

“I was in no man’s land” - Parental Experiences of Termination of Pregnancy for Fetal Anomaly in Changing Legal Contexts on the Island of Ireland

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Research Article

Keywords: congenital anomaly, pregnancy loss, termination of pregnancy for fetal anomaly (TOPFA), abortion, legal context, health and wellbeing

Posted Date: October 28th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10928788/v1>

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Additional Declarations: No competing interests reported.

Abstract

Background

Although termination of pregnancy for fetal anomaly (TOPFA) has become more accessible following recent legal reforms in Ireland and Northern Ireland, little is known about how changing legal frameworks have influenced parents' healthcare experiences.

Aim

To explore the impact of legal context on the healthcare experiences of parents on the island of Ireland who had a termination of pregnancy for fetal anomaly.

Methods

A qualitative study was conducted between 2020 and 2021. Data were collected through semi-structured interviews and written narrative accounts from parents who had experienced TOPFA. Interviews were audio-recorded, transcribed verbatim and analysed using template thematic analysis.

Results

This paper reports one overarching theme examining the impact of legal context on access to and experiences of TOPFA care. Six sub-themes were identified: (1) Care refused and split between health services; (2) Time of change; (3) Legislative grey area in Ireland; (4) Impact of legal changes on the nature and quality of services; (5) Conscientious objection and clandestine practice; and (6) Policy implications for acknowledgment of baby and recognition of loss. While legal reform improved access to care for many parents, significant inequities remained. Parents described the distress associated with travelling abroad for care, fragmented healthcare pathways, uncertainty arising from legislative ambiguity, inconsistent service provision and barriers created by conscientious objection.

Conclusion

Legal context continues to have a profound influence on parents' access to and experience of TOPFA care. Although recent legislative changes have reduced the need for travel for some families, ongoing challenges relating to legislative limitations, service development and inconsistent implementation continue to affect equitable access to compassionate, high-quality care.

Patient and Public Contribution:

A study advisory group comprising individuals with lived experience of TOPFA, a mental health professional, and a representative from a relevant third-sector organisation contributed throughout the research process. Members informed the study design, recruitment materials, interview topic guide, interpretation of findings, and dissemination activities.

1. BACKGROUND

Congenital anomalies include a wide range of conditions, present at birth, which often have significant consequences for the affected baby and their family (von der Lippe et al., 2022). Advancements in diagnostic technologies and improved clinical testing have led to higher detection rates of congenital anomalies during the antenatal period (Zhang et al., 2023). However, detection rates vary globally (Braz et al., 2018), highlighting persistent health inequities (Bai et al., 2024).

Some conditions are treatable with medical or surgical interventions, while others are permanent and potentially life-threatening and/or untreatable (Varthaliti et al., 2025). The yearly number of births associated with congenital fetal anomalies worldwide is approximately 3–6% (World Health Organization (WHO), 2023). However, there are issues with the collection of data and accurate recording of cause of death which makes global comparisons difficult (Xie et al., 2025).

1.1 Termination of pregnancy as an option following diagnosis

Although detection rates for fetal anomalies have improved, in-utero treatment options for major anomalies remain limited, leaving parents with few choices following diagnosis (Antiel et al., 2018). Typically, parents must decide whether to continue the pregnancy or seek a termination of pregnancy (TOP), where permitted. Currently, TOP is broadly legal in approximately 60% of countries worldwide (Center for Reproductive Rights, 2025). Despite a global trend toward the liberalization of abortion laws, 40% of women of reproductive age reside in countries with restrictive legal frameworks (Center for Reproductive Rights, 2025). Laws allowing TOP in cases of fetal anomaly vary widely in scope and stipulations. Some jurisdictions limit access to cases involving non-viable pregnancies or fatal fetal impairments, while others require that the condition be classified as “serious” or “permanent.” In contrast, some countries adopt a broader interpretation of what constitutes a fetal anomaly. The absence of universally accepted medical definitions contributes to legal ambiguity, resulting in inconsistent access to and availability of TOP.

Legal differences regarding the type and degree of severity of congenital anomalies considered to be grave enough to access a termination of pregnancy for fetal anomaly (TOPFA) mean that obtaining accurate data is challenging (Berer, 2017; Singh et al., 2017). European figures for TOPFA suggest a prevalence rate of 4.6 per 1,000 births (Boyle et al., 2018), higher than the prevalence rate of stillbirths for congenital anomalies (0.6 per 1,000) but comparable with the overall stillbirth rate in UK which was 4.0 per 1,000 births in 2022 (Office for National Statistics, 2023).

1.2 Termination of pregnancy as an option in Ireland and Northern Ireland

In recent history, laws governing TOP in both the Republic of Ireland (Ireland) and Northern Ireland (NI) have been described as amongst the most restrictive in the world (Bloomer et al., 2022). Most women and girls from both jurisdictions who wished to access a TOP (for any reason), had to travel to other regions to access abortion care or obtain abortion medication from providers who were able to supply it via post (Taylor et al., 2020).

In Ireland in May 2018, a public referendum saw 66.4% of the Irish electorate vote to repeal the 8th Amendment to the Constitution of Ireland, which acknowledged equal right to life of the unborn fetus and the pregnant woman (Field, 2018). Under new legislation enacted in December 2018 (the Health (Regulation of Termination of Pregnancy) Act, 2018) abortion was legalised in Ireland and from January 2019 became available free of charge. The guidelines in the 2018 Act (Section 11) state that two medical practitioners must be of the agreed opinion, in good faith, that the baby will die during pregnancy, labour or within twenty-eight days of birth for a woman to be eligible to receive a TOPFA in Ireland (Institute of Obstetricians and Gynecologists, 2019). This clause means some women who receive a fetal anomaly diagnosis in Ireland may still need to travel to access TOPFA care.

TOP has been, and continues to be, a highly politicised and divisive issue in NI (Pierson et al., 2022). Although part of the United Kingdom (UK), the 1967 and 1990 Acts governing TOP in England, Scotland and Wales, did not extend to NI (Thompson, 2016). Until 2019 The Offences Against the Person Act of 1861 (Sections 58 and 59) made procuring a miscarriage in NI a criminal offence apart from in extremely limited circumstances. A Government inquiry (CEDAW, 2019) was key in supporting the case for change and reform of abortion legislation in NI. Reform was championed and progressed by a Labour MP through Westminster parliamentary processes in the absence of a functioning NI Assembly (Bloomer et al., 2022). Consequently, abortion in NI was decriminalised in October 2019 following the introduction of the Northern Ireland (Executive Formation etc) Act (2019). The Abortion (Northern Ireland) (No. 2) Regulations (2020) were laid before the NI Assembly in March 2020 and a framework for lawful abortion services came into effect on 31st March 2020.

In countries where abortion is or has been criminalised or severely restricted, little is known about the healthcare experiences and needs of parents experiencing a TOPFA (Duffy et al., 2023; Power et al., 2021a; b). Given the relatively recent establishment of TOPFA services in Ireland and NI we aimed to explore the TOPFA healthcare experiences of parents, as well as gathering insights into the effectiveness and efficacy of the new legal frameworks in place.

2. METHODS

2.1 The Study

This study was an exploration of the healthcare experiences of parents from the island of Ireland who had a TOPFA. Within health and social care there has been an increasing recognition of the value of listening to individual experiences of service users to inform both policy decisions and improvements in clinical practice (Petty et al., 2012). A qualitative methodological approach to explore this phenomenon was therefore considered appropriate. This approach enabled an in-depth exploration and understanding of the studied phenomenon from each individual's perspective (Carter and Little, 2007). Given the significance and relevance of historical, cultural, social and legal factors on individual experiences of TOPFA, it was deemed pragmatic to take this approach.

This research study was part of a PhD project funded by the Northern Ireland Department for the Economy. The PhD researcher [SH] is a registered midwife. Chief investigator and primary academic supervisor [ÁA] is a social psychologist who specialises in sexual and reproductive health research.

2.2 Participant recruitment and selection

2.2.1 Personal and Public Involvement

Personal and Public Involvement (PPI) ensures that voices of those with lived experience inform improvements and developments in service provision (Bagley et al., 2016). To ensure this study was managed appropriately and sensitively, we established a small advisory group (AG). Members included women who had experience of a diagnosis of a fetal anomaly and termination of pregnancy, a registered mental health counsellor, and a representative from the charity, Antenatal Results and Choices (ARC). The AG had a key role in the planning, design and quality assurance of this study, for example, co-design of recruitment materials and interview guides as well as supporting recruitment.

2.2.2 Recruitment and Sampling

The study aimed to recruit 30 parent participants as units (i.e. 15 women who experienced the pregnancy and 15 partners). Individuals (either women or men) were not excluded and the aim of 30 parent participants was determined as a flexible rather than a definite target. The inclusion criteria for parents were broad to ensure a representative sample could be obtained as it was recognised that those experiencing TOPFA represent a very small percentage of births and more restrictive criteria may have made recruitment difficult. Participants were eligible to take part if they were over 18, had a TOPFA in the past 10 years and, at the time of diagnosis, were living in Ireland.

Purposive and snowball sampling, which are recognised approaches in data sampling in the study of hidden populations, were used in this study due to the sensitive nature of the topic (Holloway and Galvin, 2017). A recruitment poster and recruitment animation video were designed and distributed on social media platforms and through key stakeholder groups and organisations as gatekeepers. Parents who took part also shared details through word of mouth with other potential participants.

2.2.3 Data collection

Data were collected between November 2020 and August 2021. Parents were offered the option to take part in a semi-structured interview (individually or couple dyad) and/or to submit a written narrative account of their TOPFA experience. Interviews provided flexibility and freedom to the researcher to delve deeper into thoughts, feelings and areas which arose during an interview (Holloway and Galvin, 2017). Narrative account was offered as an option to complement interview data or as an alternative if a participant was unable to attend an interview or preferred the written medium. A semi-structured interview topic guide was developed specifically for this study in consultation with the AG and informed by relevant literature (Heaney et al., 2022) (Supplementary File 1). A pilot interview was carried out with a parent who had experienced a TOPFA, allowing the researcher to assess the length of time it would take to conduct the interview, as well as identify the types of follow-up questions that would be helpful to explore the topic area more fully.

A total of 25 interviews were conducted (19 individual and 6 couple dyad), and average length was 1 hour 31 minutes. All interviews were carried out by the first author [SH], audio recorded and transcribed verbatim. Data were managed in the software system, NVivo 12 (QSR International, 2018). To strengthen study credibility member checking was offered to all participants (Bryman, 2016). Of the 33 parent participants, 22 wished to receive a member check. A total of seven narrative accounts were received, two from participants who were not interviewed and five from individuals who had also been interviewed.

2.2.4 Data analysis

We used Thematic Template Analysis following the seven-step recursive process developed by King and Brooks (2017): (1) researcher immersion in data through critical reading of transcripts, interview field notes and reflections; (2) identification of a priori themes and inductive line-by-line preliminary coding; (3) initial codes clustered into meaningful groups; (4) after coding five transcripts and reviewing and clustering codes, an initial template was developed. This template was applied to five more transcripts; (5) following Step 4, codes were reviewed again, and the template further developed. This revised template was applied to five further transcripts and revisions made; (6) the template developed in Step 5 was then applied to the entire data set; (7) findings were written up for presentation.

During step 5 of the analysis process, detailed above, the researchers noted emerging themes organically represented different levels within healthcare systems. At this stage, Ecological Systems Theory was useful in furthering the organisation and structuring of the data (Bronfenbrenner, 1977; 1986). From this a modified Socio-ecological model (Fig. 1) was applied to this study and used as a framework to structure parents' findings (Wold and Samdal, 2012).

Figure 1: Modified SEM model

2.2.5 Ethical considerations

Prior to recruitment, ethical approval was obtained from Queen's University Belfast Faculty of Medicine, Health and Life Sciences Research Ethics Committee in May 2020 (Ref: MHLS 20_40). Following confirmation of eligibility, study information was shared and an opportunity for questions or clarifications provided. For those who wished to proceed, a time was arranged for data collection and informed written consent was obtained from each participant prior to the commencement of interview. Participants also verbally confirmed consent before beginning an interview. Parents were advised of their right to withdraw from the study without reason at any stage. Each participant was assigned a unique identifier code so that their data was pseudonymised following data collection; PW represents 'participant woman' and PP represents 'participant partner'. A Study Distress Protocol was designed as a safeguard for participants should their participation resulted in emotional distress, and all participants were signposted to support organisations.

3. RESULTS

3.1 Participants

Thirty-three parents took part in this study, 23 mothers and 10 fathers, representing 23 TOPFA experiences. Participant characteristics are displayed in Table 1.

Table 1
Parent participant characteristics

Characteristic	No. of Participants
Parents	
Women	23
Men	10
Total	33
Jurisdiction of Experience	
Republic of Ireland	22
Northern Ireland	11
Total	33
Legal Context of Experience (by Jurisdiction)	
Republic of Ireland Pre Law Change	6
Republic of Ireland Post Law Change	16
Northern Ireland Pre Law Change	3
Northern Ireland Post Law Change	8
Total	33
Gestation at TOPFA	
<13 weeks	0
13–16 weeks	3
16–20 weeks	5
20–24 weeks	17
24–28 weeks	7
>28 weeks	1
Total	33
TOPFA Location	
Care in Northern Ireland/Republic of Ireland	18
Travelled for TOPFA*	15
Total	33
*Travelled for TOPFA	
Pre-law change	9 (3 – NI; 6 – Ireland)
Post-law change	6 (6 - Ireland)
Total	15
TOPFA Procedure	
Medical induction of labour and vaginal birth	30
Surgical procedure	3
Total	33

3.2 Themes

We identified five main themes and 19 sub-themes in our study analysis (see Table 2). For this paper, we have chosen to report on one of the main themes (Theme 5) due to the in-depth nature of the analysis and vast amount of data. This decision ensured we can include rich descriptions and full quotations from participants. Findings related to Theme 2 are published elsewhere (Heaney et al., 2024).

Table 2
All themes and sub-themes

Themes	Sub-themes
1. An experience unplanned and unwanted	1. "It was just a blur" - Reactions to news of an anomaly 2. "There is no choice, it's Sophie's choice" - TOPFA decision making: stigma, guilt and shame 3. "Saying hello and goodbye at the same time" - The birth experience 4. "Our hearts just shattered" - Loss and grief
2. Quality of relationships and interactions with healthcare professionals	5. "I'm really sorry we had to meet this way, but it's been lovely meeting you" - Compassionate and non-judgemental care 6. "We knew that our daughter would be treated like a person" - Care for baby and facilitation of memory making 7. "I am a dynamic person, I can handle knowing what's going on" - Parents' value of and need for effective information and communication 8. "We had an anchor around us, a consistent anchor of people" - Continuity of care
3. Perception of service quality, effectiveness and appropriateness	9. "The service needs to be centered around women and what they need and what they want and respect for their choices" – Efficient and responsive service 10. "They did not seem to know how to deal with it" – Clear and integrated care pathways 11. "A waiting room full of pregnant women" – Sensitive care environments
4. Social supports in the community	12. "When you're in that tunnel of darkness, you need people with experiential knowledge" - Baby loss groups and lived experience 13. "Shone a light on the people who are really important to us" - Personal and social network
5. Impact of legal context on accessibility to and experience of TOPFA care	14. "I was in no man's land, I don't belong anywhere" – Care refused and split between health services 15. "Catching up with the rest of the world" – Time of change 16. "It's not looking as good as we thought we fought for" – Legislative grey area in Ireland 17. "It was such a relief to know I could be looked after in Ireland" - Impact of legal changes on the nature and quality of services 18. "Any doctor with ideologically compromised morals can put you through the same hell that we went through" – Conscientious objection and clandestine practice 19. "She doesn't legally exist anywhere" – Policy implications on acknowledgment of baby and recognition of loss

In this paper we present Theme 5: *Impact of legal context on accessibility to and experience of TOPFA care*. There were six corresponding sub-themes (see Table 2: Sub-themes 14–19). This theme sits within the *Policy* level of the SEM. Policy within the SEM model relates to governmental laws, policies and infrastructure which shape the nature, funding, availability, and accessibility of services within a country or legal jurisdiction. The 33 parents in this study shared TOPFA experiences reflective of care both pre- (n = 9) and post-legislation (n = 24) changes in both jurisdictions and their accounts described experiences of care received both at home in NI or Ireland and England.

3.2.1 "I was in no man's land; I don't belong anywhere" – Care refused and split between health services

Pre-law change, all participants (N = 9) travelled to access TOPFA care in England. The dominant feelings of all those parents were of distress, anger, fear and abandonment by their healthcare professionals (HCPs), their hospital and also by their country, *"I felt so wronged and so abandoned"* (PW06). For all, it compounded what was already a difficult and traumatic experience, creating *"a nightmare on top of a nightmare"* (PW06).

Several alluded to the fact that many women from Ireland travelled to receive this care, *"I just thought it was very sad, the room that they use, is actually, the nickname is the Shamrock Suite, because that's what they use for the Irish girls"* (PW04). One woman reflected on her arrival to the English hospital:

"We went in and up to the reception, I asked for the fetal medicine unit, I'm sure they knew what we were there for, like Irish accents, rocking in first thing on Monday morning looking like you haven't slept in a year" (PW07).

For the women who travelled to England the legal situation left them feeling a strong sense of shame, isolation, stigma (PW20; PW23), and of feeling like *"criminals"* (PP06):

"I really wish we could have been supported here. It has been the most stressful and heart-breaking experience of my life [...], travelling like this made me feel shame [...] I have felt suicidal. If I could have been looked after here maybe I wouldn't feel this way" (PW23).

Parents who had to travel for a TOPFA described how poorly supported they felt when their care was split between two health services *"it was hard 'cause you're kind of neither here nor there"* (PW01). Many felt they were no-one's responsibility:

"It felt like I was in no man's land. Like I don't belong anywhere [...] like I've been released from my hospital and I'd nowhere else to go" (PW07).

The feelings of being let down and abandoned by the healthcare system particularly in Ireland was further exacerbated on discharge from hospital in England:

"They said 'you can go home', but I was like we're not really going home yet are we [...] you were kind of in this limbo of just like well like I've just had a baby, but I'm not under the care of any maternity services. So what do I do?" (PW08).

Some parents felt that having to travel to get a TOPFA impacted negatively on the time they might have had to focus on their baby and the opportunity to grieve and mourn for the loss to come as their time was dominated by the practicalities of having to self-organise their care, including travel, accommodation, and childcare for other children:

"If we had been at home, it would have been different that you would have had that time in that interim period to acknowledge the loss and acknowledge that process of actually saying goodbye. Whereas because we were kind of in this like kind of trauma of having to travel and be away from home and go through all of that" (PW08).

The costs of having to travel for care was mentioned by some parents and was seen as an additional burden to worry about (PW01; PW02; PW06; PW18; PP05; PP06; PP08). Costs included travel, accommodation and the TOPFA procedure. Several received financial support from family members to help with the costs (PW02; PW06; PW15), while others used their own savings, including one couple who used their savings for their wedding, *"we were actually saving to get married at the time, so we had money there" (PW07).*

3.2.2 "Catching up with the rest of the world" – Time of change

Parents who experienced their TOPFA prior to legal changes (n = 9) commented on their contribution to changing things in their respective jurisdictions by sharing their stories, taking part in campaigning, or giving evidence to courts and committee enquiries. For them there was a sense of joy when the law changed, *"it was a massive sense of celebration I felt when that changed. I thought this is good, thankfully, finally you know catching up with the rest of the world" (PW06).* Some acknowledged that for many women the repeal of the eighth constitution has *"helped thousands of women in Ireland which is absolutely amazing" (PW23)* and has legally created access to TOP for pregnancies up to 12 weeks in Ireland so women no longer have to travel to England or elsewhere. Participants in NI assumed legal changes had meant huge progress for reproductive rights for women, however were 'confused', 'angry' and felt 'let down' that services did not initially receive funding or commissioning from the Department of Health NI [services were not fully commissioned in NI until late 2023] and several called for the government to 'be held more accountable'.

Several parents reflected on the period of legal change, particularly in Ireland, not ever imagining that the law change would impact on their lives:

"I didn't really relate it [referendum] to myself I actually related it to my daughters, and that was my ultimate decision about if they were ever in a position where they have to make a choice what was the right decision for them? And so that's actually how I made my decision on how I voted and not even thinking that it ever would come to me, the arrogance of having two healthy pregnancies you never think that there's going to be something goes wrong" (PP01).

For many the repeal of the eighth amendment to the constitution was seen as much about the rights of women in Ireland as about access to abortion services:

"Having been pregnant during the referendum and argued with many on the rights of women during this time I felt this was another telling sign that in this country women, and especially pregnant women are still second-class citizens. Never thinking [...] about the woman who receives life altering and devastating news at their 20-week scan would turn out to be me" (PW20).

3.2.3 "It's not looking as good as we thought we fought for" – Legislative grey area in Ireland

For N = 24 parents, their TOPFA experience was after law change in their respective jurisdiction. For those people who supported, campaigned, or voted for changes in IE, it came as a shock that the law they had voted for did not guarantee a TOPFA and that many women in these circumstances still needed to travel to England:

"And then my husband was like, 'do you mean we have to travel?' And she [HCP] was like, 'yeah, you'll have to go to London'. And we were just like, what, why? We've voted for this. We repealed the 8th [...] we were kind of left stunned" (PW18).

"There are only a couple of conditions that you're basically guaranteed a compassionate termination [...] it's not looking good unfortunately; it's not looking as good as we thought we fought for" (PW15).

While participants believed access to TOP for women with pregnancies up to 12 weeks in Ireland had improved post law-change, there was disbelief, dismay and a similar sense of abandonment to those who had had to travel to England for a TOPFA pre-law change:

"I felt hopeless about this country, I had given up on dear old Eire [Ireland]– she had nothing to give me. I knew now what the women of the 8th meant when they said they felt abandoned by their country" (PW20).

There was also a feeling of injustice that there was no help for couples in their own homeland:

"With the most wanted and loved unborn little baby who had been dealt the cruellest of hands [...] people at their lowest and most vulnerable [...] this needs to change, Ireland needs to support its people going through this" (PP08).

The requirement for two medical practitioners to agree that the baby will die before or within 28 days of birth was viewed as wrong and as Ireland “*paying lip service*” (PP05) to providing access to TOP as this clause allows people to “*slip through the cracks*” (PW02). The fact that some women were unable to access a TOPFA in Ireland post-law change and had to travel to England even in cases that “*are extremely severe and in the end fatal*” but where “*doctors cannot say with certainty that the baby will live or die within 28 days of birth*” (PW15) was commented on as being divisive:

“The only women that are traveling are ones that are in the grey area and that is so much more stigmatising for women right now [...] I actually feel it was better eight years ago than it is now for women because then everyone had to travel, we were all in literally the same boat. Whereas now we’re divided, divided between fatal and not fatal. And it’s tough, it’s really tough” (PW07).

Several participants commented on this ‘grey area’ and how they wished for the worst possible scenario, “*I’m actually wishing that it is going to come back with a fatal diagnosis because it’s too grey at the moment*” (PW02) or as one parent said the diagnosis was “*not fatal enough*” (PW23). The wish for a poorer prognosis was echoed in other parents’ accounts because they so wanted to receive care at home, “*I was left wishing that we’d had a worse off diagnosis, so that we could be looked after at home. Is that not just so wrong?*” (PW13). Those that got a poor prognosis counted themselves lucky:

“We were just lucky enough that our prognosis was bad enough to fit the Irish Statute” (PP07).

3.2.4 “It was such a relief to know I could be looked after in Ireland” - Impact of legal changes on the nature and quality of services

All parents post-law change in NI (N = 8), who opted for a TOPFA were able to be cared for at home and generally reported a positive experience of the service they received. Of the ten parents from Ireland who received their care at home post law change, most felt that Ireland was not prepared:

“The country wasn’t prepared [...] I just feel we had all of Ireland’s inexperience to deal with. It was the first time for everyone. It just to me, really heightens the experience” (PW03).

Of the ten participants from Ireland who received care at home, five received all their care in their local hospital and five were transferred to another hospital to receive specialist antenatal input. One of those five who had their antenatal care transferred were able have their birth in their local hospital. However, of the other four couples, two were unable to access labour and birth care at their local hospital as it had not yet established a TOPFA service and the other two were refused care in their local hospital. Those who received care in their local hospital were more positive than those who had their care transferred.

All parents in NI received a medical induction of labour at their local hospital and none expressed issues with accessing services. Participants were grateful, and some suggested “*lucky*” (PP03) to have been able to receive their care at home in NI, noting, “*it just seems crazy that you would have had to have gone to England [if experience was a year previous] to go through that*” (PW10).

3.2.5 “Any doctor with ideologically compromised morals can put you through the same hell that we went through” – Conscientious objection and clandestine practice

Many participants, mainly from Ireland commented on how the legislative changes appeared to have heightened fear of prosecution for HCPs. Some felt the requirement for two medical practitioners to agree, that the baby would die within or before a specified time limit was potentially open to abuse by medical practitioners as “*everything can be debatable by any doctor, as we experienced*” (PP10). Another participant felt this clause offered consultants a “*get out of jail free card because they are not God [...] they can’t tell you how long a child is going to live*” (PW20). They queried why consultants should be the ones “*to determine the quality of life*” (PW20) for a child that they were not responsible for as a parent.

Parents gave a number of examples of what they considered to be defensive practice by HCPs such as giving women their own files to send to a hospital in England because “*we can’t send it*” (PW04), or writing cryptically in notes, for example, “*refer to UK?*” with no direct reference to what the referral was for (PW20). These actions were interpreted as HCPs trying to ensure there could be no link made with them helping women to obtain a TOPFA.

“The whole situation here, it’s all clandestine, it’s all cloak and dagger stuff. They need to be more transparent” (PW04).

Parents said they felt like ‘criminals’ when things happened in a clandestine manner magnifying their sense of isolation, fear and shame. This theme about criminalisation and fear of prosecution was referenced by several parents who felt it “*compounded the already existing tragedy*” (PP06) and created a culture of defensive and unhelpful practice within institutions because staff “*would be worried about getting sued for making recommendations of what to do and where to go*” (PP05). A father reflected, “*effectively we were criminals, and I suppose the doctors were also possibly criminal as well*” (PP06).

Conscientious objection (CO) of HCPs to TOPFA was identified as an issue by several participants with the view that it made, “*the situation ten times worse*” (PW04). One woman said, “*my consultant here who’s [...] against the repeal of the 8th, [...] handed me my file and said I can’t look after you*” (PW13). There was consensus that HCPs who have a conscientious objection should not be involved in the care of families going through a TOPFA:

“I know we all have our thoughts about things but if you are really that way inclined, you’re in the wrong job” (PW04).

“I think that for any service that it would be very important that only people who are supportive would be involved in any team because it’s subtle, but it becomes very obvious very quickly who’s judgmental and who’s not” (PW08).

One couple (PW20, PP10) felt that a senior fetal medicine specialist actively obstructed their care and the care of other women, advising they would not be able to access care in Ireland:

"I fear that there was a definite vein of activism here and a reluctance to give me the treatment I needed [...] And he has sent other women out the door of that hospital, women that I now know that have had to go to the UK for fatal fetal abnormalities, and they could have been taken care of here" (PW20).

While most people's experiences were based on interactions with individual HCPs, some parents also reflected on how it was *"the politics of the law that's in place"* (PP05) that influenced practice within institutions in Ireland (PP05; PW20; PP10). The leadership and culture within institutions impacted on the nature and quality of services:

"It's not just the hospital, it's not just that consultant, it's a culture [...] and the legislation is fielding them [...] because it's not fit for purpose" (PW20).

3.2.6 "She doesn't legally exist anywhere" – Policy implications on acknowledgment of baby and recognition of loss

This sub-theme includes issues relating to the transport of the baby's body, maternity leave and pay, registration of birth and death, and a ceremony to mark the death of their baby.

While it is not clear if parents were advised that a birth would not be legally recorded pre-24 weeks gestation, some parents reflected they would have greatly valued some form of formal recognition of the birth of their baby, *"something that really still bothers me is that she doesn't legally exist anywhere"* (PW07). One mother said they would have considered delaying treatment to be able to do so:

"It was a day [baby was born at 23 + 6 weeks gestation] and I think if I'd known that, I possibly would have said no I'll happily wait to register her, so at least she's there, somewhere" (PW07).

Laws and practicalities relating to how bodily remains could be transported was another traumatic experience for parents who received care away from home. Their distress was compounded by a fear of judgement and criminalisation, *"there was just an element of like fear and just the unknown the whole time [...] we felt like we were smuggling drugs"* (PW04). A lack of information or support around the practicalities of bringing a baby's body home or how best to preserve the baby's body during transit also proved stressful. One mother spoke of having to stop at a grocery shop on the way home to get "fresh ice" to preserve her baby's body (PW13). Others shared issues about organising transport:

"I remember ringing the places to bring the body of our daughter home [...] someone answering the calls in the [airline] call centre [...] was extremely rude after she discovered our circumstances" (PP10).

Having a ceremony to mark the death of their baby was important to many parents. Hospital Chaplains were identified as a positive support by almost all parents, whether cared for at home or away, who used this service. For those who were away from home, the absence of family and friends, an important source of comfort and support at the time of a loss was regretted:

"Unfortunately, due to the cruelty of this country at that time, none of her family could meet her and say goodbye" (PW15).

Some parents were unable to attend the baby's funeral as they couldn't afford to travel back to England for it:

"I sometimes can't believe I actually had to do this, I had to leave my baby in another country. How cruel it is that we had to do this, it actually leaves me speechless [...] we arranged [baby's] funeral from the prayers right to the music I wanted to be played [...] We couldn't go because we simply couldn't afford to" (PW15).

Another area where public policy and law affected parents' perceptions of how their loss was treated relates to maternity leave and pay. If the loss of a baby is before 24 weeks women are not entitled to any paid maternity leave, and if the loss is after there is some form of maternity pay package available:

"It's almost like maternity eligibility at 24 weeks like if you get to the point where you're taking maternity like does it further justify [...] You know I'm off on maternity because I had a baby as opposed to off sick because I lost a baby" (PP11).

4. DISCUSSION

Political, legal, economic and socio-cultural factors have traditionally played a more minor role in health research studies (Mengesha et al., 2017). However, the findings in this study highlight how pivotal these are on TOPFA provision and on the impact of individuals' healthcare experiences of TOPFA (Heaney et al., 2022). These will be explored in this section as they provide a greater insight into the complex interplay and dynamics between structural factors, healthcare services, professional practice and people's individual healthcare experiences (Holder and Ramagem, 2012).

4.1 The impact of the law on access to TOPFA healthcare

Abortion is among a wide range of women's issues such as equal pay, sex, contraception, childcare, domestic violence, forced marriage, and female genital mutilation that have required political intervention to achieve change (United Nations Population Fund, 2014). The right of a woman or girl to make decisions about her own body and reproductive functions is recognised as fundamental to her human rights to equality and privacy (Guttmacher Institute, 2022a). In spite of legal changes, TOPFA remains a sensitive, controversial and divisive global issue (Pierson et al., 2022). As demonstrated in the current study, even when abortion services are decriminalised and funded publicly, there remains a strong stigma and anti-abortion lobby (Statham and Ringrow, 2022), and future challenges for parents and healthcare professionals will undoubtedly persist.

A central concern for healthcare relates to the ambiguity of the definition of a 'fatal' diagnosis required by legislation in many countries. A review of perinatal deaths in Ireland from 2011–2016 identified that less than half of the congenital anomaly diagnoses would be classified as *fatal* within current Ireland legal

statue, however, all resulted in death, highlighting the complexity of this area (Power et al., 2020). Support groups for parents who receive a fetal anomaly diagnosis in Ireland have called the current law '*not fit for purpose*' (TFMR Ireland, 2022, pg. 4) and have called for this clause to be amended to permit '*serious*' anomalies as well as '*fatal*' (TFMR Ireland, 2022).

As noted, this '*fatal*' diagnosis has implications for access to healthcare. The number of women travelling from Ireland to access a TOP in England and Wales for any reason has reduced since 2018, following the legal changes, with a corresponding increase in the TOP rate in Ireland from 6577 in 2020 to 10,852 in 2024 (Department of Health and Social Care, 2021; 2022; Department of Health Ireland, 2020; 2025). The number of women accessing a TOP due to fetal anomaly in Ireland over the same period has increased only modestly (97 in 2020; 129 in 2023; 108 in 2024). In contrast to the substantial overall increase in terminations following legal reform, TOPFA numbers have remained comparatively low, accounting for just under 1% of all terminations in Ireland in 2024 (Department of Health Ireland, 2025). Furthermore, the proportion of women travelling from Ireland to England and Wales for a TOPFA remains disproportionately high relative to other grounds for termination, accounting for 50% of all travel-related terminations in 2021, 37% in 2022 and 55% in 2023 (Department of Health and Social Care, 2021; 2024; 2026). Together, these figures suggest that access to TOPFA continues to be constrained by the more restrictive legislative provisions governing fetal anomaly.

4.2 Impact of individual practice on access to TOPFA and quality of experience

While a small number of parents from Ireland had strong views that there was a cohort of medical practitioners in the healthcare system who were anti-abortion and were blocking parents' access to a TOPFA, most parents' criticism of judgemental practitioners was targeted at individuals. Some suggested that the legal framework surrounding TOPFA may inadvertently protect individual medical practitioners by legitimizing opinion-based decision-making, thereby allowing them to restrict access to TOPFA with limited accountability (Scholl et al., 2018). This discretionary power is intended to support clinical judgment and is important to empower HCPs to deliver individualised care on a case-by-case basis. However, it is potentially open to misuse, leading to biased outcomes in determining who is deemed eligible for TOPFA. Although it is difficult to empirically verify the concerns raised by affected parents, recent investigations into systemic failures in healthcare practice have underscored the extent of professional autonomy in clinical settings often exercised with minimal oversight or review of diagnoses and decision-making processes (Independent Neurology Inquiry, 2022; Ockenden Report, 2022; The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). These findings suggest an urgent need for hospital boards, regulatory bodies, and professional associations to implement mechanisms for the quality assurance and review of healthcare professionals' diagnostic and decision-making practices, ensuring the balance between practitioner autonomy and equitable healthcare experiences.

A survey of medical ethics literature shows that elements of CO are in dispute (Trigg, 2017) and there are some within the medical profession who also think any claims to CO should be rejected (Fiala and Arthur, 2017; Schuklenk and Smalling, 2017). Conversely, others argue that a HCP's religious beliefs should not be demoted to a position below the requirements of the health service (Pellegrino, 2014). Strong lobbies and anti-abortion groups remain active in Ireland, campaigning against current legislation. The fall of *Roe v Wade* in USA (Guttmacher Institute, 2022b, c), which has been described by Amnesty International's NI Director as a "*painful reminder of the fragility of progress*" (Amnesty International UK, 2022) may encourage anti-abortion groups to intensify their efforts to challenge the legislation. Parents felt that there should be more training for all staff involved in TOPFA services and better management of conscientious objectors within the service (Cowley, 2017). Employers and professional bodies should give consideration to how CO could be managed constructively in respect of TOPFA services.

5. STRENGTHS & LIMITATIONS

This study has a number of key strengths, notably its originality and timeliness. Most research into TOPFA has focussed primarily on women's experiences at specific points, such as the diagnosis or the birth experience (Paton et al., 2020; Lotto et al., 2018; Jones et al., 2017). This research adds to the literature, offering a holistic view of the overall healthcare experience. Furthermore, given the recent legal changes in both jurisdictions, this study was a timely opportunity to capture the views of parents, contributing towards shaping and improving TOPFA services in this context (Bloomer et al., 2022; Power et al., 2021a; b).

Another strength of this study was the involvement of an advisory group throughout the entire research process. This group was established in the first few months of this work beginning and involved people with personal or professional experience. The group was particularly helpful in providing advice, assurance and quality control to ensure the language and terminology for participant facing documents were appropriate and sensitive.

In spite of the strengths, this study is not without its limitations. While recruitment was anticipated to be challenging, due to the personal nature of the topic and broader contextual issues relating to stigma, perceived judgement and negative societal attitudes associated with TOPFA, we were pleased with the total number of parent participants (n = 33), and their geographical spread (n = 22 from Ireland and n = 11 from NI). However, while this study did aim to recruit 'couples', wishing to capture the less understood experience of partners, men and fathers, the parent participants were unequally represented with 10 fathers compared to 23 mothers. This is reflective of other research which reports difficulty recruiting men to research in relation to baby loss (Jones et al., 2019). Further, limitations of on-line recruitment were identified particularly in relation to the representativeness of the study sample (Hewson and Laurent, 2008). Individuals who were not members of, or who did not subscribe to, the interest or support groups, used for recruitment purposes, either through inability or choice were unlikely to be represented.

Finally, this study was exploratory in nature and thus was not attempting to make generalisations across demographically diverse locations or populations. As such, findings should be considered within the context where participants were recruited, and caution should be exercised when considering the transferability and generalisability of findings in other contexts. However, it is hoped that readers may be able to apply findings to their individual settings if they see any resonance.

6. RECOMMENDATIONS FOR FURTHER RESEARCH

Future work exploring the perceptions and needs of healthcare professionals working in TOPFA care is needed. With the law in Ireland and many other countries resulting in many parents needing to travel to other jurisdictions to access TOPFA, research into the experiences of HCPs who provide this care in these jurisdictions would be valuable to explore their experiences and identify any potential needs they have to provide care in these circumstances.

7. CONCLUSIONS

This research highlights the impact of the legal context on accessibility to and experience of termination of pregnancy following a fetal anomaly diagnosis for parents in Ireland. The range of factors affecting parents' access to TOPFA services, and the quality and consistency of those services highlights the complexity and challenges of providing a service of this nature. Literature on TOPFA in countries such as Ireland and Northern Ireland where it was, until recently, either criminalised or severely restricted is limited (Bloomer et al., 2022; Conlon et al., 2022). As with any actions or behaviours considered illegal, these often remain hidden with limited focus in practice or research. Our results provide valuable insights into parents' views and experiences of navigating access to TOPFA, pre and post legal changes. For parents in this situation, the need to travel to access care undoubtedly and profoundly increased the trauma and distress of the experience. For those who had a TOPFA post law changes, barriers and challenges to access care were present for some, with a range of contributory factors considered, including inadequate legislation, service infancy, and individual practitioners blocking access to care. Leadership and sustained commitment from within the healthcare systems and professional communities is needed to ensure the development and effective provision of a TOPFA service in each jurisdiction.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Queen's University Belfast Faculty of Medicine, Health and Life Sciences Research Ethics Committee (Ref: MHLS 20_40) prior to participant recruitment. All participants received written study information, provided written informed consent before taking part, and verbally reconfirmed consent at the start of each interview. Participants were informed of their right to withdraw from the study at any stage without giving a reason. The study was conducted in accordance with the principles of the Declaration of Helsinki. Participant data were pseudonymised and managed in accordance with applicable data protection regulations. Given the sensitive nature of the study, a distress protocol was developed, and all participants were provided with information about relevant support services.

Consent for publication

Not applicable.

Availability of data and materials

The qualitative data generated and analysed during the current study are not publicly available due to the sensitive nature of the topic and the potential risk of participant identification. Participants did not provide consent for public sharing of interview transcripts or narrative accounts. Requests for further information regarding the study may be directed to the corresponding author and will be considered on a case-by-case basis, subject to ethical approval and participant confidentiality requirements.

Competing interests

The authors do not declare any conflict of interest in preparing this paper.

Funding

We gratefully acknowledge the Department for the Economy, which funded this PhD study. The Department for the Economy is in no way affiliated to this work.

Authors' contributions

CRedit Author Statement

Author 1 [SH]: Conceptualization, Methodology, Investigation, Formal analysis, Data curation, Project administration, Writing – original draft, Writing – review & editing.

Author 2 [AA]: Conceptualization, Methodology, Supervision, Funding acquisition, Validation, Formal analysis, Writing – review & editing.

Acknowledgements

We wish to sincerely thank all of the parents who participated in this study, giving of their time and sharing their personal experience.

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Figures

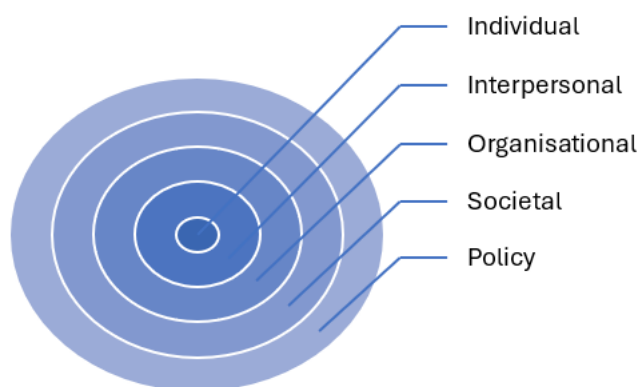


Figure 1

Supplementary Files

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