregnant women within Ireland are without universal access to anomaly scans and so are at risk of a late diagnosis.<sup>13,36</sup> Additionally, Ireland's legislation is without gestational limits and so creating the opportunity for late TOP for FFA. In other jurisdictions, however, feticide is not a legal requirement for fetal anomalies not compatible with survival, unless requested by the parents.<sup>37</sup> Despite this, approximately 1–2% of UK terminations in 2018 were confirmed to occur without feticide<sup>38</sup>. FMSs within this study expressed internal conflict regarding TOP for FFA and, in particular, around feticide. The balancing of moral and ethical beliefs is universally identified among FMSs providing TOP,<sup>39–41</sup> and obstetricians throughout Europe acknowledge the need for more resources and emotional support when providing late TOP.<sup>42</sup>

The complexity of introducing a national TOP service warrants the need for regulations, clinical guidance and protocols, and similar to other new services requires a well-developed plan supported by management.<sup>43</sup> Despite this being best practice, Irish clinical guidelines for the service delivery of TOP for FFA were rapidly developed during the introduction of the service.<sup>13</sup> The FMS experiences identified here offer learning for TOP providers in Northern Ireland during their current efforts to reform their TOP laws,<sup>44,45</sup> and for countries like Turkey, India and the USA, where TOP for FFA is legalised but there are access restrictions.<sup>46,47</sup> The retention of criminal liability can have negative implications for health outcomes and limits clinicians in providing medical services that comply with professional and ethical standards of care.<sup>13,14,33,39,48</sup> Unclear regulations, which exist worldwide, result in delay and restrictions to TOP services, including TOP for FFA.<sup>33,47,49</sup> To reduce delay and restrictions, Ireland's interim TOP for FFA guidelines have transitioned from recommending that decisions on the fatality of a condition be made by majority consensus, in an MDT,<sup>50</sup> to recommending that MDT discussions are important but that the responsibility lies with the two certifying medical

practitioners.<sup>45</sup> Over half of the FMSs in this study found MDT discussions useful in determining whether a condition met the requirements for TOP. It is noteworthy that the majority who benefitted from MDT discussions reported good institutional support. An MDT approach may be beneficial where clinicians receive organisational support and respect, but can impede delivery of care where clinicians are undermined and unsupported.<sup>13</sup>

The psychological impact of working with perinatal and neonatal death experienced by the participants, and the need for institutional and collegial support, has been documented by previous research.<sup>26,51–58</sup> TOP is controversial and divisive, however, and conflict between colleagues can disrupt the sense of belonging in their professional group,<sup>59</sup> as identified within this study. This is not isolated to the Irish experience, as UK obstetricians associate more positive experiences when their decision making is supported by a team with shared values, reducing the isolation and vulnerability associated with potential legal challenges.<sup>39</sup> FMSs would potentially benefit from the implementation of a structured collegial support system to reduce their feelings of disapproval from colleagues, assisting with clinician burnout, well-being and job satisfaction.<sup>26,55,56</sup> Despite the emotional impact, participants gained satisfaction in supporting women. This sense of fulfilment and the source of strength from supporting parents are reflective of previous research.<sup>40,52,53,59,60</sup>

## Conclusion

The legal right to TOP does not automatically ensure the provision of appropriate TOP care. Our study identified challenges regarding the suitability of Irish legislation for TOP for FFA and its rapid introduction into clinical practice. Our findings advocate for the abolishment of the retained criminal liability attached to the legislation and for the need for legislators to listen and trust FMSs in their expert management of pregnancies affected by FFA. This study suggests the need for more research on institutional support for service providers to be undertaken. The challenges that FMSs encounter when managing pregnancies diagnosed with FFA illustrates the importance of institutional support and the need for healthcare management to support FMSs in the provision of a new service.

## Disclosure of interests

None declared. Completed disclosure of interest forms are available to view online as supporting information.

## Contribution to authorship

Each author (SP, SM and KOD) made substantial contributions to the conception and design of the study, the acquisition of data, the analysis and interpretation of data, and drafting the article or revising it critically for

important intellectual content. All have approved the final version and take responsibility for its publication.

## Details of ethics approval

Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ref. no. ECM 4 (gg) 12/02/19).

## Funding

None.

## Acknowledgements

None.

## Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1.** Suggested members of the multidisciplinary team.

**Appendix S2.** Topic guide. ■

## References

- 1 Coleman PK. Diagnosis of fetal anomaly and the increased maternal psychological toll associated with pregnancy termination. *Issues Law Med* 2015;30:3–23.
- 2 Irving C, Richmond S, Wren C, Longster C, Embleton ND. Changes in fetal prevalence and outcome for trisomies 13 and 18: a population-based study over 23 years. *J Matern Fetal Neonatal Med* 2011;24:137–41.
- 3 Aite L, Zaccara A, Mirante N, Nahom A, Trucchi A, Capolupo I, et al. Antenatal diagnosis of congenital anomaly: a really traumatic experience? *J Perinatol* 2011;31:760–3.
- 4 Fleming V, Iljuschin I, Pehlke-Milde J, Maurer F, Parpan F. 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;34:23–9.
- 5 Benute GRG, Nomura RMY, Liao AW, Brizot MdL, de Lucia MCS, Zugaib M. Feelings of women regarding end-of-life decision making after ultrasound diagnosis of a lethal fetal malformation. *Midwifery* 2012;28:472.
- 6 Centre for Reproductive Rights. UN Human Rights Committee Asserts that Access to Abortion and Prevention of Maternal Mortality are Human Rights <https://reproductiverights.org/press-room/un-human-rights-committee-asserts-access-abortion-and-prevention-maternal-mortality-are2018>.
- 7 Centre for Global Justice. UPR Mid-Term Submission to the UN Human Rights Council [https://www.ohchr.org/\\_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/UPR/NGOs/MidTermReports/GlobalJusticeCenter\\_USA.docx&action=default&DefaultItemOpen=12018](https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/UPR/NGOs/MidTermReports/GlobalJusticeCenter_USA.docx&action=default&DefaultItemOpen=12018).
- 8 United Nations of Human Rights. States must act now to allow safe, legal abortions for women and girls, say UN rights experts <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23646&LangID=E2018>.
- 9 Centre for Reproductive Rights. *Abortion Worldwide: 20 Years of Reform*. New York 2014.

- 10 United Nations Population Fund. International Conference on Population and Development Programme of Action: Twentieth Anniversary Edition. In: United Nations Population Fund, editor.: New York; 2014.
- 11 McCarthy J, O'Donnell K, Campbell L, Dooley D. Ethical arguments for access to abortion services in the Republic of Ireland: recent developments in the public discourse. *J Med Ethics* 2018;44:513–7.
- 12 Government of Ireland. Eight Amendment of the Constitution Act 1983. 1983.
- 13 Donnelly M, Murray C. Abortion care in Ireland: Developing legal and ethical frameworks for conscientious provision. *Int J Gynaecol Obstet* 2020;148:127–32.
- 14 Taylor M, Spillane A, Arulkumaran SS. The Irish Journey: Removing the shackles of abortion restrictions in Ireland. *Best Pract Res Clin Obstet Gynaecol* 2020;62:36–48.
- 15 House of the Oireachtas. Health (Regulation of Termination of Pregnancy) Act 2018. Ireland 2018.
- 16 Institute of Obstetrics and Gynaecology and Royal College of Physicians of Ireland. Interim clinical guidance on pathway for management of fatal fetal anomalies and/or life-limiting conditions during pregnancy: Termination of pregnancy. Dublin, Ireland 2020.
- 17 Clarke V, Braun V. Teaching thematic analysis. *Psychologist* 2013; 26:120–3.
- 18 Holloway I, Galvin K. *Qualitative research in nursing and healthcare*, 4th edn. Chichester, West Sussex, UK; Ames, Iowa: John Wiley & Sons Inc; 2017.
- 19 Power S, Meaney S, O'Donoghue K. Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey. *Int J Palliat Nurs* 2020;26:156–66.
- 20 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 21 Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health* 2019;11:589–97.
- 22 Egan H, Keyte R, McGowan K, Peters L, Lemon N, Parsons N, et al. You Before Me': A Qualitative Study of Healthcare Professionals' and Students Understanding and Experiences of Compassion in the Workplace, Self-compassion, Self-care and Health Behaviours. *Health Prof Educ* 2019;5:225–36.
- 23 Baillie J, Anagnostou D, Sivell S, Van Godwin J, Byrne A, Nelson A. Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliat Care* 2018;17:60.
- 24 Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods* 2017;16:1–13.
- 25 Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health* 2019: 1–16. <https://doi.org/10.1080/2159676X.2019.1704846>.
- 26 McNamara K, Meaney S, O'Donoghue K. Intrapartum fetal death and doctors: a qualitative exploration. *Acta Obstet Gynecol Scand* 2018;97:890–8.
- 27 Cullen P. National Maternity Hospital orders review into abortion. The Irish Times. 2019.
- 28 Luce A, Cash M, Hundley V, Cheyne H, van Teijlingen E, Angell C. "Is it realistic?" the portrayal of pregnancy and childbirth in the media. *BMC Pregnancy Childbirth* 2016;16:40.
- 29 Bick D. Media portrayal of birth and the consequences of misinformation. *Midwifery* 2010;26:147–8.
- 30 Power S, Meaney S, O'Donoghue K. The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland. *Prenat Diagn* 2020;40:549–56.
- 31 Wilkinson D, de Crespigny L, Xafis V. Ethical language and decision-making for prenatally diagnosed lethal malformations. *Semin. Fetal Neonatal Med* 2014;19:306–11.
- 32 Dommergues M, Mandelbrot L, Mahieu-Caputo D, Boudjema N, Durand-Zaleski I, foetale ICIG-Cdm. Termination of pregnancy following prenatal diagnosis in France: how severe are the foetal anomalies? *Prenat Diagn* 2010;30:531.
- 33 Orr J. *Abortion wars: The fight for reproductive rights*, 1st edn. Bristol: Policy Press; 2017.
- 34 Lotto R, Smith LK, Armstrong N. Clinicians' perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study. *BMJ Open* 2017;7:e014716.
- 35 Garne E, Khoshnood B, Loane M, Boyd PA, Dolk H, Grp EW, et al. Termination of pregnancy for fetal anomaly after 23 weeks of gestation: a European register-based study. *BJOG* 2010;117:660–6.
- 36 Hayes-Ryan D, McNamara K, Russell N, Kenny L, O'Donoghue K. Maternity Ultrasound in the Republic of Ireland 2016; A Review. *Ir Med J* 2017;110(7):598.
- 37 Royal College of Obstetricians and Gynaecologists. *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales REPORT OF A WORKING PARTY*. United Kingdom: Royal College of Obstetricians and Gynaecologists; 2010.
- 38 Department of Health and Social care. Abortion Statistics, England and Wales: 2018. UK. 2019.
- 39 Fay V, Thomas S, Slade P. Maternal–fetal medicine specialists' experiences of conducting feticide as part of termination of pregnancy: a qualitative study. *Prenat Diagn* 2016;36:92–9.
- 40 Farsides B, Williams C, Alderson P. Aiming towards "moral equilibrium": health care professionals' views on working within the morally contested field of antenatal screening. *J Med Ethics* 2004;30:505–9.
- 41 Crowe L, Graham RH, Robson SC, Rankin J. Negotiating acceptable termination of pregnancy for non-lethal fetal anomaly: a qualitative study of professional perspectives. *BMJ Open* 2018;8:e020815.
- 42 Habiba M, Da Fre M, Taylor DJ, Arnaud C, Bleker O, Lingman G, et al. Late termination of pregnancy: a comparison of obstetricians experience in eight European countries. *BJOG* 2009;116:1340–9.
- 43 World Health Organization and Department of Reproductive Health and Research. *Safe abortion: technical and policy guidance for health systems*, 2nd edn. World Health Organization: Geneva: 2012.
- 44 BBC News. Abortion: Assembly to debate recent changes to NI laws. Accessed at: <https://www.bbc.com/news/uk-northern-ireland-52878836>. 6th June 2020; 2020.
- 45 Pocklington D. *Abortion law – Northern Ireland*. Cardiff: Newstex; 2019.
- 46 Savage W. Debate: Will abortion law in Northern Ireland finally move into the 21st century? *Public Money & Management*. 2019;1–2.
- 47 Berer M. Abortion Law and Policy Around the World. In Search of Decriminalization. *Health Hum Rights* 2017;19:13–27.
- 48 Chavkin W, Stifani BM, Bridgman-Packer D, Greenberg JMS, Favier M. Implementing and expanding safe abortion care: An international comparative case study of six countries. *Int J Gynaecol Obstet* 2018;143(S4):3–11.
- 49 Albaladejo A. A "witch hunt against poor women": across the americas, abortion laws are harming health and security. *World Policy J* 2016;33:26–34.
- 50 Institute of Obstetrics and Gynaecology and Royal College of Physicians of Ireland. Interim clinical guidance on pathway for management of fatal fetal anomalies and/or life-limiting conditions during pregnancy: Termination of pregnancy. Dublin, Ireland 2019.
- 51 Heazell AEPD, Siassakos DMD, Blencowe HM, Burden CMD, Bhutta ZAP, Cacciatore JP, et al. Stillbirths: economic and psychosocial consequences. *Lancet* 2016;387:604–16.

- 52 Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy Childbirth* 2016;16:16.
- 53 Shorey S, André B, Lopez V. The experiences and needs of healthcare professionals facing perinatal death: A scoping review. *Int J Nurs Stud* 2017;68:25–39.
- 54 Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. *BJOG* 2014;121:1020–8.
- 55 West CP, Dyrbye LN, Rabatin JT, Call TG, Davidson JH, Multari A, et al. Intervention to promote physician well-being, job satisfaction, and professionalism: a randomized clinical trial. *JAMA Intern Med* 2014;174:527–33.
- 56 West CP, Dyrbye LN, Erwin PJMLS, Shanafelt TDP. Interventions to prevent and reduce physician burnout: a systematic review and meta-analysis. *Lancet* 2016;388:2272–81.
- 57 Steen SE. Perinatal death: bereavement interventions used by US and Spanish nurses and midwives. *Int J Palliat Nurs* 2015;21:79–86.
- 58 Puia DM, Lewis L, Beck CT. Experiences of obstetric nurses who are present for a perinatal loss. *J Obstet Gynecol Neonatal Nurs* 2013;42:321–31.
- 59 Britton LE, Mercier RJ, Buchbinder M, Bryant AG. Abortion providers, professional identity, and restrictive laws: a qualitative study. *Health Care Women Int* 2017;38:222–37.
- 60 Chiappetta-Swanson C. Dignity and dirty work: nurses' experiences in managing genetic termination for fetal anomaly. *Qual Sociol* 2005;28:93–116.