Ollscoil na hÉireann, Corcaigh.
National University of Ireland, Cork.

Experiences of pregnancy with major fetal anomalies

Thesis presented by
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Research conducted at INFANT Centre and Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, Cork University Maternity Hospital, Cork.

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List of Abbreviations

BMI	Body Mass Index
CEO	Chief Executive Officer
DoH	Department of Health
DoHC	Department of Health and Children
DNA	Deoxyribonucleic Acid
ENNDs	Early Neonatal Deaths
EUROCAT	European Surveillance of Congenital Anomalies
FFA	Fatal Fetal Anomaly
FMS	Fetal Medicine Specialists'
HSE	Health Service Executive
IRG	Independent Review Group
MDT	Multidisciplinary Team
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NPEC	National Perinatal Epidemiology Centre
NPRS	National Perinatal Reporting System
PPC	Perinatal Palliative Care
RCOG	Royal College of Obstetricians and Gynaecologist
RoI	Republic of Ireland
SBs	Stillbirths
TOP	Termination of Pregnancy
TOPFA	Termination of Pregnancy for Fetal Anomaly

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

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‘No (wo)man is an island’

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Research Outputs and Achievements

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Power, S. Meaney, S. and O'Donoghue, K. (2020) 'Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: A qualitative study', *BJOG: An International Journal of Obstetrics and Gynaecology,* 128(4), pp. 676-684. doi: 10.1111/1471-0528.16502

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- Best poster presentation at the Children's Research Network PhD Symposium 2018, Dublin
- Best oral presentation of the Rapid Fire Round at Society for Social Medicine Annual Scientific Meeting 2018, Glasgow

Abstract

Background

Two to three percent of pregnancies will receive a diagnosis of a congenital anomaly, of which a proportion are fatal. While the prevalence of congenital anomalies is low it is the leading cause of fetal death and child mortality. More women are receiving a diagnosis of a fetal anomaly during their pregnancy as a result of advancements in technology. While there is no universally agreed definition, the term fatal fetal anomaly (FFA) is widely used to describe a condition likely to lead to death of the fetus in utero or within 28 days of birth. Delivering a diagnosis of a FFA is usually unexpected and is an unwanted and traumatic event for parents. Little is known about what conditions are most responsible for perinatal mortality. Following a FFA diagnosis, parents face multiple challenges, primarily whether to continue and avail of PPC or terminate the affected pregnancy. Regardless of the choice, the outcome is ultimately the same, ending in a fetal, neonatal or infant death. The need for the decision to be an informed one is paramount. Information is an essential factor to develop patient's knowledge and empowers them in their decision-making. Media offers an insight into health-related information widely available to the public. FFA has generated international media attention as termination of pregnancy (TOP) for FFA was legislated for, for the first time in Ireland. However, it is identified that what the people voted for has not materialised in the legislation relating to practical terms of delivering abortion care.

Following pregnancy loss or perinatal death, parents require various levels of support during their bereavement. There is an over reliance on voluntary organisations to provide peer support to families to meet their needs that often surpass that of standard maternity hospital provision. Education is essential in healthcare in order to keep up-to-date with best practice. This is of particular importance as TOP for FFA, without gestational limits, was provided for within legislation for the first time in Ireland from 2019. This change in legislation warrants an exploration into Volunteers experiences of supporting families, and

Fetal Medicine Specialists' (FMS) experiences of caring for parents following a FFA diagnosis. The overall aim of this thesis was to explore various aspects of pregnancies diagnosed with FFA, during this change in service provision.

Methodology

To address the thesis's aims, both qualitative and quantitative methods were employed. Employing a mixed methods approach to study a phenomenon allows for flexibility to explore different aspects in each of the studies. A secondary analysis was undertaken on anonymised data obtained from the National Perinatal Epidemiology Centre, pertaining to perinatal deaths from January 2011 to December 2016 in Ireland. A national cross-sectional telephone survey was undertaken to assess the public knowledge on FFA. For these quantitative studies, descriptive and inferential statistics were utilised to analyse data. A critical discourse analysis was undertaken to examine the relations between discourse and social and cultural phenomena. Habermasian's framework facilitated an objective analysis of text in the Irish media, to facilitate interpretation and understanding of socially produced meanings. A modified Delphi study, involving two rounds and inclusive of free text, was undertaken to identify educational needs of Volunteers. Lastly, for two of the qualitative studies an interpretive descriptive approach facilitated the researcher to delve into Volunteers' and FMS experiences of supporting and caring for parents who receive a diagnosis of a FFA at a time where TOP for FFA is being provided for, for the first time. This inductive approach represents a co-constructed truth, it moves beyond the level of description of the phenomenon and articulates a meaning of and explanation for these experiences, generating implications for practice and application of these. Both of these studies adopted a data analysis methodology based on the principles of thematic analysis.

Results

A lack of accurate knowledge relating to FFA, its classification, diagnosis and supports available to parents experiencing a pregnancy affected by a FFA among the general public was illustrated within this thesis. Additionally, the data identified misrepresentations in the information relating to FFA delivered to the general public. Outlined by these findings, opportunistic politicians were found to utilise the media to highlight their party's ideological perspective regarding FFA, to derive political advantage to gain popularity and power.

This thesis identified that the uncertainty of what conditions were deemed fatal in accordance with the legislation was related to the ambiguity and restrictiveness of the Irish TOP legislation as long-term survivors are known to many of the conditions considered a FFA. The lack of a universal agreement of what constitutes as a FFA and a list of conditions that are associated with this term, adds additional challenges to diagnosing a congenital anomaly as fatal. On examination of perinatal deaths with a congenital anomaly as a main cause of death, reported between 2011 and 2016, only 42% could be deemed a FFA in accordance with the criteria implemented by the Irish legislation. Many of the conditions in isolation may not be a FFA however, when combined they have the potential to be fatal. The suitability of the Irish legislation for TOP for FFA generated further difficulties for FMS due to its rapid introduction into clinical practice. FMS reported the lack of organisational support, time to prepare and additional resources as challenges for the introduction of a new service. These challenges were exacerbated by FMS fear of criminalisation attached to the TOP legislation if a TOP was carried out for a condition not deemed to be fatal and the subsequent media scrutiny.

The data from these studies also revealed the importance of education and keeping up to date in order to deliver the best evidence based peer support and healthcare. The need for information specific to TOP for FFA provision in the Republic of Ireland was highlighted. Both Volunteers and FMS emphasised the importance of collaborative working (Volunteers requiring the support of healthcare professionals and FMS requiring the support of their colleagues) to

meet the needs of parents following a FFA diagnosis while also acknowledging the importance of teamwork in supporting them in their peer support or clinical role. Organisational and collegial support is essential to sustain the delivery of peer-to-peer support for Volunteers and to reduce the feeling of isolation and judgement for FMS providing TOP for FFA. Thus, assisting both Volunteers and FMS in their own self-care while working in an emotive environment involving pregnancy loss and perinatal death.

Conclusion

These data suggest there is a need for better knowledge of FFA, particularly regarding the complexity relating to the presentation of infants with a fetal anomaly that leads to them being fatal.

These studies acknowledge the need for a universal term and definition that represents fetuses/infants with conditions that cause perinatal death to ensure a standard of care for women and their partners following a FFA diagnosis. It promotes the need for a universal database designed to collect essential epidemiologic information on congenital anomalies within the Republic of Ireland to support the labelling of a condition as a FFA. Additionally, the importance of education and the need to provide support and care to parents following FFA that reflects best practice and responds to their needs. FMS providing TOP for FFA services require organisational and collegial support to effectively deliver this new service. Furthermore, this thesis promotes the need to support both Volunteers and healthcare professionals involved in the delivery of care for parents following a FFA diagnosis through a collaborative approach, one that values and respects all members. The findings of these data outline several recommendations for the Irish TOP legislation, healthcare policy and clinical practice. It argues the need to reform the TOP legislation by removing the retained criminalisation, amending Section 11 and remove the restrictive 28 days. Furthermore, it is recommended that the Act refers to clinical practice guidelines informed by FMS and those healthcare

professionals working within the abortion services. Finally, it identifies areas that warrant further research, such as the exploration of parents' experiences of care and support received following a FFA diagnosis, to inform future intervention and improve care delivered to parents following a FFA diagnosis.

Chapter 1 - Introduction

Chapter 1 – Introduction

1.1 Introduction

For most women, pregnancy and birth are regarded as a time of joy and happiness. A unique and affectionate relationship develops between the woman and her unborn infant[1] with prenatal attachment developing with each frequent fetal movement.[2] Moreover, the psychology of pregnancy suggests that the affection the parents have for their unborn increases as the pregnancy continues[3–5] as parents envision their life as parents with their infant.[6] Parents attend their antenatal visits anticipating confirmation of a healthy baby and the discovery of a fetal anomaly generates fear and anxiety, often exacerbated by diagnostic and prognostic uncertainty.[7–9] Parents are faced with difficult and complex decisions including whether to continue the pregnancy and prepare for the birth of an affected baby or to terminate the pregnancy.

While the majority of babies are born healthy, the National Perinatal Epidemiology Centre in Ireland recorded 381 perinatal deaths (of at least 500g birthweight or 24 weeks gestation) arising from 62,076 births occurring in 2017.[10] These perinatal deaths occurred at a rate of 5.6 per 1,000 births and 3.5 per 1,000 births when corrected for congenital anomalies.[10] While the prevalence of congenital anomalies is low at 2.1 per 1,000 births, it is the leading cause of fetal death and child mortality[11] and has a significant societal health impact.[12] Boyle et al. (2018) identified that there has been little progression in the prevention of congenital anomalies in Europe over the last thirty years and associates this with the lack of implementation of public health policy in antenatal care.[12] Advancements in technology however has resulted in more women receiving a diagnosis of a fetal anomaly during their pregnancy.[13] Despite these improvements, inequalities and socioeconomic deprivation exist worldwide in relation to access and timing of antenatal screening.[14–17] In Ireland, where termination services have been more restricted until recently, inequalities in the provision and uptake of antenatal

screening are evident.[18–20] Antenatal screening offered to women reflected their geographical location rather than a clinical standard of care.

Congenital anomalies which are considered lethal or fatal have received much political and societal attention in connection with abortion laws worldwide, including in Ireland.[21–26] However, little research has focused on fatal fetal anomalies (FFA) and experiences of pregnancy with such a diagnosis. Due to the significant impact FFA has on parents and society as a whole, the inequalities relating to antenatal care and screening and the lack of research on the area, it was deemed necessary to explore this topic. It was considered even more important within the Irish context as Ireland's abortion laws have been reformed and termination is now permitted for FFA for the first time.[27]

This chapter will give a brief overview of antenatal care delivered to pregnant women both internationally and nationally. It will inform the reader of the role antenatal ultrasonography plays in identifying structural anomalies, in addition to prenatal screening and diagnosis of congenital anomalies, and set this context within Ireland. The definition, incidence and risk factors of congenital anomalies will also be described with a specific focus on the conditions considered fatal. In addition, the management of pregnancies affected with a FFA, termination of pregnancy and the introduction of this new service in Ireland will be presented.

1.2 **Antenatal care**

1.2.1 Antenatal care internationally

Antenatal care encompasses the care delivered to the woman and her infant during pregnancy by skilled healthcare professionals. It is inclusive of health promotion and education, screening and diagnosis for both the mother and the fetus, identifying risk, and prevention and management of pregnancy-related diseases with the aim of reducing maternal and perinatal deaths.[28,29] Additionally, it is care that is delivered in partnership with the woman to ensure it addresses

the woman's needs through a collaborative approach, promoting continuity of care.[29–31] Antenatal care aims to identify women who will require specialist support while facilitating low-risk pregnancies to develop with minimal interference.[32]

Despite international guidance, antenatal care provided to women varies worldwide, whereby approximately 40% of women do not have access to early antenatal care visits.[33] Significant differences in antenatal care provided are observed between low and lower-middle income countries compared to upper-middle and high income countries.[34] Antenatal care models are influenced by local contexts, resources and drivers to adapt a woman-centred approach.[35,36] Symon et al. using a systematic scoping review identified four antenatal care models delivered worldwide.[35] These included universal provision for all women; a restricted 'lower-risk' model that is midwifery led; augmented provision as per the universal provision but improved by clinical, educational or behavioural interventions and 'higher-risk' provision. The aforementioned models of antenatal care are delivered by both healthcare professionals and lay workers.[35]

The World Health Organization (WHO) recommends a minimum schedule of at least eight antenatal visits for uncomplicated pregnancies.[28] The National Institute for Health and Care Excellence guidelines suggests that nulliparous women benefit from ten visits compared to seven visits for parous women.[29] It is recommended that antenatal care commences within the first trimester to support early detection of conditions that can negatively impact the pregnancy.[34] Furthermore, it facilitates that women be provided with the necessary information to empower them to make informed decisions for their pregnancy.[29]

1.2.2 Antenatal care in Ireland

Within Ireland, all pregnant women who reside in Ireland benefit from the Maternity and Infant Care Scheme. This mirrors the universal provision approach

to antenatal care. This care is free and is provided by the woman's General Practitioner (GP) and an Obstetrician within the Maternity hospital/unit. Following the initial examination confirming the pregnancy, usually before twelve weeks, nulliparous women receive five visits with the GP during pregnancy.[37] Parous women receive a total of six GP visits following the initial examination.[37] They also attend the maternity unit/hospital for approximately five or six visits and these visits are alternated between the GP and maternity unit/hospital. Women can attend the hospital for additional visits as clinical need is warranted. The mixed antenatal care within Ireland is a result of the wide variation in local and national governance arrangements and their management by either the HSE or Voluntary Organisations, within Irish maternity hospitals and units.[38] The Health Information and Quality Authority identified the difficulties this can create when unable to accurately assess the quality and performance of the maternity service nationally.[38]

1.2.2.1 The Nineteen Maternity Units

There are currently nineteen maternity units in Ireland which are divided into six hospital groups; Ireland East Hospital Group, RCSI Hospital Group, Dublin Midlands Hospital Group, University Limerick Hospitals Group, South/South West Hospital Group and Saolta Hospital Group.[39] Of these maternity units, four are standalone hospitals and not co-located with any other care service.

1.2.2.2 Models of Care

Within the hospital setting, the care women receive is consultant-led and provided by a team of midwives and non-consultant hospital doctors. However, those who opt for private care will choose a particular Obstetrician and attend that Consultant's clinic for antenatal visits, only being seen by another doctor if they are unavailable, on annual leave, or away at the time of appointment/birth.[40]

There are two midwife led units available to low-risk pregnant women in two locations in Ireland; Cavan General Hospital and Our Lady of Lourdes Hospital Drogheda. These units are located within the maternity departments but care is solely planned, coordinated and delivered by midwives.[41] Domiciliary In and Out care is available for low-risk pregnant women, within some of the maternity units.[42] While this model differs slightly between maternity units, it is midwifery-led and allows women to avail of antenatal visits within the community or hospital setting.[42] Regardless of the model of care the woman chooses or maternity hospital/unit attended, a dating ultrasound within the first trimester and a fetal anomaly scan, while not universally provided are essential components of good antenatal care.[18]

1.2.3 Antenatal Ultrasonography

Ultrasound imaging is a non-invasive diagnostic technique that involves bouncing ultrasonic waves, above the threshold of human hearing, at body structures (anatomical) or tissues (functional), and detecting the echoes that bounce back.[43] Antenatal ultrasonography first dates back to the seminal Lancet paper of Ian Donald in 1958.[44] Donald, with his team, pioneered in the design and use of the ultrasound and its application in Obstetrics. Antenatal ultrasonography has since progressed with technological developments of real time imaging, colour and power doppler, transvaginal sonography and 3/4D imaging.[44] It is now widely used in pregnancy to confirm intrauterine pregnancy and gestational age, to enhance the assessment of fetal growth, wellbeing and anatomy, screening for fetal anomalies and prediction of pre-eclampsia and pre-term birth.[44–47] Additionally, it has become an essential component in fetal therapy.[44]

Ultrasound is a sensitive method of evaluating early pregnancy which will facilitate the delivery of optimised antenatal care.[46,48] It confirms viability and number of fetuses, establishes gestational age and identifies physiological and pathological

problems before they manifest clinically.[46,48,49] First trimester fetal ultrasound is undertaken from the time at which viability is confirmed up to 13 + 6 weeks of gestation.[47] Towards the end of the first trimester, ultrasound measurements of fetal nuchal translucency, alongside other sonographic soft markers and serum markers provides clinicians with the ability to screen for aneuploidies and detect major fetal anomalies.[48,50] Major structural fetal anomaly can be identified via ultrasound as early as eleven to thirteen weeks.[51,52]

Despite ultrasound being an integral part of routine antenatal care, recommendations for its delivery vary worldwide.[45,50] The Department of Health within the United Kingdom aims to offer pregnant women a minimum of two ultrasound scans.[53] The American College of Obstetricians and Gynaecologists recommends fetal anomaly screening prior to twenty weeks with the optimal timing for a single ultrasound being eighteen to twenty weeks, but this is in the absence of first trimester examination.[54]

The International Society of Ultrasound in Obstetrics and Gynaecology (ISUOG) identified that while local guidelines potentially exist in many countries, they have not always been implemented.[46] ISUOG suggests that most countries provide at least one ultrasound scan (mid-trimester) as part of their antenatal care, but its availability is influenced by the availability of qualified practitioners and equipment, financial cost and local medical practice and legal influence.[46] Similarly, the World Health Organisation (WHO) recommends one ultrasound scan before twenty four weeks gestation.[34] National Institute for Health and Care Excellence (NICE) guidelines recommend a two-scan approach for women; first trimester between ten weeks zero days and thirteen weeks and six days to determine gestational age and second trimester screen for fetal anomalies between eighteen weeks zero days and twenty weeks and six days.[29]

1.2.4 Second trimester screening for anomalies

Second trimester ultrasound in addition to determining gestational age, facilitates the detection of growth abnormalities, congenital anomalies and offers diagnostic information to enhance antenatal care being delivered.[46] The fetal anomaly ultrasound scan facilitates the best visualisation of fetal anatomical structures.[18,55] Advances in ultrasound have provided clinicians with the ability to detect structural abnormalities which can be suggestive of underlying aetiologies thus leading to improvements in congenital anomaly detection with a reduction in false positives.[51–56] ISUOG argues that all pregnant women should be routinely offered a fetal anomaly ultrasound between eighteen and twenty-two weeks as it provides an opportunity to date the pregnancy (albeit more accurately when performed earlier) and detect major congenital anomalies.[46] An integral part of any screening is the provision of information for women.[57]

In Ireland, there is currently no national guidance or standards on obstetric ultrasound practice.[45] This has resulted in an inequity of standardised ultrasound screening being delivered to pregnant women nationally.[18,45,58,59] Ireland's maternity strategy however, addresses these inequities and advocates for equal access to standardised ultrasound services inclusive of a dating ultrasound scan and fetal anomaly ultrasound scan, as part of a planned Prenatal Fetal Diagnostic Service.[39] The Health Service Executive (HSE) (2020) recommends that all women are offered a dating scan prior to fifteen weeks and reports that some women will be offered a fetal anomaly scan between eighteen and twenty-two weeks.[60]

1.2.5 Other types of prenatal screening

1.2.5.1 Triple Screening

The American College of Obstetricians and Gynaecologists recommend performing maternal blood tests in addition to an ultrasound.[61] The triple screening test involves the measurement of three maternal serum markers; alpha-

fetoprotein, maternal serum free β-human chorionic gonadotropin and unconjugated estriol.[62–65] It provides a reasonably accurate risk estimate of the probability that the fetus has an aneuploidy based on the woman's age.[62–65]

1.2.5.2 Quadruple Screening

The quadruple blood test, undertaken between fourteen and twenty-two weeks, measures four different substances (alpha-fetoprotein, maternal serum free β-human chorionic gonadotropin, estriol and inhibin A) in the woman's blood and has the ability to identify the risk Down Syndrome, Edward's Syndrome and neural tube defects.[61,66–68]

1.2.5.3 Nuchal Translucency

Nuchal translucency is measured in the first trimester of pregnancy and refers to the thickness of fluid under the skin behind the neck of the fetus.[68–70] The nuchal thickness with maternal age calculates the chance of the fetus being affected by Down syndrome, Patau syndrome, Edwards syndrome and other fetal anomalies, including cardiac defect, abdominal wall and skeletal defects.[61,68–70]

1.2.5.4 Combined Screening

Combined screening includes ultrasound findings (fetal nuchal translucency thickness), maternal bloods (maternal serum free β-human chorionic gonadotropin and pregnancy associated plasma protein-A) and maternal factors (age and weight) can estimate the risk for a congenital anomaly within the first trimester.[51,71] A more accurate result can be obtained from combining the first and second semester blood test results however, this means that test results are not available until the second trimester.[61]

1.2.5.5 Integrated Screening

The integrated screening consists of various serum biochemical marker screening tests (maternal serum free β-human chorionic gonadotropin and pregnancy associated plasma protein-A), late first trimester nuchal translucency with maternal age and the combined test.[65,67,72] This approach to screening provides a single estimate of the risk of the fetus being affected by Down syndrome.[71] Wald and Bestwick (2013) identified that the integrated screening was advantageous in determining what women would benefit from receiving a deoxyribonucleic acid (DNA) test.[66]

1.2.5.6 Non-Invasive Prenatal Testing

In 1948, fragmented cell free DNA molecules were discovered in the human circulatory system.[73,74] Fan et al. (2008) and Chiu et al. (2008) reported that fetal aneuploidy could be detected through using parallel sequencing as a counting mechanism to analyse cell-free DNA.[75–77] This has become known as non-invasive prenatal testing (NIPT) and non-invasive prenatal screening.[77] Non-invasive prenatal testing analyses small fragments of DNA, called cell free DNA, that is released from the placenta into a pregnant woman's bloodstream.[61,78] This cell free DNA can be screened for Down syndrome, Patau syndrome, Edwards syndrome, and extra or missing copies of the sex chromosomes. NIPT can be done as early as ten weeks of pregnancy and is quickly replacing conventional screening for Patau, Edwards, and Down syndromes.[78,79] The accuracy of the test however varies by disorder and at times can detect a genetic condition in the mother[78] and so management decisions should not be based solely on the results of NIPT.[80] Similar to preconception screening, there is no guidance on how often, or to who this is offered to with many private clinics offering this screening. Information regarding NIPT is widely available to women on the health service executive's website, maternity units' private webpages and women's health information websites.[40,81,82]

These aforementioned methods, combined, quadruple and NIPT testing, merely determine the risk that the fetus will be born with certain genetic anomalies.[61] Regardless of any advancements in prenatal screening, more invasive prenatal diagnosis such as chorionic villus sampling during first trimester and amniocentesis in the second trimester remain the gold standard.[56]

1.3 **Congenital Anomalies**

1.3.1 What are Congenital Anomalies

Congenital anomalies can be defined as a physical (structural and/or functional) defect that develops during intrauterine life and can be identified during the antenatal period, at birth, or later in infancy.[5656,83,84] A congenital anomaly is a condition that may potentially cause the death of the infant in utero, soon after birth or require treatment to support survival and optimise health.[10,68,85,86]

1.3.2 Prevalence

Congenital anomalies affect approximately 2-4% of all births worldwide.[56,87–89] Despite their low prevalence congenital anomalies are a leading cause of fetal death, infant mortality and childhood morbidity.[11] EUROCAT, the European network of population-based registries on congenital anomalies reports that approximately 2.5% of infants will be born with a congenital anomaly.[11] Within Ireland, the National Perinatal Epidemiology Centre reported major congenital anomaly as the second leading cause of stillbirth (27%) and the primary cause of death in over half of the 111 neonatal deaths (60%) in 2017.[10] Of these 111 neonatal deaths, chromosomal disorders were the most common classification of congenital anomaly (42%) followed by those affecting the cardiovascular systems (16.2%) and central nervous system (11%).[10]

1.3.3 Risk factors

While approximately 50% of all congenital anomalies cannot be linked to a specific cause a number of risk factors have been associated with an increased risk of congenital anomaly.[83] Genetic factors including inherited genes that code for specific anomalies, spontaneous mutations and consanguinity play a significant role in congenital anomalies.[83] Maternal factors and lifestyle are also important contributors to congenital anomalies, for example advanced maternal age increases the woman's risk of chromosomal abnormalities.[83] Additionally, maternal obesity, recreational drug use (including tobacco and alcohol), maternal illness (e.g. diabetes mellitus, epilepsy) and exposure to certain prescribed medications, folic acid deficiency, nutritional deficiencies, some infectious diseases all place the woman at a higher risk of an affected pregnancy.[83,89–92] Environmental factors (physical, chemical and biological), increased and concurrent exposure to chemicals, certain pesticides, waste sites and mines can also place the woman at higher risk of a congenital anomaly.[83,89] Congenital anomalies are multifactorial, a result of the interaction of the aforementioned risk factors and genetics which occur more frequently among the lower socioeconomic groups.[93] Approximately 94% of severe congenital anomalies occur in low- and middle-income countries.[83] There is consensus that through health promotion and education pre and peri-pregnancy and appropriate screening, these risk factors are potentially modifiable.[91] Thus, identifying the lack of progression in preventing congenital anomalies as a significant failure and concern, warranting further research to address the need for health promotion in antenatal care.[12]

1.3.4 Diagnosis of Congenital Anomalies

Detection of congenital anomalies are influenced by the type of anomaly, availability and sophistication of ultrasound equipment as well as the experience and skills of the operator.[94,95] As previously stated, major structural fetal anomaly can be identified on ultrasound as early as eleven to thirteen weeks.[51,52] Fetal

magnetic resonance imaging (MRI) acts as another important diagnostic imaging modality, in adjunct to ultrasonography within the second and third trimester.[96] It can confirm ultrasound findings or provide additional information if visualisation of the fetus is difficult and the anomaly could not be adequately assessed.[96–98] and is particularly useful in the assessment of brain development.[96] For cardiac defects, fetal echocardiography can evaluate the fetal heart and assess for any complex structural cardiac anomalies.[99,100] Fetal echocardiography performed and interpreted by trained paediatric cardiologists have a high diagnostic accuracy for major cardiac abnormalities.[100–102]

The most common cause of major congenital anomalies responsible for perinatal death within Ireland are reported as chromosomal conditions (38 of 64 stillbirths and 26 of 62 early neonatal deaths).[10] In Europe, chromosomal conditions were responsible for an estimated 15% of the major congenital anomalies diagnosed within the first year of life and 25% of the major congenital anomalies responsible for perinatal death.[103] Just under one fifth of early neonatal deaths with a congenital anomaly as the cause of death was classified as a chromosomal condition.[103] Throughout Europe, the rate of all congenital anomalies during 2011 to 2017 (live birth, still birth and termination of pregnancy for fetal anomaly) was 43.84 per 10,000 births.[104] Thus, there is a need for prenatal genetic diagnostic testing that includes chorionic villus sampling and amniocentesis. Chorionic villus sampling involves inserting a needle in to the woman's abdomen or a tube or small forceps through the cervix (method being influenced by the position of the fetus and the placenta) and obtaining a tissue sample from the placenta between ten and a half and fourteen weeks of pregnancy.[68,71] Amniocentesis is performed any time after fifteen weeks of pregnancy and involves a needle inserted in to the woman's abdomen and a sample being obtained from the amniotic fluid.[71] These diagnostic tests enable chromosomal analysis and have a 99.9% accuracy that the fetus has a chromosomal abnormality.

While a significant amount of major congenital anomalies will be picked up prior to twenty-two weeks gestation, a diagnosis will not always be given at this

time.[105,106] Detection rates vary depending on numerous factors including the organ system being examined, sonographer experience and the equipment available.[105]Furthermore, it is important to note, that there is no prenatal screening policy nor routinely offered prenatal cytogenic diagnosis in Ireland[107] with provision being influenced by maternal factors and geographical variations in service provision observed.[18,39]

1.3.5 Importance of antenatal diagnosis

Screening and diagnosis has become a routine part of antenatal care, and with improvements in technology, screening and diagnostic tests there is an increase in antenatal diagnosis of congenital anomalies.[108] Tonks et al. (2013) suggests an early diagnosis of a FFA, is both clinically and emotionally beneficial for parents.[109] Firstly, if the FFA results in a miscarriage, an antenatal diagnosis of the condition can provide parents with the reoccurrence risk.[109] An antenatal diagnosis of a congenital anomaly provides information to determine the suitability for fetal intervention or to plan the most appropriate type, timing and place of delivery to optimise postnatal management if the pregnancy continues.[45,56,100,108,110] Therefore, for specific congenital anomalies it can improve perinatal and long term outcome.[56] Furthermore, it offers the parents a choice, whether to continue with the pregnancy and prepare for the birth of an affected infant or terminate the pregnancy.[18,45,95,108,110] Early terminations are clinically safer as risk complications increase later in the pregnancy.[111] Furthermore, some cultures and religions only permit the option for termination early in the pregnancy, and so an antenatal diagnosis provides them with a choice that complies within their beliefs.[109] In instances where perinatal outcomes cannot be improved, as aforementioned it gives parents the option to continue with the pregnancy or terminate. In areas that prohibit TOP for FFA, researchers argue the ethical implications of providing antenatal screening.[112] However, an antenatal diagnosis does not solely create the option for a TOP for FFA, but allows the family to prepare for an affected baby and

deliver in a specialised centre.[18,95] The absence of an antenatal diagnosis results in a delay in the provision of supports and preparation.[95]

Additionally, Walsh et al. (2013) suggest the diagnosis of a major congenital anomaly may help avoid unnecessary caesarean section in the fetal interest.[45] This belief is potentially related to Obstetricians concern with causing harm to the woman for what is perceived as little measurable benefit for the fetus.[113] McNamara et al. (2013) however suggests the encouragement of minimal intervention but ultimately, care needs to be based on the specific needs of each pregnant woman.[31]

While screening enables identification of people's risk of a particular condition it is important that the public are aware of the benefits, risks, and limitations of the screening process (NHS 2018).[114] As discussed above, screening during pregnancy can provide early detection of a condition, offering the potential to provide treatment, choice for TOP or prepare for the birth of an affected baby. However, parents must be informed of the risks and limitations that is associated with screening regarding their accuracy and the risk of false positives and false negatives and the implications these have (UK NSC; NHS 2018).[114,115] Inaccurate results can leave parents opting unnecessarily for invasive diagnostic testing that carry some risk to their unborn while for others, it can falsely reassure them of a healthy baby (UK NSC; NHS 2018).[114,115]

1.3.6 What is a Fatal Fetal Anomaly

FFA is not a medical term, however, it has gained popularity within Ireland, following its use by political parties in attempt to amend the Eighth amendment with the Protection of Life During Pregnancy (Amendment) (Fatal Foetal Abnormalities) Bill 2013 and Bill 2015.[116] There is much debate as to what this term means. Within the Cambridge dictionary lethal and fatal mean 'able to cause' or 'causing death'.[117] Wilkinson et al. (2012) suggests when these terms are

associated with a perinatal condition, they have several ways of being theoretically interpreted including a condition that; invariably leads to the fetal death during pregnancy, usually leads to the fetal death during pregnancy or in the neonatal period or is associated with fetal death during pregnancy or in the neonatal period.[118] Furthermore, the term fatal is interchangeably used with lethal[57,119] and life-limiting.[120] The most widely accepted interpretation, is that a FFA is a condition that will likely lead to the death of the fetus within utero or within the neonatal period (28 days of life) despite active treatment.[118,119] While this definition is generally accepted, there is no universally agreed definition of what constitutes a FFA, nor is there a list of conditions that belong to this term. Wilkinson et al. (2012), from a systematic literature review, provides a list of conditions that are consider lethal/fatal as presented in Table 1.1.[118]

Table 1. 1: Lethal Malformations

Potter's syndrome/renal agenesis
Anencephaly/acrania
Thanatophoric dwarfism
Trisomy 13 or 18
Triploidy
Holoprosencephaly
Hydranencephaly
Some cases of hypoplastic left heart syndrome and pentalogy of Cantrell
Severe osteogenesis imperfecta
Multicystic/dysplastic kidneys / Polycystic kidney disease
Congenital severe hydrocephalus with absent or minimal brain growth
Severe congenital diaphragmatic hernia with hypoplastic lungs
Sirenomelia
Complex or severe cases of meningomyelocele
Large encephaloceles

Acardia
Some cases of giant omphalocele
Inoperable conjoined twins
Cranioradischisis
Exencephaly
Iniencephaly
Harlequin fetus
Meckel–Gruber syndrome
Non-immune hydrops with major cardiac defects

(Wilkinson et al. 2012)[118]

The Wilkinson et al. (2014) definition does not however adequately describe many of the conditions associated with this term as known survivors are linked to many of these conditions.[121] Furthermore, little is known regarding the incidence of the conditions that would be considered a FFA that result in a perinatal death in Ireland. There are a few published studies on prevalence and survival rate of conditions more frequently described as fatal[121]; Renal agenesis, Anencephaly, Trisomy 13 and 18.

1.3.6.1 Renal Agenesis

Bilateral renal agenesis is a condition characterised by the absence of development of both kidneys and is accompanied by absent ureters.[122] Maternal insulin dependent diabetes mellitus and male sex of the fetus has been noted as risk factors for renal agenesis however, there is no specific etiology in the majority of cases.[123] In some cases of renal agenesis, teratogenic, syndromal and single gene causes can be a causative factor.[123] While fetal losses are common, the majority of those born alive will die within twenty-four hours while less than five percent will survive beyond one week.[121] A week survival rate of twenty-one percent and fifteen percent surviving one year, following aggressive intervention has been noted for renal agenesis.[124] Nguyen et al. (2018) identified infants with

bilateral renal agenesis and anencephaly have the highest mortality rate within the first day of life and median survival of one day.[124]

1.3.6.2 Anencephaly

Anencephaly is the absence of both cerebral hemispheres, cranial vault, skull and scalp.[125–127] Anencephaly is as a result of the failure of closure of the neural tube by the fourth week of pregnancy.[125,128] There is a significant amount of evidence to support the role of folic acid in preventing anencephaly.[129–132] While the majority of infants are stillborn, some are liveborn and die shortly after birth.[125–127] In Ireland, Obeidi et al. found that twenty-three percent of anencephalic fetuses died in utero, thirty-five percent during labour and neonatal survival reported up to eight days.[125] Survival up to twenty-eight days was reported by Jaquier et al. for babies born with anencephaly.[133] However, anencephaly is recognised for its lethality with no possibility for fetal intervention, thus care provided following birth is solely comfort care.[125,126,134]

The condition is uniformly lethal and not treatable. No fetal intervention is possible and treatment after birth is supportive. The condition is uniformly lethal and not treatable. No fetal intervention is possible and treatment after birth is supportive. Anencephalic fetuses were most likely to die after birth, with 23% dying in utero and 35% during labour with a potential forneonatal survival of up to 8 days being reported.

1.3.6.3 Trisomy 18 and 13

Trisomy 18 and Trisomy 13 are the second and third most common type of autosomal aneuploidy following Down Syndrome.[135,136] Trisomy 18 and 13 occurs when there is an extra chromosome or a partial trisomy of the long arm of the 18th or 13th chromosome.[136,137] Mosaicism demonstrates a variable phenotype, the extra chromosome is present in only some of the body's cells and effects only a

small proportion of those diagnosed with Trisomy 18 or 13.[136,137] Houlihan and O'Donoghue (2013) referring to Irish birth registers, records and reports identified approximately fifty percent of babies with Trisomy 13 and Trisomy 18 will die within the first week.[135] This is consistent with other international studies, estimating that only half of these babies will survive the first week.[136,138] Irving et al. (2011) and Meyer et al. (2016) identified slightly higher survival rates than those previously reported in the literature.[13,139] All studies suggested a first year survival rate of three to ten percent.

1.3.6.4 Fatal fetal anomaly survival rates

There are several possible explanations for improved survival rates for babies born with a FFA. Wilkinson et al. (2012) suggests survival rates are imprecise as only live births are represented and survival is influenced by parents' decisions before and after birth.[118] With a greater amount of women receiving an antenatal diagnosis of a FFA, there is potential for the more severely affected fetuses being terminated and therefore less affected infants being born alive.[118,139] These studies potentially include the influence of more aggressive medical intervention and/or the inclusion of infants with mosaicism and translocations (who have improved long-term survival compared to infants with full trisomy).[139] Additionally, Wilkinson et al. (2012) suggests bias in research undertaken by parent support groups or those with personal experiences of FFA, selecting participants who are less affected.[118] Furthermore, Wilkinson et al. (2009) presents perinatal palliative care (PPC) as a self-fulfilling prophecy, meaning that providing PPC will mean that majority of infants born with a FFA will not receive medical intervention and therefore not experience prolonged survival.[140] However, this does not truly reflect the true essence of PPC. Together for short lives (2018) reports that some families and clinicians continue to hold the view that palliative care is a last resort.[141] On the contrary, palliative care is the 'active and total approach to care' that is delivered from diagnosis, throughout the child's life, death and bereavement and embraces a family centred care approach to ensure the holistic needs of the child and family are met.[141–144]

1.3.6.5 Perinatal Palliative Care

PPC promotes parallel planning, providing treatment to either cure or prolong life while ensuring quality of life and decision making that reflects the child's best interest, all whilst acknowledging the need to prepare for a good death.[141] More specifically, PPC is holistic multidisciplinary support for families facing the potential death of their newborn infant.[143,145,146] It refers to the coordinated care that focuses on maximising quality of life and comfort for newborns, symptom management and is provided alongside medical treatment.[147] A PPC approach serves to ensure humanity and dignity are preserved and parents are fully informed and supported in making decisions related to their infant.[142,148] Discussions surrounding FFA are emotionally charged and unfamiliar to parents.[148] Thus, Carter (2016) promotes the need for clinicians to inform parents of all possibilities when their fetus is diagnosed with a FFA and prepare them to 'expect the unexpected' through advanced care planning.[149] Hence, it is questionable whether the term fatal or lethal continues to be appropriate as it does not accurately describe conditions associated with this term, as survivors are linked to all conditions.[121,124,150] There is a genuine concern that the use of such terms could misinform families[124] as using such terms omits the integration of uncertainty related to the future of these infants.[150] In doing so, this can result in parents making poor-informed decisions regarding the use of intervention, PPC, and alternative forms of management.[124] However, there is limited published evidence on experiences of families with PPC[151] and so this area warrants further investigation.

1.4 **Management of pregnancy with a congenital anomaly diagnosis**

1.4.1 Role of the Fetal Medicine Specialist

Fetal Medicine Specialists' (FMS) are medical practitioners who have either undergone further training in diagnostic ultrasound or an approved Maternal-Fetal Medicine fellowship or has extensive experience within the area of fetal medicine and underwent their training prior to these fellowships being available.[52,152] The maternal and fetal medicine subspecialty curriculum produces doctors with the knowledge and skills to treat pregnant women presenting with maternal and fetal medical conditions.[153] The Society for Maternal-Fetal Medicine recognise this role as complementary to obstetric care in holistically caring for women with complicated pregnancy[154] FMS are expected to organise and supervise services, contribute to academia and research in maternal and fetal medicine and provide supports and guidance to non-subspecialist colleagues.[153,154] Within Ireland, a diagnosis of a FFA is ordinarily confirmed by the local Obstetrician and/or Fetal Medicine Specialist. For those whose diagnosis is confirmed by an Obstetrician in a local centre, they are usually referred to a tertiary hospital and reviewed and further investigated by the Fetal Medicine Specialist.[152] There are six fetal medicine units within Ireland. These and their associated maternity unit are presented in Table 1.2.

Table 1. 2: The Nineteen Maternity Units as per hospital group and fetal medicine availability.

Hospital Group	***Maternity Hospital/ Unit***	***Stand Alone***	***Fetal Medicine Unit***
Ireland East Hospital Group	National Maternity Hospital	✓	✓
	Midland Regional Hospital, Mullingar		
	St Luke's General Hospital, Kilkenny		
	Wexford General Hospital		
Royal College of Surgeons Ireland	Rotunda Hospital Dublin	✓	✓
	Our Lady of Lourdes Hospital, Drogheda		

(RCSI) Hospital Group	Cavan General Hospital		
Dublin Midlands Hospital Group	The Coombe Women and Infant University Hospital	✓	✓
	Midlands Regional Hospital, Portlaoise		
University Limerick Hospitals Group,	University Maternity Hospital Limerick	✓	✓
South/South West Hospital Group	Cork University Maternity Hospital		✓
	University Hospital Waterford		
	University Hospital Kerry		
	South Tipperary General Hospital		
Saolta Hospital Group	University Hospital Galway		✓
	Sligo Regional Hospital		
	Letterkenny University Hospital		
	Mayo General Hospital		
	Portiuncula Hospital		

For fetal anomalies confirmed with a definitive diagnostic test and undisputable prognosis, these can be managed at local hospital level once under the care of the resident or visiting Fetal Medicine Specialist.[(147)] The woman will potentially attend the territory hospital for investigations but results will ultimately be communicated to the Obstetrician in her local unit.[(147)] The Irish Interim Clinical Guidance Pathway recommends Fetal Medicine Specialist as one of the signatories on the certification documents where termination of pregnancy (TOP) for FFA is chosen and should be involved in the antenatal care and diagnosis delivered to the woman.[52,152]

1.4.1.1 Delivering a diagnosis of a fatal fetal anomaly

Delivering a diagnosis of a FFA is usually unexpected and is an unwanted and a traumatic event for parents.[6,155] How the news of a fatal diagnosis is communicated by clinicians significantly influences how parents subsequently

respond to the difficult news.[156,157] It is generally agreed that it is the role of the Obstetrician/Fetal Medicine Specialist to deliver the diagnosis of a FFA, incorporating a multidisciplinary approach to care.[152,155] While there is little published on Fetal Medicine Specialists' experiences of delivering a FFA diagnosis, evidence available suggests the need for specific education and training for clinicians to enable them to sensitively inform parents of bad news during their pregnancy.[155,157–161]

Within a private and quiet environment without interruptions, it is deemed best practice for the woman to be fully informed of hers and her unborn's health and consent obtained from the mother for the diagnosis to be disclosed in the presence of the person accompanying her.[155] Atienza-Carrasco et al. (2018) recommends that patients are assessed regarding the amount of information relating to the diagnosis that they desire.[155] The communication of bad news is a process in which the delivery of information is gradual to combat parents' state of shock and inability to process all information being delivered.[155] In an Irish study, Lalor et al. (2008) identified the need to match parents coping styles with information preferences, to assess whether women have high information needs or a desire to retrieve information slowly as they are ready.[162] Language used to inform parents is required to be simple, adapting to the patient's health literacy and ensuring communication is reciprocal to promote understanding.[155] It is essential that the woman and her partner are emotionally supported during and after the breaking of bad news.[31,155,156,162]

1.4.1.2 Prenatal Counselling

Prenatal counselling refers to the communication between the clinician and parents in which parents are informed of their child's congenital anomaly.[163] Prenatal counselling aims to alleviate anxiety and facilitate parents to make informed decisions regarding continuing the pregnancy and preparing for the birth of an affected baby or the TOP.[8,164] Discussions regarding parents' wishes, hopes

and fears is required to respond effectively to parents needs and facilitate informed shared decision making.[152] Parents' thoughts and beliefs require discussion to address prescriptive responses influenced by parents with similar demographics during their decision making.[165] Clinicians are required to deliver accurate information to parents in an empathetic and balanced way[166], having an ethical and legal obligation to ensure the patient is fully informed, facilitating their autonomy in decision making.[155] Information needs to include the challenge of predicting the time of fetal or neonatal death[31] and the range of possible outcomes.[32,166] A multidisciplinary approach to counselling and clinical management is argued as a contributing factor in improved understanding of a prognosis.[57]

It is essential that clinicians respect parents' decisions to enable compassionate supportive care.[152,166] While TOP is the right decision for some parents, it is important for clinicians to understand that it is not, as is usually understood as a 'choice'.[152] Lalor et al. (2009) identified that parents regain some form of control when enabled to make an informed decision to either continue or terminate the pregnancy.[167] Marokakis et al. (2016) within their systematic review, identified that the majority of parents preference for prenatal counselling to follow immediately after diagnosis in order to facilitate timely decisions regarding termination and minimise stress associated with this.[163] However, a minority of parents suggested time between diagnosis and counselling was beneficial[163] suggesting an individual approach is in the parents' best interest.

1.4.2 Voluntary Organisations

1.4.2.1. Volunteers role

Volunteers' enormous and varied contribution to society is difficult to capture within a definition with informal volunteers 'lending a hand' as required and formal volunteers committing to set times coordinated by a voluntary

organisation.[168] The European Commission (2011) however define a volunteer as someone who undertakes a certain role by choice and with no financial gain.[169] Globally, voluntary organisations contribute significantly to healthcare and society, meeting the unmet needs of the general public, addressing deficits within healthcare provision and contributing to policy.[170–177] More specifically, voluntary organisations play an important role in holistically supporting bereaved parents[172,178,179] and collaboratively working alongside statutory bodies in order to comply with best practice.[175]

1.4.2.2 Volunteers role in bereavement care within Ireland

Bereaved parents often require on-going supports that surpass the standard maternity service provision.[178] The negative emotions and amplified grief associated with the lack of appropriate follow-up care or social acknowledgement is well documented within the national and international literature.[57,178,180–184] This inadequacy of care following pregnancy loss and perinatal death is associated with the over reliance on voluntary organisations to provide peer support in order to respond to parents' bereavement care needs.[178,185] While the voluntary organisations play a key role in filling gaps in healthcare provision and are motivated to respond to bereaved parents' needs, volunteers potentially lack the competence and skills necessary to meet these needs.[172] There is however, a lack of research exploring volunteers' learning needs, if any. Furthermore, despite the significant role voluntary organisations play with this vulnerable population, as identified within the National Bereavement Care Standards,[120] there is little published evidence about their role in pregnancy loss and perinatal death and even less specifically related to bereavements due to FFA.

1.4.3 Care pathways

In 2016, the Health Service Executive launched the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.[120] These Standards identified the need for parents to receive a standard of care that responds to their needs following a miscarriage, ectopic pregnancy, stillbirth, neonatal death and a FFA diagnosis.[120] They identified the variation in the bereavement care being delivered throughout the maternity units in Ireland and aimed to remove the geographical inequalities observed. Furthermore, the Bereavement Care Standards contributed to the development of a clinical pathway for pregnancy following a FFA diagnosis. This care pathway was proposed to ensure equal access to uniform and high quality standards of care for parents following a diagnosis of a congenital.[52,68,152] It aims to develop and communicate advanced care plans for when parents chose to either continue with the pregnancy or terminate.[152]

1.4.4 Options

Following a FFA diagnosis, parents face multiple challenges, primarily whether to continue or terminate the affected pregnancy. For a few parents, they may have the option for fetal therapy. For those who do not, despite the pathway chosen, an integrated approach to care, inclusive of bereavement care, that continues through the pregnancy, delivery, and into the postnatal period is required.[52,120,152] This includes the need for care to continue to address the routine physical antenatal and postnatal care, as would be provided to a non-bereaved mother.[31,120]

1.4.4.1 Continue with pregnancy

Once parents decide to continue with their pregnancy, following a FFA diagnosis, parents will benefit from a PPC referral. Routine antenatal care is required to monitor the mother's health and any increase of risk to her health addressed and her emotional wellbeing support.[31,146] A multidisciplinary approach is used in the advanced care planning to give parents autonomy, explore their wishes regarding their infant's care, their planned location of birth and in particular to end of life, what should be done and by whom.[146,147,149,152,186–189] Furthermore, advanced care planning allows parents' decisions regarding what should not be done.[152] It is necessary that parents' wishes and decisions must be documented clearly and concisely.[142,188] During parents antenatal care, they should be supported in being parents, continuing to build a relationship with their unborn infant and on individualised memory-making, holistically preparing parents for the birth and death of their baby.[147,152,190] Good communication is necessary to ensure all planned care is documented and shared appropriately between tertiary and local hospitals and within the maternity unit itself.[147,152] For parents who receive a diagnosis of a condition where prognosis is uncertain, it essential that parents are informed of all potential outcomes and parallel planning implemented to prepare for ongoing care needs in the event of survival.[142,149,152,166,191,192]

1.4.4.2 Fetal therapy/ Fetal surgery

Fetal therapy involves intervention on the fetus within utero and aims to reduce associated postnatal complications and irreversible damage to the unborn's organs.[193–195] While the most current options for parents with a diagnosis of a FFA are either to continue or terminate the pregnancy[196] progress in fetal therapeutic interventions have resulted in both medical treatments and surgical interventions being available for some placental disease and structural abnormalities.[195,197] For the purpose of this thesis, this section will solely focus on fetal surgery.

Fetal therapy has resulted in fetoscopic interventions and open surgery potentially offering immediate benefit and reducing complications that arise postnatally for a

small number of anomalies.[195,198,199] These include congenital structural anomalies such as spina bifida, diaphragmatic hernia, congenital heart defects and identical twin placental complications and are usually performed during the second trimester.[196,200] The availability of fetal therapy however is dependent on the local healthcare system with the expertise and interventions that can be offered as well as parental wishes.[197] There is little published data available on what, if any, fetal surgery is available in Ireland for structural congenital anomalies, with knowledge of only fetoscopic laser ablation for twin placental complications provided in the Rotunda Hospital Dublin.[201] Furthermore, many of the fetal therapies available are still considered experimental with potential risk to both mother and fetus and are lacking quality evidence of their effectiveness.[195] Interventions being evaluated within the UK include in utero closure of spina bifida to improve neurological function, endoscopic placement of balloon inflated in the fetal trachea to address a diaphragmatic hernia through improved lung growth, and for the male fetus with presumed urethral valves, percutaneous vesicoamniotic shunting.[57] Adzick et al. (2011) comparing prenatal and postnatal repair of myelomeningocele found while improving the postnatal presentation of these infants, their motor outcomes and reducing their need for shunting, there were associated maternal and fetal risks.[202] Preliminary research developed by the John Hopkins Center for Fetal Therapy (2020) has observed improved survival in babies with diaphragmatic hernia following fetoscopic endotracheal occlusion.[203] Nevertheless, the implementation of fetal therapy into clinical practice must consider an ethical framework balancing benefit versus harm.[195] It is noteworthy, at present, that the conditions we refer to as FFA are not amenable to fetal therapy.

1.4.4.3 Termination of pregnancy for fatal fetal anomaly

For some, TOP for FFA is the only option following a FFA diagnosis. Following the decision to have a TOP, parents require adequate information related to TOP procedures in order to make informed choices about their care.[57,120,204] Similar to parents who continue pregnancy affected by a FFA, parents are encouraged to

continue building a bond with their unborn and should be facilitated to engage in memory making.[52,152,205] Similarly, RCOG (2010) promotes that parents are given the opportunity to see and hold their baby and receive mementoes such as hand and foot prints and photographs.[57] Advanced care planning is necessary in particular for TOP at later gestations as knowledge of parents preferences regarding TOP methods, and view about whether feticide is required is essential.[52,57] Furthermore, knowledge of parents' wishes regarding fetal monitoring and how the baby will be cared for and handled following TOP are required.[31,52,149,206] Communication is of utmost importance and healthcare professionals must ensure parents care plan is shared with those involved in their care to facilitate continuity of.[52,57,205] Empathetic, supportive and non-judgemental care is essential for parents who fear being judged for deciding on a termination for FFA.[31,57,204,205] Furthermore, parents need to receive appropriate emotional support following the death of their baby.[31,52,57,206–208]

1.5 **Termination of pregnancy**

1.5.1 What is a termination of pregnancy

Within the MedlinePlus (2020) dictionary a TOP is defined as a procedure to end a pregnancy through removing the embryo or fetus and placenta from the uterus using medicine or surgery.[209] Similarly, the Irish Health (Regulation of Termination of Pregnancy) Act 2018 describes TOP as a medical procedure which is implemented with the intention to end the life of the fetus.[27] TOP is generally a safe procedure, however, similar to other medical procedures there is a small degree of risk, influenced by stage of pregnancy and procedure used.[52,111] Ensuring women understand the level of risk, complications and psychological sequelae is essential for informed decision making.[52,204,210] There are two types of TOP procedures; medical and surgical.[68]

1.5.2 Termination of pregnancy procedures

1.5.2.1 Medical

A medical termination involves the woman taking mifepristone to stop an essential pregnancy hormone so that the pregnancy can't continue and 24 to 48 hours later, taking misoprostol to break down the lining of the womb resulting in the loss of the pregnancy.[68] Women are required to attend the hospital for the mifepristone, to leave and return the next day to be administered misoprostol.[211] The woman is admitted until the TOP is complete and this rarely requires an overnight admission.[211] The death of the fetus occurs from the inability of the compromised fetus to tolerate induced labour or by feticide (induced fetal demise) performed by an Obstetrician.[52,57]

1.5.2.2 Surgical

A surgical termination involves having the procedure with either a local anaesthesia, procedural sedation or general anaesthetic.[68,211] There are two surgical procedures available which are influenced by the stage of pregnancy. A vacuum aspiration which uses suction to remove the pregnancy can be used prior to fifteen weeks.[68] Medication is administered to soften the woman's cervix to enable the womb to be gently widened and the pregnancy suctioned from the womb.[211] A dilatation and evacuation is usually used around and after fifteen weeks gestation and involves the use of forceps to remove the pregnancy.[211] Dilation and evacuation must be undertaken by specialist practitioners who regularly engage in this skill to maintain competency and have access to the required instruments.[57] Within Ireland at present, surgical termination after twelve weeks is not available.[52]

1.5.2.3 Feticide

The RCOG recommends for feticide to be performed prior to medical termination after 21 weeks and 6 days of gestation to prevent the chance of a live birth.[57] The Irish Interim Clinical Guidance Pathway for TOP for FFA (2020) concurs that TOP for fetal anomalies which are not immediately lethal requires feticide after 21 weeks and 6 days of gestation to prevent the chance of survival. They acknowledge that a live birth and survival contradicts the intention of TOP.[52] Furthermore, there are potential emotional, ethical and legal benefits with inducing fetal death prior to a medical TOP for FFA as an infant born with signs of life can be traumatic for the woman and healthcare professionals providing care.[52,57] Graham et al. (2009) identified that for many parents', there decision making process regarding feticide is influenced by their perceptions of whether their baby will suffer during or after birth.[212] Parents presented similar accounts of grieving whether feticide was provided or not and that feticide while seen as unpleasant, prevented an event deemed to be even more unpleasant. [212]

The Royal College of Obstetrics and Gynaecology (2010) suggests a referral to the Fetal Medicine Specialist for TOP at later gestational age and/or requiring feticide.[57] Within Ireland, a feticide must be performed in a tertiary maternity hospital by a Fetal Medicine Specialist with the appropriate competency.[52] Feticide is most commonly performed by injecting intra-cardiac potassium chloride to ensure fetal asystole can be undertaken by the Obstetrician to cause the death in utero.[52,57] This procedure may be repeated if asystole has not occurred after 30-60 seconds with asystole required to be documented for two minutes and scan repeated to ensure fetal demise. [52,57] Potassium chloride can also be administered via the umbilical cord although this is not as reliable as the intra-cardiac route.[57] Alternatively, digoxin may be used via intra-amniotic or intrathoracic and lignocaine via umbilical venous or intra-cardiac however, these procedures do not consistently induce fetal demise.[52,57]

For anomalies considered fatal, where early neonatal death is inevitable, irrespective of the gestation at delivery, feticide is not essential.[52,57] Wilkinson

(2012) refers to the potential emotional and psychological benefits of live birth following a fetal anomaly.[113] As a result, some parents decline the option for feticide[213] hoping to spend time and hold their baby whilst alive.[52,206,212] Further development of the issue of feticide is necessary in order to discuss the risks of resuscitation being implemented if the fetus is born alive. All multidisciplinary team members and parents must agree to a care plan prior to the TOP, that directs the commencement of a supportive pathway into palliative care in the instance where the baby is born alive following a TOP without feticide.

1.5.2.4 Induction

Plans for induction, labour and delivery are particularly important as parents need to be counselled for the potential outcomes of an induction in the absence of feticide. These include intrapartum death or a live birth at later gestations and the provision of PPC followed by a neonatal death or transition to the neonatal unit, home or location chosen by the parents.[52,142,214] Parents' personal wishes relating to comfort care delivered to their baby, memory making and bonding and their cultural and religious preferences should be known, documented and facilitated.[52,141,149,189] Additionally, appropriate local policies are essential to inform healthcare professionals of their role in the event of a live birth and protect them from potential ethical and legal dilemmas.[52,214] Additionally, the overriding legal and ethical principle is that decisions are based on the best interest of the baby.[142] Following the death of the infant, the baby should stay with the parents as long as they wish and parents prepared for the physical changes expected to occur following death.[52,141,214]

1.5.3 Legislation for termination of pregnancy

Abortion is an emotive and divisive topic, saturated with controversy and generating much debate.[215] Throughout the world, there is an abundance of various convoluted laws and restrictions.[216] Within clinical practice in many

countries abortion has long required providers to comply with professional and ethical standards of care above and beyond those required for other medical procedures.[215,217–220] The United Kingdom's National Health Service, while it provides TOP, the legal framework regulating it remains conservative and punitive.[220] Similarly in the United States where abortion is legal, laws at the state and federal level withhold funding, resulting in increasingly limited access to abortion care.[221] Women's rights to universal access to reproductive health and safe abortion has long been advocated for.[222–224] The United Nations Human Rights bodies have played a dominant role in advocating for progressive abortion law reform for women.[216] This has ensued a reform in abortion laws to either permit abortion or broaden their existing services in some countries.[23,225]

The abortion debate has been positioned as a battle between the fetus' right to life and the woman's autonomy although Jotkowitz and Zivotofsky (2010) suggests that most proponents of abortion support TOP for FFA and life limiting conditions.[226] However discussions relating to TOP for FFA have expressed concern of promoting stigmatisation of disabilities.[227] There is very little research however focusing on this area of the abortion debate and those requiring TOP for FFA have been described as the forgotten ones.[228] The impact of restrictive abortion laws on healthcare professionals has also received minimal attention.[215]

1.6 **Termination of pregnancy for fatal fetal anomaly in Ireland**

1.6.1 Women's options prior to 2018

Prior to the Electoral Referendum on May 28th 2018 when the Irish people with a 64% turnout voted to repeal the Eighth Amendment of the Constitution by a two-thirds majority, Ireland held one of the most restrictive abortion legislations in the world.[217,218,229,230] As a result, pregnant women living in Ireland had to continue a pregnancy affected with a FFA or travel to avail of abortion services in another jurisdiction where abortion was legal.[218]

1.6.2 The Eighth Amendment

Ireland's Eighth Amendment of the Constitution was the first of its kind worldwide to enshrine fetal rights in 1983.[231] The Eighth Amendment protected 'the right to life of the unborn' and recognised the life of the fetus to be 'equal' to the right of the mother.[232] This legally enshrined view of the maternal-fetal relationship resulted in women's healthcare needs often being overlooked.[229,233] Abortion was permitted for women whose life was at substantial risk to physical illness or suicide while all other cases, including TOP for FFA, were criminalised and the clinician and patient potentially subject to fourteen years imprisonment.[218] This Amendment forbade referring patients to other countries to avail of abortion services however, it did not preclude parents from acquiring knowledge about and travelling abroad to obtain a TOP for FFA (The Regulation of Information (Services Outside the State For Termination of Pregnancies) Act 1995). Additionally, following a TOP for FFA, women could return to Ireland and avail of postnatal care and medical follow up within the maternity hospitals, with their GP and avail of bereavement care.[120,230]

1.6.3 Repeal of the Eighth Amendment

1.6.3.1 Ireland violating Women's reproductive rights

In the United States in 1973, Roe versus Wade gave motion to the Women's rights movement worldwide, with particular attention on woman's reproductive rights and right to have an abortion.[234] This movement gathered momentum with Ireland's restrictive abortion laws found to be in violation of the European Convention on Human Rights.[235,236] The A, B, and C versus Ireland in 2010 forced the Irish Government to address the controversial topic of abortion.[235] More specifically to FFA, the legal cases, Mellet versus Ireland 2016 and Whelan versus Ireland 2017 resulted in the United Nations Human Rights Committee ruling that

Ireland was again in violation of women's human rights due to their criminalisation of abortion.[237,238] Upon hearing these women had to travel for a TOP for FFA, subjecting them to inhuman and cruel treatment, the United Nations ordered Ireland to provide compensation for the suffering experienced by these women and reform its abortion laws. [237,238] In 2018, an international campaign for safe abortion was generated following the United Nations Human Rights Committee's General Comment on the Right to Life, confirming that abortion is a human right.[222]

1.6.3.2 Referendum

Citizens' Assembly

In 2016, a Citizens Assembly was established by a parliamentary resolution and tasked with open and respectful discussion and deliberation on TOP, FFA, and TOP for FFA, including the Eighth Amendment.[229] The Assembly is a form of deliberative democracy, composed of an appointed chairperson by the Government and ninety-nine randomly selected citizens of Ireland, representative of the general public.[218,229,239,240] Deliberation on the Eighth Amendment occurred during November 2016 until April 2017 and involved five weekend sessions, a review of three hundred submissions from members of the public and presentations from twenty-five experts.[239,240] The Citizens' Assembly overwhelmingly agreed that the Eighth Amendment should not be retained in full (87%).[241,242] Over half recommended the amending of the Eighth Amendment or replaced by permitting the Oireachtas to legislate on matters relating to TOP.[240–242] The Assembly's findings, inclusive of recommendations the legislation ought to cover, was submitted to the Oireachtas on the 29th of June 2017 and reviewed by the Joint Committee of both Houses of the Oireachtas.[240,241]

Joint Oireachtas Committee on the Eighth Amendment of the Constitution

Following agreement by the Dáil Éireann, the Joint Oireachtas Committee on the Eighth Amendment was established with members from both Houses of Oireachtas on April 2017.[241] This Committee was tasked with the consideration of the Citizens' Assembly report and recommendations on the Eighth Amendment of the Constitution.[241] This report reflects the Committee's opinion that lies between the two traditional polar positions in order to represent the Irish society opinion.[241] The Joint Committee agreed with the need to remove the Eighth Amendment but in contrast to the repeal and replace recommendation of the Citizens' Assembly, proposed a simple repeal.[239–241] This was in order to provide greater scope to the Oireachtas to legislate for TOP.[241]

Referendum campaign

On the 29th January 2018 the Taoiseach of the Republic of Ireland, Leo Varadkar, announced the decision to propose a referendum on Ireland's constitutional abortion ban.[239,243] On the advice of Attorney General Séamus Woulfe, the proposed amendment accorded with the repeal and replace as recommended by the Citizens' Assembly.[239,244] The Thirty-sixth Amendment of the Constitution Bill 2018 would repeal the Eighth, Thirteenth and Fourteenth Amendments and be replaced with the provision made by law for the regulation of TOP.[239] This Referendum Bill was passed March 21st and 28th 2018 by the Dáil and Seanad and May 28th confirmed for the vote to take place.[239]

The Yes campaign were supported by the Abortion Rights Campaign, the Coalition to Repeal the Eighth Amendment and the National Women's Council of Ireland and by the majority of the Irish political parties.[239] Additionally, professional and cultural organisations, such as Doctors Together for Yes adopted supporting positions with the Yes campaign drawing much attention to medical arguments and supportive Obstetricians and Gynaecologists.[239] Furthermore, voluntary organisations consisting of parents who had experienced a pregnancy with a FFA

and had been negatively affected by the Eighth Amendment played a key role in the referendum.

The No campaign consisted of two major organisations; Love Both and Save the Eighth.[239] In contrast to the Yes campaign, the No campaign received significantly less political support, with Independents Teachta Dála (TD) Mattie McGrath and Senator Rónán Mullen acting as supportive voices.[239] Additionally, some members of Fianna Fáil supported the No campaign, despite their leader TD Mícheál Martin and other important members of the political party being in favour of the Yes campaign.[239] Renua Ireland was the only registered political party to fully promote the No campaign.[245] The No campaign messaging largely argued that the proposed legislation was too extreme and would likely result in mass abortions.[239] Mediation and coordination between the two campaigns was facilitated by the Iona Institute.[239]

1.6.3.3 Fatal fetal anomaly and the referendum

FFA was centrally positioned within the referendum by both the Yes and No campaigns. Prior to the 2018 Referendum, politicians made numerous attempts to legislate for TOP for FFA.[116] During the ballot for reasons which TOP should be allowed, 89% of the Citizens Assembly's Members voted in favour of TOP if the unborn was diagnosed with a fetal anomaly that would likely lead to death in utero or shortly after birth.[242] The Joint Oireachtas Committee report included medical experts' reference to the detrimental effect travelling for TOP for FFA and leaving their support network had on women's psychological well-being.[241] Similarly the Together for yes campaign emphasised the tragic situation women experienced having to travel abroad for a TOP for FFA for a much wanted pregnancy and the need for them to be compassionately cared for at home in Ireland.[246] The No campaign, also focused on TOP for FFA and expressed concerns about 'vulnerable' cases, babies with disabilities being terminated to reduce the number of children being born with additional needs.[239] This argument paid particular attention to the

diagnosis of Down syndrome and that legalising TOP would result in infants with this diagnosis being extremely susceptible to being terminated.

1.6.3.4 Parents/voluntary Organisations role in the referendum

Parents and voluntary organisations have played a significant role in repealing the Eighth Amendment. As previously mentioned, Human Rights bodies were critical of Ireland's abortion laws but a constitutional reform was not called for until 2014 following the involvement of organisations representing women who had been harmed by punitive state policies.[218] Mellet and Whelan shared their personal experiences of having to travel for a TOP for FFA resulting in Ireland being found in violation of women's rights (Taylor et al. 2020).[218] Additionally, during the referendum, women and voluntary organisations were provided a platform to share how their lives were influenced and negatively affected by the Eighth Amendment.[218,229,239] Furthermore, this gave them the opportunity to advocate for Ireland to recognise abortion as women's reproductive and human rights as directed under international human rights law.[218] Field (2018) highlighted that creating awareness of women's traumatic experiences and promoting compassion, love and support for women requiring an abortion emotionally appealed to society.[239] Similarly, parents who had continued their pregnancy and given birth to children with a FFA and other disabilities shared their experiences of how the Eighth Amendment positively protected the lives of infants like their own.[247,248] This emotional strategy was referenced as an important component in the success of the marriage referendum.[239] It was equally as important in the success of the abortion referendum as peoples stories and experiences were identified as a key factor that influenced the repeal votes and the referendum.[231,249]

1.6.3.5 The Health (Regulation of Termination of Pregnancy) Act 2018

In December 2018 Ireland legislated for TOP for FFA in the Health (Regulation of Termination of Pregnancy) Act 2018.[243] Fetal rights under the constitution no longer silenced the views and health of pregnant women.[218] The Health Act 2018 legally permits a TOP for FFA if two medical practitioners (one being an Obstetrician) diagnoses a pregnancy with a condition 'likely to lead to death of fetus' in utero or within the first 28 days of birth.[243] Donnelly and Murray (2020) comment on the uncertainties of the legislation and important gaps within the Irish abortion legislation.[217] The legislation lacks clarity whether it takes into account medical and life sustaining interventions, is without gestational limit and remains grounded in criminal law framework.

Taylor et al. (2020) acknowledges that while most women in Ireland who need abortion care should have access from their community based provider or hospital, not all women will.[218] This is true for women who receive a diagnosis of a fetal anomaly with an unknown or uncertain prognosis. As discussed within *1.3.6 What is a Fatal Fetal Anomaly,* there is no universal agreed list of conditions that belong to the term FFA as death in utero or within 28 days of birth is not guaranteed for many of the conditions associated with this term. Therefore, Clinicians face many challenges in diagnosing conditions as fatal in accordance with the Irish legislation due to this uncertainty. These challenges are further compounded by Clinicians working within the TOP legal framework, within a law that potentially criminalises them, leading to conservative practices and inconsistencies and limit Clinicians in the care they provide.[87,217–219,221,250] These provide compelling arguments to support the need for a reform of the Act, for the abolishment of the retained criminal liability, removal of the 28 days in Section 11 of the Act, and the need for legislators to listen and trust FMS in their expert management of pregnancies affected by FFA. Additionally, there is a need for national governance in terms of service provision, to ensure a standard of care is provided to all women who opt for a TOP for FFA. As the legal right to abortion does not automatically ensure the provision of appropriate abortion care[217] it is necessary to review the TOP for FFA service being provided and the suitability of

the Irish legislation for TOP for FFA. Only through national governance can continuous improvement in the quality of services and safeguarding of high standards of care be ensured. Furthermore, the Act itself and the Ministerial regulations within the Act would benefit from referring to Clinical practice guidelines developed by the healthcare professionals working with the abortion services.

An area of concern is that the officials in the Department of Health responsible for the legislating of TOP for FFA sought minimal guidance from professional bodies' representations, with only those who had personal experience of TOP for FFA and related advocacy groups influencing the legislation. While patient and public involvement is necessary it is important for scientific based knowledge and professional experience to be represented thus a shared partnership is desired to influence the overall outcome.[251]

1.7 **Implementation of termination of pregnancy in Ireland**

1.7.1 Introduction of termination of pregnancy services

On January 1st 2019 Ireland enacted the Health (Regulation of Termination of Pregnancy) Act 2018.[243] The rapid introduction of the legislation, from the initial repeal on the 28th of May, publication on the 20th December and enactment on January 1st, presented many challenges for the nineteen maternity units. Media reports included senior medics concerns regarding the January 1st deadline and referred to it as 'dangerously unrealistic'.[252,253] The Coombe Women and Infants University Hospital publicly announced that they were not in a position to provide abortion services on the intended date.[254] Only nine of the maternity units provided TOP services for the January deadline.[253] More specifically to FFA, Irish clinical guidelines for the service delivery of TOP for FFA were rapidly developed alongside the introduction of the service and published in the January 2019.[217]

1.7.2 Fetal Medicine working group and clinical guidance pathway

Following a Department of Health appeal to the Institute of Obstetricians and Gynaecologists, Dr Cliona Murphy, Chair of the Institute of Obstetricians and Gynaecologists requested the development of a fetal medicine working group.[52] The purpose of this group, chaired by Dr Keelin O'Donoghue, was to develop the Interim Clinical Guidance Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed during Pregnancy: Termination of Pregnancy.[52] Prior to the publication of this document, the Royal College of Obstetricians and Gynaecologist Guideline was the only Guideline of its kind, to refer to TOP for FFA.[57] The Irish care pathway aimed to facilitate staff in delivering evidence based and high quality ongoing care for families following a FFA diagnosis, whether they continue with the pregnancy or terminate.[52] It provides uniform standards through offering clinical guidelines to healthcare professionals regarding Section 11 of The Health Act 2018, regarding TOP for a condition likely to lead to death of the fetus or the neonate.[52] Following a year of implementation these guidelines have been updated to address any shortcomings experienced by users, in particular Fetal Medicine Specialists' in 2020 however, while they have been widely circulated they are not yet published.

1.7.3 Delivery of termination of pregnancy for fatal fetal anomalies

Following a year and a half since its implementation on January 1st 2019, little is known about the provision of TOP for FFA in Ireland. Neither the Health Service Executive nor the nineteen maternity units have published material on any aspect of the TOP care provision. The Abortion Statistics in England and Wales for 2019 has identified an 87% reduction in the number of women presenting for abortions following the provision of abortion in Ireland.[255] However, the proportion of TOP provided for under Ground E, in the case of a substantial risk that the baby will suffer from physical or mental abnormalities as to be seriously handicapped if

born[57], increased from 3% to 17% in 2019.[256] During 2019, 6,666 abortions were carried out in Ireland with 100 performed due to the fetus being diagnosed with a condition likely to lead to the death of the fetus in utero or within the neonatal period (first 28 days of life).[257]

1.7.4 Media and the provision of termination of pregnancy for fatal fetal anomalies

Within weeks of providing TOP for FFA the National Maternity Hospital was subject to media scrutiny and an independent review was called for on a termination carried out for FFA.[258] McNamara et al. (2018) has reported on the Irish media's readiness to regularly report on adverse obstetric events, suggesting mismanagement and naming Clinicians involved.[259] It is well documented that negative media attention can have an unfavourable impact on both healthcare professionals and parents.[260,261] Furthermore, media's influential nature on its reader and its power to represent social topics in a particular way is well known.[262,263] There is little known however, how information on FFA is represented in Irish media.

1.7.5 The lobbying for change in legislation continues

Legalisation of abortion does not automatically equate to the provision of a standardised abortion service.[217] While the law may have changed in Ireland many women continue to struggle to access abortion services and so the process of reform of Ireland's abortion law continues.[218,246] Due to the prioritisation and rapid introduction of service delivery the government failed to move the legislative framework away from criminalisation and direct more focus on women's human rights and equitable access to care.[218] The retention of criminalisation can impact Clinicians working within the TOP legal framework as fear of prosecution can lead to conservative practices and inconsistencies[87] and

limit Clinicians in the care they can provide.[217–219,221,250] This results in Clinicians, once again acting as gatekeepers of law that potentially criminalises them, having to decide whether a condition meets the threshold for TOP for FFA resulting in those whose pregnancies fall outside this remit having to travel abroad for a TOP.[217] Despite no reference to Fetal Medicine Specialists' involvement in TOP for FFA within the legislation, the Interim Clinical Guidance Pathway (2020) promotes their active involvement and recommends that they should be one of two signatories on the certification document.[52] Little is known about Fetal Medicine Specialists experiences of prenatal diagnosis and the counselling and care involved in pregnancies affected by a FFA.

1.8 **Summary**

While the prevalence of congenital anomalies and those considered fatal are low, they have a significant impact on both, parents who experience a pregnancy with such a diagnosis and those who provide care from prenatal diagnosis right through to bereavement care. Improvements in antenatal screening and diagnostics have resulted in more women receiving a diagnosis of a FFA. As a result, parents are faced with difficult choices, primarily whether to continue or terminate the pregnancy. Regardless of the choice, the outcome is ultimately the same, ending in a fetal, neonatal or infant death.

The journey to reform the Irish abortion laws has been a complex one, fraught with difficulties and legal cases and involving human rights advocacy, governmental processes and feminist activism. Following a referendum in May 2018, the Irish citizens voted to remove the Eighth Amendment, one of the most restrictive abortion bans in the world permitting Irish legislators to legalise abortion. The Health (Regulation of Termination of Pregnancy) Act 2018 permitted TOP for FFA if two practitioners agree that the fetus is suffering from a condition likely to lead to death in utero or the neonatal period (28 days). The abortion law however is complex with gaps and uncertainties, and its rapid introduction has

faced challenges. Firstly, there is a lack of a universal agreement of what constitutes a FFA or a list of conditions that belong to this term. Furthermore, there are known survivors linked to many of the conditions associated with being fatal. The retention of criminal liability also creates barriers in the provision of TOP for FFA.

It is clear that FFA has a significant societal impact however, despite the adverse effect a diagnosis of a FFA can have on parents and Clinicians, very little is known about these pregnancies. In particular, there is an absence of knowledge within the Irish context, on the incidence of FFA, what is known about FFA, how it is presented in the media and experiences of both volunteers and Fetal Medicine Specialists supporting women who receive a diagnosis of a FFA.

1.9 **Thesis Outline**

This thesis is comprised of six papers exploring various aspects of FFA. Firstly it identifies the incidence of FFA associated with perinatal mortality in Ireland and assesses the general public's knowledge of FFA during the referendum to repeal the Eighth Amendment. Furthermore, a critical discourse analysis on the influence of media commentary on Fatal Fetal Anomaly in Ireland was undertaken. Additionally, a Delphi survey facilitated the identification of volunteers, who provide support to bereaved parents, educational needs in order to develop an education day responsive to these needs. Lastly, both volunteers and Fetal Medicine Specialists experiences of providing care and support during the implementation of a new service of TOP for FFA. Prior to presenting these studies each study's aims and objectives are presented in *1.10 Thesis Aims and Objectives.* For ease of reading, this thesis is presented as:

Chapter 1: Introduction, aims and objectives

Chapter 2: Original Research; The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland

Chapter 3: Original Research; An assessment of the general public's knowledge of fatal fetal anomalies

Chapter 4: Original Research; Critical discourse analysis on the influence of media commentary on fatal fetal anomaly in Ireland

Chapter 5: Original Research; Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey

Chapter 6: Original Research; Experiences of volunteers supporting parents following a fatal fetal anomaly diagnosis

Chapter 7: Original Research; Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: A qualitative Study

Chapter 8: Discussion

1.10 Thesis Aims and Objectives

The overall aim of this thesis was to explore various aspects of pregnancies diagnosed with FFA. The specific objectives for each chapter are presented in Figure 1.1.

Figure 1. 1: Individual chapter's objectives

Chapter 2

- To identify the incidence of congenital anomalies contributing to perinatal mortality.
- Of these, identify how many conditions are considered 'fatal', 'potentially fatal' or 'not fatal' in accordance with the criteria for termination of pregnancy implemented by the 2018 Irish legislation

Chapter 3

- To examine the public's knowledge on FFA, TOP for FFA and PPC
- To identify how accurate their understanding is and to expose knowledge gaps

Chapter 4

- To examine how information on FFA, TOP for FFA and PPC was delivered in Irish published media

Chapter 5

- To obtain a consensus on what the support groups learning priorities were
- To develop and deliver an education day
- To evaluate the education day

Chapter 6

- To explore formal volunteers' experiences of supporting families following a FFA diagnosis, prior to and following, the legalisation of TOP for FFA for the first time in Ireland

Chapter 7

- To explore Fetal Medicine Specialists' experiences in caring for women diagnosed with a FFA during a change in service provision for TOP for FFA

Chapter 2 - The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland

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Chapter 2 - The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland

2.1 Abstract

Objective: The term fatal foetal anomaly (FFA) describes a condition likely to lead to death of the fetus in utero or within 28 days of birth. This study aimed to identify what congenital anomalies are responsible for perinatal death and whether they are classified as a FFA in accordance with criteria outlined in Irish legislation.

Methods: Anonymised data pertaining to perinatal deaths from 2011 to 2016 in Ireland were obtained from the National Perinatal Epidemiology Centre. Secondary data analysis were conducted using SPSS.

Results: Of the 2,638 perinatal deaths, 939 (36%) had a congenital anomaly. Nearly half were chromosomal (43%, n=406 of 939) with 36% of the cases (n=333 of 938) having more than one anomaly. Additional information was available for 777 of these congenital anomaly, of which 42% (n=328) could be classified a FFA.

Conclusion: This study identified that less than half of the congenital anomalies could be classified as a FFA, however all were fatal. This acknowledges the complexity of these cases. In isolation the congenital anomaly may not be fatal but combined as multi-organ system anomalies it is. Knowledge is required to inform clinical practice and counselling of parents who receive such a diagnosis. There is a need for a universal definition that represents fetuses with conditions that cause perinatal death.

What's already known about this topic?:

• There is no agreed definition of what constitutes a fatal foetal anomaly or agreed list of conditions associated with fatal foetal anomalies.

• Subjective language in legislation, which is open to interpretation, can result in subjective decision-making.

What does this study add?:

• Highlights the complexity relating to the presentation of infants with congenital anomalies that leads them to being fatal.

• Need for a universal term and definition that represents fetuses with conditions that cause perinatal death.

2.2 **Background**

Currently, there is no agreed definition, or list of conditions associated with lethal/fatal anomaly. Wilkinson et al. describe a lethal/fatal fetal anomaly (FFA) as a condition that causes a death in utero or within the newborn period (first 28 days of life) despite supportive treatment, and this description is generally accepted.[118,119] However, this description does not accurately describe many of the conditions that are recognised as a FFA by healthcare professionals in clinical practice as known survivors are linked to many of these conditions.[119]

Knowledge relating to FFA is imperative as improvements in antenatal testing result in a greater number of women receiving a diagnosis of FFA during their pregnancy.[13] An antenatal diagnosis of a fetal anomaly can create much uncertainty about the fetal prognosis.[6] Parents are then faced with the difficult decision whether to continue with the pregnancy and prepare for the birth of an infant with a congenital anomaly or terminate the pregnancy. There is a need for accurate information on FFA and the prevalence of FFA-related perinatal deaths, to inform clinical practice and counselling of parents following such a diagnosis. Healthcare professionals are required to provide information to women and their partners to facilitate the decision-making process.[87] Parents have the right to accurate and comprehensible information, on which they base their maternity care decisions.[264] Power et al. however, identified that the Irish public has limited knowledge of FFA, and demonstrated there is much confusion around what conditions are associated with this term.[265] This is no surprise when there is a lack of an agreed international definition of FFA.[118]

Within Ireland, the term FFA gained popularity following its use by political parties, in attempts to amend the Eight Amendment with the Protection of Life During Pregnancy (Amendment) (Fatal Foetal Abnormalities) Bill 2013 and Bill 2015.[116] In 2018, following an Electoral referendum, Ireland legislated for termination of pregnancy for FFA in the Health (Regulation of Termination of Pregnancy) Bill 2018, for the first time.[27] Within this legislation, it describes a 'Condition likely to lead to death of foetus' and indicates a termination of pregnancy may be carried

out following a diagnosis that will cause death of the foetus in utero or within 28 days of birth. This part of the legislation is without gestational limits and it is unclear if it takes into account medical or surgical intervention. Without a general agreement, of what constitutes a FFA, clinicians face many challenges when trying to practice within this legislation.

In 2016, the National Perinatal Epidemiology Centre (NPEC) reported that stillbirths (SBs) and early neonatal deaths (ENNDs) accounted for 61% and 31% respectively of all 407 perinatal deaths in Ireland that year (10). Of note, major congenital anomalies were the primary cause of death in 31% of SBs and 55% of ENNDs.[266] In Ireland, little is known about these perinatal deaths and associated congenital anomaly, for example, what anomalies are most responsible for perinatal mortality and at what stage this occurs. Therefore, there is a need for accurate information on FFA and the prevalence of FFA related perinatal deaths to inform clinical practice and counselling of parents. This study aimed to analyse data pertaining to perinatal deaths (deaths occurring to at least 500g birthweight or at least 24 weeks gestation and within 7 completed days of birth) associated with congenital anomaly that occurred in the Republic of Ireland between 2011 and 2016. The aims of this study were to identify the incidence of congenital anomalies contributing to perinatal mortality and of these, identify how many conditions are considered 'fatal', 'potentially fatal' or 'not fatal' in accordance with the criteria for termination of pregnancy implemented by the 2018 Irish legislation.

2.3 **Methods**

2.3.1 Design

A secondary analysis using anonymised data collected by the National Perinatal Epidemiology Centre (NPEC) between January 2011 and December 2016 was undertaken. It is important to note, the study period corresponds with a time in Ireland where approximately 64% of women were being offered a second trimester fetal anomaly ultrasound scan.[18]

2.3.2 Data collection

Designated coordinators (Obstetricians, Midwives, Neonatologists and/or Neonatal Nurses) within each of the 20, but since 2014, 19 maternity units in the Republic of Ireland, collate data directly form the patient's charts and submit data on SBs and ENNDs using NPEC's Perinatal Death Notification form.[266] In Ireland, a stillbirth (SB) is an infant born without any signs of life from 24 weeks gestation and/or with a birth weight equal to or greater than 500g while an early neonatal death (ENND) is the death of a live born infant within the first 7 days of life.[266] The NPEC Perinatal Death Notification Form is a standardised form based on the validated Centre for Maternal and Child Enquiries Perinatal Death Notification Form.[267] The Perinatal Death Notification dataset includes the collection of data on maternal and infant characteristics including conditions diagnosed, causes of death and investigations carried out. Data are validated directly with the respective maternity units to ensure accuracy of information on perinatal mortality.[266] In addition, NPEC consolidates their data with the perinatal surveillance body in Ireland, the National Perinatal Reporting System (NPRS), responsible for the collection and reporting of all births in the Republic of Ireland. For the purpose of this study, all data related to congenital anomaly being coded as either main cause of death and/or an associated factor, between 2011 and 2016 was utilised for this study.

Following permission, granted by the NPEC access committee, data on SBs and ENNDs were analysed for what congenital anomaly was associated with the perinatal death. Within their classification system, NPEC currently organises major congenital anomalies into; Central Nervous System, Cardiovascular, Respiratory, Gastro-intestinal, Urinary and Musculo-skeletal systems, Multiple anomalies, Chromosomal and Metabolic disorders and Others. They present information on the incidence of SBs and neonatal deaths using this classification system. In many cases, there is more than one anomaly present resulting in more than one classification system being recorded.

The purpose of the NPEC notification form is to classify the congenital anomalies associated with perinatal deaths into the broad categorisation and not to collect detailed information on the congenital anomalies themselves. Maternal and fetal conditions associated with the death are inputted in a tick box section using the classification system. Space is provided to enable the coordinator to name other 'major congenital anomaly' and 'chromosomal disorders'. A subsequent section facilitates the coordinator to input information on the main condition/event causing the death. It was this data that was referred to, to classify the anomaly as a FFA, potential FFA or not a FFA.

Through a review of the literature, a list of whether the congenital anomalies present in the NPEC data were considered to be a FFA, a potential FFA or not a FFA was created (see Supplementary File III). This was challenging as there were contradictions present within the literature regarding whether a condition could be deemed a FFA or a potential FFA. All three authors independently reviewed these conditions against the literature, prior to coming together to identify whether the congenital anomaly associated with the perinatal death was considered a FFA, potential FFA or not a FFA. As the chair person, the senior author had discussions with, the Fetal Medicine Clinical Advisory Group (associated with the Institute of Obstetricians and Gynaecologists) regarding what congenital anomalies would be considered a FFA and potential FFA during the preparation of

Clinical Guidance for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed during Pregnancy: Termination of Pregnancy. Thereafter, the senior clinician made the final decision.

2.3.3 Statistical Analyses

Analysis was conducted using SPSS Version 24. Data were analysed to assess the incidence of perinatal deaths and then the incidence of pregnancies with major congenital anomalies which resulted in a perinatal death. This list of FFA, potential FFA and not a FFA (see Supplementary File III) was used to identify how many of these congenital anomalies were deemed as a FFA and potential FFA and how these diagnosis were investigated and confirmed. As previously stated, the purpose of the NPEC form is to classify the congenital anomalies in to the broad categorisation, however, there is an optional space for the designated coordinators to input additional information relating to the congenital anomaly.

Rates were calculated per 1,000 births when analysing perinatal deaths across the five years. However, due to the small numbers when categorising the congenital anomaly to fatal, potentially fatal and not fatal and when analysing the five most common FFA, these rates were calculated per 10,000 births. Univariate analysis was undertaken to explore associations between perinatal deaths attributed to a FFA and maternal and infant characteristics to identify any risk factors for the all of the 939 perinatal deaths associated with congenital anomalies.

2.3.4 Ethics

Additional ethical approval was not obtained for this study as it was a secondary analysis using anonymised data collected by NPEC. Ethical approval for this National Audit undertaken by NPEC was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (g) 05/08/08, ECM 3 (GG) 13/08/19).

2.3.5 Data Availability

As data were only requested from NPEC for use in this study we were not granted permission for the data to be held in an open repository.

2.4 **Results**

Of the 2,638 perinatal deaths during 2011-2016, 939 perinatal deaths had an associated congenital anomaly as presented in Table 2.1. The rates of congenital anomaly associated perinatal deaths was consistent from 2011 to 2016 with an average rate of 2.3 per 1,000 births. As the input of additional information relating to the congenital anomaly is not mandatory, detailed information was only provided for 777 of the 939 perinatal deaths reported to be associated with a congenital anomaly. Of these cases, one was noted as an anomaly but was awaiting a coroner's report before finalising classification. Therefore, after removing the perinatal deaths where the congenital anomaly was unknown, 777 of the 939 perinatal deaths were categorised as one of 'FFA', 'potential FFA' and 'not a FFA'. Of the 777 perinatal deaths associated with congenital anomalies, 42.1% (n=328) of the congenital anomalies recorded were considered to be a FFA (a rate of 7.9 per 10,000 births), however over one third (37.9%, n= 296) were considered not to be a FFA (Table 2.2).

2.4.1 Maternal Demographics

Between 2011 and 2016, there were 473 SBs and 466 ENNDs with an associated congenital anomaly. As presented in Table 2.3 over half the women who experienced perinatal death with an associated congenital anomaly were aged 30-39 years (58.4%, n= 540). Women ranged in age from 17 to 47 years. The majority of women who experienced a SB or ENND were of white Irish origin (79.1%, n= 374 v 76.7%, n=356). Almost one third of women who experienced a SB or ENND were

overweight (28.6%, n= 114 v 28.8%, n= 106) while almost a quarter of women were obese (23.9%, n=95 v 23.9%, n= 81). BMI ranged from 10.14 to 55.04. Medical conditions were reported for 21.9% (n=201 of 915) of the cases. The two most common maternal medical conditions reported to be present were psychiatric (5.5%, n=50) and endocrine conditions (4.6%, n=42). Smoking was reported by 13.0% of the women (n=129 of 921, missing data for n=18). Maternal demographics are further presented in Table 2.3.

2.4.2 Fetal and Neonatal Characteristics

Of the 934 perinatal deaths 52.6% (n=491) were male infants. There were 10 infants of indeterminate sex. The majority of SBs (86.5% n=409) and ENNDs (65.0% n=303) weighed less than 2499g. Birth weights ranged from 105g to 5010g. Infant characteristics are presented in more detail in Table 2.4.

2.4.3 Classification

Of the 939 perinatal deaths, nearly half of the conditions were classified as chromosomal (43.2%, n=406). A quarter were classified as cardiovascular (23.1%, n=217) while 19.1% (n=179) were classified as of the central nervous system. There was more than one anomaly present in 35.5% of the cases (n=333 of 938) with 21.4% (n=201) having 2 systems affected, 8.8% (n=83) having 3 systems affected, 3.4% (n=32) having 4 systems affected and 1.8% (n=17) having 5 or more systems affected. As presented in Table 2.5, these cases were recorded under several classifications. Of those that had a chromosomal anomaly, 58.7% (n=230 of 392) of these were identified as a FFA. Further information on the rate of severity of the classifications are presented in Table 2.5.

Table 2.6 presents the five most prevalent FFA identified as the main cause of death during 2011 to 2016. Edwards Syndrome (Trisomy 18) represented the most common FFA (15.2% n=118). Renal agenesis/potter syndrome gradually increased

in prevalence over these years, from a rate of 0.5 in 2011/12 to 1.2 in 2013/14 and 1.5 in 2015/16.

2.4.4 Postnatal Investigations

Within this cohort, 35.9% (n=326) of infants had an autopsy performed while almost half were offered an autopsy but declined (47.6%, n=432). It is important to note that where an antenatal diagnosis of a genetic and chromosomal condition is given, it is common that an autopsy is not requested. Placental histology was undertaken for 86.1% of all perinatal deaths in this cohort (n=799 of 928). Greater detail on postnatal investigations are presented in Table 2.7.

2.5 **Discussion**

This study analysed data pertaining to all perinatal deaths with a congenital anomaly as the cause of death, or in the one case where post mortem results were pending, associated with the death, that occurred in the Republic of Ireland between 2011 and 2016. This study identified that 939 perinatal deaths were attributed to a congenital anomaly, of which there were 473 SBs and 466 ENNDs. However, the analysis identified that while all of these congenital anomalies contributed to a death, less than a half (42%) would be considered a FFA using the description provided in the Health (Regulation of Termination of Pregnancy) Bill 2018.[27] This study offers knowledge on what conditions are deemed a FFA and the rate in which they contribute to perinatal death in Ireland.

The identification of less than half of the anomalies responsible for perinatal death being classified as a FFA highlights the complexity relating to the presentation of infants with congenital anomaly, as well as associated anomalies and progression of conditions during pregnancy that ultimately leads to them being fatal. More than a third of cases reviewed had more than one anomaly present which suggests that while an anomaly may not be considered a FFA, when combined with multiple

anomalies it subsequently can become fatal. O'Donoghue and National Bereavement Care Standards Implementation Group concurs, that while many of the conditions in isolation may not be a FFA, combined they have the potential to be fatal.[152] This promotes the need for a universal agreed definition or a review of the Irish legislation to facilitate a more accurate description of a FFA, one that adequately describes foetuses/infants with conditions that can cause perinatal death.

This is an important area not least for Ireland as the legislation has changed, but also internationally where different legislation exists with regard availability of termination of pregnancy for fetal anomaly. Dommergues et al. identified that where the language in legislation is subjective and open to interpretation as is the case in many countries, this can result in subjective decision making.[268] England and Wales have identified challenges associated with interpretation of their legislation; "substantial risk of physical or mental abnormalities as to be seriously handicapped".[269] Within this Act, the subjectiveness of what a disability is, is highlighted[270] and the difficulty in defining the terms 'substantial' and 'serious'.[87] It is necessary that healthcare professionals are knowledgeable and skilful so that families are provided comprehensive and balanced counselling, where the best available information on potential outcomes is provided.[57,152,163] Healthcare professionals are required to be definitive in their knowledge and decision making on all aspects of FFA presentation and diagnosis, especially where criminalisation of medical professionals remains in the legislation, as it does in Ireland and many other countries.

This latter issue is of particular importance as it can create the potential to encourage conservative interpretations of the legislative framework and thus the avoidance of classification of a severe congenital anomaly as a FFA. Lotto et al. suggests that when interpretation of the law is optional and opportunity for legal challenge and criminal charges exist, this can create difficulties and inconsistencies in service provision.[5] In addition, while the lack of an agreed list of what conditions

are deemed as a FFA is controversial, this study identifies the need for such, suggesting it also allows for complex diagnoses, multiple anomalies and progression of conditions to be considered.[118,119] Kose et al. concurred, suggesting that categorising and simplifying a list of congenital anomaly and how fatal they are could assist in minimising subjectivity and standardising healthcare provision following a diagnosis of a FFA.[271]

Potential risk factors for pregnancies and congenital anomalies were inclusive of maternal obesity, lower birth weight, prematurity, maternal age of 35 and older, and male infant gender. These findings are similar to those of past studies assessing the risk factors associated with presence of congenital anomalies.[272–274] While this study demonstrates an association of these factors to perinatal deaths with congenital anomalies, due to the limited information within the NPEC data and in the absence of comparison groups no conclusions can be generated.

An increase in the incidence of renal agenesis from a rate of 0.5 in 2011/12 to 1.5 in 2015/16 was identified, while Edwards syndrome was the most common FFA. Recording and analysis of epidemiological information on congenital anomalies has numerous benefits including the facilitation of warnings of teratogenic exposures and assessing the impact of improvements in antenatal screening.[275] Baldacci et al. highlights the need for a primary prevention strategy and prioritisation of congenital anomalies in public policies and healthcare.[276] Research into the main causes of congenital anomalies and changes in prevalence is essential for evaluating current preventative strategies and their effectiveness.[275,277] This can inform development of new preventative methods.[275,277]

The findings of low uptake of autopsy and sub-optimal investigations are similar to national and international studies that addressed autopsy rates of all perinatal deaths.[278–282] Autopsy and postnatal investigations are essential to explore the underlying reasons for perinatal mortality thus informing perinatal audit.[281,282] Furthermore, it is an important component in recognising a potential recurrence risk and in the management of subsequent pregnancy.[281,283] and antenatal

interventions.[283] However, similar to Manning et al., this study identifies the need for factors affecting autopsy rates to be further explored, with particular interest in the perinatal deaths with a congenital anomaly as its main cause of death.[266] An antenatal diagnosis will influence the autopsy rates and prior to 2016, the NPEC Perinatal Death Notification form did not include whether an antenatal diagnosis of a chromosomal condition was given and how diagnosis was made. Given that an antenatal diagnosis will influence the autopsy rates, it is difficult to critically discuss these findings. However, research shows, there was an inequity of access to routine antenatal ultrasound services during the study period in Ireland.[18] A standardised ultrasound service is currently being improved following recommendations made in the National Maternity Strategy 2016.

2.5.1 Limitation

Information collected on the NPEC Perinatal Death Notification form regarding congenital anomaly is limited as the sole purpose of this coding system is to conduct a national clinical audit of perinatal deaths rather than provide specific information relating to the congenital anomalies associated with the perinatal deaths. However, as previously stated there is a section that facilitates the coordinator to input additional information relating to the congenital anomaly. Collaboration with European Surveillance of Congenital Anomalies (EUROCAT) would be preferable as it would facilitate addition of essential epidemiologic information on congenital anomaly. Currently, only Dublin, South East Ireland, and Cork and Kerry are member registries in Ireland and submit epidemiologic surveillance of congenital anomalies to EUROCAT's database.[275]

2.6 **Conclusion**

This descriptive analysis from a national registry of perinatal deaths in Ireland from 2011 to 2016 illustrated that there were 939 cases with congenital anomaly as their cause of death. This study found that of these 939 cases, less than half would be classified as a FFA using the criteria set out in the Irish Termination of Pregnancy legislation. It identified the complexity relating to the presentation of infants with congenital anomaly that leads them to being fatal and recognises that many of the conditions in isolation may not be a FFA however, when combined they have the potential to be fatal. As these cases are complex, knowledge is required to inform clinical practice and appropriate counselling of parents who receive a diagnosis of a fetal congenital anomaly. Finally, there is a need for a universal term and definition that represents foetuses/infants with conditions that cause perinatal death.

2.7 **Tables**

Table 2. 1: Perinatal deaths attributable to a congenital anomaly from 2011-2016

	2011 n (rate)	**2012 n (rate)**	**2013 n (rate)**	**2014 n (rate)**	**2015 n (rate)**	**2016 n (rate)**	**Total n (rate)**
Total births	74265	71755	69146	67663	65904	64133	412866
Perinatal Deaths	448 (6.0)	440 (6.1)	456 (6.6)	466 (6.9)	454 (6.9)	374 (5.8)	2638 (6.4)
CAs reported as the cause of perinatal death	157 (2.1)	148 (2.1)	160 (2.3)	151 (2.2)	174 (2.6)	149 (2.3)	939 (2.3)

Note: Rates are per 1,000 births.

Table 2. 2: Comparison of severity of congenital anomalies attributable to perinatal deaths as per criteria in Irish Law from 2011-2016*

	2011 n (rate)	**2012 n (rate)**	**2013 n (rate)**	**2014 n (rate)**	**2015 n (rate)**	**2016 n (rate)**	**Total n (rate)**
Perinatal deaths classified as FFA	34 (4.6)	60 (8.4)	70 (10.1)	71 (10.5)	67 (10.2)	26 (4.1)	328 (7.9)
Perinatal death classified as Potential FFA	18 (2.4)	34 (4.7)	22 (3.2)	23 (3.4)	38 (5.8)	18 (2.8)	153 (3.7)
Perinatal death classified as Not a FFA	36 (4.8)	53 (7.4)	67 (9.7)	55 (8.1)	67 (10.2)	18 (2.8)	296 (7.2)

Note: Rates are per 10,000 births.

*Perinatal deaths without information relating to the CA are removed resulting in 777 cases classified as FFA, potential FFA and Not a FFA.

Table 2. 3: Maternal Characteristics

Age in years	**SBs n=466**	**ENNDs n=458**	**Total n=924**
Mean (Standard Deviation)	33.7(6.2)	31.9(6.0)	32.8(6.2)

Age Group (years)	**SBs n=466**	**ENNDs n=458**	**Total n=924**
<20	7 (1.5)	9 (2)	16 (1.7)
20 – 24	42 (9)	50 (10.9)	92 (10)
25 – 29	66 (14.2)	88 (19.2)	154 (16.7)
30 – 34	109 (23.4)	150 (32.8)	259 (28)
35 – 39	167 (35.3)	114 (24.9)	281 (30.4)
>40	75 (16.1)	47 (10.3)	122 (13.2)

Ethnicity	**SBs n=473**	**ENNDs n=464**	**Total n=937**
White Irish	374 (79.1)	356 (76.7)	730 (79)
Irish Traveller	9 (1.9)	19 (4.1)	26 (2.8)
Other White	43 (9.1)	52 (11.2)	95 (10.2)
Asian	11 (2.3)	13 (2.8)	24 (2.6)
Black	16 (3.4)	12 (2.6)	28 (3)
Mixed	12 (2.5)	4 (0.9)	16 (1.7)

Body Mass Index (BMI)	**SBs n=398**	**ENNDs n=368**	**Total n=766**
Mean (Standard Deviation)	**26.7(5.9)**	**26.2(5.2)**	**26.5(5.6)**

BMI	**SBs n=398**	**ENNDs n=368**	**Total n=766**
Underweight (< 18.5)	3 (0.8)	6 (1.6)	9 (0.9)
Healthy (18.5-24.9)	186 (46.7)	175 (47.6)	361 (39)
Overweight (25-29.9)	114 (28.6)	106 (28.8)	220 (23.8)
Obese (>30.0)	95 (23.9)	81 (23.9)	176 (19)

Previous Pregnancy	**CA Present n= 698**	**Previous SB n= 698**	**Previous ENND n= 698**
	32 (3.4)	17 (1.8)	10 (1.1)

Delivery Mode	**Total n=939**	**SBs n=473**	**ENNDs n=466**
Vaginal Cephalic	436 (47.1)	268 (57.3)	168 (36.8)
Assisted Delivery	25 (2.7)	6 (1.2)	19 (3.2)
Assisted Breech	145 (15.7)	106 (22.6)	39 (8.5)
Vaginal Breech	46 (5.0)	37 (7.9)	9 (2.0)
Pre Labour Caesarean Section	203 (21.9)	43 (9.2)	160 (35.0)

Table 2. 4: Fetal and Neonatal Characteristics

	Total	**SBs**	**ENNDs**
Birthweight (g)	**n=939**	**n=473**	**n=466**
Median (IQR)	**1800(1353)**	**1360(1265)**	**2125(1230)**

	Total	**SBs**	**ENNDs**
Birthweight categories	**n=939**	**n=473**	**n=466**
<500g	41 (4.4)	38 (8.0)	3 (0.6)
500g-1499g	318 (33.9)	219 (46.3)	99 (21.3)
1500g-2499g	353 (37.6)	152 (32.2)	201 (43.1)
2500g-3499g	178 (18.9)	56 (11.8)	122 (26.2)
>3500g	49 (5.4)	8 (1.7)	41 (8.8)
Gestational Age at Delivery			
<22 weeks	5 (0.5)	5 (1.1)	0
22-27 weeks	140 (14.9)	105 (22.2)	35 (7.5)
28-31 weeks	131 (14.0)	87 (18.4)	44 (9.4)
32-36 weeks	357 (38.0)	160 (33.8)	197 (42.3)
37-41 weeks	291 (31.0)	110 (23.3)	181 (38.8)
>42 weeks	15 (1.6)	6 (1.9)	9 (1.9)

Note: Values are show as n (%) unless otherwise stated

Table 2. 5: Rates of congenital anomalies attributable to perinatal deaths by congenital anomaly clarifications

Classification	All deaths	Deaths with additional information on severity of congenital anomaly	FFA	Potential FFA	Not FFA
Central Nervous System	179 (19.1)	65	35 (53.8)	9 (13.8)	21 (32.3)
Cardiovascular	217 (23.1)	114	39 (34.2)	28 (24.6)	47 (41.2)
Respiratory	74 (7.9)	41	9 (22)	9 (22)	23 (56.1
Gastro-intestinal	80 (80.5)	39	11 (28.2)	4 (10.3)	24 (61.5)
Musculo-skeletal	79 (8.4)	35	17 (48.6)	10 (28.6)	8 (22.9)
Multiple Anomalies	140 (14.9)	61	31 (50.8)	12 (19.7)	18 (29.5)
Urinary Tract	126 (13.4)	42	24 (57.1)	9 (21.4)	9 (21.4)
Metabolic	7 (0.7)	2	0	1 (50)	1 (50)
Other	167 (17.8)	156	33 (21.2)	55 (35.3)	68 (43.6)
Chromosomal	406 (43.2)	392	230 (58.7)	41 (10.4)	121 (30.9)

Note: Classification of CA in accordance with the NPEC Form, Categories are not mutually exclusive

Table 2. 6: Most prevalent FFA identified as the main cause of death between 2011-2016.

Rate	2011/ 2012 Rate (95%CI)	2013/2014 Rate (95%CI)	2015/2016 Rate (95%CI)	Total Rate (95%CI)
Edwards Syndrome	2.5 (1.7-3.4)	4.0 (3.0-5.2)	2.2(1.4-3.1)	2.8 (2.4-3.4)
Anencephaly	1.2 (0.7-1.9)	2.1 (1.4-3.0)	1.0 (0.5-1.7)	1.4 (1.1-1.8)
Patau Syndrome	1.0 (0.5-1.6)	1.7 (1.1-2.6)	1.2 (0.6-1.9)	1.3 (0.9-1.7)
Renal Agenesis/ Potter Syndrome	0.5(0.3-1.3)	1.2 (0.9 -1.5)	1.5 (0.8-2.2)	1.1 (0.9-1.5)
Triploidy	0.4 (0.1-0.8)	0.4 (0.1-0.9)	0.3 (0.1-0.9)	0.4 (0.1-0.8)

Note: Rates are per 10,000 births. Categories are not mutually exclusive

Table 2. 7: Postnatal Investigations

	Frequency n=907	*SBs n=466	**ENNDs n=441
Autopsy performed	**326 (35.9)**	**167 (35.8)**	**159 (36.1)**
Autopsy offered but declined	**432 (47.6)**	**236 (50.6)**	**196 (44.4)**
Autopsy not performed and not offered	**149 (16.4)**	**63 (13.5)**	**86 (19.5)**

	Total	Frequency	SBs	ENNDs
MRI	**938**	**10 (1.1)**	**3 (0.6)**	**7 (1.5)**
X-Ray	**938**	**194 (20.7)**	**94 (19.9)**	**100 (21.5)**
CT	**938**	**5 (0.5)**	**1 (0.2)**	**4 (0.9)**
External Examination	**938**	**477 (50.9)**	**235 (49.7)**	**242 (52)**
Postnatal Genetic Testing	**322**	**47 (14.6)**	**21 (13.5)**	**26 (15.7)**
Placental Histology	**928**	**799 (86.1)**	**434 (92.1)**	**365 (78.3)**

***Data missing on 7 cases** ****Data missing for 25 cases**

Chapter 3 - An assessment of the general public's knowledge of fatal fetal anomalies

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Chapter 3 - An assessment of the general public's knowledge of fatal fetal anomalies

3.1 Abstract

Objective

The objective of the study is to evaluate the general population's knowledge of fatal foetal anomaly (FFA).

Methods

Descriptive statistics were utilised to describe the data. Chi-square tests assessed associations with knowledge of FFA, termination of pregnancy (TOP) for FFA, and perinatal palliative care (PPC).

Results

Nine hundred seventy adults of the Irish population selected by random digit dialling with 83.9% (n = 814) agreed to partake. Only 30% could correctly define FFA with little knowledge demonstrated regarding the classification of FFA. Almost half of the respondents were unaware that medical intervention was required for survival once born. Half of respondents stated that they did not know if PPC could commence at diagnosis, once the baby reached 24 weeks or not until the baby was born alive. One in 5 had knowledge that medical follow-up after TOP for FFA was available, and a third were unaware that bereavement care was available following a TOP for FFA.

Conclusion

This study identifies lack of accurate knowledge on FFA, its classification, diagnosis, survival, and supports available following a diagnosis of FFA among the general public. This knowledge deficit highlights the need for improved health information about FFA in antenatal education and public health campaigns to facilitate informed decision-making following a FFA diagnosis.

What's already known about this topic?

• Improvements in antenatal screening have increased the number of foetal anomalies being diagnosed during pregnancy.

• A fatal foetal anomaly (FFA) diagnosis and the subsequent discussion on termination (TOP) for FFA and perinatal palliative care (PPC) are associated with emotional distress and grief.

What does this study add?

• Identifies knowledge inaccuracies among the general public regarding FFA, PPC, and supports available for TOP for FFA.

• Recognises the need for health education within maternity services regarding FFA.

3.2 **Introduction**

Improvements in antenatal screening have greatly increased the number of major fatal anomalies being diagnosed during pregnancy.[13] Within Ireland, 2-3% of live births and 14-24% of stillbirths receive a diagnosis of a congenital anomaly[89] and this was responsible for 39% (n=146) of the 374 perinatal deaths that occurred in 2016.[266] A congenital anomaly is generally accepted as an abnormality that the baby will potentially die from soon following birth, or a condition that may require treatment prior or following birth to optimise health and support survival.[85]

Antenatal diagnosis of a fetal anomaly comes unexpectedly for parents and is associated with intense sadness and negative feelings.[7] Parents are confronted with their child's mortality[284] as they are informed about the diagnosis where terms such as 'incompatible with life', 'fatal' and 'lethal' are used.

Parents face multiple challenges when receiving a diagnosis of a congenital anomaly, primarily whether to continue with the pregnancy and avail of perinatal palliative care (PPC) or terminate the pregnancy (TOP). These decisions are potentially made more challenging in the absence of agreement on which congenital anomalies are considered fatal. The term 'fatal' is frequently used in Ireland to describe fetuses that are diagnosed with conditions that are expected to die in utero or soon after birth or at minimum have a short life.[116] Wilkinson et al. (2012) discussed the "language of lethality" and referred to the potential reasons that healthcare professionals use 'fatal' and related terminology.[118] It was suggested that these reasons included healthcare professionals' 'discomfort with uncertainty', their attempts to aid the decision-making for either TOP or PPC with the information of no survival or the potential attitudes of professionals believing that a fetus with such a condition will have no quality of life.[118] In addition, Wilkinson et al. (2012) argues that once professionals are clear in their communication, the terminology used may not be of importance.[118] However, they do suggest that the fatal language may not be clear or reflective of conditions associated with such terms, as there is no agreement on a definition or a list of conditions for fatal fetal anomaly (FFA).

The Royal College of Obstetricians and Gynaecologist (RCOG) Guideline is the only Guideline that refers to termination of pregnancy for a fetal anomaly (TOPFA). However, this Guideline does not include a definitive list of conditions or a legal definition of serious handicap.[57] While the RCOG Guideline discusses the arguments presented to reach a TOP decision, they solely recommend decisions be made on an individual basis whereby two practitioners assess the seriousness of the fetal abnormality in light of all available clinical information.[57]

While acknowledging the lack of agreement of definition, it is widely accepted that FFA is a condition that causes a death either in utero or in the newborn period, regardless of supportive treatment.[118,119] Despite the lack of clarity relating to a FFA definition, the RCOG (2010) guideline offers assistance to healthcare professionals to support women and their families who receive a FFA, in their decision making surrounding whether or not to terminate a pregnancy.[57] Within Ireland, the current law prohibits TOP (including TOP for FFA) and women must travel outside of the country to access this service. However, healthcare professionals can legally inform women of their options and the availability of TOP in another jurisdiction and resume care in Ireland following TOP for FFA.[230]

Following an electoral Referendum on May 25th 2018, the 8th Amendment of the Constitution, which protects the "the right to life of the unborn" and deems the life of the unborn to be "equal" to the right of the mother[232] was repealed and replaced with a constitutional provision giving the Oireachtas the opportunity to legislate for TOP.[241] This was a historic event for Ireland as despite being one of the few countries where abortion was historically illegal and a punishable offence, the people voted to repeal the 8th Amendment of the Constitution by a two-thirds majority (67%) and with a 64% turnout.

TOP for FFA in particular was an influential piece in securing this result, as it was centrally positioned in the argument to support the removal of the 8th Amendment of the Constitution. FFA gained currency in public affairs as politicians made

numerous prior attempts to introduce legislation[116] on these grounds. Media focused on the experiences of women who had to travel overseas for TOPFA and the detrimental effect it had on their psychological and physical well-being. This was supported by the Oireachtas Health Committee's report where medical experts referred to sub optimal care being provided to women traveling for a TOPFA and being removed from their support network.[241] In addition, women's rights and discrimination themed many of the arguments, highlighting cases where the United Nations Human Rights Committee found Ireland to be in breach of the International Covenant on Civil and Political Rights and directed Ireland to allow TOP for FFA.[241]

Nonetheless, whatever the choice for parents in any country following an antenatal diagnosis of FFA, the need for the decision to be an informed one is paramount. Information is an essential factor to develop patient's knowledge and empowers them in their decision-making.[285] Acknowledging all maternity patients popularity with accessing information from relatives and friends[286,287], it is important to assess what the general public's knowledge is on FFA, PPC and TOP as this will potentially show how accurate this information sharing is. Further, in Ireland, responsibility of legislating for the regulation of TOP now lies with officials and politicians in the Department of Health, who are also representative of the general public. This further supports the need to examine the public's knowledge on FFA, TOPFA and PPC to identify how accurate their understanding is and to expose knowledge gaps, as such an important change in health services provision must be based on accurate information.

3.3 **Methodology**

A cross-sectional telephone survey was undertaken to assess the public knowledge on FFA. A commercial omnipoll survey company (IPSOS MRBI) was commissioned to facilitate the survey. Using census derived quota controls[288], they collect a representative national sample of adults aged eighteen years and older on a fortnightly basis. Respondents were sampled ensuring representativeness with regards to, sex, age, social class and region. They were contacted using random digit dialling, ensuring those who had listed and unlisted telephone numbers had equal probability of being contacted as well as those using both mobile and landline numbers. The data were collected over a two-week period in November 2017.

The survey was designed by the research team and covered the following eleven areas: (1) What is FFA (2) incidence of FFA in Ireland (3) conditions classified as FFA (4) timing of diagnosis via ultrasound (5) survival of FFA (6) personal knowledge of someone who has had a diagnosis of FFA (7) choices available to women with a diagnosis of FFA within Ireland (8) what stage PPC could be implemented (9) awareness of FFA prevalence (10) awareness of TOP for FFA and at what stage TOP for FFA can be carried out in countries which allow TOP (11) knowledge of supports for parents who chose TOPFA in Ireland.

Verbal consent to participate was ascertained before commencement of each interview. Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (e) 07/11/17).

Descriptive and inferential statistics were utilised to analyse data with IBM SPSS Statistics version 24.0. Data were re-categorised using the census class system with high and low professional grades merged together and manual and semi-skilled merged together. The data relating to area was also categorised from Irish provinces to urban and rural. Chi-square tests were used to assess associations of the respondents and their knowledge of FFA, TOPFA and PPC.

3.4 **Results**

There were 970 respondents contacted to complete the survey. Of the 970, 83.9% (n=814) agreed to partake. As outlined in Table 3.1, the over 65+ age group were most likely to refuse to take part in the study (31.4% n=49). The lowest refusal rate was from the 18-24 age group (10.3% n=16). Half of those that refused to partake in the survey were working (53.2% n=83), with a third of those who refused being retired (31.4% n=49).

Of those who agreed to partake in the survey, the majority represented those in rural Ireland (69.7% n=567 v 30.3% n=247). Two thirds of respondents were reported as working (65% n=529). More from the professional groups agreed to partake compared to the manual group (87.7% n=565 v 76.4% n=249).

3.4.1 Experiences of FFA

One third of the population surveyed (31.9% n=260) stated that they knew of someone who had experienced a diagnosis of FFA. Women were more likely to know someone who experienced a diagnosis of FFA (39.1% n=158 v 24.9% n=102; P<0.001) compared to men, while more professionals knew of someone who had experience of a diagnosis of a FFA (35.5% n=200 v 24.1% n=60; P=0.006) than those working in manual grades.

3.4.2 Knowledge of FFA

More than two thirds of the population were unaware that a FFA is a condition that can potentially cause the baby to die during the pregnancy or soon after being born, regardless of attempted treatment to save them (70.4% n=573). Women were more likely to know the correct definition compared to men (31.9% n=129 v 27.3% n=112; P<0.001). Almost a quarter of the population surveyed thought FFA was a condition that will definitely cause the baby to die during the pregnancy (24.9% n=203). Men were more of the opinion that FFA would definitely cause death in utero (29.8% n=122 v 20.0% n= 81; P<0.001).

Half of the respondents, 56% (n=456) were aware that medical intervention was required for a fetus with a diagnosis of a FFA to survive once born. Of those who believed medical intervention was not required for survival (n=353) the majority of respondents 73.2% (n=164) reported that they could only survive hours while half, (52.7% n=118) reported that a baby with a FFA could survive days without medical intervention.

3.4.3 Classification of FFA

Respondents were given a definition for each condition and were asked to classify if it was an FFA or not. As outlined in Table 3.2, nearly half of the public were unaware that Anencephaly (45.8% n=373) and Renal Agenesis (48.5% n=395) was classified as a FFA. Greater than two thirds of the respondents were unaware that Edward's Syndrome was a FFA (75.4% n=614). This study identified that women consistently had greater knowledge regarding the classification of FFA with men more likely to reply 'I don't know' (Table 3.2).

3.4.4 Diagnosis of FFA

Only 55.7% (n=453) correctly responded that FFA is not always picked up at a 12 week ultrasound scan (Figure 3.1). Women had greater knowledge than men that a 12 week scan could not always give a diagnosis of FFA (62.4% n= 252 v 49% n=201; P=0.001). A greater amount of those under 45 years old were aware that a diagnosis of FFA could not always be given at a 12 week ultrasound scan (68.1% n=258 v 44.9% n=195; P<0.001) compared to the over 45's. More from the professional groups were aware that a diagnosis of FFA could not always be given at a 12 weeks ultrasound scan compared to the manual group (61.8% n=349 v 41.9% n=104; P.000) who were more likely to reply 'I don't know'. Over half (58.6% n=477) of the respondents incorrectly answered that a FFA will always be diagnosed at the 20-22 week ultrasound scan.

3.4.5 Options within Ireland

The majority of respondents, 81.8% (n=663) were aware that TOPFA is unavailable within Ireland and that the woman had a choice to travel outside of Ireland for this service (87.5% n=710). Over half, (60.5% n=491) were aware that PPC was an option for women who receive a diagnosis of a FFA. The majority of respondents, 80.5% (n=653) were aware that the women could receive routine antenatal care; more women were aware of this service compared to men (87.3% n=350 v 73.9% n=303; P<0.001).

Almost half of the respondents, 49.6% (n=404) reported that they did not know if PPC could commence at antenatal diagnosis. Of those who were aware of the availability of PPC from diagnosis (41.5% n=338), a greater proportion of those were aged under 45 years (45.4% n=172 v 38.2% n=166; P=0.003) with more of those over 45 years reporting 'I don't know' (54.9% n=239 v 43.5% n=165; P=0.003). Of those who were aware that PPC was available, over half (56.6% n=461) reported that they did not know if PPC could commence from 24 weeks or when the baby was born alive (49.8%; n=405). A greater amount of respondents under 45 years reported that PPC did not only commence at 24 weeks (34.6% n=131 v 23.7% n=103; P0.001) nor only upon birth (30.3% n=115 v 20.0% n=87; P=0.001).

3.4.6 Supports available to Irish women following TOPFA

Nearly half of the respondents incorrectly reported that women, upon returning to Ireland following a TOPFA in another jurisdiction cannot avail of medical follow up in the maternity hospital (53% n=427) (Table 3.3). More of those under 45 years were unaware of this service compared to those over 45 years (58.5% n=220 v 48.1% n207; P=0.001), however more of the respondents aged 45 years or older reported they didn't know (25.8% n= 111 v 15.2% n=57; P=0.001). Just over half of the population had knowledge that women can receive a medical follow up with their General Practitioner (GP) following a TOPFA outside of Ireland (59.2% n=574). Greater than

one third of respondents (37.2% n=300) answered that women who have a TOPFA outside of Ireland cannot avail of bereavement care upon return to Ireland.

3.5 **Discussion**

3.5.1 Main Findings

This study identified that almost one third of respondents knew someone who had a FFA, however a lack of accurate knowledge on FFA was evident. Only 30% could correctly define FFA with little knowledge demonstrated regarding the classification of FFA. Almost half of the respondents were unaware that medical intervention was required for survival once born. Poor knowledge regarding PPC was identified with half of respondents stating that they did not know if PPC could commence at diagnosis, once the baby reached 24 weeks or not until the baby was born alive. Only one in five had knowledge that medical follow up after TOPFA was available in Irish maternity hospitals and a third were unaware that bereavement care was available in Ireland following a TOPFA.

3.5.2 Knowledge and Classification of FFA

Recognising the absence of an agreed definition or a list of conditions for FFA, it is no surprise that there is a lack of accurate knowledge of FFA and its classifications among the general public in this study. While Wilkinson's et al. (2012; 2014) definition is widely agreed and used, it does not accurately describe congenital anomalies that are often associated with the term.[118,119] One potential source for confusion is the fact that fetuses with conditions diagnosed as fatal or lethal can potentially survive for an unknown amount of time, even if this is rare.[118,119] Wilkinson et al. (2012) argue that no agreement can be made on the probability of death that would justify labelling a condition as 'lethal'.[118] This is particularly pertinent to Ireland where during the lead up to the recent electoral referendum, much media attention focused on FFA, and referred to associated conditions e.g.

Anencephaly, Renal Agenesis and Edward's Syndrome. Yet here, more than two-thirds of the respondents were unaware of what a FFA was and at minimum, half of them were unaware that these aforementioned conditions were 'fatal'.

The limited knowledge of the necessity of interventions to potentially support life of a baby born with FFA was also evidenced within this study, with almost half of the respondents suggesting they could survive without any medical intervention. While there is much debate regarding medical interventions for babies with FFA diagnoses, there are reports of occasional long-term survivors following intensive support.[289] As a result, medical, ethical and legal challenges are evident when fetuses with anomalies are classified as fatal.[289] This finding implies the need for a FFA definition to be agreed upon amongst relevant healthcare professionals and accurate information regarding the potential for survival after birth shared with the public.

3.5.3 Diagnosis

Antenatal diagnosis is necessary to assess suitability of intervention following a congenital anomaly diagnosis, but also to give parents and families the opportunity for information and preparation or choice.[110] This study identified that nearly half of those surveyed believed that a FFA could always be picked up at a twelve-week ultrasound scan while a greater amount believed a FFA diagnosis could always be given at the 20-22 week ultrasound scan. While prenatal diagnosis within the first trimester has advanced[49,290,291] a FFA diagnosis will not always be given during this time. Those surveyed were unaware that while a diagnosis is possible at any time, prenatal diagnosis is dependent upon availability of equipment, skills and experience.[95] This is of particular relevance in Ireland where an inequity of maternity ultrasound services still exists.[18]

Researchers argue the ethical implications of providing antenatal screening services to detect congenital anomalies in areas that prohibit TOPFA.[112] However, it is widely agreed that an antenatal diagnosis, in addition to creating the option for TOPFA, allows the family to prepare for an affected baby and opportunity to deliver in a

specialised centre.[18,95] It is noteworthy, that where anomaly scans are not provided, it may result in a failure to diagnose or diagnose late, resulting in reduced options for parents[110] and a delay in the provision of supports and preparation.[95]

3.5.4 Options and Supports available

Within this study, little is known about PPC as an option in continuing a pregnancy after an antenatal diagnosis. This is of significant concern as congenital anomalies affect 1-6% of viable pregnancies worldwide[292] and that the option for PPC appears to be an increasing choice for parents.[293,294] Within Ireland, major congenital anomalies are some of the most frequent causes for neonates requiring PPC and are accountable for a significant proportion of perinatal deaths.[266,295,296] In countries where TOPFA is illegal (e.g. Nicaragua, Dominican Republic, El Salvador), without travelling for a TOP, PPC is then the only option. However, current unavailability of TOPFA in Ireland did not preclude parents from acquiring knowledge about and travelling abroad for termination prior to the removal of the 8th Amendment of the Constitution. The rate of termination for congenital anomaly varies from 15%-59% in Europe.[297] Ireland's rates, while unrecorded officially, are likely to be lower, secondary to both legal and cultural reasons. This is set to change following the recent referendum, with new legislation providing for the regulation of TOP just published and expected to be enacted in 2019.[27]

Despite the general public demonstrating knowledge of the need to travel outside of Ireland for TOPFA in this study, they were unaware of the supports available to women on return to Ireland following a TOPFA. Almost half reported that women could not avail of medical follow up in maternity hospitals, while one in four were unaware that a medical follow up with the GP should be available. Further, a third were unaware of the availability of bereavement care. This is of interest since the Health Service Executive (HSE) launched National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death in 2016 with the purpose of enhancing bereavement services for parents who experience any type of pregnancy loss or

perinatal death. The Standards act as a resource to both professionals and parents[120] providing information around necessary supports and expected standards of care including after TOPFA and in PPC.

The identified gap in knowledge of supports for TOPFA within this study is worrying and possibly reflects the culture and relative stigma surrounding TOPFA in Ireland.[162,298] Therefore, the need for health education within the maternity services is highlighted in this study. Martin et al. (2013) identified health education's importance in prenatal testing and diagnosis of FFA and suggested it was essential in empowering parents to engage in decision making.[299] Confidence in one's own knowledge is necessary for patient participation and decision making in healthcare.[300] In addition, it is necessary to understand the socio-cultural context and perceptions of adverse pregnancy outcomes prior to development of public health programmes and education, to assess for any associated stigma which can create issues around disclosure, information and health-seeking behaviour.[301] Further, while evidence based information is necessary for the legal and ethical sanction of informed consent[302,303], O'Brien et al. (2018) argue that for women, their antenatal choices are influenced by their sense of responsibility towards the safety and wellbeing of their unborn baby.[304] Therefore, all management options require clear and truthful sharing as to assist the women in deciding what is best for her unborn baby. This is necessary as women's experiences have identified the influence of medical counselling and management available has had on their decision making following a FFA diagnosis.[159,305] It is acknowledged that personal, familial, cultural, religious and social aspects influence their decision-making process.[306]

Seeking informal information on pregnancy related matters is extremely popular with maternity patients.[286,287,307,308] These informal sources include mothers/mothers in law, relatives, friends and internet forums that offer social support while seeking antenatal knowledge[251,287] and discussions on antenatal screening for anomalies.[308] Such sources are readily available and usually free to

women, facilitating their popularity.[287] For this reason, it is important that the general public are also fully informed to ensure information shared is accurate.

Women's healthcare has for many years not been openly discussed in Ireland and is not often the subject of national healthcare policies. Similar to other countries, women's healthcare issues have not tended to be on the political agenda. This is evident as officials in the Department of Health who are responsible for the first Irish legislation regulating TOP for FFA have sought only limited guidance from professional bodies' representatives in the drafting of legislation. Much of the 'expert' knowledge was sought from those who have experienced a pregnancy with a FFA, and related advocacy groups. While patient participation and empowerment is extremely beneficial, as they have first-hand experience of the phenomenon, it is important not to omit the expertise the healthcare professionals as their knowledge is science based and objective.[309] Ideally, a shared partnership should be facilitated where perspectives of both healthcare professionals and patients share their knowledge and influence the overall outcome.[309] Lack of professional input raises concern as accurate knowledge is essential in the change of service provision, yet knowledge deficits are evident in our findings and need to be addressed. This suggests that the general population's opinions are more important politically than those of the medical profession at present, and that these opinions may have a significant political influence. This has international relevance, particularly in the United States where abortion laws are slowly being limited under the current ruling of pro-life Republicans[310] and are becoming more restrictive in an attempt to reduce the number of abortions carried out.[311] Demonstrating paternalism and restrictive abortion laws are never completely impermissible and loaded with political influence.

3.5.5 Strengths and Limitations

The strengths of this study were that through using a robust methodology, it established a baseline of knowledge about classification, options and services available for FFA from a representative sample of a general population. The sensitivity of the subject could be seen as a limitation; however, there was an 84% response rate, which supported an adequate representation.

3.6 **Conclusion**

This study identifies a lack of accurate knowledge on FFA, its classification, diagnosis, survival and supports available following a diagnosis of FFA among the general public. This is of relevance as the general public are regularly a source of information to women and parents experiencing such a diagnosis and who potentially may experience a FFA diagnosis themselves. Further, there is an expectation that women should make fully informed decisions in their best interests on whether to continue a pregnancy with FFA or to terminate the pregnancy. The gap in knowledge highlights the need for improved health information about FFA in both antenatal education and public health campaigns worldwide to facilitate informed decision making following a FFA diagnosis. This is of particular relevance in Ireland, where the first ever legislation for TOP in FFA cases will shortly be introduced, and maternity hospitals will be expected to provide all management options in pregnancies complicated by FFA.

3.7 **Figures**

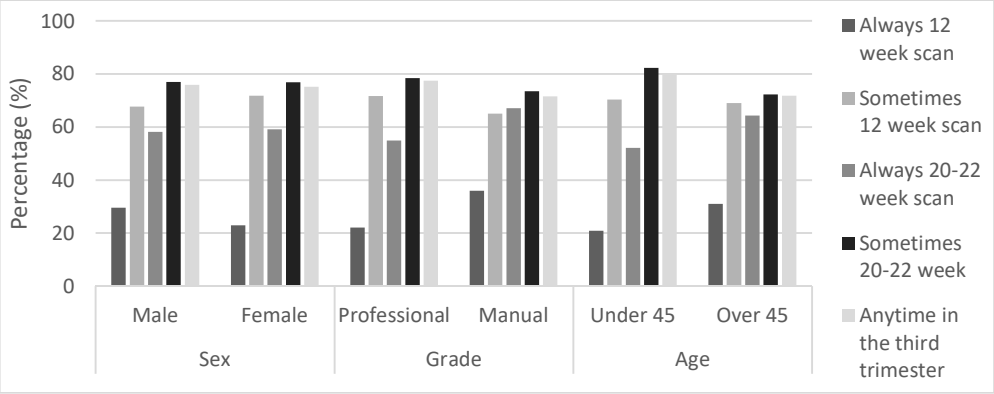

Figure 3. 1: Diagnosis of FFA

3.8 **Tables**

Table 3. 1: Sample demographics

	Total n (%)	Responder n (%)	Non-responder n (%)
Sex			
Male	497 (51.2)	410 (50.4)	87 (55.8)
Female	473 (48.8)	404 (49.6)	69 (44.2)
Age			
18-24	85 (8.8)	69 (8.5)	16 (10.3)
25-34	180 (18.6)	157 (19.3)	23 (14.7)
35-44	177 (18.2)	153 (18.8)	24 (15.4)
45-54	172 (17.7)	153 (18.8)	19 (12.2)
55-64	163 (16.8)	138 (17)	25 (16)
65+	193 (19.9)	144 (17.7)	49 (31.4)
Grades			
Professional	644 (66.4)	565 (69.4)	79 (50.6)
Manual	326 (33.6)	249 (30.6)	77 (49.4)
Employment status			
Working	612 (63.1)	529 (65)	83 (53.2)
Student	46 (4.7)	38 (4.7)	8 (5.1)
Full-time Homemaker	33 (3.4)	26 (3.2)	7 (4.5)
Unemployed	48 (4.9)	39 (4.8)	9 (5.8)
Retired	222 (22.9)	173 (21.3)	49 (31.4)
Other	9 (0.9)	9 (1.1)	
Area			
Urban	279 (28.8)	247 (30.3)	32 (20.5)
Rural	691 (71.2)	567 (69.7)	124 (79.5)

Table 3. 2: Classification of FFA among demographics combined

Condition	Sex		Grade		Age	
	F n (%)	**M** n (%)	**Prof.** n (%)	**Manual** n (%)	**Under 45** n (%)	**Over 45** n (%)
Anencephaly						
Yes	240 59.4)*	201 (49)*	312 (55.2)*	129 (51.8)*	224 (59.1)*	217 (49.9)*
No	92 (22.8)*	92 (22.4)*	130 (23)*	54 (21.7)*	86 (22.7)*	98 (22.5)*
Don't Know	72 (17.8)*	117 (28.5)*	123 (21.8)*	66 (26.5)*	69 (18.2)*	120 (27.6)*
Edwards Syndrome						
Yes	110 (27.3)*	89 (21.7)*	142 (25.1)	57 (23)	117 (30.9)*	82 (18.9)*
No	118 (29.3)*	100 (24.4)*	166 (29.4)	52 (21)	113 (29.8)*	105 (24.2)*
Don't Know	175 (43.4)*	221 (53.9)*	257 (45.5)	139 (56)	149 (39.3)*	247 (56.9)*
Down Syndrome						
Yes	37 (9.2)*	62 (15.2)*	56 (9.9)*	43 (17.3)*	49 (13)	50 (11.5)
No	360 (89.1)*	324 (79.4)*	493 (87.4)*	191 (77)*	319 (84.4)	365 (84.1)
Don't Know	7 (1.7)*	22 (5.4)*	15 (2.7)*	14 (5.6)*	10 (2.6)	19 (4.4)
Spina Bifida						
Yes	68 (16.8)*	86 (21.1)*	101 (17.9)	53 (21.4)	88 (23.3)*	66 (15.2)*
No	321 (79.5)*	277 (67.9)*	422 (74.8)	176 (71)	258 (68.3)*	340 (78.3)*
Don't Know	15 (3.7)*	45 (11)*	41 (7.3)	19 (7.7)	32 (8.5)*	28 (6.5)*
Renal Agenesis						
Yes	216 (53.5)*	202 (49.4)*	305 (54)*	113 (45.6)*	211 (55.7)	207 (47.7)
No	107 (26.5)*	89 (21.8)*	134 (23.7)*	62 (25)*	86 (22.7)	110 (25.3)
Don't Know	81 (20)*	118 (28.9)*	126 (22.3)*	73 (29.4)*	82 (21.6)	117 (27)

*P < .5

Table 3. 3: Supports available in Ireland following a TOPFA

Supports available in Ireland following a TOPFA	**Yes** n (%)	**No** n (%)	**Don't Know** n (%)
Medical follow up with Maternity Hospital	211 (26.2)	427 (53)	168 (20.8)
Medical follow up with GP	574 (71.1)	131 (16.2)	102 (12.6)
Bereavement Care	386 (47.8)	300 (37.2)	121 (15)

Chapter 4 - Critical discourse analysis on the influence of media commentary on fatal fetal anomaly in Ireland

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Chapter 4 - Critical discourse analysis on the influence of media commentary on fatal fetal anomaly in Ireland

4.1 Abstract

Background

Fatal Fetal Anomaly (FFA) has generated international media attention as termination of pregnancy (TOP) for FFA was legislated for, for the first time in Ireland. Media offers an insight into what health-related information is available to the public and how it is presented to them. The aim of this study was to examine how information related to FFA, TOP for FFA and perinatal palliative care (PPC) were framed in Irish published media.

Methods

A critical discourse analysis, which examines the relations between discourse and social and cultural phenomena was implemented. Habermasian's framework facilitated an objective analysis of the text, to facilitate interpretation and understanding of socially produced meanings. A broadsheet and online journal were chosen.

Results

Dated from 2012 to 2017, 129 articles were identified. Themes of personification of the unborn, human rights and power and politics were embedded in the discourse, creating political influence to sway perceptions and views. Terminology were chosen by different ideological perspectives to create varying contexts and support arguments. PPC was suppressed within the published media.

Conclusion

This study highlights misrepresentations in the information delivered to the public and suggests the need for healthcare professionals to expand their media literacy and develop these skills with their patients.

Keywords: Congenital Anomaly, Palliative Care, Abortion, Media, Critical Discourse Analysis

Highlights

- A fatal fetal anomaly diagnosis can cause prolonged grief and distress
- Media has the power to represent social topics in a certain way creating influence
- It is important to analyse the accuracy of information available to the public
- Change in health service provision requires accurate knowledge
- Need to prioritise women's health on the political agenda and healthcare policy

4.2 **Introduction**

Media contact has potential effects at a cognitive, behavioural, and physiological level.[312] In today's world we are saturated with and have easy access to information from the media.[312] While readers are active and selective in their interpretations of text, the influential nature of media is well documented as readers are constrained by the framing of texts.[263] Media has the power to represent social topics in a particular way[262] and effects are of particular relevance where a certain opinion or influence are intended by political or social stakeholders.[313]

As an important public health issue, women's reproductive rights have long been a topic of debate. In America, media frequently references its current climate for abortion as increasingly restrictive.[26] Within the Republic of Ireland, this topic recently received worldwide media attention[25] during the Electoral Referendum in Ireland where the Eighth Amendment of the Constitution which protected the 'right to life of the unborn'[232] was repealed. Prior to the referendum, the lack of choice women experienced during pregnancy was identified as a human rights issue by the United Nations Human Rights Committee.[24] As Ireland's healthcare is embedded in politics, this identified women's healthcare as an important subject on the political agenda and for healthcare policy makers.

The Eighth Amendment of the Constitution ensued that termination of pregnancy (TOP) including TOP for fatal fetal anomaly (FFA) was treated as a punishable offence. For this reason, TOP for FFA was one of the arguments centrally positioned to influence securing the referendum result in favour of removing the Eighth Amendment on May 25th 2018, giving the Oireachtas (the legislature of Ireland, consisting of the Irish President, House of Representatives and the Senate) the opportunity to legislate for TOP for the first time.[314] It is generally agreed that a FFA or lethal fetal anomaly is the diagnosis of a condition that despite medical intervention leads to death in utero or in the newborn period.[118] The term FFA, while not a medical term but more of a political expedient shorthand, gained popularity and use in Ireland following its use by political parties, in two attempts to amend the Eighth Amendment with the Protection of Life During Pregnancy (Amendment) (Fatal

Foetal Abnormalities) Bill 2013 and Bill 2015.[116] Therefore, it was deemed appropriate to reference this term.

Two to three percent of pregnancies receive a diagnosis of a major congenital anomaly[89], of which some are fatal. Antenatal diagnosis of a FFA confronts parents with their child's mortality and intense helplessness[9] creating difficult decisions including whether to terminate or continue with the pregnancy. Whatever the choice, the outcome results in a pregnancy loss which can result in grief, guilt, and post-traumatic stress.[315]

Through the examination of the language in use, this study aimed to examine how information on FFA, TOP for FFA and perinatal palliative care (PPC) was delivered in Irish published media and the nature of this media coverage. The examination of the information aimed to assess if these topics were represented comprehensively, truthfully and for legitimacy and sincerity. Additionally, it aimed to assess for the presence of political influence, if all ideologies were equally represented within the media, and the potential influence of the media coverage on an important health matter.

4.3 **Methodology**

Discourse represents both written and oral texts[316] and their use, in a structure which reflects people's patterns within varying social domains.[317] Critical Discourse Analysis (CDA) is the analysis of these patterns. CDA studies the presence of social power abuse or dominance and inequality and how these are resisted in the social and political context.[318] Furthermore, CDA explores how language is a component of social practice[319,320] i.e. how the discourse contributes to the creation of social issues. The social practices are defined by people involved, their actions and the entire context of the identified situation.[321] Analysing media text requires an analysis of its structure and understanding the way in which the text exerts power over society.[263]

This study implemented an approach to CDA that applied Habermas theory of communicative action. Habermas focuses on discourse within the public and argues that the ideal discourse is one where there are equal voices, ensuring an absence of deception and coercion.[322] Habermas analyses how institutional actors such as the media and lobby groups use their political and social power to influence agendas and frame public issues.[323] This analytical framework guides the arguments and its text to be assessed on its clarity, truthfulness, legitimacy and sincerity[324,325] as presented in Figure 4.1. Potential distortion is then determined by assessing the text for any confusion, mis-representation, illegitimacy and false assurances.[324,325] It facilitates an assessment of who and what is represented, how they are represented and why they are represented in a particular way. It analyses what ideological claims are silenced or ignored, while facilitating analysis of subtle language, metaphors and connotations. These processes combined within the social context assist in generating a meaning.[324,325] The analysis of the text and visuals, language used, actors involved and its context assists in the deconstruction of text to facilitate interpretation and understanding of socially produced meanings, recognising the ability of language to generate a social world.[326]

Whereby, this analysis followed an inductive and interpretive approach[327,328], firstly a context was established i.e. a topic to be explored and appropriate media chosen and knowledge gained of when and how the media were published and their readership. Relevant sources within the media were identified and prepared for data analysis within Nvivo12. An inductive analysis was undertaken to identify overarching themes and the background of each text examined for their social and historical context and to assess the wider social context related to the timing of their publications.[327] Furthermore, their social relations and how the social practices inform the arguments within the text and in turn their influence on social practices were analysed.[327] The internal relations in the text were then assessed for clarity, truthfulness, legitimacy and sincerity and the data were then interpreted to produce a meaning.[327] Researcher SP undertook the data analysis with SM providing an

external check on the analytical process followed by a consensus discussion regarding theme development.

In addition, Kress and van Leeuwen visual analyses framework was implemented to analyse the images as it provides a systematic means to examine discourses in visual form.[329] Kress and van Leeuwen argue that visual design is its own semiotic system by conveying ideological attitudes and facilitating interaction between the sign-maker and sign-reader.[329] The focus is at a descriptive level and examining general attributes of what/who is in the image, placement of images and image composition.[329] This descriptive level of analysis allows for the identification of the data's formal properties.[330,331] Similar to an approach taken by Feltham-King and Macleod (2016), a content analysis was undertaken to enhance the insights of the discourse analysis, in particular, to evaluate and quantify the presentation and distribution of media.[332] Using a conceptual analysis approach, both explicit content, what was clearly stated and implicit content, the deeper meaning embodied within the text was analysed.[333] This facilitated the researcher to quantify how many of the sources took a pro-life or pro-choice or unbiased approach and referenced PPC and the Catholic Church and what meaning was given to this discourse as presented in Table 4.1. Furthermore, it enabled the researcher to identify the use of terms abortion versus termination and the context to create meaning. A content analysis contributed to the critical discourse analysis through facilitating an assessment of media sources for bias in their delivery of all information. A combination of CDA and content analysis enables a critical engagement with the discourses being presented and their contingency over time, thus enabling a deepened analysis of the data.[332]

Similarly, to other countries, Ireland's healthcare is embedded in politics. As a result, healthcare issues regularly generate much media attention. This methodology created an opportunity to analyse the political partisanship, beliefs of key interest groups and the nature of media coverage and its potential influence on the general public on an important health matter.

The Irish Times, an Irish broadsheet and TheJournal.ie, an online journal were chosen for this study. These were chosen as both sources were similar in that they had a

daily readership in excess of 300,000, had daily outputs and were accessible online. Furthermore, they were picked due to their different styles of journalism, with one being a broadsheet and the other similar to a tabloid. A broadsheet paper is regarded as less sensationalist than tabloids. Search engines within the online sites were utilised to conduct to the search. The search date were restricted to articles from 2010 to the present day of searching as the online journal only came into existence in 2010. Search terms were adapted, using both English and American spellings and using the terms singularly and together, to ensure all relevant articles referring to FFA were found. These terms included fatal fetal, life limiting, palliative care, hospice, termination of pregnancy and abortion. Thirty-eight broadsheet articles referencing FFA, TOP for FFA and PPC were identified; which dated back to November 2014. Ninety-one online articles referencing FFA, TOP for FFA and PPC were also identified; which dated back to May 2012. All articles identified were included in the analysis. The Supplementary File IV includes a list of the articles and a summary of each one. Empirical materials were also accessed to assist with the analysis of truth claims. These included full text multidisciplinary articles referencing FFA, PPC and TOP for FFA, available on PUBMED, SCOPUS, MEDLINE, psycINFO and CINAHL and past and present Irish Legislation.

Language and visuals of these articles were analysed to identify exaggerations of certain descriptions of reality and the potential to influence the reader. The analysis included a close examination of the use of recurring words, phrases, metaphors and ideologies[262] related to FFA, TOP for FFA and PPC and how these patterns and genres and the ways of society were expressed and represented within the current context.[320]

4.4 **Results**

The importance of terminology used, framing (technique used to influence opinions using certain terms) and semantics (relationship between sentences/words and their meanings) was evident in representing different ideological standpoints in attempts

to create varying contexts, support arguments and create emotional appeal to the reader. While both papers shared similar themes, they presented and distributed media differently. Three themes embedded in the discourse identified were personification of the unborn, human rights and power and politics.

4.4.1 Terminology used to express an ideological perspective

The importance of language in the debate on TOP was evident throughout the media discourse and its presence was referred to within one of the Broadsheet articles (July 23rd 2015). This article highlighted the importance of language in the debate on TOP and how 'to refer to someone on either side of the debate as "anti-choice" rather than "pro-life"; or as "pro-abortion" rather than "pro-choice", is to take a position on the core element of the argument'. This was an accurate observation of this editor. This example of semantics, demonstrates the importance of the relationship between words and their meanings. Other examples included the use of the term 'termination'. 'TOP' is used with FFA as opposed to 'abortion' to potentially avoid the connotation that it is an unwanted pregnancy. Within the online paper, 73% (n= 66 of 91) of the articles reference TOP or ending a pregnancy while 82% (n= 75 of 91) referenced abortion. Over half (59% n= 54 of 91) used both terms whereby the term 'abortion' was used in relation to laws, bills or in general and TOP being used in relation to FFA in 83% of these cases (n= 45 of 54). Similarly, of the 23 Broadsheet articles that referenced both TOP and abortion, 82% (n=18 of 22) reference TOP for FFA and abortion with law, bills or in general. Within the Broadsheet, those with a pro-life ideology referenced the term abortion in over half of the articles (55% n= 12 of 22). Those with a pro-choice position often referenced the TOP for FFA as a 'birth' and 'very peaceful when she was born' (Online February 4th 2015), 'asleep' and as 'stillborn' (Broadsheet July 1st 2017). This is potentially an attempt to portray their feeling of TOP for FFA as a gentle and kind procedure, done as an act of 'love' and 'compassion'.

Much debate existed over the terms 'FFA' and 'incompatible with life' versus 'life-limiting condition'. Those who were pro-choice used the term FFA and terms that described the lethality of the diagnosis; 'suffered from Trisomy 13', "incompatible with life"' (Broadsheet June 13th 2017) and 'will not survive outside the womb' (Online May 2nd 2013). This was potentially to portray no hope for survival. Furthermore, TOP was referenced as the preferred choice of women who receive a diagnosis of a FFA (Online May 2nd 2013; Online Nov 13th 2013). Whereas those who were pro-life valued a term that describes the potential for life. They argued against the term FFA and lethal references, reporting 'that names are not only hurtful, but can be used to label, exclude and dehumanise' (Broadsheet February 27th 2016). These pro-life groups and politicians submitted an 'Amendment to the Disability Act' in the Dáil to make it an offence for medical staff to describe an 'unborn child with a disability' as "incompatible with life"' (Broadsheet November 25th 2014). The 'Dáil' is the lower house, and principal chamber, of the Oireachtas (Irish legislature), which also includes the President of Ireland and Seanad Éireann (the upper house). Those with a pro-life ideology favoured the term 'life-limiting condition' and suggested that the 'majority of Irish parents who receive a 'terrifying prognosis for their babies proceed with the pregnancy'. They associate negativity with TOP for FFA and suggest that parents 'are told to go away and decide whether they want a late term termination – all in the name of compassion' (Broadsheet February 15th 2015). Data extracts from the media sources and examples of meanings interpreted from the data in relation to terminology and the following three themes are presented in Supplementary File IV.

4.4.2 Theme 1: Personification of the Unborn

Terminology used to describe the fetus was also used to create a certain influence over the reader. Emotional appeal was frequently used by both ideological perspectives in attempts to portray a desired perception and view of the unborn to the reader.

‘Baby’/’unborn’ and ‘children’ were used by those who were pro-life to personify the person being terminated (Broadsheet July 6th 2016). Families with a pro-life view highlighted the ‘unpredictability’ of a FFA diagnosis; they were informed that their baby would not survive but ‘she lived for six days’ (Broadsheet July 14th 2016) and how doctors were wrong about the outcome (Online February 15th 2015). These families highlighted the importance of time given with their ‘baby’ as ‘precious’ and how a ‘few moments with him in my arms meant everything’ (Online February 15th 2015). Those with a pro-life ideological perspective reported the need for ‘a change in mind-set’ ‘to one that sees them as human beings with short but incredibly meaningful lives’ (Broadsheet January 17th 2015) and described how the mother while pregnant was a ‘safe haven’ for the baby (Broadsheet July 14th 2016).

The positive aspects of having a child with FFA and the ‘normal’ life these children can experience through attending ‘special school with joy’ (Broadsheet January 17th 2015) and ‘walks in the park’ (Broadsheet July 14th 2016) were presented. Imagery was often used to support ideologies presented in the media. Figure 2 presents an image of a parent with their child who had been given a diagnosis of a FFA, the daughter is held by the mother, both smiling while the sun shines upon them. Figure 3 is an image of a baby who has died dressed in white, lying in her white crib looked upon lovingly by two women who have their hands placed on the baby. These images further create emotional appeal and support the above ideology through personifying these babies and demonstrating the love between the parent and the affected child.

The vulnerability of the parents and their need for ‘kindness and expert support’ upon receiving a FFA diagnosis was also referenced to create an opportunity to advertise PPC (Broadsheet February 15th 2015). However, PPC was suppressed in the media with minimal information present. Fifteen of the broadsheet articles referenced PPC (using either the terms palliative or hospice) with six of these having it as a major theme. The online paper referenced PPC nine times, with one article arguing that PPC terminology was cruel and barbaric and questioned how it would ‘help their family' (Online May 2nd 2013) while another referenced palliative care as

a team being present to medicate the baby while she 'lasted minutes at most' (Online February 4th 2015). The pro-choice ideological perspective made comments that if people were made continue the pregnancy, the affected baby would have been on 'life support machine', 'every day in hospitals' (Online June 26th 2013). This is to potentially dismiss PPC as a valid option.

Those with a pro-choice ideological perspective frequently used the term fetus in the context of avoiding recognition of life. However, at times 'baby'/'unborn'/'daughter' was used by pro-choice to create a context of the emotional difficulties of travelling for a TOP for FFA as they loved and 'wanted' this 'baby' (Online February 7th 2015). Similarly to the pro-life ideological perspective they personified the fetus who was terminated with the inclusion of; 'Inside the cardboard box was a wooden box with Aoife, our daughter's name, and her date of birth on it' (Online June 26th 2013) to potentially appeal to the reader and create awareness of how difficult this would have been for the 'vulnerable' parents. These terms; 'baby'/'daughter' and 'fetus' were used intermittently when potentially trying to convey both messages. They described 'women who had to carry to term fetuses which would not survive outside the womb' and how they described 'not a person on this earth wanted' their babies to live more than they did (Online February 7th 2015). Similarly, to the pro-life ideological perspectives, pro-choice presented the personal stories of those who faced many challenges when travelling for a TOP for FFA to create awareness of how difficult this would have been for the 'vulnerable' parents were also shared. They referred to travelling for a TOP for FFA as a 'barbaric practice of exporting vulnerable women and couples to neighbouring countries for the medical care and the support they deserve' (Online June 26th 2013). Furthermore, women's vulnerability was highlighted through reporting of financial implications of travelling for TOP for FFA, with 'not even enough money to buy a sandwich' and their lack of accurate information received, asking staff in the abortion clinic 'if they are going to die because that's what they've been told at home' (Broadsheet December 14th 2015). Finally, they shared their stories regarding the lack of post abortion care and bereavement counselling following a TOP for FFA (Online November 13th 2013).

Parents' experiences and their ethical dilemmas were evident within the media to support both ideological perspectives. Those with a pro-choice ideological perspective were represented by parents who shared their difficulties in firstly deciding what the best option for them and their unborn baby including a description of how difficult the decision-making process was. Their experiences of accessing TOP for FFA and supports and the detrimental effects it had to their overall well-being, as well as the shame and guilt associated with choosing a TOP, were included to emotionally appeal to the reader. Those with a pro-life ideological perspective shared their difficulties of continuing a pregnancy and being in receipt of negative attitudes towards their unborn and 'expecting' them to terminate the pregnancy. This ideological perspective favoured referencing ethical implications such as the eradication of people with disabilities such as Down syndrome and science exceeding ethical discussion. Politicians regularly used parents' experiences to position the argument and ideological perspective and identify to the reader, the group of people who they represented, to potentially gain political popularity.

4.4.3 Theme 2: Human Rights

Media strongly portrayed Ireland as a country that failed women at one of their most vulnerable times. It reported that those who had to travel for TOP for FFA had 'very specific, very heart-breaking, very clear-cut case' (Online May 2nd 2013). The pro-choice ideological perspective included international institutions; 'United Nations bodies' and 'Council of Europe's human rights commissioner' to reference 'Ireland's continued "violation" of women's human rights on the abortion issue' (Broadsheet December 28th 2016). Both the United Nations and Council of Europe's human rights commissioner questioned the morals of the Government who were not minding women having abortions 'as long they're not here in Ireland' (Broadsheet December 14th 2015). In addition, attention was given to cases being taken and won against the State for discrimination and violation of human rights where women were 'subjected to cruel, inhuman or degrading treatment' (Online June 14th 2017).

Media focus on international influence and court cases implied that if foreign groups and the courts are ruling against the State then they are guilty of wrong doing and that TOP for FFA should be legal, encouraging the reader to do the 'right thing'.

In response, pro-life ideological perspectives questioned Amnesty International's advocacy for rights of the woman to choose termination because they highlight their role as 'promoting and protecting human rights' however advocate 'for the right to deny amnesty to certain unborn lives' (Broadsheet July 15th 2015). The pro-life position presented the vulnerability and fragility of the unborn. This was to potentially emphasis the need to protect them and help 'all families to have the possibility of living through these devastating diagnosis without having to resort to ending brief and fragile lives even earlier than is necessary' (Broadsheet August 20th 2016).

4.4.4 Theme 3: Power and Politics

Power and politics played an intrinsic role within the media, being referenced or discussed within 50% (n=19 of 38) of the broadsheet articles and 78% (n=71 of 91) of the online articles. Power and politics were embedded in the discourse to create political influence and appeal to the emotional side of the reader to influence perceptions and views. The Government were often the targets for blame and those with a pro-choice ideological perspective commented that they were 'humiliated by our own Government' due to the 'breach of human rights' (Online June 14th 2017). Such a quote sparks negative connotations against the Government suggesting they are in the wrong by not repealing the Eighth Amendment which gave equal rights to the life of the unborn and of the mother, making TOP illegal in Ireland. The Government received media attention indicating scepticism of Government proceedings (Broadsheet July 23rd 2015) during the Citizens' Assembly which was developed by the Irish Prime Minister. This Assembly was developed to involve citizens in the discussion of TOP, TOP for FFA and FFA. Representation of all ideological viewpoints within this Citizen Assembly group was questioned by those

with a pro-choice ideological perspective as 'not representative at all' (Broadsheet April 29th 2017). In addition, the Government's structure of the Citizens' Assembly separate to the Oireachtas Committee (members of the Oireachtas/Irish legislature chosen to consider the subject TOP, TOP for FFA and FFA) was referenced as a delay tactic by those with a pro-choice position. They suggested there were 'no excuses for delay' had they worked in parallel as recommended by a pro-choice group (Online June 14th 2017). Furthermore, following the implementation of the 'National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death' by the Health Service Executive (2016) it was suggested that there had been pro-life influences in the document due to the term 'life-limiting condition' being used rather than the term 'fatal fetal anomaly'. This again, directed the blame on the Government siding with the pro-life movement. Similarly, the pro-life ideological perspective attempted to place blame on the Government with regards their policy proposing access to abortion where they reported that abortion would be the only option available to women who receive a diagnosis of a FFA (Online March 9th 2015). The placing of blame on the Government, indicates power with the Government rather than the people. Furthermore, the media was utilised by political parties to highlight the politicians' ideological perspective in a potential attempt to derive political advantage and gain popularity and more power. This was evident with political parties changing from one ideological perspective to another in media coverage to reflect whatever ideological perspective was the perceived preferred choice of the public and their voters at that time. For example, Sinn Fein (Political Party) made clear their ideological perspective as pro-choice within three days of abstaining on a bill despite 'passionately' speaking 'both in favour of and against' abortion a few months prior (Online March 7th 2015). At the time their party were claiming to be pro-choice, media attention was focusing on TOP for FFA being the preferred choice of the public. A quick change to adapt a pro-choice view was potentially strategic to gain popularity even though months later media alluded that 'not everyone is on the same page' within their party and they feared that 'people lose the party whip' (Online June 28th 2015). Due to a prohibited free vote on this topic, politicians were at risk of losing their position if their views did not fit with their

party's as seen with 'rebel TD (Irish Minister) kicked off committee after he seeks abortion hearings' (Online July 6th 2015).

Politicians themselves created opportunities to criticise the opposition party or party members. For example, a politician with a pro-life ideological perspective concluded that he is 'never confident with this Government, especially the way they've been behaving' (Online June 16th 2015). References of a Minister being 'irresponsible for a legislator' (Broadsheet July 16th 2016) and attempting to cause 'mischief' and make a 'vain attempt to court attention for himself' (Broadsheet March 9th 2015) was also presented. Imagery often supplemented these texts to assist in portraying the desired meaning of the article as Figure 4 illustrates a professional photo of a senator supporting the use of the term for life-limiting conditions. Following much criticism, the paper produces an article the following day showing the same minister who looks more dishevelled and concerned (Figure 5). The subsequent article used this opportunity to emotionally appeal to the reader through the use of this image and using text to defend the aforementioned Minister by including that the senator 'regrets if people were upset by his comments'.

4.4.5 Suppression of Catholic Church and Religion

Religion was silenced within the media with only 9% (n=12) of the articles referring to the Catholic Church or religion. Five of the six articles that referenced the Catholic Church or religion within the online journal included negative associations. One article placed blame on the church through the 'Irish Catholic law' making women travel for TOP for FFA (Journal May 2nd 2013) and 'Catholic fundamentalists' who 'got their hands on Ireland's constitution and planted their Eighth Amendment' (Online Feb 13th 2015). The 'Catholic hierarchy' and other midwifery scandals was also highlighted (Online December 29th 2013). Only one presents the 'Catholic church's' voice to argue 'against abortion in all cases' (Online December 9th 2016). The six references to the Catholic Church and religion within the Broadsheet are more unbiased with Catholicism being mentioned in relation to the institutions the

speakers belong to. One broadsheet compares the views of Protestants and Catholics on abortion (Broadsheet June 16th 2017) and one includes questioning of parents who had a TOP for FFA if they had a Christian burial (Broadsheet January 31st 2017). Similar to the online journal, the broadsheet had two articles where the Catholic Church argued that abortion was not the answer (Broadsheet December 14th 2015) and called to 'reject abortion law' and advocate for 'care until natural death' (Broadsheet February 9th 2016).

4.4.6 Presentation and Distribution of Media

Control over the decision of which news is distributed and the standard of its content is seen as an important symbolic resource of power.[334] Both papers gave more media attention and distributed articles relating to FFA during times of maternity scandals, involvement of the United Nations and when FFA received political attention in attempting to amend the Irish legislation to permit TOP for FFA. While the two papers shared similar themes, both approached their reporting differently with regards how they presented these themes. Differences included the use of a greater amount of imagery and how the produced the same story multiple times. The content analysis identified that the online paper took a significantly greater pro-choice with over half of their articles compare to one third of the broadsheet articles having a pro-choice ideology (55% n= 50 v 34% n=13). The broadsheet had a greater amount of articles with both ideologies included compared to the online paper (29%, n= 11 v 11%, n=10). These are further presented in Table 4.1. While the online paper had a greater number of unbiased articles it is noteworthy that almost half (44%) of these were opportunities to discuss politicians and political parties whereas the entire broadsheet unbiased articles focused on healthcare matters. When comparing the articles covering the same story on the same dates, the broadsheet presented more factual information with only references to personal experiences and input from pro-choice and pro-life groups. In contrast, the online journal focused more on personal aspects of the story with little facts on the wider social story and used the opportunity to include opinions on the Irish Government. Furthermore, the online journal distributed several articles on the same day or subsequent days referencing

the same story whereas the broadsheet delivered a story once. In the one instance where the broadsheet had subsequent articles referencing FFA, the newest article would focus on the new aspect of the story or an up-to-date news story.

4.5 Discussion

4.5.1 Main Findings

Terminology, personification of the unborn, human rights and power and politics all played a significant role within the media discourse. The two ideological standpoint were pro-life and pro-choice. The term 'anti' was avoided if referencing one owns ideological perspective however, when referencing that of the opposite position, the term 'anti-choice' and 'anti-abortion' was used. This carries a negative connotation of being against something. Terminology was purposely chosen dependent on the ideological perspective and how they wanted to emotionally appeal to the reader. Both ideological perspectives personified the unborn whether to describe the difficulty of TOP for FFA or acknowledge the person who may be terminated. Media made references to international influence and Irish cases taken to the United Nations. This in itself suggested the Eighth Amendment was discriminatory against women. Finally, power and politics was evident throughout the media with political parties using the referendum as an opportunity to generate political popularity. The aforementioned findings highlight the importance for healthcare professionals to have knowledge of the influence media, language and politics potentially has on important health matters and what information is available to women and families who receive a diagnosis of FFA.

4.5.2 Truth and Misrepresentation

Language is not neutral and therefore it is important to analyse the information being delivered through media to the general public. As presented in Figure 4.1, it was important to assess the accuracy of the information available and its potential to influence women's healthcare choices. Within this study, information delivered would suggest that at times information in the media was misrepresented to create potential distortion. This creates concern as Power et al. identified a lack of accurate knowledge on FFA among the general public and recommended the need for improved health information about FFA to facilitate informed decision-making.[265]

This is of significant relevance as all media attention which focused on FFA, referred to the restrictive abortion laws in Ireland and significantly influenced and led the way to the recent referendum. This was evident through the description of a FFA as a definite death in utero and the use of terms 'incompatible with life'. Courtwright et al. reports of occasional long-term survivors who receive a FFA diagnosis following intensive support.[289] Both ideological perspectives claimed that both TOP and continuing with a pregnancy diagnosed with a FFA was the preferred choice of women who receive a diagnosis of FFA. However, there is currently no database in Ireland recording the number of parents travelling for a TOP for FFA. Misrepresentations were also observed relating to the supports available to women who receive a diagnosis of a FFA.

Media with a pro-choice ideological perspective focused on the lack of support for those who opted for TOP for FFA and omitted the availability of face-to-face-counselling and free post abortion counselling and medical check-up on return to Ireland.[120,335] PPC was similarly misrepresented with reference that the affected baby would have been on 'life support machine' with their lives being dominated by hospital stays. Palliative care is an active and total approach to care from diagnosis, throughout the child's life, death and beyond[336] that ensures the physical, psychosocial and spiritual needs of the child and family are met.

The pro-life ideological perspective provided misrepresentations through referring to the policy proposing abortion as the only option available to women who receive a diagnosis of a FFA. Legislation for TOP for FFA offers TOP as an option, in addition to continuing the pregnancy and PPC.

4.5.3 Legitimacy and Illegitimacy

Legitimacy assesses the social context and norms embedded in the text.[325] It analyses not only what is present in the text but what is silenced as presented in Figure 4.1. Journalistic meaning is expressed as much by what is absent as by present.[337] For example, those with a pro-choice ideological perspective who opted for a TOP for FFA shared their experience as 'very specific' and 'heart-breaking'. No text referenced that their 'heartbreak' was associated with the diagnosis of FFA alone despite intense helplessness and grief being associated with this diagnosis.[9] Similarly, within articles with a pro-life ideological perspective, parents share their experience of normality and happiness in having a child with a FFA. They provide imagery of happy families and smiling children. Evidence of difficulties and care burden associated with caring for a child with additional needs i.e. sleep deprivation, social isolation and disruption of family routine[338] are absent. This is potentially to influence the reader in thinking there are only positives aspects of parenting a child following a FFA diagnosis. A personal narrative is identified as experiential data[339] and so are utilised to provide evidence of the effects FFA has on parents and families to support the suggestions of both ideologies.

Religion and the Catholic Church's voice is also silenced within the media. This is potentially due to the declining popularity of the Catholic Church in Ireland.[340] The Catholic Church historically assumed vast power and influence over Irish politics, social and religious developments, however, a variety of influences including family planning have undermined the Church's dominance, status and privilege in Irish politics and society.[341] While the Church's social power has reduced, the Christian values still remain throughout Ireland. These values however were managed through

the media presenting FFA as a definite death in utero, facilitating TOP for FFA to be morally acceptable as there was no hope for survival.

The content analysis identified a greater number of pro-choice articles than pro-life articles present within the media. According to Habermas CDA, for an ideal discourse, there is a need for the absence of deception and coercion, which is created when all parties' gets an equal voice.[322] This potentially suggests the influential nature of the media content being delivered on FFA, TOP for FFA and PPC.

Lastly, the human rights of women was dominant in the media compared to the rights of the unborn. In 1973, Roe versus Wade, created universal attention to the woman's right to have an abortion and gave motion to the Women's rights movement.[234] This has since gathered momentum with the European Court of Human Rights in A, B and C v. Ireland in 2010 identifying Ireland's 'harsh abortion law' and violation of European Convention on Human Rights.[235,342,343] This forced the Government to address the controversial topic of abortion.[235] The United Nations Human Rights Committee in the Mellet v. Ireland case, made a ground breaking ruling that Ireland was in violation of women's human rights with criminalisation of abortion.[237] In addition, the United Nations Human Rights Committee's General Comment on the Right to Life which affirms that abortion is a human right generated the international campaign for safe abortion.[222] Abortion as a woman's human right has not just been isolated to Ireland. The United States receive calls from the Global Justice Centre and the United Nations Human Rights office to 'remove their blanket abortion restrictions' and ensure that women have access to safe abortions.[224,344] This is in response to the United States increasingly restrictive abortion laws.[26] Discourse relating to abortion being a woman's human right can support women as was evident within the Electoral Referendum in Ireland where the Eighth Amendment of the Constitution which protected the 'right to life of the unborn'[232] was repealed. Sambaiga et al. concurs and acknowledges the ability of abortion discourse to create an environment that facilitates abortion related knowledge and services to be shared.[345] In contrast, silencing abortion discourse can suppress women's human rights, as is evident in the United States where President Trump

orders a 'global gag rule' and prohibits 'abortion language' in the UN Security Council, forcing the withholding of critical reproductive healthcare information from women.[346,347] One can argue that the unborn baby's rights are silenced resulting in a poor outcome for the fetus however, when abortion is implemented for a fatal fetal anomaly the outcome will also be the same, it is the timing of the fetal demise/baby's death that will differ.

4.5.4 Comprehensibility, Sincerity and False Assurance

As would be expected in published media discourse[324], there is no concerns regarding the comprehensibility. As presented in Figure 4.1, sincerity is the analysis of the text's consistency, i.e. what is said reflects what is meant.[325] During the analysis of the texts sincerity, metaphors, hyperboles and connotations were found to supress understanding. Pro-choice ideological perspective attempted to supress understanding through referring to TOP as 'born asleep' and 'stillborn'. However, TOP is defined as a medical procedure, which is performed on a pregnant woman, which is intended to end the life of a fetus.[27] Those with a pro-life ideological perspective attempted to create false assurances through a suggestion that the Government was behaving inappropriately. As those with a pro-life ideological perspective were in the minority within the media, this was a potential attempt at removing some of that power and credibility from the pro-choice ideological perspective. Overall, many ideological claims were unexamined and lacked evidence to support them. This led to many inaccuracies and overall potential distortion which is of concern, as media is readily accessible to women which can result in potential service users being misinformed.[262,263]

4.5.5 Service Provision

Change in health service provision requires accurate knowledge. This analysis raises concerns regarding inaccurate information available to the legislators. The officials in the Department of Health are responsible for the first Irish legislation regulation of TOP for FFA. However, minimal guidance from professional body representatives have been sought with advocacy groups providing much of the information for the drafting of legislation. These advocacy groups are potentially influenced by how abortion is framed in the media therefore affecting policy. Woodruff and Rachul and Caulfield concurs that news coverage can frame abortion in ways that shape public opinion and subsequently affect policy.[26,348] Media plays an essential role in providing information to service users regarding supports and services and evidence-based research on health issues.[349] This highlights the necessity for all healthcare professionals to take note of the power of media and opportunistic politicians, accuracy and truthfulness of information being shared. Healthcare professionals must expand their media literacy skills and develop these skills in their patients to produce critical autonomy, enable them to deconstruct media texts and engage in more meaningful conversations regarding their health choice and concerns.[349] Informed decision making is key for patient satisfaction, reduced anxiety and improved health outcomes.[350] This analysis raises concerns due to the inaccuracy of information and biased information shared in the media which are easily accessible to women. In the absence of media literacy, women will trust the biased and unreliable information available to them, particularly as the accurate academic journals may not be openly available to the general public.

4.5.6 Limitations

It is important to note, that each papers' search engine was used to conduct this search. While various terms, with both English and American spelling were used to ensure all relevant articles referencing FFA, TOP for FFA and PPC were identified, we cannot guarantee these search engines produced all articles. However, a total of 129

articles were identified, over a six-year period, which can be considered representative of the media relating to FFA, TOP for FFA and PPC being generated in Ireland during this time. Upon reflection of this study, another limitation is the failure to record the overall numbers of articles screened as this would have been useful to capture the volume searched. A limitation of CDA is that it does not provide an insight into the impact of media on the audience members and therefore, further research is warranted to explore how these sources on FFA, TOP for FFA and PPC specifically influenced the reader. However, it did facilitate the researchers to analyse how specific actors construct the arguments within the Irish Times and Journal.ie and how these fits into the wider social practices which demonstrated the potential for influence.

4.6 **Conclusion**

This study highlights the influential nature of language and significant misrepresentations in the information being delivered to the public, particularly in relation to supports available to women who receive a diagnosis of a FFA. The findings support the importance of analysing information being delivered to the public to ensure accurate and reliable information is shared. This is of particular importance where mass media through communicating health information in a particular way can shape public perceptions and influence the reader and their decisions about health.[349] The authors do acknowledge the limited influence healthcare professionals and researchers have over the presentation of media, therefore, this study argues for the need for improved health literacy among healthcare professionals in order to develop these skills in their patients and engage in meaningful conversations. Furthermore, this study identifies women's health inequalities and suggests the need for women's health to take priority on the political agenda and healthcare policies in relation to public health matters. The findings of this study are of relevance as a change in health service provision requires the

delivery of accurate knowledge to the public and to those responsible for the change in health service provision.

4.7 **Figures and Tables**

Figure 4. 1: CDA Analytical Framework (Shirazi 2013)

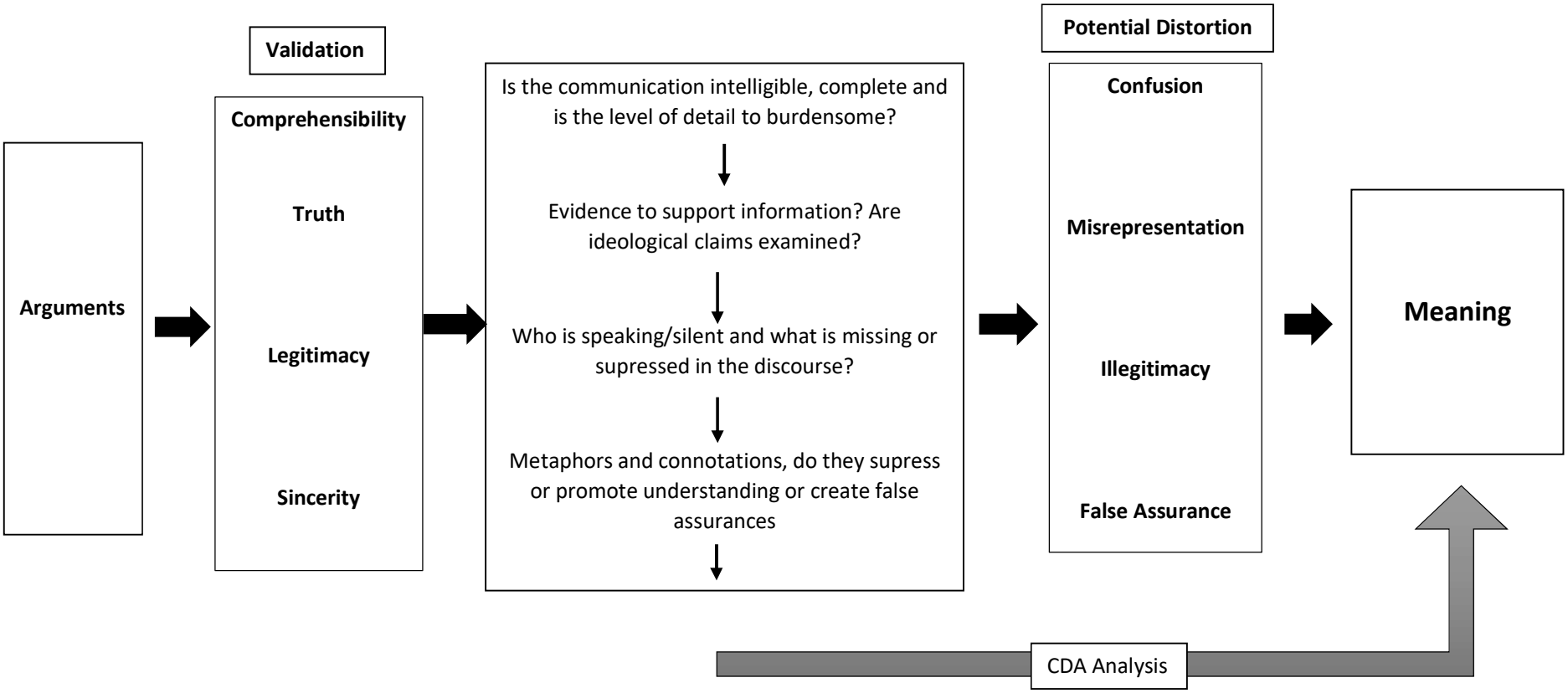

Table 4. 1: Number of Pro-life and Pro-choice Ideology present within the Broadsheet and Online Paper

Ideology Present	**Broadsheet 38 Papers n (%)**	**Online 91 papers n (%)**
Pro-life ideology	10 (26)	7 (8)
Pro-choice ideology	13 (34)	49 (55)
Both ideology	11 (29)	10 (11)
Unbiased	4 (13)	25 (27)

Chapter 5 - Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey

Stacey Power, Keelin O'Donoghue, Sarah Meaney (2020)

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Chapter 5 - Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey

5.1 Abstract

Background

There is a reliance on voluntary organisations in healthcare. Education is necessary to keep up-to-date with best practice. Our aim was to identify education priorities of voluntary organisations who support parents who experience pregnancy/perinatal loss, to inform the development of an education day.

Method

A modified Delphi study was undertaken to identify education needs. There were two Delphi rounds, inclusive of free text, where voluntary group experts reflected on responses in order to develop a consensus among the group.

Results

There were 12 responses to Round One and 7 responses to Round Two. From a list of 10 subjects, Round one identified 64 sub-topics which were then determined as essential, desirable or not relevant in Round Two. The final 55 sub-topics were included in the education day.

Conclusion

This study identified educational needs of voluntary organisations. A standardised approach was necessary to develop an education day responsive to their learning needs.

Keywords

Bereavement care, Pregnancy loss, Perinatal death, Patient and Public Involvement, Education.

Key Points:

- Education is necessary to keep up to date and to continue to improve healthcare practice.
- Voluntary organisations require educational opportunities as they play a significant role in providing support to bereaved parents.
- A two-way sharing of knowledge between healthcare professionals and voluntary organisations is desirable as knowledge by experience is equally valuable as professional knowledge.
- Patient and public involvement is fundamental in improving overall outcomes for service users through creating a more holistic, in-depth understanding of complex health issues.

CPD Reflective Questions:

- Reflect on how you, as a healthcare professional, have worked effectively with a volunteer within a voluntary organisation to ensure adequate care to your patient?
- Within your healthcare setting, what could be done to ensure patient and public involvement, to improve bereavement care delivered to families?
- What does your healthcare setting implement to measure what the educational needs are of those who support parents who are bereaved?
- Reflect on how your healthcare setting evaluates the effectiveness of the bereavement support delivered to bereaved parents?

5.2 **Introduction**

While there has been a marked decline in pregnancy loss and perinatal death, it remains a worldwide health concern.[178,351,352] Ireland has seen a decline from 504 perinatal deaths in 2014 to 407 perinatal deaths in 2016.[266,353] Miscarriage however remains one of the most common complications in pregnancy with approximately one in four women experiencing miscarriage[354] while there are an estimated 2.6 million stillbirths worldwide.[352] Within Ireland, the National Perinatal Epidemiology Centre reported 5.8 perinatal deaths per 1,000 births and identified major congenital anomaly as being the primary cause of death in stillbirths (31.2%) and neonatal deaths (54.8%).[266]

The loss of a baby is a traumatic event that can have long-lasting effects on the overall wellbeing of parents and families, regardless of when the loss occurs.[178,355,356] Parents and families require various levels of support during their bereavement.[39,120,357] Social support networks are essential for improved outcomes for parents and families who experience pregnancy loss or perinatal death.[182] Follow-up care is necessary to identify and support the woman and her family through the risk of grief reactions, anxiety and depression and to improve psychological well-being.[57,355,356,358]

In Ireland, maternity care is high on the public agenda with much focus on implementing a standard of care that is evidence-based, to ensure women have access to an appropriate level of care and support with informed choice.[38,39,120] Within the Maternity setting, the Health Service Executive (HSE), responsible for the provision of health and personal social services for Irish residents, developed a programme to provide these babies and families with palliative, end-of-life and bereavement care.[39] The HSE launched *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* in 2016 with the purpose of enhancing bereavement services for parents who experience any type of pregnancy loss or perinatal death. The Standards are a resource to both professionals and parents providing information around necessary supports and expected standards of care.[120]

Voluntary support groups acted as key stakeholders during the development and implementation of the Bereavement Care Standards.[120] Their knowledge of supporting women and their families who experience a pregnancy loss or perinatal death provides an important source of knowledge that is different, but equally important as scientific or professional knowledge.[359,360]

The importance of voluntary organisations in supporting parents who experience a pregnancy loss or perinatal death was identified within the Bereavement Care Standards.[120] This is of no surprise as the ongoing care required by parents at the time of pregnancy loss or perinatal bereavement exceeds that of the Maternity hospital admission.[178] In the absence of appropriate follow up care or social acknowledgement, parents can experience negative emotions and amplified grief.[178,180,181,183,355] The inadequacy of care provided after pregnancy loss and perinatal death has been linked with the resulting development of voluntary support groups to respond to parents' bereavement care needs and provide peer support.[178,185]

Similar to the United States, Australia and United Kingdom there has been a historical reliance on voluntary support groups in forming an integral part of the overall healthcare in Ireland.[175,179,361–365] At a time of social and economic pressures internationally, voluntary support groups played a key role in filling gaps in healthcare provision, responding to the unmet needs of individuals and policy.[170,171,174,366] This included voluntary support groups responding to the holistic needs of bereaved parents and children.[175,178,179,367] Furthermore, there is a shift towards more collaborative working between statutory and voluntary bodies to ensure the delivery of agreed services to nationally determined standards of care and compliance with best practice.[175] While the voluntary sector is willing to respond to the individuals needs of care closer to home,[175,363] volunteers may lack the competence and skills to meet the level of care required.[367]

The Bereavement Care Standards[120] identified the need to develop appropriate education and training programmes for all those caring for parents and families who experience a perinatal loss or perinatal death.[120] Through individual meetings with

voluntary support groups, by members of the National Implementation Group, support groups shared their need for education. Therefore, the aim of this study was firstly to obtain a consensus on what the support groups learning priorities were, secondly to develop and deliver an education day and finally to evaluate the education day.

5.3 **Methods**

5.3.1 Design

A modified Delphi approach was implemented for the purpose of this study. The Delphi method is an approach developed to collect, collate and reach consensus on the opinions of a group of 'experts' (those knowledgeable and skilled with the ability to influence policy in a particular field)[368,369] concerning future events[370]. The Delphi method provides an opportunity for anonymity, controlled feedback, and a statistical group response[370]. These expert groups were asked to anonymously complete a survey. Following completion of this survey, the group of experts received feedback pertaining the group response and were asked to repeat the process of completing another survey[370,371]. This enabled them to assess where their opinion sat within the group of experts[371] while reducing the range of responses and ensured expert consensus was achieved. Each round of the Delphi survey was allocated three weeks for participation. Delbecq (1975) suggests two weeks be given to participants to complete each round of the Delphi survey[372]. The extra time and consensus building approach to data collection facilitated participants to reflect on their answers and suggestions[371]. For the above reasons, the Delphi method was chosen as the best method to identify the voluntary support groups learning needs.

5.3.2 Recruitment

During the Bereavement Standards implementation, the identification of the support groups whose sole purpose is to provide bereavement care to parents and their

families who experience pregnancy loss and perinatal death within Ireland was achieved. This was undertaken by the Referral and Integration Work-stream within the National Implementation Group of the Bereavement Care Standards. Members of this group included healthcare professionals and parents who using their clinical and personal experiences and knowledge identified potential support groups. This process identified 23 support groups who provided care to parents and families who experienced pregnancy loss or perinatal death. The Delphi method requires that the 'experts' are selected according to their expertise in order for them to contribute to the topic[373]. It was from this list that the support groups to be contacted were identified. The types of pregnancy loss and perinatal death that these groups supported included losses due to first, second and third trimester miscarriage, ectopic pregnancy, stillbirth, fatal fetal anomaly/life limiting condition, termination for medical reasons, neonatal death and supporting future pregnancies following a pregnancy loss or perinatal death. Of the 12 support groups who completed Round One of the Delphi survey, nine (75%) of the groups offered support for future pregnancies following a pregnancy loss or perinatal death and support following a neonatal death; eight of the groups (67%), offered supports to those who experience second trimester loss, third trimester loss or stillbirth while half of the groups (n=6) offered support to women and their families who experience an ectopic pregnancy. Many of the groups offered more than one type of support. These are presented in Figure 5.1.

As the support groups represented a diverse group and due to the time constraints of the proposed education being delivered within one day, it was required that a consensus should be obtained to recognise what the learning priority of these support groups were.

All 23 support groups who provide bereavement care for parents and families who experience a pregnancy loss or perinatal death were contacted via email to their Chief Executive Officer (CEO)/Head of Organisation with a participant information sheet and the Delphi survey.

5.3.3 Development of Data Collection Tool

The development of the modified Delphi survey for Round One and Two received input from members of the National Implementation Group of the Bereavement Care Standards. This was of particular importance for Round One as members of the National Implementation Group of the Bereavement Care Standards held meetings with members of the larger support groups. While these were informal meetings, it did facilitate the identification of the learning needs of the Irish volunteers who were offering peer support to women who experienced a similar pregnancy loss or perinatal death, to ensure both professional and patient perspectives were incorporated from the outset. This process identified a broad range of learning needs, based on their personal experiences of being a volunteer, which were used to inform the questionnaire in Round One of the Delphi. In addition, an extensive literature review which included National Standards for Bereavement Care[120] and national and international research[189,355,374–380] (these included; Meaney et al. 2017; Ellis et al. 2016; Snaman et al. 2016; Basile and Thorsteinsson 2015; Wool 2013; Gallagher et al 2012; Cacciatore 2010a; D'Agostino et al 2008; Browning and Solomon 2005) also informed the questionnaire for Round One. Furthermore, input from members of the Pregnancy Loss Research Group, University College Cork was also sought. This group is representative of members from Obstetrics and Gynaecology, Midwifery, Nursing, Sociology, Psychology, Chaplaincy, Pathology, Social Work, Service Users, Bereavement Care Specialists and Paediatric Palliative Care. Input from all of these disciplines was to ensure the Delphi survey reflected all fundamental care components identified by volunteers, service users and healthcare professionals, which are essential for parents who experience a pregnancy loss or perinatal death. These were based upon clinical experience, academic research and the National Standards for Bereavement Care.[120] The use of a structured questionnaire in Round One is a common and acceptable modification of the Delphi process once it reflects a review of literature and best practice.[371]

Due to the nature of this study and its aim to explore support groups learning priorities, the Delphi design was modified to facilitate free text options to accompany the survey. Opportunity for free text was provided to create an opportunity to elaborate on answers or add in topics not identified within the survey, which counteracted the rigidity often associated with Delphi designs.[381]

5.3.4 Modified Delphi Process

Google forms was utilised to create and disseminate the Delphi survey. This Delphi process involved questioning the participants on two separate occasions. In Round One, participants were given 10 broad subjects related to the care required by women and their families who experience a perinatal loss or perinatal death, supported by a brief definition explaining these subjects. These included; 'Antenatal diagnosis', 'Decision making', 'Follow-up care', 'Holistic care', 'Investigations', 'Management and delivery', 'Perinatal Palliative Care', 'Postnatal care', 'Rainbow baby' (future pregnancy following a pregnancy loss or perinatal death) and 'Rights of women'. Support groups were asked to rate each of these subjects on a ten point scale ranging from 'not important' (score of 1) to very important (score of 10) in order to their organisation. Support groups were then asked to prioritise the subjects by ordering the subjects using a ten point scale ranging from 'highest priority-first choice' (score of 1) 'lowest priority-last choice' (score of 10). Following two reminders to the support groups to encourage participation in the Delphi survey, the answers from Round One were combined and summarised. Subjects identified as priorities and the free text, obtained from Round One, where appropriate, were formulated into a series of more specific topics. This was done with the help of the Pregnancy Loss Research Group and members of the National Implementation Group of the Bereavement Care Standards through identifying all specific topics associated with the subject. Free text was utilised by the expert panel to either provide rationale for ranking, reiterate topics that would have been intended in the subjects presented to

them or request topics outside the remit of the education day, for example, support with child loss.

In Round Two, all 23 support groups were presented with the results of the first round and asked to identify if these specific topics were 'essential', 'desirable' or 'not relevant', for inclusion in an education session. Following two reminders to the support groups to identify their learning needs through the Delphi survey, the results of Round Two were then analysed and scored. This Delphi process is demonstrated in Figure 5.2. A second researcher analysed the scoring of each subject and specific topic to ensure accuracy of topics prioritised for the education day. As the education day was being delivered within one day, the highest scoring topics were given priority for inclusion. Furthermore, specific topics were only included if there was a presenter available with the expertise in that area which resulted in one specific topic being omitted.

5.4 **Results**

Of the 23 support groups approached to complete the Delphi survey, a response rate of 52% (n=12) was achieved in Round One.

5.4.1 Round One

As illustrated in Figure 5.3, all subjects were rated as important by the support groups whereby the lowest scoring topics, 'Investigations' and 'Rainbow Baby', still received high scores of 7.9 out of 10. 'Decision making' was identified as the most important to the support groups scoring 9.75 out of 10 with 'Holistic Care' and 'Postnatal Care' scoring high at 9.66 and 9.41 out of 10 (Figure 5.3).

When asked to prioritise what subjects they would benefit most from being included in the education day, 'Management and Delivery', 'Postnatal care', 'Follow-up care', 'Holistic care', 'Decision Making', and 'Rights of women' were identified as the top six priority subjects (see Figure 5.4).

Free text offered nothing new to the subjects presented in the Delphi survey. With input from members of the Pregnancy Loss Research Group and the National Implementation Group of the Bereavement Care Standards, the six priority subjects were broken down into more specific topics. An overview of the 64 specific topics are presented in Figure 5.5 with 25 related to 'Management and delivery' , 19 related to 'Postnatal care' , eight related to 'Follow-up care' seven related to 'Holistic care' and five topics related to 'Rights of women'. It was agreed that the subject 'decision making' was a core element of all subjects and would be covered in all education sessions. Many of the 64 topics could be associated with more than one subject heading and so the 64 specific topics were presented to each of the 23 groups using no subject headings in Round Two of the Delphi survey to allow concordance between the two rounds to be assessed.

5.4.2 Round Two

A response rate of 30% (n=7) was achieved in Round Two. Of the 64 specific topics identified in Round One, all participants identified 11% (n=7) of the specific topics as 100% essential. Of these seven, six belonged to the subject identified as most priority, 'management and delivery'. For 16 of the specific topics, six of the participants identified them as essential and one group identifying them as desirable. Fifteen of the specific topics were identified as essential by five participants and desirable by two while 14 of the specific topics were identified by four participants as essential and desirable by three participants. Only one participant reported that eight of the specific topics were not relevant (12%) with two participants reporting just one topic as not relevant. There were 56 specific topics where greater than half of the participants identified them as essential. These results are presented in Figure 5.5. Due to the education day being delivered in one day, it was decided that these 56 specific topics would be included in the education day and those identified as essential by less than half of the participants would be omitted. One other specific topic was omitted due to lack of expertise in the area being available.

5.4.3 Education Day

Following prioritisation of topics to be included in the education day, academics and clinicians across Ireland, with expertise in each topic, were identified to provide the sessions. Related topics were grouped together as appropriate and a programme developed, as presented in Table 5.1.

These topics were delivered in a morning and afternoon session by healthcare professionals from various backgrounds including; Maternal Fetal Medicine Specialists, Bereavement Clinical Midwife Specialist, Perinatal Pathologist, Consultant Neonatologist, Paediatric Palliative Care Nurse, Healthcare Chaplain and a retired Director of Midwifery. The education day closed with a Question and Answer session. The education day was evaluated using surveys. The evaluation survey asked participants to rate their overall satisfaction with the day and if they found it beneficial, satisfaction with the programme for the day, and they were asked to rate the quality of the teaching. It also sought suggestion for topics they would like taught in future education sessions. Opportunity was also given to support groups to share their feedback via phone call or email following the education day.

5.4.4 Education Day Evaluation

There were 26 attendees at the education day representing 10 different organisations supporting women and their families who experience a pregnancy loss or perinatal death. Of the 26 attendees, 13 completed the evaluation form, while 1 evaluated the education over the phone and 1 via email. The education day was evaluated positively as presented in Figure 5.6. Participants scored an average of 8.4 out of 10 for overall satisfaction with the day and satisfaction with the education day programme. The benefits of the information delivered was rated as 8.6 out of 10 while the quality of teaching was rated 8.5 out of 10. Suggestions for topics they would like taught in future education sessions included ‘More discussion on supporting parents who decide to terminate following a diagnosis in pregnancy’ and ‘more information on private or public’. Attendees reported that there were ‘benefits

of hearing from other parents and support groups' and how 'useful' the education day was for new and existing volunteers. Feedback regarding improvements to the current National Bereavement Care Standards for pregnancy loss and perinatal death was also received. The support groups also requested to work closer to healthcare professionals in the Maternity settings within the area of pregnancy loss and perinatal death.

5.5 **Discussion**

Education is necessary to keep up to date and to continue to improve healthcare practice.[382] As there is a reliance on voluntary organisations to support parents who experience a pregnancy loss or perinatal death in Irish healthcare[120], their educational requirements were considered as equally important as those of statutory bodies. Therefore, it was deemed important, using a standardised approach, to identify the educational needs of voluntary support groups. The modified Delphi approach was necessary to guide and direct the development of an education day responsive to voluntary support groups learning needs. From an initial list of 10 broad subjects, 64 specific topics were identified as potential learning needs. This facilitated convergence of opinion, as the top scoring subjects were relayed back to the participants in the format of specific topics. This expanding of the subjects in to topics was necessary to ensure their specific learning needs were identified and therefore met during the education day. Of the 64 specific topics, seven specific topics were recognised by all participants as 100% essential. Listing the specific topics in priority and identifying expert speakers, 55 of these specific topics were chosen for inclusion within an education day. These topics were categorised together and delivered to support groups in December 2018.

As previously mentioned, voluntary organisations supporting parents who experienced a pregnancy loss or perinatal death were developed to address the gaps in care provision.[178,185,365] Many of the support groups who provide voluntary bereavement care to parents and families who have experienced a pregnancy loss or

perinatal death, have them themselves experienced this grief and share similar experiences.[383] It is argued that peers with shared experiences are better placed to develop more trusting relationships[384] and empathetic understanding.[383] While support groups are willing to fill gaps in care however, some may lack competence to provide the level of care required by their target population.[367] However, this is unknown as outcomes are seldom measured by either the voluntary organisations or statutory bodies. Peer support could potentially have negative effects if the social environment responded inadequately to their needs or did not enable parents to talk about their child.[385] Inadequate care and support is known to exacerbate parental grief.[90] The lack of optimal care for bereaved families impacts on the physical and mental health of parents, siblings, subsequent children and future generations.[358]

Considering the role voluntary support groups play in healthcare provision, it is necessary that their knowledge and practice reflects the constant changing needs of the service users. Little is known about the educational needs of volunteers. Healthcare professionals have long identified their need for up to date education to assist them in providing adequate bereavement care for families who experience a pregnancy loss or perinatal death.[386–388] It was felt that volunteers providing this bereavement care warrant similar educational opportunities. Furthermore, education is a social determinant of health as it provides service users with the knowledge of how to access information and services to manage their own health (Institute of Public Health in Ireland 2008). The Delphi survey participants in Round one, identified all subjects as high importance with 'Management and Delivery', 'Postnatal care', 'Follow-up care', 'Holistic care', 'Decision Making', and 'Rights of women' being prioritised for inclusion in the education day. These subjects include learning regarding the diagnosis of a pregnancy loss, perinatal death or major congenital anomaly and the process relating to informing the parents of such a diagnosis. It includes information given to parents at this time regarding their care options, their rights and supports and services during and after their pregnancy, to name but a few. Providing such education to voluntary organisations provides the knowledge for volunteers to not only respond to parents' needs or signpost them to

a service who can, but as Layne (2006) identified, these volunteers are potential future service users also.[365]

The Delphi technique is an appropriate method for gathering data from 'experts' within a chosen area as it can be repeated until consensus has been achieved.[371] A standard approach was required to ensure a consensus was reached with regards how important the subjects were and what subjects and specific topics would be included in the education day. While it was evident in Round One of the modified Delphi study that all participants deemed the subjects to be important, two rounds was sufficient in identifying what specific topics were priority to meet their educational needs. The Delphi technique has been identified as best suited to obtain consensus in healthcare education research.[371] The evaluation of the education day, measured how beneficial the education day was for these volunteers, therefore potentially suggesting that the findings of the Delphi survey was reflective of their learning needs. Through meeting voluntary support groups educational needs we facilitate the delivery of quality of care to women and families who experience a pregnancy loss or perinatal death.

Ultimately, an integrated coordinated approach involving all stakeholders is essential in meeting the needs of bereaved parents and families. A collaborative approach between those who experience the phenomenon and healthcare professionals who provide scientific and evidence-based information to support and inform patients is essential[309], particularly where there is just one opportunity 'to get it right'.[161] While the Delphi survey focused on voluntary support groups learning needs and appropriate professionals in that field providing information on same, on the day, it was a two-way sharing of knowledge and experiences. Learning from each other's practice and experience is as equally beneficial as the usual structured approach to learning.[382,389] The Department of Health Children (2009) suggested the need for the HSE and voluntary support groups to develop close working relationships, and to develop an integrated framework for healthcare provision. Furthermore, through the evaluations of the education day, voluntary organisations themselves requested closer collaborations with healthcare professionals.[367] A framework that respects the

autonomy and identity of the support groups and regulatory and public responsibilities of the HSE is required.[367] Inclusion of service users and voluntary support organisations is fundamental in improving overall outcomes and experiences of service users, and has the ability to create a more holistic in-depth understanding of complex health issues.[178]

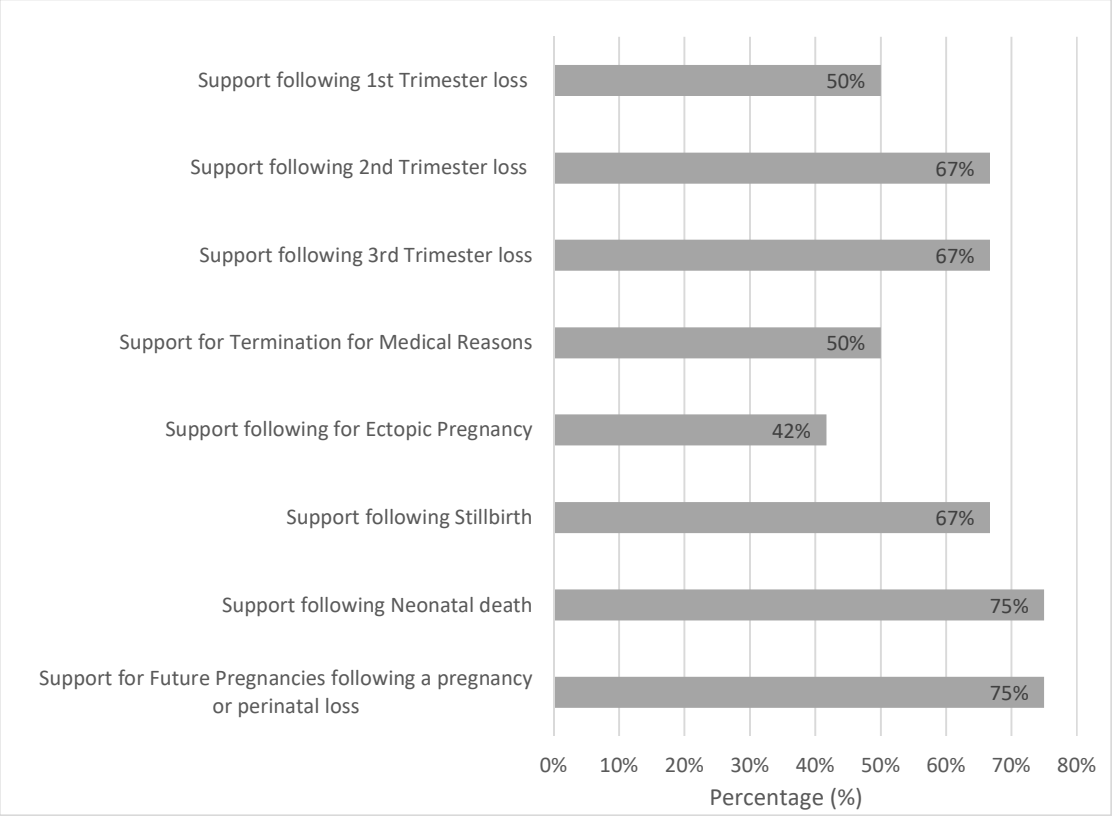
5.5.1 Strengths and Limitations

Response from support groups appears low and is a potential limitation. Participation and a high response rate is necessary for a successful Delphi study.[371] It is important to note that these responses represented completed surveys. Two groups responded that they were unable to contribute due to the support they offered being so specific or to a very small cohort of people. It can be argued that when it is a homogenous group, like voluntary support groups for parents who experience a pregnancy loss or perinatal death is, a lower response rate is adequate.[372] Another identified limitation of the study is that topics which were prioritised were only included where there was an available expert to present information at the education day. However, this resulted in only one topic being omitted. Furthermore, there was a significant amount of time allocated to questions and answers which gave an opportunity for questions left unanswered to be addressed.

5.6 **Conclusion**

Education is essential in healthcare in order to keep up to date with best practice. This study identified educational needs of voluntary support groups who play an important role in supporting parents who experience a pregnancy loss or perinatal death. The Delphi technique offered a standardised approach in collecting information of the study interest. A standardised approach was necessary to guide the development of an education day responsive to voluntary support groups' educational needs, to assist them in supporting women who experience pregnancy loss or perinatal death.

5.7 **Figures**



Note: Categories are not mutually exclusive.

Figure 5. 1: Types of support offered by the groups

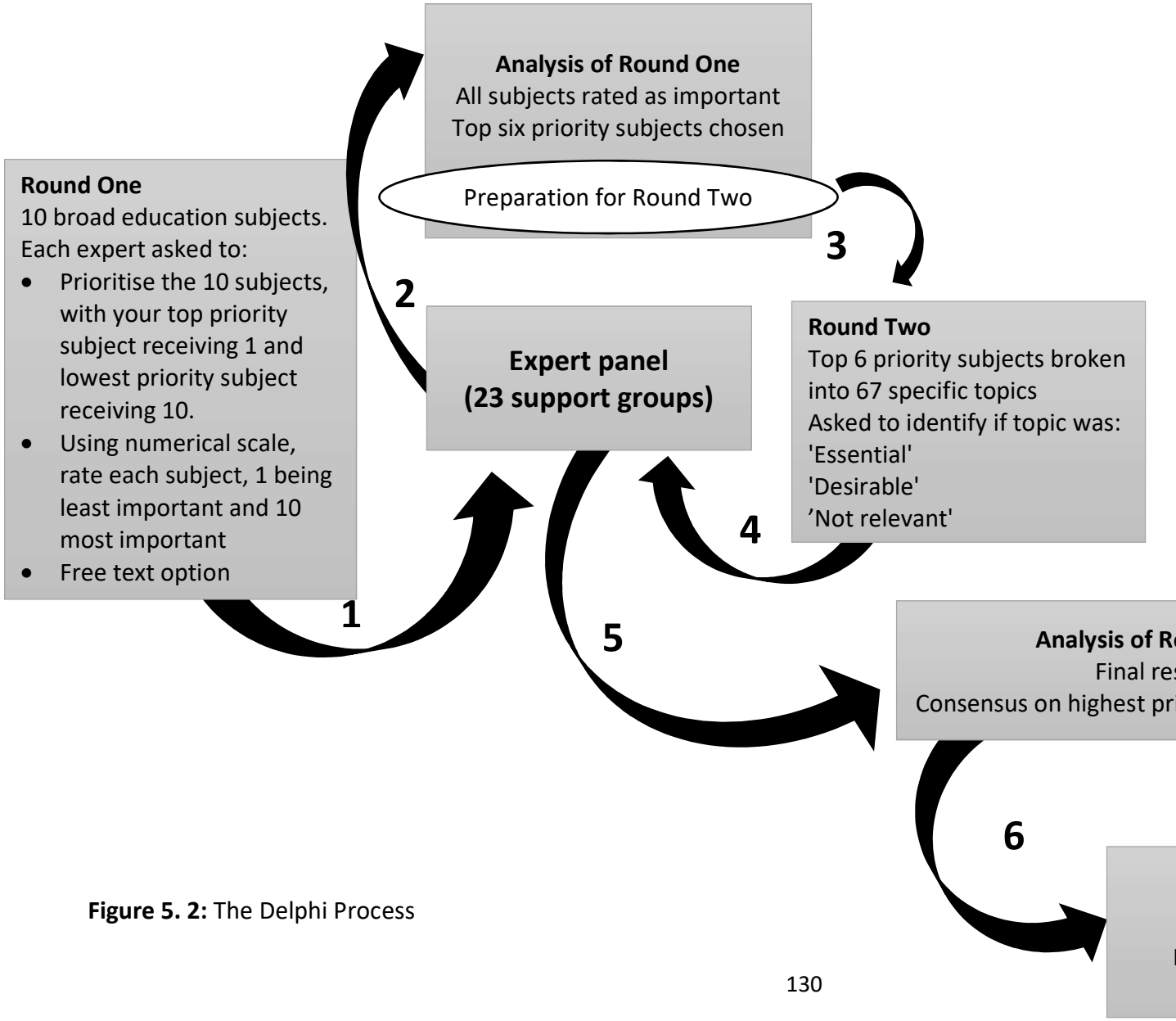


Figure 5. 2: The Delphi Process

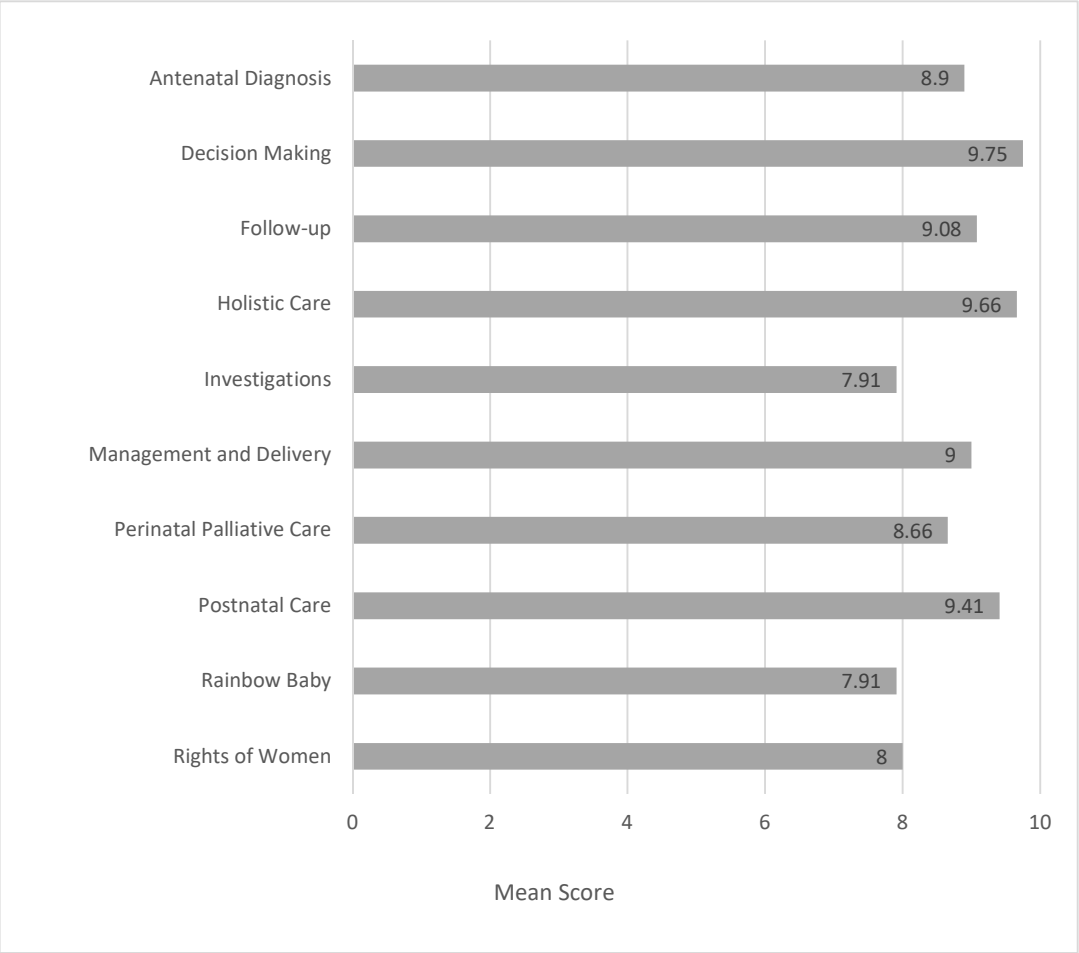


Figure 5. 3: Rating of Importance

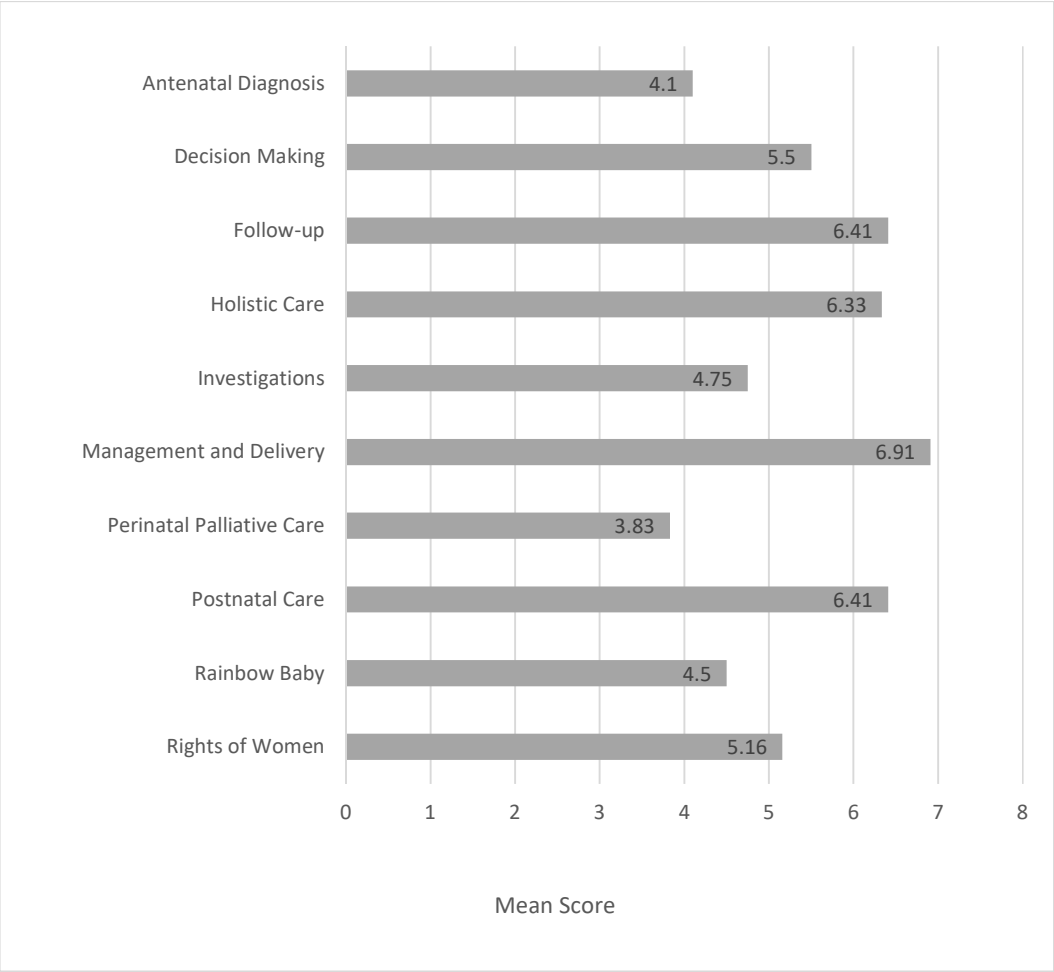


Figure 5. 4: Prioritisation of Topics to be included in the Education Day

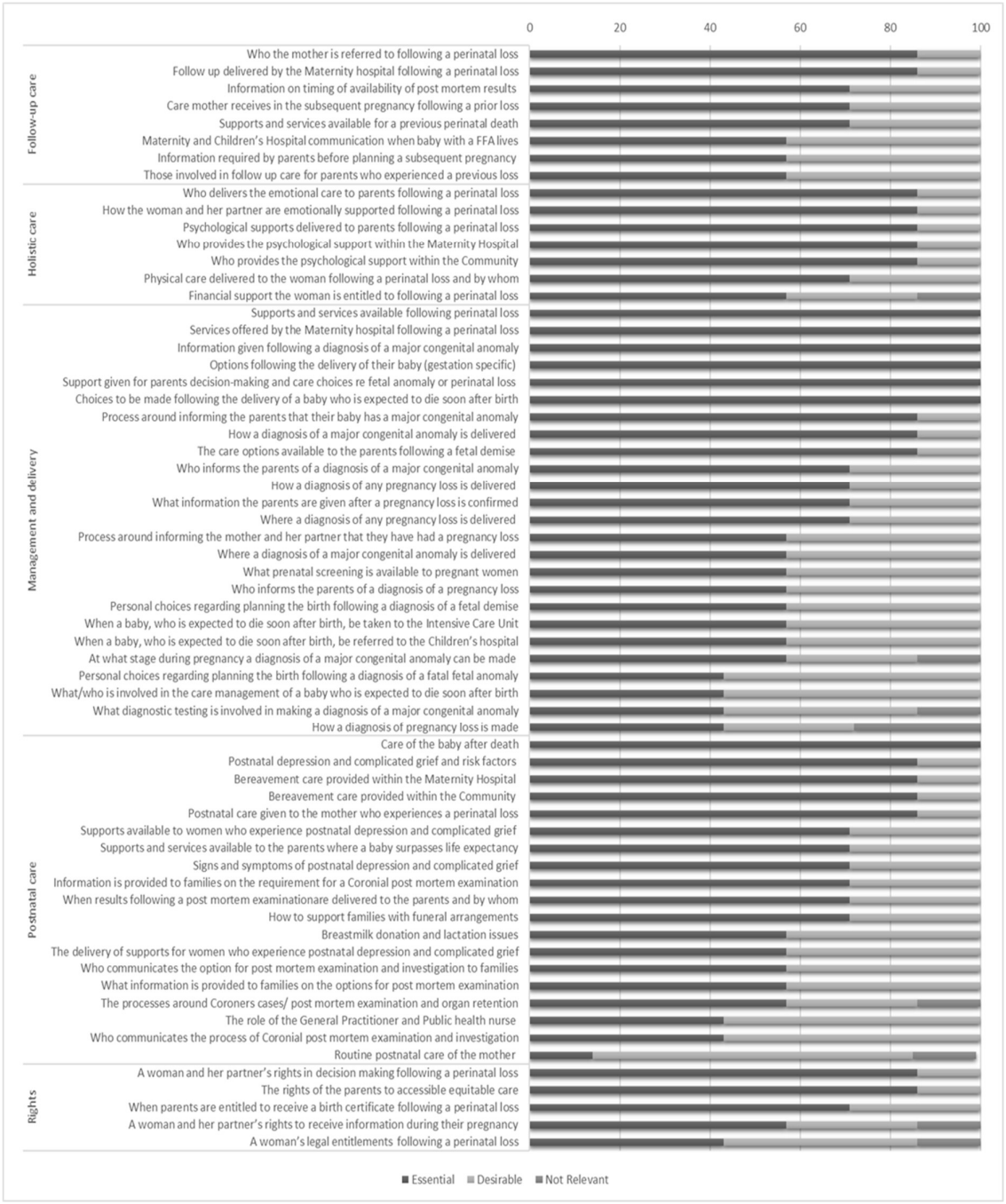


Figure 5. 5: All 64 Specific Topics under their associated Subject

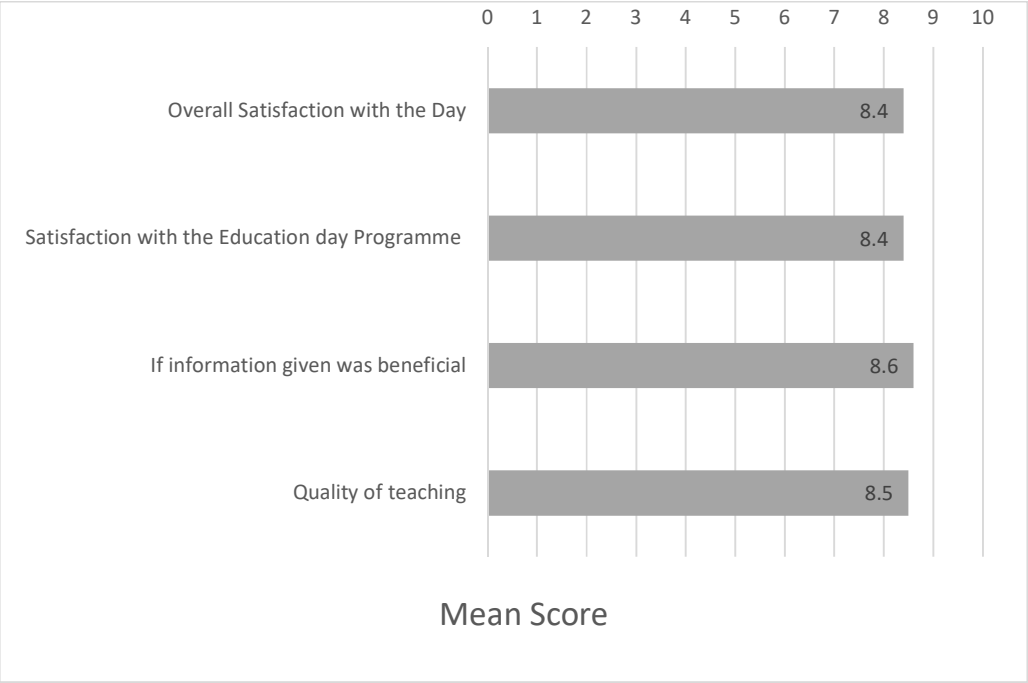


Figure 5. 6: Evaluation of the Education Day

5.8 **Tables**

Table 5. 1: Title of topics delivered

Screening and Prenatal diagnosis	Management of Pregnancy
Overview of pathology investigation	Postnatal Care and breastmilk donation
Care of the parents and baby with a diagnosis of a fatal fetal anomaly/ life limiting condition	End of life care and transition to the children's hospital or home and palliative care supports
Bereavement care for families who experienced a loss	Bereavement supports available to families following a loss
Supporting families through their subsequent pregnancies	Rights of women as patients in maternity hospitals

Chapter 6 - Experiences of volunteers supporting parents following a fatal fetal anomaly diagnosis in Ireland

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Chapter 6 - Experiences of volunteers supporting parents following a fatal fetal anomaly diagnosis in Ireland

6.1 Abstract

Objective: Ireland has had a reliance on voluntary groups to provide peer-to-peer bereavement support. The aim of this study was to explore volunteers', within these voluntary groups, experiences of supporting parents following a fatal fetal anomaly diagnosis.

Methods: Purposive sampling was used to recruit volunteers (n=17) and face-to-face interviews undertaken. NVivo12 was utilised to assist in the thematic analysis of the data.

Results: Five themes; 'motivation for altruistic acts', 'being challenged', 'value of education and training', supporting volunteers to support others' and 'it is not a sprint, it is a marathon' were identified. Volunteers felt comfortable in their peer-support role but found the lack of knowledge regarding newly implemented TOP services challenging. The importance of education/training was identified, emphasising the need for collaboration with healthcare professionals and other voluntary organisations for support.

Conclusions: The findings illustrate the need for collaborative working between healthcare professionals and volunteers to assist them in supporting bereaved parents.

6.2 **Introduction**

Internationally, approximately 3% of pregnancies receive a diagnosis of a major congenital anomaly.[88] In Ireland, major congenital anomaly was the primary cause of death for a quarter of the stillbirths (27%) and over half of the neonatal deaths in 2017 (60%).[10] The loss of a baby can evoke an emotional response effecting the physical and psychological wellbeing of the parents.[178,284,352,355,356] An estimated one in five parents will experience a more prolonged and intense grief following pregnancy loss.[182] Parents' emotional distress and intensified grief is associated with the absence of appropriate follow up care and social acknowledgement[178,183,352,355,390] highlighting the need for parents to receive various levels of supports at the time of their perinatal bereavement.[120,356]

There has been much discussion generated globally with regards volunteering, in particular volunteering within the healthcare sector, due to the significant contribution volunteers make to society.[175–177] Both informal and formal volunteers play an important role, with informal volunteers 'lending a hand' and formal volunteers committing to regular times coordinated by a voluntary organisation.[391] In the midst of developing a National Strategy for Volunteering in Ireland, the enormity of volunteers' value highlights the inability of current definitions to accurately represent the range and diversity of their role.[391] The European definition however is generally accepted, identifying all forms of activity that is undertaken of a person's choice with no financial gain as volunteering.[169]

Within Ireland, the Health Service Executive (HSE), responsible for the provision of health and personal social services for Irish residents, launched the *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* in 2016 with the purpose of enhancing bereavement services for parents who experience pregnancy loss or perinatal death. The Standards provide information on necessary supports and expected standards of care from point of diagnosis right through to the death of the baby.[120] Within the development and implementation of these Bereavement Care Standards, voluntary support groups

acted as key stakeholders[120] and their experiences of supporting bereaved parents deemed invaluable.[359,360]

Voluntary support groups have long played a significant role in healthcare in responding to the unmet needs of individuals and policy worldwide.[174,175,392,393] This was of particular relevance, prior to January 1st 2019, when termination of pregnancy (TOP) for fatal fetal anomaly (FFA) was prohibited by Law in Ireland. At that time, healthcare professionals could legally inform women of their care options and abortion services available in other jurisdictions and provide follow up care following TOP.[230] However, an Irish study revealed the limited knowledge the general public has regarding such follow up care.[265] This potentially led to parents considering and deciding on a TOP for FFA seeking peer-to-peer support. As of December 2018, Ireland legislated for TOP for FFA in the Health (Regulation of Termination of Pregnancy) Bill 2018, for the first time.[27] This Bill, implemented January 1st 2019, legislated for TOP for FFA for a 'condition likely to lead to death of foetus' either before or within 28 days of birth.

Regardless of when or how the death of the baby with a FFA occurs, whether it is the result of a TOP or natural death, parents have various needs at the time of their bereavement. These needs can surpass that of the hospital admission with parents developing high levels of distress in the absence of formal follow-up care and supports.[178,394] This has resulted in an over reliance of voluntary support groups to respond to the unmet holistic needs of bereaved parents.[120,178] Furthermore, parents report positive outcomes from sharing their experience with people with similar experiences and circumstances.[395] Consequently, there has been a development of registered charities (voluntary support groups) to provide peer-to-peer support following a diagnosis of a FFA, pregnancy loss or perinatal death worldwide.[172,178,185]

While the importance of parental support for pregnancy loss and perinatal death is recognised, a systematic review[182] emphasised that little is known about the role of bereavement care and the effectiveness of the various approaches in supporting parents and families. Only one clinical trial was identified which was

awaiting classification, highlighting the need for more research within this area.[182] Additionally, there is little research on the experiences of formal volunteers offering peer support to parents who experience a FFA diagnosis, particularly from an Irish context where TOP for FFA is now being implemented for the first time. Therefore, the aim of this study was to explore formal volunteers' experiences of supporting families following a FFA diagnosis, prior to and following, the legalisation of TOP for FFA for the first time in Ireland.

6.3 **Methods**

6.3.1 Design

Qualitative research allows exploration and understanding of concepts such as experiences, motivation and intention and facilitates interpretation and understanding of social phenomena.[396] Qualitative research is a rich, diverse and complex field that facilitates an interpretation of how people make sense of their experience.[396,397] Individuals are best placed to describe and give meaning to their own personal experience giving the researcher access to their social reality.[397] A qualitative, interpretive descriptive approach therefore facilitated the researcher to delve in to volunteers' experiences of supporting parents who receive a diagnosis of a FFA at a time where TOP for FFA is being provided for, for the first time. This inductive approach described by Thorne and others represents a co-constructive truth, it moves beyond the level of description of the phenomenon and articulates a meaning of and explanation for these experiences, generating implications for practice and application of these.[398–400] It acknowledges the researchers' knowledge on the phenomena of study[399]; a children's palliative care nurse undertaking a PhD in fetal anomalies, a Social Researcher working in a Perinatal Epidemiology Centre and a Fetal Medicine Specialist. The result of interpretive description is a persuasive professional narrative rather than isolated themes (Hunt 2009).

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).

6.3.2 Recruitment

During the implementation of the National Bereavement Care Standards for Pregnancy loss and Perinatal death, 23 voluntary organisations who provide care to parents and families who experienced pregnancy loss or perinatal death were identified. Purposive sampling was carried out to ensure only those who delivered supports for pregnancy loss and perinatal death for FFA were included in this study. This resulted in ten voluntary organisations being contacted to participate in the study. The chairperson of each of the voluntary organisations were contacted via email. Within this email, they were provided with the participant information leaflet and asked to share this among their volunteer members. One organisation replied at this time, reporting that they did not provide support to those who experienced a FFA and so this organisation was excluded. Of the nine potential organisations, seven responded and agreed to share the participant information leaflet with their volunteer members who offered supports to parents who experience a pregnancy with a FFA. Volunteers who agreed to participate contacted SP.

A topic guide was used to aid the interviewers (Supplementary File V). All interviews were transcribed verbatim from their recordings by SP and then reviewed by SM. A qualitative methodology was undertaken to examine volunteers' experiences of supporting parents who experience a FFA diagnosis.

6.3.3 Sample

Data collection was undertaken between June and August 2019. Within the seven voluntary organisations, 17 participants came forward to participate in semi structured face-to-face interviews; 15 females and two male participants. All

participants were of Irish nationality and all bar two had personal experience of perinatal death with 12 of these experiences FFA related. Eight participants were in full-time employment, four in part-time employment or semi-retired and five unemployed or retired. These interviews occurred at a time and place convenient to the participant. Interviews lasting from 35 mins to 75 minutes were recorded using a Dictaphone. Interviews were transcribed verbatim and returned to the participant to ensure it was a true reflection of their experiences and opinions and to offer an opportunity to include any additional information.

6.3.4 Analysis

This study adopted a data analysis methodology based on the principles of thematic analysis.[401] Thematic analysis provides researchers with flexibility relating to their research question, sample size, data collection method and approaches to identifying meaning relating to participants' experiences and perspectives.[402] This method involves breaking down the data in to 'units' and coding them into categories. These categories derive from two parts, those that reflect the participants' language and those that the researcher identify as significant to the research question, looking beyond what is just said.[403] This approach ensures that the analysis is more than simply summarising the data, but interpreting and making sense of it.[403] To facilitate this, the researcher read and reread the transcripts to become familiarised with the data and identify preliminary themes and patterns. Open coding facilitated the researcher to identify units of meanings (text segments) as themes that related to the research question. The next phase of analysis involved the categorisation of codes by grouping related codes in to categories with some being re labelled or actively generated in to similar codes. This new structure facilitated the research to break down the restructured categories in to themes and sub themes to enable a more in-depth understanding of the meaning of the participants' experiences. Continuous analysis allowed the researcher to generate clear definitions and names for each theme by refining the specifics of each theme and the overall story

the analysis tells. This contributed to development of in-depth knowledge on the focus-of-inquiry. Braun and Clarke (2019) argue that because meaning is generated through interpretation, one cannot predict the number of data items or when to cease data collection during reflexive thematic analysis.[404] Data saturation was reached at the 16th interview, therefore active recruitment was discontinued and a further one interview which had been scheduled was honoured and completed. Therefore, data were collected until no new themes were identified and inductive thematic saturation was perceived.[404] NVivo12 was utilised to assist in the analysis of the data and enhance this study's trustworthiness by acting as an audit trail.

6.4 **Results**

The analysis of volunteers' experiences of supporting parents who receive a diagnosis of FFA identified a number of sub-themes categorised under the overarching themes of 'motivation for altruistic acts', 'being challenged', 'value of education and training', 'supporting volunteers to support others' and 'it is not a sprint, it is a marathon'. Almost all participants had a personal experience of pregnancy loss or perinatal death with the majority of these due to a FFA. Nearly all of the participants who experienced a pregnancy loss or perinatal death had negative healthcare experiences, receiving care from 'horrible', 'unhelpful' and 'cruel' healthcare professionals. Despite their negative experiences, they all found positives, usually an encounter with a healthcare professional who provided support. All participants reported that it was these personal experiences that influenced and motivated them to volunteer.

> *BARBARA: Because while things were a lot better for me than they were for my mother, 40 years' earlier, I still felt that there was a long way to go*
> *CARLA: Luckily we had a beautiful midwife… she was great and she… But I just thought what about the couples who don't have her, how do they cope?*

LAUREN: The sense in myself that having been through the experience that you could point them in the right direction… a sense of trying to spare somebody else the intensity of certain parts of the experience that you could by sharing your own experience.

6.4.1 Motivation for altruistic acts

Motivation for altruistic acts includes 'continuing bonds', 'personal experience' and 'being ready' as sub-themes. The participants who had a personal experience of a perinatal death, over half of the participants shared that volunteering was a way of honouring their baby and continuing bonds. Volunteering was 'time for their baby' because 'when you have other children everything is about them'. Therefore, this time allowed them to 'reconnect' with their baby who had died. This reconnection was created by volunteering, enabling them to feel like they were doing something 'for' their baby, to carry on their 'legacy' and in their 'memory'. Furthermore, participants described that volunteering gave further meaning to their loss. Through helping other bereaved parents, it gave their baby's life and the trauma they experienced from the death of their baby a sense of purpose.

CARLA: it (grief) gave me that sort of feeling of using it for something good, that it wasn't just this pointless horror that I went through, that it had a point, it had a use and that I was able to take it and put it into something constructive

ISLA: I get to live her legacy you see…I guess that for me it is the continuing bond…

NINA: I wanted to go, I wanted to be there, I wanted to try and do something in (Baby's name) name just to help out.

All volunteers demonstrated altruistic behaviours as motivators to volunteer. Most of the volunteers had positive experiences of peer-to-peer support following their bereavement and therefore chose to volunteer with their organisation to continue the support that they benefitted from. The few that had either negative

experiences, believed that improvements could have been made, or who had no supports, volunteered with alternative organisations to prevent other parents suffering from the lack of support such as they had experienced. There was one exception, who from seeing improvements to be made, stayed within their organisation in attempts to improve the service they provided.

> *ALAN: to give back, to keep the organisation going for other children*
>
> *GEORGINA: it was just my way of giving something back to the organisation…*
>
> *OLWYN: I did contact a support agency that was run by volunteers and, not to be mean about anybody but it just wasn't up to par, it wasn't any help…*

Regardless of which organisation the participants volunteered with, the majority of participants shared the need to be emotionally ready and healed before volunteering to help other bereaved parents. For some, they themselves and their organisations felt that time was a healer, only allowing parents volunteer a set time after their loss. Other volunteers' reported that they themselves didn't volunteer until years after their loss, when they were emotionally ready. Some felt that those early in their grief could volunteer as it makes a 'difference in their own grief'. A few participants discussed how having other children enabled them to volunteer.

> *ANTOINETTE: …it was definitely a good time. For the most part you empathise with people but it is not as raw for you, occasionally it will bring you back but for the most part you can separate… (6 years bereaved commencing volunteer work)*
>
> *OLWYN: …very important for helping organisations, you have to be healed… before you can even try to give to others (2 years bereaved commencing volunteer work).*

In addition some volunteers, who in hindsight felt that they volunteered too early, reflected on how they found it emotionally difficult to volunteer and how

potentially a volunteer can be too focused on their own experience to listen to the parent they are supporting.

> *EMMA: …in the first year you can obviously be very self-involved in it so if you were doing a support call you would end up nearly talking about yourself too much, which is not what someone who needs the support needs… So that is why we said we give people a year, it gives them the space to do their grieving and then they might be in a good head space for supporting (less than a year bereaved commencing volunteer work)*
>
> *NINA: so I think maybe emotionally while I wanted to help sometimes I found it difficult… looking back on it, maybe it is better to actually give yourself a bit more time... I think there needs to be a period of time that you are grieving yourself… I don't regret getting involved but I just think to mind yourself you might need to give yourself a bit more time (4 months bereaved commencing volunteer work).*

There were however, personal motivators to volunteering with nearly half of the participants identifying that volunteering was the 'most rewarding thing' they could do, that it taught them a lot about themselves and helped with their own healing.

6.4.2 Being Challenged

Being challenged presents the difficulties experienced by the volunteers and includes the sub-themes of 'volunteering as a challenge' and 'challenged by TOP for FFA'. Despite volunteers being motivated to volunteer, they faced many challenges within their voluntary role. Nearly all participants reported difficulties that they faced in their voluntary role with one sharing that they could not think of the challenges they faced because if they did, they wouldn't continue volunteering. The majority of participants reported being emotionally challenged in their peer support role, with one participant describing a moment that resulted in them physically crying. For those with a personal experience, they shared that

supporting women at times brought them back to when they 'were that person' and reliving their own experience. For the volunteers who did not have a personal experience of a perinatal death, they empathised and found the parent's situation overwhelming. Additionally some volunteers found they were 'able to switch off' and 'separate' themselves from the parents' pain, while a few reported how volunteering impacted on their 'home life', 'personal life' or 'wellbeing'.

> *BEN: … just cried my eyes out. I remember thinking the car was parked around the corner, I had to get around the corner without anyone realising I was crying*
> *MANDY: you have to realise once you put yourself out there things are going to affect you in some way and not to try and pretend that it doesn't*
> *NINA: difficult… because you see where the person is coming from…you have been there, you have walked in their shoes…you think back to when you were that person.*

The voluntary organisation also created challenges for the majority of the participants. Nearly half of the participants reported the importance of funding however, fundraising posed difficulties at times, getting enough money to 'keep going'. Other organisational challenges included experiences of conflict between members caused by personality clashes and disagreements relating to the running of the organisation. A few volunteers felt there was a lack of support in 'sharing the workload' and shared the difficulties of being on call '24/7'.

> *ALAN: I went to a meeting that they had some issues over the website*
> *LAUREN: it probably could be more formal, a bit more of a formality around who takes what. It is a little bit haphazard at the moment. We probably do need to tighten up on that and make it a more formal, nearly a rota of who covers what… (a rota is a schedule which would ensure tasks are fairly divided and rotated between volunteers).*

Volunteers also experienced concerns regarding members' conflicting views and opinions regarding who their organisation should provide support to or who the member themselves would support.

> *ANTOINETTE: you would get very strange notions (a person's belief or idea) from some people and you would be afraid of how they would be received… I remember meeting a girl… she stopped going to the meetings because she had lost her daughter at full term and she didn't think people deserved to be there who had lost their babies at say 20 weeks*
> *BARBARA: And there was one in particular that I saw and I thought okay I wonder is that a conversation I should have with that person because the person was a member of the pro-life campaign… I am still a bit conflicted about that*

While nearly all participants spoke about the need for non-judgemental care to those who had a TOP for FFA, sharing that it was the 'same loss' and 'same grief', they did share challenges experienced following the implementation of TOP for FFA. Some volunteers felt they were 'busier' with 'a lot more referrals' which was resulting in 'stretched' resources. For some of the participants, challenges were related to the restrictive nature of the legislation, creating a 'divide' which they felt excluded those with a diagnosis of a non-fatal but severe fetal anomaly. Volunteers shared the challenge of trying to support parents who with the same diagnosis were treated differently, for example with one couple qualifying for a TOP for FFA in Ireland and the other having to travel to another jurisdiction to obtain this service. Another volunteer shared the 'shocking' reports of parents being 'judged' depending on the maternity unit attended.

> *CARLA: things were so cut and dried before, there was no abortion in Ireland which was easy when we were able to say for every circumstance you will have to travel and now there is this sort of invisible line between the people who can terminate here and the people who can't… So you could*

have somebody with the same diagnosis as somebody else one will have the termination here and one has to travel. And I think that it has created this divide sort of…

EMMA: Before everyone just had to leave… whereas now it is nearly like a lottery it feels at times. And even some of the diagnoses that we are hearing, we are like we would have always thought that was fatal and now they are saying that is not fatal enough basically. Fatal enough has actually been a term we have heard the parent being told.

Furthermore, many participants felt they had insufficient knowledge to support parents who opt for a TOP for FFA. Some of these participants felt because they had not experienced a TOP for FFA themselves, they did not know how to support someone that had or who were considering a TOP for FFA. Others felt they were unaware of what the new service within Ireland entailed. Whether the participants was familiar with TOP or not, these volunteers expressed the need for information on the practicalities of a TOP for FFA in Ireland, that 'learning curve for all'. The value of education was noted by nearly all of the volunteers.

ALAN: we don't have anybody experienced with termination

KAREN: well it is a whole new thing, we haven't really done that before and none of us have any experience of termination so we have no experience of that because everyone keeps their child or they just go through with their pregnancy

6.4.3 Value of education and training

Within value of education and training, all participants identified the importance of education/training and that 'there is always learning' with nearly half identifying the need for further training. Participants acknowledged that while they were offering peer-to-peer support, as a parent, and could listen and share their own experiences, ongoing education and training was required to keep their

'standards up'. One participant felt that specific counselling training would be beneficial while others shared that formal training would assist them to not rely solely on their personal experiences but on best practice. A few did share the difficulty to 'know what to say' while one participant was unsure of what training would help when speaking with a parent who is in 'shock'.

> *ISLA: I always think there is always learning, there is huge learning…*
> *LAUREN: We are all volunteers, none of us has any specific counselling training and that is something that probably would be helpful.*

Additionally, most of the participants shared how previous training and education with their organisation and/or their professional role assisted them in their voluntary role. Many of the volunteers drew on the skills and knowledge they had gained from their professional lives (administration, information technology, healthcare etc.).

> *GEORGINA: we met with a lot of their people over there and we had two days of full training which was really, really invaluable to be honest. So we built on that…*
> *HANNAH: And she came to our training day and talked to us about introducing ourselves in a room and how to just be with people… So she was very, very helpful.*
> *ALAN: …I was in to the IT… I had the skills, and I got it going (Organisations website)*
> *JENNY: The main support team… of the ten, eight are professionals in their own right so they don't have to, you know, they do their CPD anyway (referring to the need for keeping up to date with training).*

6.4.4 Supporting volunteers to support others

Supporting volunteers to support others presents the sub-themes 'collaboration with healthcare professionals' and 'collaboration with other voluntary organisations'. Nearly all volunteers reported the need for support from healthcare professionals and other voluntary organisations to assist them in caring for parents who experienced a diagnosis of a FFA. Volunteers shared that they felt healthcare professionals were not informing parents of their organisation within the maternity settings. These participants reported that this resulted in parents finding the organisation later in to their grief when they would have benefitted from availing of supports at the time of diagnosis or time of death (e.g. for remembrance photography). They therefore identified the need for healthcare professionals to inform parents of the voluntary supports available. In addition, one participant identified the need for volunteers to have a referral pathway to a General Practitioner or Consultant, to act as a 'safe netting' in the case of a concern for someone's mental health, being recognised.

> *DEIRDRE: Well we would like to know that if somebody is getting a diagnosis that maybe the hospital would be proactive in maybe advising that there are groups out there such as ourselves… you would think that people would know about us, but there are still parents who say I didn't know about you before when I got my diagnosis…*
> *KAREN: We also find that we have information in hospitals but we find it doesn't always get to the parents… a parent will have a baby…and say we never got any of the information.*

Some volunteers shared their need to collaborate with other voluntary organisations. They identified that their organisation did not have volunteers nationally and collaborating with other organisations would ensure all parents nationally would receive support. Additionally, volunteers identified that organisations who had experiences in different care (those who have experience

with TOP for FFA and those who have experience with continuing the pregnancy) could complement each other and provide parents with an overview of their options to meet their various needs.

> *JENNY: If we feel that they need more specific support there are two other organisations we refer to and that would be (Organisations names)… Well we would let everybody know about other groups because we are not fit for everybody. For instance if I thought that somebody was wishing to terminate I would say I am not an expert in this area why don't you talk to somebody else and that we are still with you, it is not either or, it is as well as*
>
> *FELICITY: We wouldn't have a member of the parent support team in every county in Ireland but I would say between the different charities there probably is so it would be great to know okay we don't have someone in Mayo but (Organisation's name) do, that you would be able to have that communication.*

Despite the challenges participants faced and the need for support identified, nearly all participants reported feeling comfortable in their peer-to-peer role. Over half of the participants reported that they drew from their personal experience to support parents. Some of the participants referred to the people they met through their volunteering becoming like 'family' and 'friends'.

6.4.5 It is not a sprint, it is a marathon

Within the fourth and final main theme, it is not a sprint, it is a marathon, participants' shared the importance of self-care through two sub-themes 'family support' and 'peer-to-peer within the organisation'. Almost all participants recognised that 'you can't pour from an empty cup' and if volunteering is 'to be sustainable you have to look after yourself'. 'It is not a sprint, it is a marathon' refers to the participant's emotional wellbeing with over half of the participants

sharing activities; running, walks on the beach, journaling and taking breaks, to self-care. Nearly all of the participants shared that they felt emotionally supported in their voluntary role. Half of the volunteers shared that they benefitted from formal supports.

> *BEN: So I always say to the other (Volunteers) don't be afraid, don't be some eejit thinking I am going to keep on going here. It is not a sprint, it is a marathon, so you need to slow down a bit*
> *CARLA: there was a great group of psychologists who got in touch with us during the referendum campaigning for self-care for us and I think we should have probably kept their services going*
> *DEIRDRE: If I've had a particularly bad call or upsetting conversation… If I wanted to, either see (therapist attached to Organisation) one to one or just phone him.*

Nearly half of the participants referenced a family member who knew they volunteered and support them with it. Support they received was through tea and talking or simply just spending time with a partner or children.

> *HANNAH: …a cup of tea and a chat is most helpful… in my own family my mum had had two losses herself… We never talked about them until I started with (Organisation). Typically when I am coming from a session she is the first call I make and I find it very helpful to chat with her…*
> *OLWYN: So the last day I was in (Training) it was a very, very intense day… but the next day I will totally stay at home, regenerate, stay at home with (child) and totally recover myself.*

Volunteers supporting volunteers was identified by almost all of the participants as beneficial. Volunteers shared how being supported and receiving support helped them to continue in their voluntary role. For these participants, support was provided through several forms, with most volunteers referencing WhatsApp

groups where they could openly discuss any concerns or experiences and others referring to smaller groups who meet in person.

> *BARBARA: What has helped me is the fact that I am not on my own, that is crucial. When I am recruiting volunteers I say… you will be nervous but anything you need to ask, put it into that WhatsApp group, you will have an answer within minutes, you will have very good support*
> *FELICITY: so I suppose (names of other volunteers) and I, because we have similar experiences and because we are running that particular group together we are our own support network. We meet up every couple of months for dinner midway and a chat and that is our support*
> *GEORGINA: It is making sure our volunteers don't get burnt out… I have had one volunteer ring me and say, 'I haven't had a session in about two months.' No you haven't because I put you on break because you have done six sessions. So the team know there is always somebody watching their back.*

The need for peer support was further highlighted from one case where the participant shared their struggle with having no peer support and no one to 'vent' and 'off load' to.

> *ISLA: I suppose just having a backup person to support me in that when I take holidays that I can leave the phone with and I can share some of... I suppose it is both, it is sharing the workload, but not just the workload for me… being able to off load to somebody and vent at times when I need to and having no peer support etc. I struggle with that at times.*

Despite their approach to self-care and support received from family, friends and other volunteers, some volunteers did emphasise that they would welcome some kind of formal counselling while one participant felt reassured 'that there was opportunity' for counselling within their organisation.

6.5 **Discussion**

This study of 17 dedicated and experienced volunteers illustrated that participants own personal experiences of pregnancy loss and perinatal death motivated them to volunteer. Most participants made altruistic references with wanting to help others while many of the participants volunteered to pay tribute to their own baby's legacy. While most of the volunteers reported feeling comfortable in their peer-support role, they faced challenges. These included the emotional challenge of supporting parents who experienced a pregnancy with a FFA, organisational challenges and the change in service following the implementation of TOP for FFA for the first time in Ireland. All participants shared their need to be knowledgeable, with half of the volunteers requesting further education to ensure they are delivering a good standard of care and support. In addition to maintaining accurate knowledge and skills to support parents with a FFA diagnosis, they expressed the importance of collaborative work with both healthcare professionals and other voluntary organisations. Participants identified the importance of good self-care and the support of family, friends and other volunteers being an important sustaining factor in their voluntary role while some volunteers welcomed the opportunity for formal counselling supports.

The negative psychological and physical impact of baby loss is well documented. Parents require sensitive bereavement care[120,356,374] individually tailored to meet their needs[390] to support them to cope with the death of their baby.[182] In the absence of effective support, parents can experience long-lasting psychological distress.[178,183,352] Most of the volunteers who experienced a pregnancy loss or perinatal death reported negative experiences of care or lack of care within the maternity setting at the time of their loss. However, all of those who expressed negative experiences, they also shared positives found within those negative experiences, such as a supportive, empathetic or knowledgeable healthcare professionals. These experiences, alongside both the positive and negative experiences of receiving support from voluntary organisations acted as motivators

to become a volunteer. Lim and DeSteno (2016) identified individuals exposed to suffering have an increased tendency for prosocial behaviour; increasing concern for the welfare of others in need and perspective taking.[405] Altruism born of suffering and reciprocity as motivators in volunteering are essential to give intrinsic meaning to their volunteering.[178,185,406] This altruistic behaviour resulted in nearly half of the volunteers reporting self-healing and feeling rewarded as a result of supporting parents who received a diagnosis of a FFA. Improved overall health, emotional and psychological wellbeing and higher life-satisfaction has been associated with volunteering.[406–409] Lafarge, Mitchell and Fox (2013) in a study exploring women's experiences of coping with TOP for FFA identified the benefit from both getting support as well as providing support to peers with a common experience.[207] Along with the acknowledged benefits of volunteering, nearly all participants shared challenges they experienced.

The emotional burden of working and volunteering with death and dying are well known.[386,393,410,411] Burnout associated with prolonged emotional demand resulting in physical, mental and emotional exhaustion is increasingly gaining social relevance.[412] While there is a paucity of research on the emotional burden on volunteers supporting parents who experience a pregnancy with a FFA diagnosis, the majority of volunteers within this study reported emotional challenges. Their emotional difficulties were attributed to having 'walked in their shoes' and forcing them to relive their own personal experience. Within this study, participants referenced ways of supporting the volunteer to support others. While the majority of participants shared these emotional difficulties, only some welcomed more formal approaches to debriefing, with nearly all volunteers reporting support for their volunteering coming from their family, friends and particularly from other volunteers within the organisation. However, similar to Boyle et al. (2015) and Brighton et al. (2017) organisational responses and support are required for volunteers to sustain the delivery of peer-to-peer support.[178,411]

The value of training was inherently implied. Boyle et al. (2015) and Aho et al. (2018) both reported the desire for educational needs to be addressed among

peer supporters for pregnancy loss and perinatal death.[178,395] While training needs of volunteers need to be considered carefully due to their services being influenced by the principles of peer support[178,413], volunteers are required to manage highly emotive situations while balancing their own internal states.[413] Furthermore, voluntary organisations knowledge and practice is required to be of optimal quality and reflect that of the changing needs of service users.[120,178,392] While volunteers are willing to provide peer-to-peer support they may lack the competence to respond appropriately to the needs of their peers.[172] This is of particular importance where Power et al. (2018) highlighted the need for improved health information about FFA to respond to the lack of accurate knowledge on FFA, diagnosis, survival and supports available among the general public.[265] As previously suggested, inadequate support and care at the time of parent's bereavement can result in long lasting psychological effects. However, within this study, nearly all volunteers reported being comfortable being a peer-to-peer support to those more recently bereaved. Bartone, Bartone, Gileno and Violanti (2018) acknowledges the development of more trusting relationships and empathetic understanding from those who have shared experiences.[383] This study however did identify a knowledge deficit regarding TOP for FFA. Within this study, many participants reported the need for knowledge on how to support parents who chose TOP for FFA while some participants expressed the challenges they face relating to the 'divide' created between fatal and 'not fatal enough' and the lack of standardised care with TOP for FFA services.

The Department of Health officials responsible for the legislating of TOP for FFA included limited guidance from professional bodies in the drafting of the legislation. The legislation describes FFA as a 'Condition likely to lead to death of the foetus' and allows for TOP to be carried out following the diagnosis of a condition likely to lead to the death of the fetus in utero or within the neonatal period (28 days of birth).[27] The legislation lacks clarification whether it takes into account medical or surgical intervention. Additionally, in the absence of a clear definition of what constitutes a FFA, practicing within this legislation can be

challenging for clinicians, particularly when criminalisation remains in the legislation. Volunteers' experience of a lack of standardised care and an increase in women receiving a 'not fatal enough' diagnosis could potentially be as a result of conservative interpretation of the legislative framework. When opportunity for legal challenge and criminal charges are associated with ambiguous legislation, this can result in inconsistencies with the subjective interpretation of the law.[87]

In addition, the introduction of the legislation for TOP for FFA (December 2018) resulted in maternity services being instructed to provide abortion services from January 1st 2019. Implementation of new services and managing change in healthcare is a complex process, made more so when they occur rapidly, challenging how healthcare workers adapt and respond effectively.[414] Additionally, public involvement and healthcare professionals should engage in a two-way sharing of knowledge to identify priorities and develop improvements based on patients' needs rather than assumptions.[309] Despite acknowledged best practice, little time was allocated for this, with clinicians developing guidelines alongside the implementation of TOP for FFA. There remains a need for voluntary organisations to work alongside healthcare professionals as identified within this study. Clarke and Quin (2007) in a previous Irish study reported Volunteers feeling unsupported and described themselves as having to "take up the slack" from the statutory services.[393] A collaborative approach between statutory and voluntary bodies is required to facilitate the delivery of services reflective of best practice and standard of care.[175] An integrated framework that respects both the autonomy and identity of voluntary organisations and public responsibilities of the HSE while creating close working relationships is required.[172] With just one opportunity to 'get it right'[161] support and care offered to patients experiencing a pregnancy with a FFA needs to be based on scientific evidence, personal experiences and prioritised needs as identified by the service users.[309,415] Such collaborative approaches promote holistic in-depth understanding of complex health issues improving the overall experiences of service users.[178] This is of utmost importance as TOP for FFA is being delivered in Ireland, for the first time. A two-way sharing of knowledge is required to ensure those who have experience

of a pregnancy with a FFA and those providing TOP, have the appropriate knowledge to adequately support women who are considering or avail of a TOP for FFA within the Irish context. Chavkin, Stifani, Bridgman-Packer, Greenberg, and Favier (2018) concurs, identifying the need for information to be disseminated among service providers and users to raise awareness.[416]

6.5.1 Strengths and Limitations

The use of qualitative research to explore volunteers' experiences of providing peer-to-peer support to bereaved parents is a strength of this study. This research approach facilitated an understanding of volunteer's experiences of being a peer support to parents who experience a diagnosis of a FFA. Volunteers within this study had various roles from one-to-one or group face-to-face support, telephone support, online support, once off memory making role (remembrance photography), or held senior roles within the organisation. Therefore, experiences identified give a good representation of different and diverse group of volunteers'. However, the small sample size and minimal male participants may limit the generalisability of the results beyond this cohort. Additional interviews with a greater amount of male participants would be of benefit, to enable further explanation of experiences, explore their implications for healthcare and facilitate generalisation of the identified themes. Additionally, almost all participants had experience of a pregnancy loss or perinatal death, therefore this study may not represent volunteers who have no personal experiences of the phenomena being studied. This is a finding in itself, that these voluntary organisations are primarily consisting of those who have experienced the phenomenon in question; pregnancy loss, perinatal death and FFA. However, even those who have personal experience, it must be acknowledged that a volunteers' experience will also be limited in several different ways depending on the gestational age of own loss or their chosen care pathway etc. Therefore, those without personal experience of loss or working in different maternity care settings may still identify with the study's findings.

6.6 **Conclusion**

Voluntary organisations play a key role in filling gaps in healthcare provision and health policy, responding to the bereavement care needs of individuals. Volunteer's knowledge and practice needs to reflect that of best practice and respond to the ever changing needs of service users. Therefore, they should be given educational opportunities and provided with information on how to access services to manage their own health and assist others in doing so. Volunteers require various emotional and physical supports to continue in their voluntary role. Our findings illustrate the need for collaborative working between healthcare professionals and volunteers to assist them in supporting parents who experience a FFA. Furthermore, it suggests the need for voluntary organisations to collaborate with each other to promote the delivery of accurate information and continuity of care to all parents who require peer-to-peer support. Being supported in their role and sharing the workload would assist them in their own self-care and therefore facilitate wellbeing while acting as a volunteer.

Chapter 7 – Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: a qualitative study

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Chapter 7 - Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: A qualitative Study

7.1 Abstract

Objectives: To explore fetal medicine specialists' (FMS) experiences of caring for parents following a fatal fetal anomaly (FFA) diagnosis, during the implementation of termination of pregnancy for fatal fetal anomaly (TOPFA) for the first time.

Design: Qualitative study.

Setting: Fetal medicine units in the Republic of Ireland.

Population: Ten FMS from five of the six fetal medicine units.

Methods: NVivo12 assisted in the thematic analysis of semi-structured in-depth face-to-face interviews.

Main outcome measures: FMS 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'. FMS feared getting a FFA diagnosis incorrect due to the media scrutiny and criminal liability associated with the TOPFA 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 diagnosis of FFA, provision of feticide and palliative care to infants born alive following TOPFA. Participants reported challenges implementing TOPFA, including the absence of institutional support and 'stretched' resources. FMS experienced

internal conflict and a psychological burden providing TOPFA, but did so to 'provide full care for women'.

Conclusions: Our study identified challenges regarding the suitability of the Irish legislation for TOPFA 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: Maternity Services, fetal medicine and surgery, termination of pregnancy, medical law, qualitative research

7.2 **Introduction**

Approximately 3% of pregnancies receive a diagnosis of a major congenital anomaly[88] and more women now receive a diagnosis of a fetal anomaly during pregnancy due to advancements in prenatal testing.[13] Such a diagnosis creates much uncertainty regarding the fetal prognosis and[6,284] parents face many difficult decisions, primarily whether to terminate or continue with the pregnancy.[7]

Universal access to reproductive healthcare and safe abortion has long been advocated for as a woman's human right[222–224] resulting in countries reforming laws to facilitate and broaden abortion services.[23,225] The Republic of Ireland legislated for termination of pregnancy (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 abortion in the world[229]; the Eighth Amendment of the Constitution protected "the right to life of the unborn"[232] and ensured that abortion, including TOP for FFA, was a criminal offence.[217,218] On January 1, 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.[27] TOP outwith 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 Guidelines for TOP for FFA recommends that discussions with the fetal medicine multidisciplinary team (see Supplementary File VI for suggested members) regarding the diagnosis and prognosis should form a component of the assessment of fetal anomalies.[52]

There is little qualitative research, however, on the lived experience of fetal-medicine specialists, (FMS) who are involved in prenatal diagnosis, counselling and care of pregnancies complicated by FFA. This study aimed to explore FMS

experiences in caring for women diagnosed with a FFA during a change in service provision for TOP for FFA.

7.3 **Methods**

A qualitative research design was utilised as it facilitated interpretation of how people make sense of their lived experience.[52,396,397] This methodology facilitated the researcher to examine FMS experiences of changing practice of caring for parents who receive a 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 FMS 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 twelve FMS and encouraged them to share study information with their FMS colleagues. The topic guide was developed by all three authors and input sought from members of the Pregnancy Loss Research Group, which include representatives of the multidisciplinary team (MDT) and service users.[392] No other input was sought from patient and public representatives. Data collection occurred between November 2019 and January 2020. Ten FMS, seven female and three male, with varying years of experience (presented in Table 7.1) 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 FMS practising in Ireland with varied involvement in TOP. A topic guide was used to aid the interviews conducted by SP (Supplementary File VII). 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.[401] The transcripts were read and reread to become familiarised with the data and identify initial codes. Further analysis facilitated the categorisation of codes through grouping the initial codes, developing them into potential themes and sub-themes and generated definitions and names for each theme. NVivo12 was utilised to assist in the analysis of the data and enhance this study's trustworthiness 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 of assumptions that unwittingly may have been overlooked.[417–419] Coding is a reflexive process that bears the mark of the researcher.[417] 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.[420] 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' experience of 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 due to her position as a FMS but did review the finalised themes for publication to further limit bias. Reflexive thematic analysis argues that meaning is generated through interpretation therefore, inhibiting the prediction of the number of data items or when to cease data collection.[404] Therefore, data were collected until no new themes were identified and inductive thematic saturation was perceived.[404]

7.4 **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 7.2. Direct quotes to support each theme are presented in Table 7.3.

7.4.1 Not fatal enough

Patients' best interest motivated FMS to ensure a 'diagnosis is correct' and that they 'are doing everything to inform women and their partners'. FMS identified that 'where the default is termination is the worst outcome' it leaves them 'exposed', meaning if a TOP for FFA has been performed and the diagnosis is found to be incorrect, FMS 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.

Half of the FMS 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, that there is always an 'outlier' (a baby that will live longer than expected). A couple of FMS commented on the relief experienced when the baby dies, confirming 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. over the 28 days referenced within the legislation. Legislative challenges were identified by most participants, primarily, its ambiguity, 'understanding what the legislation allows for', what conditions are deemed fatal and therefore legally terminated. 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 FMS faced difficulty with conditions which 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 FMS shared that the distinction between fatal and severe resulted in women being 'ostracised' as only those with a fatal diagnosis can legally obtain a TOP in Ireland, while those 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 the MDT was 'supportive' with their decision-making. MDT discussions gave FMS an opportunity to include other 'specialties' and 'experienced colleagues' to assist in their decision-making. However, some FMS expressed 'lament having to bring' discussions to the MDT as some disciplines were too 'vocal' and 'strong' with their 'anti-abortion' opinions.

7.4.2 Interactions with colleagues

Almost all FMS identified that a good working relationship with MDT members was 'essential' to provide good quality care. Over half of the FMS identified midwives as 'essential'; they were 'more available' and 'better' in supporting women. Teamwork benefitted the FMS directly as local and national colleagues acted as both a source of learning and peer support. Nearly all FMS identified the need to 'debrief' with those who understand their challenges as '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 FMS described meetings as 'divisive' involving 'contentious cases'. They shared that there was 'a massive uncomfortableness' and 'suspicion'

with TOP. Over half of the FMS experienced conflict with Neonatologists. Participants reported frustration that these colleagues would engage in decision-making for TOP for FFA but refuse to care for the woman and her baby 'if the driving force was termination'. This generated concern for FMS 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 FMS: 'dare I say the word feticide'. Over half of the FMS experienced differences of opinion relating to feticide. Some participants' expressed 'friction' with Neonatologists due to an expectation for 'universal feticide' to ensure no baby was born alive. Half of the FMS identified a 'role for feticide', 'depending on the anomaly' while some expressed that feticide needed to be mandatory for late gestations because it was in the best interest of the baby not to be born alive. A couple of FMS 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 FMS experienced opposition with conscientious objectors. While acknowledging people's right to conscientious objection, they were frustrated with what they called 'conscientious obstruction'. Some felt treatment was delayed at times, for example where 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 FMS expressed feelings of being 'undervalued' and 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 FMS experienced difficulties when implementing the TOP service. Half of the FMS reported that they had to self-prepare, alongside their colleagues,

in the absence of institutional support. An unsupportive environment resulted in FMS feeling unable to 'ask for help' while 'providing a new service with no new colleagues' with an 'increased workload'. These FMS acknowledged that while a small number, these cases take up 'a lot more time' and can require multiple visits. The few FMS who had organisational support reported positive experiences with the implementation of TOP for FFA. Despite their initial challenges, it 'bedded in' and became 'normalised'.

7.4.3 Support for pregnant women

Nearly all FMS shared the need to give parents a 'warning shot that something's not okay' when diagnosing a FFA. A warning shot enabled FMS to encourage women to have support when receiving a diagnosis of a FFA as some participants expressed difficulties when informing women of a FFA when alone. Half of the FMS 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', to 'pitch' it at a level they 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 a FFA.

7.4.4 Internal conflict and emotional challenges

Internal conflict was experienced by almost all FMS as a result of caring for women with a 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 FMS

expressed internal conflict due to 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'. However, almost all FMS 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'. FMS 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 FMS. A couple referred to themselves as 'doctor death', dealing with death and dying or with opinions from others that they 'are trying to terminate everything'. Half of the participants expressed that this however was their job, that they have 'chosen' 'to support (parents)' and 'it's important to do it well'.

7.5 **Discussion**

7.5.1 Main Findings

This study, within an Irish context where TOP for FFA is being provided for the first time following an Electoral Referendum, identified fears of FMS working in prenatal diagnosis due to the potential for media scrutiny and criminal liability if a fetal condition terminated was not deemed to be a 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. While they recognised teamwork as essential, conflict and opposition was widespread within their practice, due to differences of opinion regarding what qualifies as a FFA and the practice of feticide. Internal conflict and psychological burden among FMS providing TOP for

FFA was highlighted, but FMS identified services needed to be provided and supporting parents motivated them to develop these services.

7.5.2 Interpretation

Within this study, FMS expressed fear of media scrutiny and being questioned on their diagnosis of FFA. Irish media regularly reports on adverse obstetric events suggesting mismanagement and names clinicians involved[392], as was evident within weeks of introducing TOP services.[258,259] Such media attention can have a negative impact on healthcare professionals and parents.[260,421] FMS fears stemmed from the 'difficult legislation' and the various definitions of what constitutes a FFA. Such definitions do not accurately describe many of the conditions associated as a FFA, as known survivors are linked to many of these conditions.[119,422] Additionally, diagnosing conditions as FFA in accordance with the Irish legislation is complex as many anomalies in isolation may not be considered a FFA however, when combined are potentially fatal.[422]

FMS within this study shared experiences of opposition from colleagues relating to decision-making on the fatality of conditions. Dommergues et al. (2010) suggests, in all countries where TOP for FFA is legalised, interpretation of the legislation is feasible.[268] Where criminal liability of clinicians exists, as it does in Ireland, the UK and throughout the US[219], there is a potential for conservative interpretations of legislation leading to service provision inconsistencies.[87] Power et al. (2020) identified the need for a universal definition, to include an accurate description of a FFA that results in perinatal death to aid diagnosis, reduce subjectivity and standardise healthcare provision.[422] Furthermore, FMS 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 FMS sharing pressures experienced from Neonatologists to conduct feticide. FMS identified these experiences as a source of tension and conflict as they identified 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. While the majority of TOP for FFA occur within the second trimester, before viability [423], unfortunately, some pregnant women within Ireland are without universal access to anomaly scans and so are at risk of a late diagnosis.[18,217] Additionally, Ireland's legislation is without gestational limits and so creating the opportunity for late TOP for FFA. However in other jurisdictions feticide is not a legal requirement, unless requested by the parents, for fetal anomalies not compatible with survival.[57] Despite this, approximately 1-2% of UK terminations in 2018 were confirmed having no feticide. [255] FMS 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 FMS providing TOP.[250,424,425] and Obstetricians throughout Europe acknowledge the need for more resources and emotional support when providing late TOP.[426]

The complexity of introducing a national abortion service warrants the need for regulations, clinical guidance and protocols, and similar to other new services requires a well-developed plan supported by management.[427] 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.[217] FMS experiences identified offer learning for abortion providers in Northern Ireland during their current efforts to reform their abortion laws[428,429] and countries like Turkey, India and US where TOP for FFA is legalised but there are access restrictions.[216,430] 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.[217–219,250,416] Unclear regulations that exist worldwide, result in delay and restrictions to abortion services, including TOP for FFA.[216,219,221] To reduce delay and restrictions, Ireland's interim TOP for FFA guidelines transitioned from recommending that decisions on the fatality of a condition be made by majority consensus among MDT[52] members to recommending that MDT discussions are important but responsibility lies with the two certifying medical practitioners.[52] Over half of the FMS in this study found

MDT discussions useful in determining whether a condition met the requirements for a TOP. It is noteworthy, that the majority who benefitted from MDT discussions reported good institutional support. A MDT approach may be beneficial where clinicians receive organisational support and respect but can impede delivery of care where clinicians are undermined and unsupported.[217]

The psychological impact of working with perinatal and neonatal death experienced by the participants and the need for institutional and collegial support is documented in previous research.[259,352,374,431–436] However, abortion is controversial and divisive, and conflict between colleagues can disrupt the sense of belonging in their professional group[215] 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 isolation and vulnerability associated with potential legal challenges.[250] FMS 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.[259,433,434] Despite the emotional impact, participants gained satisfaction in supporting women. This sense of fulfilment and source of strength from supporting parents are reflective of previous research.[215,374,424,431,437]

7.5.3 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 which potentially may have influenced the content of their interviews. Nonetheless, this study is the first to explore experiences of FMS during a significant national change in service provision for TOP for fetal anomaly.

7.6 Conclusion

The legal right to abortion does not automatically ensure the provision of appropriate abortion care. Our study identified challenges regarding the suitability of the Irish legislation for TOP for FFA and its rapid introduction into clinical practice. It advocates for the abolishment of the retained criminal liability attached to the legislation and the need for legislators to listen and trust FMS 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 FMS encounter when managing pregnancies diagnosed with FFA illustrates the importance of institutional support and the need for healthcare management to support FMS in the provision of a new service.

Disclosure of interests:

The authors have no relevant financial, personal, political, intellectual or religious interests to disclose.

Contribution to authorship:

All authors (SP, SM and KOD) have made substantial contributions to all of the following:

1. The conception and design of the study, acquisition of data, analysis and interpretation of data, 2. Drafting the article or revising it critically for important intellectual content, and 3. All approved the manuscript being submitted and take responsibility for its publication.

Details of ethics approval:

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None

7.7 Tables

Table 7. 1: Years' 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 7. 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

Table 7. 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)

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

Discussion and Conclusion

8.1 Discussion

Worldwide, congenital anomalies affect approximately 2-4% of all births[56,87–89] of which a proportion are fatal. Despite their low incidence, congenital anomalies are one of the leading causes of fetal and infant mortality.[11] Further, the negative impact is not only felt by the woman, but also by parents, families and wider communities.[438–441] Advancements in antenatal screening and diagnostics have increased the number of women receiving a diagnosis of FFA during pregnancy.[13] Such a diagnosis comes unexpectedly and creates intense sadness for parents.[6,7,155] Parents face difficult decisions, primarily whether to terminate the pregnancy or continue and prepare for the birth of an affected infant. Women living in the Republic of Ireland (RoI) have availed of TOP for FFA through travelling to other jurisdictions to avail of abortion care legally since the 1990's following the Thirteenth and Fourteenth Amendment to the Constitution of Ireland. These amendments legally allowed women in Ireland to learn about abortion services in other countries and travel to other countries for a TOP.

Following a much publicised referendum, the RoI enacted the Health (Regulation of Termination of Pregnancy) Act 2018 on January 1st 2019, permitting TOP for FFA for the first time. Research is lacking relating to the influence of media commentary, in particular around TOP for FFA and PPC in the RoI considering it is a divisive topic which gained much attention during Ireland's referendum to repeal the Eighth Amendment and reform Irish abortion laws. Regardless of which pathway the parents choose however, the result is ultimately the same for these conditions, a pregnancy ending in a fetal or infant death. Parents require varying amounts of support during and after their pregnancy with their needs often surpassing that of the standard maternity hospital provision.

In addition, there little knowledge regarding the learning needs of voluntary organisations who the Irish healthcare system rely heavily on to provide bereavement care to parents. Lastly, little is known about these Volunteers and

the Fetal Medicine Specialists' experiences of providing support to and/or caring for parents who experience a FFA in pregnancy.

In order to address these deficits in the literature, six research studies were undertaken to investigate:

- The incidence of FFA associated with perinatal mortality in Ireland (Chapter 2)
- An assessment of the general public's knowledge of FFA (Chapter 3)
- Critical discourse analysis on the influence of media commentary on FFA in Ireland (Chapter 4)
- Exploring what education is priority for voluntary organisations who deliver supports to parents who experience perinatal loss (Chapter 5)
- Experiences of Volunteers supporting parents following a FFA diagnosis in Ireland (Chapter 6)
- Fetal Medicine Specialists' experiences of providing a new service of TOP for FFA: A qualitative Study (Chapter 7)

These studies are undertaken within the Irish context and therefore, due to the specific cultural, socio-demographic and health services background in the RoI, this thesis's findings may prove difficult to generalise entirely to other countries. Despite the differing cultures and geographical locations, however, these results have implications for many healthcare services internationally. It is important for all healthcare providers and policy makers worldwide to have awareness of the need for antenatal education and public health campaigns to ensure women are knowledgeable about FFA in pregnancy. A universal awareness of the influence of media on women's reproductive rights and healthcare, as media has the power to represent social topics in a particular way in order to influence the reader[262] is also beneficial. Healthcare providers need to analyse information available to women for its accuracy and reliability and assess how it may impact decision making in pregnancy. Further, the over dependence on voluntary organisations to support parents following a bereavement is not an isolated issue to Ireland. Countries in

which Volunteers play a significant role can learn from recognising Volunteers educational requirements as being as important as those of healthcare providers. Additionally, this thesis promotes the need for a more collaborative approach between healthcare professionals and Volunteers to assist them in their volunteering role in order for them to continue providing support to bereaved parents. Similarly, as noted in previous international research, those working in FMS also require teamwork and organisational support when caring for parents following a FFA and performing TOP for FFA in order to combat feelings of disapproval from colleagues, isolation and vulnerability. Lastly, countries reforming their abortion laws, or who will do in the future, can use the findings within this thesis to act as guidance. These findings offer an insight into healthcare professional's requirements when implementing abortion services for the first time, in order to provide a high standard of care to parents following a FFA diagnosis.

The interpretation of the main findings and implications for further research are discussed within the following themes;

- Knowledge of FFA
- The complexity of FFA
- Delivering a TOP for FFA service
- Education opportunities for Volunteers
- Supporting those caring for and supporting pregnancies with a FFA

8.2 **Knowledge of FFA (Chapter 3 and Chapter 4)**

8.2.1 Main Findings

The cross-sectional national telephone survey presented in Chapter 3, identified the general public's lack of accurate information related to FFA. Knowledge regarding what a FFA is and its classification was minimal with over two thirds of the participants unaware that a FFA was a condition which would cause death in utero or within the neonatal period despite medical intervention (most widely

accepted definition as per Wilkinson et al.[118,119] A quarter of respondents answered that a FFA would definitely cause death in utero while half suggested infants affected by a FFA could survive without medical treatment. Almost half of the participants were unaware that Anencephaly and Renal Agenesis were classified as a FFA. This lack of accurate knowledge is of no surprise as the critical discourse analysis presented in Chapter 4 suggests that information available to the general public via Irish media was misrepresented to potentially distort the truth. Examples of this included the description of a FFA as a definite death in utero and referring to a FFA diagnosis as 'incompatible with life'. While rare, there are known survivors following intensive support, linked to many of the conditions we consider fatal.[13,118,119,124,135,136,138,139,289] Additionally, the Irish media portrayed images of children living meaningful lives with FFA however withheld any of the daily challenges that parents and families face when having a child with complex care needs.[442–446] Knowledge on the antenatal diagnosis of FFA was also inadequate during the lead up to the abortion referendum and little was known about the options in Ireland following a FFA diagnosis and regarding TOP for FFA or PPC, as presented in Chapter 3. This was unsurprising as discourse related to PPC was supressed within the two online media sources studied (one broadsheet and one online journal) analysed dating from 2012 to 2017. Where PPC was included it was often portrayed as a negative approach to care, described as life support machines and a life of hospitals, which does not reflect the ethos of palliative care.[336] The lack of accurate information among the public and unreliable information being delivered within media sources is of concern as pregnant women regularly seek informal health information on pregnancy related matters from media and online information sources as well as friends and family.[251,286,287,307,447,448] Pregnancy related information sought by women includes that of antenatal screening for fetal anomalies[308], reinforcing the need for improved availability of information to assist women making informed decisions related to their maternity care.[449]

As identified in Chapter 4, some Irish politicians utilised the media to highlight their party's ideological perspective regarding FFA, in attempt to derive political advantage presumably in order to gain popularity and power. Their ideological perspectives tend to reflect what was perceived as the preferred choice of the public and voters at that time. This thesis raises concerns regarding inaccurate information available to the legislators which is cause of concern as officials in the Department of Health were responsible for the drafting legislation of TOP for FFA.[246] As identified in Chapter 7, it seems they sought minimal guidance and input from professional bodies.

8.2.2 Implications for Practice and Research

All types of media that communicates to a wide audience, whether through the internet, print, or broadcast, plays an important role in providing health information related to supports and services to service users[349] and has the ability to frame abortion in order to shape public opinion and subsequently affect policy.[26,348] Thus, the findings discussed above raise significant concerns as a change in health service provision requires accurate knowledge in addition to regulations, clinical guidance and protocols.[427] Information widely accessible to women needs to be assessed for its accuracy. Healthcare professionals need to be mindful of the power of media and the potential for unreliable information being shared which is easily accessible to prospective parents and opportunistic politicians. Pregnant women require information for both their own and their baby's wellbeing[287] and to assist in their decision making during their pregnancy.[350] Thus, healthcare professionals need to analyse information available to pregnant women and ensure accurate up to date information is available via information leaflets and websites, which should be monitored and updated by those working in the maternity service.

The lack of knowledge among the general public on FFA is concerning and recognises the need for improved health information regarding FFA. This is because the general public also consists of those who have or will experience a pregnancy with a FFA and those whom act as a source of information to these parents. This gap in knowledge identifies the need for improved antenatal education and public health campaigns. Women require information on all potential outcomes following a FFA, including the potential for survival after birth. Further research is warranted to explore what is most beneficial for women regarding how information on FFA is delivered and whether educational opportunities are delivered prior to pregnancy or during pregnancy. By implementing educational approaches, it would ensure women's decisions regarding their healthcare are informed therefore reducing anxiety and improving their health outcomes.[350] Recognising the need for improved antenatal education and public health campaigns to inform pregnant women regarding FFA, Kamali et al. promotes that women's information needs should be considered when planning education programmes.[287] Providing education responsive to women's learning needs facilitates with addressing knowledge deficits and inaccuracies identified within Chapter 3. Thus, future research to investigate what depth and level of information women routinely require during their pregnancy, to prepare them in the event of an antenatal diagnosis, would be beneficial.

8.3 **The complexity of FFA (Chapter 2, 3, 4, 6 and 7)**

8.3.1 Main Findings

This thesis, during the secondary analysis of the National Perinatal Epidemiology Centre's database presented in Chapter 2, identified the complexity relating to the presentation of infants with congenital anomaly. Within this chapter, the five most prevalent FFA in accordance with criteria outlined in Irish legislation were identified.[27] These included Edwards Syndrome, Anencephaly, Patau Syndrome, Renal Agenesis and Triploidy. While these conditions are widely referred to as fatal

and/or lethal, there are known survivors linked to the majority of these conditions.[118,119] Within the English language, these terms, fatal and lethal, are conventionally used to describe an action or agent that will cause death.[119,450,451] Through interpreting this definition, one could consider life itself as fatal as it too will inevitably lead to death. Courtwright proposes that the following definition of lethal captures its current meaning when used in neonatal literature: death will occur in almost all cases within a relatively short time from diagnosis despite aggressive medical treatment.[452] Previous research by Wilkinson et al. and Courtwright et al. have created discussion related to the terms fatal or lethal and their appropriateness for use when counselling parents following a diagnosis of a major fetal anomaly.[118,119,289,452] Authors challenge if such terminology accurately describes many of the fetal anomalies associated with these terms due to the potential for neonatal survival.[118,119] It raises questions relating to how high a chance of death is sufficient to be considered fatal.[119] The findings of this thesis, in agreement with Wilkinson et al. identifies that such terminology hinders rather than helps communication.[118] Thus, this terminology may potentially add to the lack of accurate knowledge among the general public and the unreliable information being distributed via the media as discussed in Chapters 3 and 4.

Language is not neutral and through terminology used, framing and semantics, ideological standpoints can be presented within the media to create varying contexts and influence the reader.[263,312] Additionally, language used in antenatal counselling can be influential and so healthcare professionals providing information on FFA to parents following a diagnosis are required to be mindful of language used. Not only is non-medical language and repeating of information warranted[31], information that is honest, accurate, unbiased and non-judgemental is required from empathetic healthcare professionals who take their cues from the women themselves and offer compassionate care.[31,453] How such information is delivered to women has been reported to need improvement in the past.[159] This is still relevant today as more recently, Wilkinson et al. suggests that healthcare professionals' use of fatal and related terminology is potentially due to their

discomfort with uncertainty, to aid parents' decision-making process of which care option to choose and opinions regarding expected quality of life.[118] Wilkinson however argues that terminology may not be of importance as long as healthcare professionals are clear in their communication.[118] It is further argued that the terminology used does not change management options.[118] However, in addition to clear communication, there is a need for standardised care that is easily accessible to maternity patients.[38]

Findings discussed within Chapter 6 and 7 would suggest that there is a need for more standardised care when caring for pregnancies following a FFA diagnosis. Within Chapter 6, an exploration into Volunteers' experiences of supporting women following a FFA diagnosis, Volunteers suggested that they faced challenges supporting women who chose a TOP for FFA. These challenges were due to women receiving different care whereby, despite having a diagnosis of the same FFA, some women were offered a TOP within the RoI and other women had to travel to another jurisdiction. This would imply that in contrast to Wilkinson et al. management options were being partly influenced by terminology used to describe severe fetal anomalies.[118] Within Chapter 7, FMS themselves identified the challenges they faced with the complexity of FFA. They shared the uncertainty of whether a condition is a FFA as it depends on the individual's definition of what is fatal and how there is never any certainty regarding when death will occur. FMS shared experiences of disagreements with colleagues when attempting to come to an agreement of what constitutes a FFA, frustration with conscientious objectors when it resulted in a delay in care and refusal of Neonatology colleagues to provide PPC to babies following a TOP without feticide. These findings suggest the need for a more standardised approach to ensure the care women are offered is reflective of best practice and not their geographical location[18,366] both during their pregnancy[38] and following a pregnancy loss and perinatal death.[120]

The uncertainty of what conditions were deemed fatal in accordance with the legislation and the resulting challenge of offering a TOP was related to the ambiguity and restrictiveness of the TOP legislation as presented in Chapter 7.

Both FMS and Volunteers expressed concerns with the current 'restrictive' legislation as it was now creating a divide, excluding women whose condition while deemed non-fatal was 'absolutely not going to survive' and forcing them to travel for a TOP for FFA. The Irish legislation was also referred to as 'difficult', as it does not allow for survival of babies beyond the 28 days referenced within the legislation and because of the fear of criminal liability if found to be practising outside its remit. Thus, raising the question within this thesis, what probability of death occurring prior to 28 days is sufficient to meet this requirement as there is always an outlier, a baby with a FFA that will live longer than expected (as discussed within Chapter 7).

The secondary analysis of the National Perinatal Epidemiology Centre's perinatal mortality data, as presented in Chapter 2, further illustrates the complexity relating to the presentation of infants with congenital anomaly and the difficulties with the legislation. While all of the congenital anomalies contributed to a death, only 42% would be considered a FFA using the description provided in the Health (Regulation of Termination of Pregnancy) Bill 2018.[27] The identification of less than half of the anomalies responsible for perinatal death being classified as a FFA relates to the presentation of infants with congenital anomaly, the associated anomalies and the progression of these conditions that results in them being fatal. While many of the conditions in isolation may not be a FFA, combined they have the potential to be fatal.[152] Legislative challenges as discussed in Chapter 2 and 7, are also a result of the ambiguous language used within the law. Subjective language within the law, as is the case in many countries, can result in subjective decision-making due to its openness to interpretation.[268] Therefore, healthcare professionals are required to be knowledgeable, evidence-based, skilful and unbiased to ensure comprehensive and balanced counselling is provided to parents following a FFA diagnosis.[57,152,454] Due to the criminalisation of medical professionals retained in the Irish legislation, as it is many other countries, healthcare professionals need to be definitive in their knowledge and certain in their decision-making on all aspects of FFA presentation.

8.3.2 Implications *for practice and research*

First and foremost, healthcare professionals are required to be knowledgeable regarding the complexity relating to the presentation of infants with a fetal anomaly that leads to them being fatal. Expertise is required to identify those anomalies which in isolation may not be a FFA, however when combined have the potential to be fatal. Further, these findings promote the need for a universally agreed definition of what constitutes a FFA or list of conditions that are deemed to be a FFA, to facilitate a more accurate description of a FFA that describes fetuses/infants with conditions that can cause perinatal death. We acknowledge a definition and list of conditions is controversial. It is possible that developing these criteria might provide those FMS caring for parents following a FFA diagnosis a standardised care pathway to identify the inclusion of complex diagnoses, multiple anomaly syndromes and progression of conditions to be considered as FFA. Moreover, this approach should minimise subjectivity and standardise healthcare being provided to parents following a FFA diagnosis.

These findings indicate a need for a review of the Irish legislation to ensure that it accurately describes conditions that can cause perinatal death. Such a review requires the involvement of professional bodies, especially those FMS who are providing TOP for FFA in clinical practice. Legislators need to listen and trust FMS in their expert management of pregnancies affected by FFA.

Further, this study adds to existing research recommending a universal database for the RoI, one designed to collect essential epidemiologic information on congenital anomaly[275,277], for example EUROCAT (European Surveillance of Congenital Anomalies). Currently within Ireland, only Dublin, South East Ireland, and Cork and Kerry are member registries who submit epidemiologic surveillance of congenital anomalies to EUROCAT's database .[275] A national database however would provide essential, clear and up to date information for healthcare professionals to counsel parents following a diagnosis of FFA. Recording and analysis of epidemiological information on congenital anomalies is essential for

evaluating current preventative strategies, their effectiveness and to aid in the development of new preventative methods.[275,277] Thus, having access to national epidemiological information would facilitate required investigation into the increasing rate of renal agenesis from 2011 to 2016 as identified in Chapter 2. Although this is outside the remit of this study, it potentially is not an increase in numbers but an increase in those pregnancies being diagnosed through antenatal screening and postnatal investigations. This being noted, data analysed were gathered during a time where only 64% of women in the RoI were benefitting from second trimester fetal anomaly scans and so further research is required to identify trends in the prevalence of FFAs.[18]

8.4 **Delivering a TOP for FFA service (Chapter 4, 6, and 7)**

8.4.1 Main Findings

Further to the challenges regarding the suitability of the Irish legislation for TOP for FFA discussed above, Chapter 7 discussed the challenges experienced by FMS with the rapid introduction of the legislation into clinical practice. Irish clinical guidelines for TOP for FFA were developed during the introduction of the service despite the obvious need for regulations, clinical guidance and protocols to facilitate the introduction of a national abortion service and prior to its commencement.[427] The need for support from management was highlighted within this thesis, whereby in settings where hospital management held a position of conscientious objection and FMS experienced what they referred to as 'conscientious obstruction', a lack of support and being undervalued as specialists was experienced (as discussed in Chapter 7). In contrast, FMS with management support, despite experiencing implementation challenges due to the rapid introduction of the new service, had more positive experiences. Implementation of any new service and managing change can prove challenging to organisations resulting in opposing employee attitudes when implemented sub-optimally.[455] Similar to other new healthcare services, the implementation of a national

abortion service requires a well-developed plan that is supported by management for its effective and successful implementation.[414,427,455] Despite this, while the number of pregnancies effected with a FFA are small as acknowledged by the FMS, these cases can require multiple visits and demand 'a lot more time' yet FMS were 'providing a new service with no new colleagues' with an 'increased workload'.

Within this new workload, FMS shared challenges, particularly their own internal conflict, experienced with feticide. As Ireland's legislation is without gestational limits there is opportunity for late TOP for FFA. Additionally, there are pregnant women within the RoI who remain without access to anomaly scans and therefore at risk of a late diagnosis in pregnancy.[18,217] The internal conflict and balancing of moral and ethical beliefs experienced by FMS providing TOP is identified in previous research.[250,424,425] In particular, the need for emotional support and more resources when providing late TOP is noted.[426] Within Chapter 7, the challenge of feticide was exacerbated due to difference of opinion among healthcare professionals ranging from an expectation for 'universal feticide' to avoid any live birth and the need for it to be a parental choice.

Further challenges experienced by FMS as presented in Chapter 7 included the unsuitability of the Irish legislation for the reality of clinical practice. In addition to its ambiguity as previously discussed, FMS expressed fear due to the retention of criminal liability. This is an area of concern because fear of criminalisation can encourage subjective decision-making when the language in legislation is vague and open to interpretation.[268] As seen within the study presented in Chapter 6, this can result in conservative interpretations and inconsistencies in service provision.[87] Media scrutiny and being questioned on their diagnosis of FFA was also a source of fear as Irish media regularly reposts on adverse obstetric events.[259] This was evident within weeks of introducing TOP services when a TOP was carried out for suspected Edward Syndrome, a diagnosis which was later identified as incorrect following full results of the chorionic villus sampling.[258,456] Media attention also focused on cases when a TOP was not permitted. In one example the maternity hospital was criticised for not providing a service entitled by the

woman and media reporting highlighted disagreements within the maternity hospital between the Consultants.[457] The negative impact healthcare professionals and parents experience following negative media attention is documented within previous research. [260,421]

8.4.2 Implications for Practice and Research

Research needs to be conceptualised and communicated in a way that is understood and meaningful for policy makers[458] in order to inform health policy to ensure healthcare organisations deliver the most effective and standardised health service.[459] This study provides such translational evidence to offer learning for abortion providers to countries who are currently reforming their abortion laws, such as Northern Ireland[428,429] and countries where TOP for FFA while legal have access restrictions [216,430] These findings identify the challenges created from the rapid introduction of TOP for FFA and therefore the need for appropriate preparation time when implementing new healthcare service. Chavkin et al. identifies the complexity of the expansion and implementation of abortion services and the need for guidelines and protocols, trained providers and information dissemination to raise awareness among service providers and users.[416] Furthermore, this thesis concurs with previous research regarding the need for institutional support in the provision of a new healthcare service.[414,427,455]

In previous research, women with experiences of pregnancy diagnosed with a FFA identified the need for a standardised care approach despite whether they continued with or terminated the pregnancy.[460,461] In agreement with Donnelly and Murray, legalisation of abortion does not automatically equate to the provision of a standardised abortion service.[217] Thus, the findings from this thesis further highlights the need for standardised care as identified as essential within the Clinical Interim Guidelines (2020).[52] To assist FMS in the delivery of standardised care legislators need to listen and trust FMS in their expert management of pregnancies affected by FFA. The retention of criminal liability

limits healthcare professionals in providing medical services that comply with regular professional and ethical standards of care and therefore result in negative implications for women's health outcomes.[217–219,250,416] In agreement with previous research, these studies argue that vague legislation and regulations, that are evident worldwide, create restrictive abortion services, resulting in healthcare delays.[216,219,221] Therefore, in addition to reviewing the Irish legislation to ensure that it describes conditions that can cause perinatal death, this thesis advocates for the abolishment of the retained criminal liability attached to the legislation. This would remove for FMS the fear of the potential for criminalisation following a disagreement regarding their diagnosis of FFA. Moreover, as Irish media regularly reports on adverse outcomes in maternity units[259] the fear of media scrutiny that an incorrect diagnosis would create, as shared by FMS, highlights the need for research to explore the impact of media on healthcare professionals working within maternity units.

Lastly, the challenges faced by FMS and conscientious objectors and the resulting healthcare delays, promotes the need for the ethical context of conscientious objection to be explored. The TOP for FFA legislation includes that healthcare professionals are under no obligation to 'participate in carrying out' a TOP to which they have a conscientious objection. The legislation however, fails to provide clarification on what the term 'participate consists of.[217] While this term has been founded to describe a 'hands on' approach, resulting in those with a conscientious objection to TOP being able to provide ancillary tasks, in agreement with Donnelly and Murray, this is needed to be confirmed within an Irish context.[217] This is required to ensure a reduction in abortion healthcare delay.

8.5 **Education opportunities for Volunteers (Chapter 5 and 6)**

8.5.1 Main Findings

In Ireland, like many other countries, voluntary support groups play a key role in filling gaps in healthcare provision in order to meet the unmet needs of individuals.[171,173,174,462] This includes an over reliance on voluntary organisations to respond to the holistic needs of bereaved parents.[172,175,178,179,463] While voluntary organisations are willing to respond to the needs of bereaved parents, Volunteers may lack the knowledge and skills to address these needs and meet the level of care required.[172] The need to develop education and training programmes specific for those caring for parents following a pregnancy loss, perinatal or neonatal death was identified by the National Implementation Group for the Bereavement Care Standards.[120] Considering the role Volunteers play in supporting bereaved parents and through them identifying their need for education within the implementation of the bereavement care standards, their educational requirements were considered as equally important as those of statutory bodies as discussed in Chapter 5. Through interviewing Volunteers on their experiences of supporting parents following a FFA diagnosis as presented in Chapter 6, they further identified the value of education. More specifically, they highlighted the need for information relating to the TOP for FFA provision in the RoI, which is unsurprising considering the discrepancies noted among healthcare professionals working with parents who choose a TOP for FFA in Chapter 6 and 7.

Volunteers themselves acknowledged the need for the information shared with parents to be evidence based and up to date in addition to sharing their personal experiences. Research suggests that peers with shared experiences are often best placed to support bereaved parents as they develop more empathetic understanding and trusting relationships.[383,384] However, if the needs of the bereaved parents are inadequately met or parents are not facilitated to talk about their child, peer support can have a negative effect[384] and potentially exacerbate parental grief.[90] Research has noted that bereaved parents experience physical

and mental health problems, impacting on their other children or subsequent children following the absence of optimal care to meet their holistic needs.[358] Additionally, these Volunteers are potential service users themselves and therefore they require accurate information on the supports and services available.[365]Thus enabling them to make informed decisions about their care that reflects their best interest.

8.5.2 Implications for Practice and Research

Despite the historical reliance on Voluntary Organisations in Ireland and internationally, to fill the gaps within health care,[120,175,179,361–365] outcomes are seldom measured. Considering the important role Volunteers play in supporting bereavement parents, parents' experiences of this peer support warrants further research. Additionally, maternity units must respond to bereaved parents needs to prevent an over reliance on Voluntary Organisations in order for peer support to be additional rather than a necessity. The National Bereavement Care Standards following Pregnancy Loss and Perinatal Death, provides a standard of care to which the maternity units should adhere to.[120] Furthermore, Joynes et al. promotes the need for education to keep up to date in order to improve healthcare practice.[382] This thesis concurs and highlights the need for educational opportunities for Voluntary Organisations to ensure Volunteers are up to date and evidence based to facilitate them in adequately supporting parents following a FFA diagnosis and perinatal or neonatal death. While outside the remit of this thesis, there is an argument for all healthcare professionals who come in contact with parents following a FFA diagnosis to have access to regular educational opportunities. This is relevant considering the implications a negative encounter has on parents and in addition, it could potentially reduce the over reliance on Voluntary Organisations after pregnancy. Such educational workshops like **IM**proving **P**erinatal mortality **R**eview and **O**utcomes **V**ia **E**ducation (IMPROVE), and the Irish workshop, **T**eaching **E**xcellent p**A**rent pe**R**inatal, **D**eaths-related,

inte**R**actions, t**O P**rofessionals (TEARDROP) can provide significant improvement in knowledge and confidence.[278]

8.6 Supporting those caring and supporting pregnancies with a FFA (Chapter 5, 6, and 7)

8.6.1 Main Findings

The emotional challenges faced by Volunteers supporting parents following a FFA was identified within Chapter 6 of this thesis. For Volunteers, supporting parents through a perinatal or neonatal death, forced them to think back on their own experience. Volunteers shared the benefit of being supported by friends and family and other Volunteers to assist them in their peer support role. Organisational support is essential for Volunteers to sustain the delivery of peer to peer support.[178,411] Previous research documents the emotional burden of working with death and dying.[386,393,410,411] Burnout resulting in physical, mental and emotional exhaustion is increasingly gaining social attention and relevance.[412] However, there is a lack of research specifically to Volunteers' emotional burden as a result of supporting parents following a diagnosis of FFA and/or perinatal and neonatal death.

Similarly, within Chapter 7, FMS shared emotional challenges of working with parents following a FFA diagnosis. Their emotional challenges, like those of the Volunteers were associated with the death and dying of fetuses and babies. However, additionally, they experienced the psychological burden of performing feticide, inducing the death, and dealing with opinions of other colleagues - that they are 'trying to terminate everything'. As a result, FMS, similarly to the Volunteers in Chapter 6 requiring the need to debrief with their peers, shared the desire for collegial support in order to debrief to those who understand the challenges and help with their self-care. The emotional conflict and balancing of moral beliefs is universally identified among clinicians providing TOP.[250,424,425] The

provision of providing late TOP requires more resources and emotional support as illustrated by Obstetricians throughout Europe.[426] The psychological impact of caring for parents experiencing perinatal and neonatal death on healthcare professionals and the necessity of institutional and collegial support identified within this study, concurs with previous studies.[259,352,374,431–436] However, the abortion topic is divisive, as Volunteers identified in Chapter 6, through parents being ostracised when receiving a diagnosis of 'not fatal enough' and having to travel to obtain a TOP, in comparison to parents who could legally avail of a TOP for FFA in Ireland. FMS further acknowledged the conflict it can create between colleagues can disrupt the sense of belonging of healthcare professionals within their professional group.[215] As a result, a good working relationship was identified as necessary for FMS to provide good quality care. Fay et al. recognises more positive experiences when Obstetricians are supported in their decision-making by a team with shared values.[250] As presented within Chapter 7, FMS identified the benefit of an MDT approach when receiving good institutional support and respect. Such support is identified in reducing potential isolation experienced by Obstetricians and vulnerability associated with potential legal challenges.[250] However, in the absence of good support as recognised within this thesis, it can result in clinicians feeling unsupported, undermined and thus impede delivery of care.[217]

The benefits of collaboration was evident within this thesis, as expressed by both FMS and Volunteers supporting parents following a TOP for FFA. Within Chapter 7, FMS identified the necessity for collaboration and working as a team with their colleagues to improve overall healthcare being delivered to parents following a FFA diagnosis and their own self-care. The requirement of a collaborative approach between Volunteers and healthcare professionals supporting bereaved parents was presented in Chapter 5 and 6. Within this thesis, Volunteers requested a two-way sharing of information and care for bereaved parents, recognising that knowledge by experience is equally valuable as professional knowledge. A collaborative approach between those who have experience of

pregnancy loss, perinatal or neonatal death and those who have clinical and evidence based knowledge is essential in supporting bereaved parents.[309] This is particularly important as Downe et al. recognised just one opportunity 'to get it right'.[161] Previous research identifies a shift towards more collaborative working between voluntary and professional bodies to ensure the delivery of standardised care, reflective of best practice.[175]

8.6.2 Implications for Practice and Research

This thesis promotes the need to support both Volunteers and healthcare professionals involved in the delivery of care for parents following a FFA diagnosis. Volunteers would benefit from collaborative working with healthcare professionals to support them in the delivery of accurate information and to provide continuity of care and peer to peer support to parents. Boyle et al. identified the holistic in-depth understanding of complex health issues resulting from collaboration between those with personal experience of the phenomenon and those with clinical knowledge and skills and therefore the improved overall experience of service users.[178] Volunteers would also benefit from such support as it would facilitate them in their own self-care and wellbeing during their voluntary role.

This thesis also suggests that FMS would benefit from a structured collegial support system. Having the support of a MDT team, inclusive of colleagues from other specialties as well as hospital management support during decision-making for complex cases was illustrated as essential in assisting the FMS to provide good quality care, while also affording the FMS in opportunities to debrief and learn from each other. Such support is found to assist with clinician burnout, wellbeing and job satisfaction, while reducing their feelings of disapproval from colleagues.[259,433,434]

While recognising the necessity of a MDT approach in caring for parents following a FFA, FMS need to be given the recognition of their Specialist knowledge and competence. This reflects the Interim Clinical guidelines as the 2020 version transitioned from recommending the decisions on whether a condition was a FFA or not be made by majority consensus[464], to recognising that while MDT discussions are important, responsibility lies with the two certifying practitioners, [52] where one is always a FMS.

8.7 **Strengths and Limitations**

This thesis aimed to explore various aspects of pregnancies diagnosed with FFA including the incidence of congenital anomalies contributing to perinatal mortality, the assessment of the public's knowledge on FFA and how information on FFA, TOP for FFA and PPC was presented within the media. Additionally, it aimed to identify Volunteers learning priorities and explore their experiences, as well as the experiences of FMS, providing peer support and care to parents following a FFA diagnosis. To address the thesis's aims and objectives, both qualitative and quantitative methods were employed. Employing a mixed methods approach to study a phenomenon is identified as a strength of this thesis as it facilitates the production of results that are more robust when compared to single method studies.[465] This research approach allows for flexibility to explore different aspects in each of the studies and ensuring each piece of work could be conducted.

As suggested in Chapter 2, data on congenital anomaly collected on the NPEC Perinatal Death Notification Form is limited as its purpose is not to gather specific information on anomalies associated with perinatal death. However, NPEC is a national database that provided the authors with information on 777 of the 939 perinatal deaths reported to be associated with a congenital anomaly which is a substantial proportion. The response rate noted in Chapter 5 is a potential limitation as a higher rate is necessary for a successful Delphi study. Regardless,

these were completed surveys and as identified within this study, some groups felt unable to contribute as a result of the type of support they offered being specific to a very small cohort of people. In contrast, the response rate and number of media sources analysed, as presented in Chapter 3 and 4 was a strength as it provided an adequate representation of both the general public's knowledge and the media relating to FFA, TOP for FFA and PPC being generated in Ireland from 2012 to 2017.

The use of thematic analysis within two chapters of this study is identified as a strength. Thematic analysis is an established methodology in qualitative healthcare that facilitates the interpretation of how people make sense of their experience. Thus, allowing the exploration of both Volunteers and FMS experiences of pregnancies with FFA. An example of the thematic analysis undertaken on the Volunteers experiences is presented in Supplementary File II. A considered limitation of qualitative research is the sample size, however the data retrieved is rich in experience of both the Volunteers providing peer support and FMS providing holistic care to parents following a FFA diagnosis. Additionally, a risk for bias is noted when undertaking qualitative research. While undertaking this research and during data analysis, the potential for personal and professional experiences and opinions was acknowledged and addressed through continuous reflexivity. External checks and a consensus discussion regarding theme development were also undertaken by co-authors to facilitate reflection of assumptions and an agreement of final interpretations of the results. The author's reflexivity account is presented in Supplementary I.

A strength of this thesis is that it addresses a topical and timely research area, where there are major changes in Irish policy and healthcare provision following the legislation for TOP for FFA. This thesis assisted in capturing insights into those changes. To the author's knowledge, this study is the first of its kind to add new research findings concerning the lack of knowledge among the general public and the inaccuracy of information being delivered in print and online media regarding FFA. It contributes new insights in to the experiences of Volunteers of providing

peer support to parents following a FFA diagnosis and their educational and learning requirements. Additionally, the depth of qualitative data pertaining to the experiences of FMS in caring for parents following a FFA diagnosis contributes to previous findings of Clinicians' experiences of feticide. However, it provides new data on FMS experiences of introducing a new TOP service.

8.8 **Summary**

Pregnancy is a joyous happy occasion for the majority of women as a unique relationship develops between the woman and her unborn infant,[1] with attachment developing with every frequent fetal movement.[2] Parents engage with antenatal screening such as second-trimester ultrasound, hoping for confirmation of a healthy baby - so the discovery of a fetal anomaly creates intense sadness, fear and uncertainty regarding prognosis.[7,9] While the prevalence of congenital anomalies and those considered fatal are low, the significant impact a pregnancy affected by a FFA for both parents and healthcare professionals, warrants the need for further research within the area. Parents face may difficult decisions, primarily whether to continue the pregnancy or terminate. Regardless of the choice made, the outcome is ultimately the same, ending in a fetal, neonatal or infant death. It is however, essential that the decision is an informed one as evidence based information is required for the legal and ethical sanction of informed consent.[302,303] Having the necessary information to make informed decisions is particularly relevant within the Irish context as the journey to reform the Irish abortion laws has been a complex one, fraught with difficulties and legal cases played out in national media, which appears to continue despite the Health (Regulation of Termination of Pregnancy) Act 2018 now permitting TOP for FFA.

Through a survey of the general public's knowledge on FFA, this thesis illustrated that there is a lack of accurate knowledge on its classification, diagnosis and chance of survival as well as the supports available following a diagnosis of FFA. This is unsurprising as the presentation of FFA and supports and services available

to women following a pregnancy with a FFA was identified to be misrepresented within the media from 2012 to 2017, the years preceding the referendum, as presented in Chapter 4. These findings support the need for healthcare professionals to have an awareness of information and the importance of analysing information being disseminated to the general public, on its accuracy. The gap in knowledge highlights the need for antenatal education and public health campaigns to improve health information about FFA in order to facilitate informed decision making following a FFA diagnosis.

The language used to describe fetal anomalies that result in perinatal death and the lack of a universal agreement of what constitutes as a FFA or a list of conditions associated with this term compounds the complexity associated with FFA. Terms used in clinical practice, such as fatal and lethal, do not accurately describe many of the conditions associated with this term, as known survivors are linked to many of the conditions. Due to the potential for survivors and the ambiguous and restrictive legislation, the complex nature of FFA created many difficulties for both FMS and Volunteers. FMS expressed their fears of criminal prosecution and the subsequent media scrutiny if there was a disagreement with a diagnosis of a FFA made due to the lack of universal agreement of a definition of a FFA. The retained criminalisation results in conservative practices and inconsistencies[87] as was experienced by Volunteers. This was evident from their observation of a lack of standardised care from those they provide support to. Volunteers shared experiences of supporting parents with a diagnosis of a FFA whose care options offered depended not on their unborn's diagnosis but the clinician caring for them. This thesis further illustrated the ambiguous and restrictive nature of the Irish legislation as in a secondary data analysis of data pertaining to perinatal deaths, where only 42% of these deaths could be classified a FFA in accordance with criteria outlined in the Irish legislation. This is despite all conditions resulting in a perinatal death.

Due to the complexity of FFA and the need for more standardised care, during a time where healthcare professionals are at risk of potential criminal liability, these

findings suggest the need for a universally agreed definition of FFA or a list of conditions. Such an approach would ensure the inclusion of complex diagnosis, multiple anomaly syndromes and progression of conditions to be considered as a FFA. This would be further supported by the development of an accurate universal database that informs healthcare professionals on the anomalies most like to result in perinatal death. These findings also provide a compelling argument to review the Irish legislation to ensure it accurately describes conditions that can cause perinatal death and remove the restrictive '28 days'. The involvement of professional bodies, particularly FMS who provide TOP for FFA, is required to inform the review to develop a non-prescriptive framework in which they must work within. Additionally, this thesis calls for the abolishment of the retained criminal liability as this sets abortion care apart from other forms of healthcare and instils fear in the service providers and promotes conservative practice. Donnelly and Murray concur that abortion care must be treated alike other forms of healthcare and healthcare professionals answerable to the usual regulatory mechanisms of criminal and civil sanctions and fitness to practice.[217]The ambiguous legislation and complexity of FFA was the source of many challenges experienced by FMS during the introduction of the new TOP services within Ireland. Conflict and opposition was illustrated between FMS and colleagues when attempting to agree on the qualification of congenital anomalies as FFA. Additionally, the rapid introduction and the lack of preparation time, the lack of institutional support and the expectation of delivering a new service with an increased workload with no new colleagues created difficulties for FMS. Feticide also generated internal conflict for FMS as they battled with their own moral and ethical beliefs yet were motivated by parents in their care, to provide and develop these services. When feticide was not undertaken, FMS faced challenges with obtaining support to provide palliative care in the event of a live birth. Frustration was also identified when FMS faced delays in care due to conscientious objectors and a lack of institutional support for FMS for the provision of TOP services. These findings identify learning for countries planning on improving or updating their abortion services and the need for adequate preparation, guidelines, procedures

and standardisation of care when implementing a new service. The need for collegial and institutional support due to the psychological impact of working with perinatal death experienced by FMS was identified as is documented in previous research.[259,352,374,431–436]

The need for educational opportunities is also presented in this thesis, where FMS need to be knowledgeable on all aspects of FFA diagnosis to ensure comprehensive, up to date and balanced counselling is provided.[57,152,454] Volunteers educational needs were identified as equally important. Volunteers themselves recognised the need for educational opportunities to keep up to date and provide parents with accurate information on all aspects of care following a FFA diagnosis. Following an educational day in response to their identified learning needs, Volunteers responded positively, suggesting the need for on-going educational opportunities and the need to promote collaborative working and a two-way sharing of knowledge between them and healthcare professionals.

In addition to the support of healthcare professionals, Volunteers identified the need for peer to peer support to emotionally support them. Similarly to the Volunteers, FMS referenced the need for support from their colleagues, and to debrief to those who understand their challenges. Furthermore, they promoted the need for team work and the MDT approach in caring for parents regardless of what care option they chose following a FFA diagnosis. However, FMS required the need for the recognition of their specialist knowledge and competence and that their decision-making regarding the management of a pregnancy following a FFA be respected.

8.9 **Recommendations**

The findings of this thesis provide compelling arguments for several recommendations including service improvements, policy development and future research to improve care delivered to women and their partners following

a FFA diagnosis. These include the need for improved antenatal education on FFA and for healthcare professionals to expand their media literacy skills in their patients to encourage more accurate knowledge among service users. Within the current restrictive legislation and retained criminal liability, the findings promote the need for a universally agreed definition that accurately describes conditions that can lead to perinatal death or a list of conditions. This would reduce the subjective decision making and conservative practice that is associated with fear of prosection.[87] Ideally, to remove fear of criminal sanction and media scrutiny, this thesis identifies the need for a reform of the Act. The abolishment of the retained criminalisation and the need to develop a less restrictive framework is identified in order to aid healthcare professionals to provide appropriate and standardised abortion care. A review of the Irish legislation must involve professional bodies, in particular FMS, and for legislators to listen and trust their expertise in managing pregnancies affected by a FFA. As previously discussed, a universal database to accurately record conditions that are responsible for perinatal death is suggested as this would provide accurate knowledge for healthcare professionals to identify potential FFA. Additionally, there is a need for national governance in terms of service provision, to ensure a standard of care is provided to all women who opt for a TOP for FFA, regardless of the maternity unit or FMS attended. Only through national governance can continuous improvement in the quality of services and safeguarding of high standards of care be ensured. As highlighted within this thesis, in order to provide standardised high quality abortion care, an exploration of the ethical context of conscientious objectors is required, to facilitate a balance of being respectful of healthcare professionals right to conscientious objection while ensuring there are no delays or 'conscientious obstruction' as found within this thesis.

The findings argue the need for collaborative working among voluntary organisations and healthcare professionals to assist volunteers in providing peer support. It also identifies the need for structured collegial and institutional support for FMS providing TOP for FFA. Ongoing educational opportunities are also

promoted, resulting from this thesis, to assist in all those providing care and support to women following a FFA diagnosis.

More research is warranted however to further improve clinical practice and support policy making. Parents experiences of a pregnancy following a FFA is essential when developing policies and engaging in service improvement and needs to be explored. These experiences need to measure the outcomes of support received from both FMS and voluntary organisations within Ireland. Unfortunately, this was outside the remit of this thesis.

8.10 **Conclusion**

The overarching aim of this thesis was to explore the experiences of pregnancy with so-called fatal fetal anomalies. While the incidence of pregnancies with fetal anomalies, and those deemed fatal are low, they can have a devastating impact on parents and families. It is important that parents receive comprehensive, up to date, standardised care during and following their pregnancy affected by a FFA, and adequate support afterwards. Parents require non-judgemental information and counselling that reflects all potential outcomes in order to make an informed decision that reflects their best interest.

However, this thesis presented a lack of knowledge among the general public on what constitutes a FFA, its classification, diagnosis and supports available to parents experiencing a pregnancy affected by a FFA. These findings further revealed the inaccurate information relating to FFA widely available within the media. This finding highlights the need for improved education and public health campaigns, to inform potential future service users and those whom parents seek informal information from. This is even more necessary as this thesis illustrated the complexity of FFA. Thus, promoting the need for a universal agreement of what constitutes a FFA, and developing a description that accurately describes those conditions that potentially result in a perinatal death. The need for both healthcare professionals and Volunteers to be knowledgeable of all aspects of FFA

is evident from the findings from this thesis. This promotes the need for educational opportunities and opportunities for collaboration to promote a two-way sharing of information.

As a result of these studies, a number of recommendations have been made in order to ensure that care delivered to parents following a FFA diagnosis is evidence based, accurate and standardised. Therefore, this thesis promotes the need for a universal database for FFA, one that can act as up-to-date evidence and support healthcare professionals in their counselling of parents following a diagnosis of a FFA. This thesis also argues that a review of the legislation is warranted in order for it to permit FMS to appropriately care for women with a complex antenatal diagnosis that will ultimately result in a perinatal death. Furthermore, this thesis illustrates the need for the abolishment of the criminal liability attached to the legislation to prevent conservative interpretations and the need for legislators to listen and trust FMS in their expert management of pregnancies affected by FFA. The psychological burden associated with perinatal and neonatal death is documented in previous research and as illustrated within this thesis, Volunteers required support from both healthcare professionals and their volunteer colleagues. Additionally, this thesis illustrated that FMS would potentially benefit from collegial support system to reduce their feelings of disapproval from colleagues and assist with their wellbeing when providing a TOP for FFA service. Healthcare professionals and Volunteers work within their environmental and knowledge or experience limitations and in order for the care and support they provide to be effective and responsive to parents' needs following a FFA diagnosis, there is a need for professionals and Volunteers to be acknowledged and supported.

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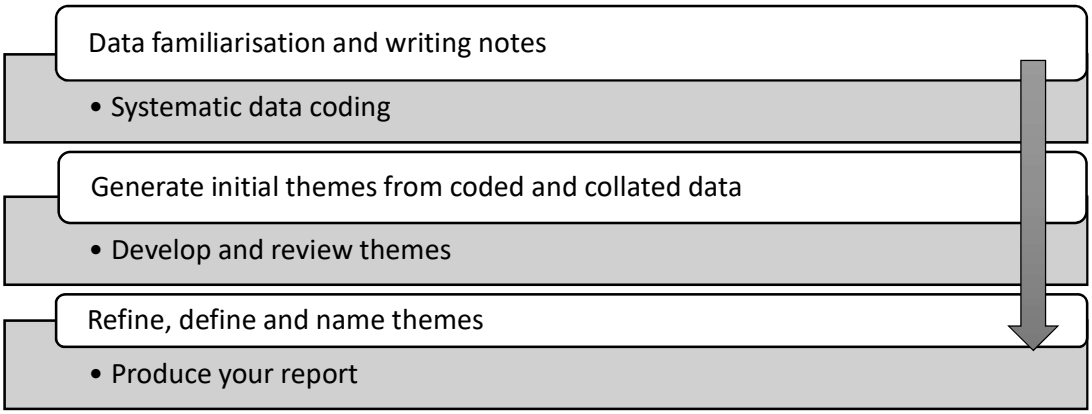
Supplementary File II - Example of the thematic analysis for theme:

Motivation for altruistic acts

Braun and Clarke Thematic Analysis[467]



Example of the thematic analysis for theme: Motivation for altruistic acts

Data	**Initial themes (Preliminary Codes)**	**Develop and review themes *(Sub theme)***	**Defined and name themes *(Theme)***
A lot of what we do has been motivated by a tribute to our babies, they have the shortest briefest of existences but we feel they have had this huge impact on our lives P14	Tribute to our babies		
So it is great, you can still chat, you can still let off steam and it is time for your baby because when you have other children everything is about them and you can say to yourself I need to just reconnect here with (name of baby). And you just don't get the time and other people screaming at you, it is really hard to prioritise, but that is time, you go there and the workshop is time for you and your baby and it is great P5	Time for you and your baby Reconnecting with your baby	Continuing bonds	
I knew the difference that it made just to talk to someone who knew what you were feeling but also I felt that there was a lack of practical, I don't know how to describe it, support isn't the right word, but advice, practical advice, you know, what is it like to deliver a dead baby? P4	Peer support made a difference to their experience Positive experience of peer support		**Motivation for altruistic acts**

I did contact a support agency that was run by volunteers and, not to be mean about anybody but it just wasn't up to par, it wasn't any help. She would say she would call and she wouldn't. And it is very strange because that call is everything. She would say, I will call you tomorrow at 12:00. And at 12:00 you are sitting there waiting for this call and it wouldn't happen and two days later she might text and say, sorry I forgot about that P17	Negative experience of peer support The phone call from a peer supporter is everything Waiting for a call	Personal experience	
I think there needs to be a period of time that you are grieving yourself. That is just looking back with hindsight. But I don't regret getting involved but I just think to mind yourself you might need to give yourself a bit more time (P16)	Giving yourself time to grief Need for a period of time before volunteering	Being ready	
Yeah it was definitely a good time. For the most part you empathise with people but it is not as raw for you (P2)	Good time to volunteer		

It is noteworthy that Braun and Clarke argues that this phase approach is not intended to be followed rigidly but merely offers guidance to those engaging in thematic analysis.[467] It is acknowledged that as the analytic skills develops, these six phases can become blended and the analytic process repetitive.[467]

Supplementary File III - Congenital Anomalies present in the National Perinatal Epidemiology Centre Data 2011-2016

Congenital Anomalies present in the National Perinatal Epidemiology Centre Data 2011-2016		
Definite FFA	**Potential FFA**	**Not FFA/Unknown**
Anencephaly	Hydrops	Spina bifida
Holoprosencephaly	bilateral severe ventriculomegaly	spina bifida and hydrocephalus
Renal Agenesis/Potter Syndrome	*Multi-organ failure secondary to congenital hepatic necrosis with large kidneys and T-lym	Hydrocephalus
pterygium syndrome or Lethal Congenital Contracture Syndrome	Acrogyndactyly/ amputation of amniotic deformity/ adhesion/ mutilation/ ADAM syndrome/ spina bifida occulta	Vein of Gallen malformation
Congenital malformation of Mullerian ducts and endodermal sinus + renal agenesis	Major congenital abnormality with non-immune Hydrops Fetalis, Lethal Multiple	Congenital Muscular Dystrophy
Trisomy 9	*CCAM, LARGE DIAPHRAGMATIC HERNIA WITH HYDROPS	Absent corpus callosum and small cerebellum
Edward Syndrome	Hypoplastic Left Heart Syndrome	Ventricular Septal Defect
Patau Syndrome	Heterotaxy syndrome with left atrial isomerism	Tricuspid atresia, Pulmonary atresia, Ventricular septal defect
Trisomy 16	Severe diffuse infantile intra-arterial calcification syndrome	Occlusion of 2 carotid arteries
Trisomy 22	Trisomy 18 mosaicism	Glanzmann thrombasthenia

Trisomy 7	Turner's Syndrome with cystic hygroma	Taussig-Bing anomaly
Trisomy 16	Turners syndrome with cystic hygroma, bilateral pleural effusion, hypoplastic lungs	AK2 SCID
Triploidy	Turners Syndrome ascites hydrops cystic hygroma	Triple X
Tetrasomy 9p	Dysplastic kidneys + hypoplastic lungs. Trisomy 21	Chromosome Deletion 1p36.3
Tetraploidy	Tracheal agenesis	Mosaic Trisomy 8
limb-body wall complex	bilateral intra pulmonary haemorrhage	Monosomy chromosome 13q
91 XXX	Omphalocele involving bowel, stomach and liver	Miller-Dieker syndrome
Congenital venous malformation of head and neck- hydrops - thromboembolism	Gastroschisis with hydrops	Klinefelter syndrome
Sirenomelia	COL2A1 TYPE 2 COLLAGENOPATHY hypochondrogone 1 A	46 XX deletion 7p
Osteogenesis imperfecta type II	Bilateral cleft lip. Amnion disruption sequence syndrome. Encephalocele schiz-encephaly polydactyly. amputated digits	Complex mosaic aneuploidy
Thanatophoric Dysplasia	polycystic kidney disease	Hydrancephaly
Thoracopagus Conjoined Twins	Bladder outlet obstruction and pulmonary hypoplasia	22q deletion
Dandy Walker and Congenital Diaphramatic Hernia	Bil anopthalmia, common arteriaethra, renal cystic dysplasia.	Sickle Cell

Neu Laxova syndrome	glycogen storage disorder	Hemophagocytic Lymphohistiocytosis
Beemer Langer Syndrome (Short - rib polydactyl syndrome) (Pulmonary hyperplasia).	amniotic band disruption sequence	trisomy 4
iniencephaly	Jarcho Levin Syndrome	Partial Trisomy 5
	Trisomy 16 confined placental mosaicism	cystic fibrosis
	Smith–Lemli–Opitz syndrome	Pleural Effusion
	Waardenburg syndrome	Pharyngeal teratoma
	Simpson-Golabi-Behmel syndrome	laryngotracheoesophageal clefts IV
	Asplenia syndrome with heterotaxy	Gastroschisis
	Congenital hypophosphatasia	Pierre Robin
	Aneuploidy	Osteogenesis imperfecta type VIII
	pentalogy of cantrell	X-linked myotubular myopathy
	collagen type 2 abnormality (COL 2 A1)	Cleft lip and palate
	urea cycle defect	Congenital Disorders of Glycosylation
	hypoplastic left heart and hydrops	MEGLANN 3-METHYLGLUTACONIC ACIDURIA
	Arthrogryposis	Sacrococcygeal Teratoma
	Spinal muscular atrophy	Kaposi hemangioma (large) on leg
	Mucopolysaccharidosis Type VII	hemangioendotheliom a
	Cystic Hygroma	Congential hypothyroidism
	Escobar Sydrome	Cornelia de Lange syndrome
	Zellweger spectrum disorders	Holt-Oram_Syndrome

	MIDAS (Microphthalmia, Dermal Aplasia, Sclerocornea) syndrome with WT-1 associated syndrome	Hemophagocytic lymphohistiocytosis
	Abnormal Chromosome 20	VACTERL
	Warburg syndrome (in the literature as walker Warburg syndrome)	CHARGE syndrome
	Tetraploidy Mosaic	Cerebrocostomandibular syndrome
	Trisomy Xq Monosomy XP	Cloacal exstrophy
	Chromosomal abnormality Tetraploidy Mosaic	Pallister-Killian Syndrome
	Monosomal 18	Phelan McDermid syndrome
	Laryngotraecheosophageal Cleft type 4, Diaphragmatic Hernia	Congenital Megakaryoblastic Leukaemia
	Laryngotracheosophageal cleft type 4,Absent Right Lung ,Hypoplastic Left Lung , Diaphragmatic Hernia	Myeloproliferative Neoplasm
	Osteogenesis imperfecta	Budd-Chiari Syndrome with hepatomegaly
		propionic acidaemia
		Tetralogy of Fallot
		Trisomy 21 with transient myeloproliterative disorder
		Coarctation with transverse arch hypoplasia with T21
		Duodenal atresia with T21
		Congenital Diaphragmatic Hernia
		Mediastinal teratomas

	Large craniofacial teratoma
	DiGeorge Syndrome
	Pallister Killian syndrome - diaphramatic hernia
	Encephalocele
	heart defect and pulmonary anomalies
	Complete AVSD, ventricular hypertrophy, N karyotype
	Dural arterio venous fistula
	Abnormal Karyotype
	Trisomy 21, cardiac abnormalities
	Shone complex and down syndrome
	Nonnes
	detection on distal sp + duplication of 20mb at sp
	terminal deletion of chromosome 13 q 32
	Chromosome IP36 Deletion Syndrome
	chromosomal gain on chromosome 3 at 3q28q29
	15q26 deletions (arr 15q 26 2q 26.3 (96,503,388-101,115,330)x3)
	46 xy (30) ish del 22 q 11 - 2q 11-2
	Chromosome 2 deletion 2q?23 and 2q?31
	Trisomy for the region Xq13.1 to q 22/ Mother a carrier of XQ triplication
	Z1C 3 gene chr Xq 26.2

	Duodenal atresia with T21
	Hepatomegaly with histological features of Budd-Chiari Syndrome
	Major Congenital anomalies (1) Cardiac: AVSD large with overriding aorta. (2) Urinary Tract: hydronephrosis probable bladder calcification, hypospadias, absent left testes
	monosomy 7p and 20g
	Deletion of chromosome 4g and large duplication of 2p
	Chromosomal imbalance; Charcot Marie tooth disease Type 1A
	Unbalanced chromosomal translocation 46xx, del (13)-(7:13)(q22)(q34)
	Unbalanced translocation (1:4) 46 xx
	Unbalanced translation T8 46 xy, der (4)t (4.8) (q35;q23.3)
	unbalanced fetal karyotype 46 xx del (2 q 35q36)

Supplementary File IV - List and summary of the articles included in the CDA

File name within Broadsheet	Date	Description
'Stop saying fetuses with disabilities are incompatible with life'	Nov 25th 2014	This pro-life article reports how the Compatible With Life, Compatible With Love campaign launched in Dublin on Tuesday has requested the discontinuation of the term 'incompatible with life'. It describes, on behalf of this group, a politician is submitting an 'amendment to the Disability Act in the Dáil* to make it an offence for medical staff to describe an unborn child with a disability as incompatible with life'. * The 'Dáil' is the lower house, and principal chamber, of the Oireachtas (Irish legislature), which also includes the President of Ireland and Seanad Éireann (the upper house)
Their lives may be short but they have huge meaning and worth	Jan 17th 2015	This pro-life article presents the launch of 'now I lay me down to sleep', a voluntary organisation who offer memory photography. It shares how a pro-life organisation are 'campaigning to ban terms like incompatible with life' reporting it as 'such a hurtful, horrible phrase, since it implies that the baby's life

		is worthless'. It concludes by advocating for perinatal palliative care (PPC).
Breda O'Brien: It's time we provide couples with perinatal hospices	Feb 15th 2015	This pro-life article promotes PPC. It reports that there is a lack of PPC within Ireland and that there is a need due to the 'unpredictability of life limiting conditions' and gives examples of babies and children with short and prolonged survival. It includes the dislike for the term FFA and how parents need to be supported and given compassion at the time of diagnosis. It argues that PPC is delivered in other countries and Ireland needs to also.
Perinatal hospice care	Feb 17th 2015	This pro-choice article is in response to the previous article. It suggests the author of the previous article and other anti-abortion campaigners suggest 'perinatal hospice care, which in itself is an entirely good idea, they are not suggesting it as an option alongside termination, but as the only option'. Within this article is suggests, that while these 'couch' their arguments in a 'language of care and compassion, but beneath it all is the basic anti-abortion position: live birth at all costs, regardless of the wishes of the pregnant person'.

Mattie McGrath says fatal foetal abnormalities Bill is attempt at ‘mischief’	March 9th 2015	This article presents both pro-life and pro-choice ideologies. It includes conflict between two politicians with different ideologies, with one politician (Mattie) suggesting the other politician's (Michael) actions are just mischievous. These allegations are denied. These allegations are made while Mattie is speaking at an event who is advocating for the term 'incompatible with life' to be discontinued.
Amnesty International and abortion	July 15th 2015	This pro-life article argues that life begins at conception and that there are two human lives involved in every abortion. It includes that Amnesty International promote and protect human rights, that they are in an odd position advocating for abortion.
Eammon McCann: Are there signs of a ‘pro-life’ group influence in HSE document?	July 23rd 2015	This pro-choice article reports the importance of terminology in the discussions on abortion. It reports that there is 'pro-life' influences in a HSE document due to their use of life limiting condition rather than FFA. It shares one woman's experience of a TOP for FFA and how crucial the term 'fatal' is for her and others like her. This article calls on the HSE to respond where the life limiting condition term has come from.

‘Sensationalist’ reporting frightening prospective mothers	Sept 24th 2015	This unbiased article presents that 'the master of Dublin’s oldest maternity hospital has attacked “sensationalist” and “out of context” reporting of high profile birth cases which served to frighten prospective mothers and families. “It has now reached the point where the confidence of the public has been severely shaken and the quality of the services provided to our mothers and babies is questioned in the media on an almost daily basis'. It includes that 'revelations in the media needed to be taken in context, which was that a hospital delivering 2,000 babies a year can expect to have between eight and 16 deaths per year. Half of these will be due to fetal anomalies or extreme prematurity and one-quarter due to unforeseen issues'.
Nearly 25,000 Irish women went to Britain for abortions in 2010-2014	Dec 14th 2015	This article contains pro-life and pro-choice ideologies. It presents how the Irish Government do not mind 'women having abortions just as long as they’re not here in Ireland'. The voice of British Pregnancy Advisory Service, says 'Irish women who come to their clinics will talk to us about how they are going to be accepted back in society and we even have religious conversations with them

		about being asked whether they're going to go to hell because of a decision they've taken to end the pregnancy'. It also includes the pro-life ideology; 'Christian organisation would disagree with abortion being the answer. The really difficult cases of fatal foetal abnormality, or life limiting disability as I prefer to talk about, or rape and incest, sexual crime, are heart-breaking. I suppose we dare to believe that in every human life there is dignity and that the premature ending of an unborn child's life does not actually solve the horrendous crime or the awful situation that they face'.
Catholic bishops urge Northern politicians to reject abortion law	Feb 9th 2016	This pro-life article presents the Catholic church advocating that the 'unborn child with life-limiting condition deserves 'care until natural death''. The church appealed to Catholics to lobby the citizens' assembly members to express their concerns. They included that there is uncertainty around a diagnosis of a 'life limiting condition' and that the child is 'worth' the life supporting interventions until the natural end.

Breda O'Brien: 'Fatal foetal abnormality' is a hurtful and damaging term	Feb 27th 2016	This pro-life article reports how labels can dehumanise and cause disrespect and equates the use of FFA to the use of 'the N word' to describe black people. It includes that mothers who continue with their pregnancy following a life limiting diagnosis are often patronised. It shared a consultant's experience of PPC being delivered within that maternity unit. It shared research on mothers who continued their pregnancy and the positive experiences of this choice. It concludes that there is no research that 'abortion' for life limiting conditions have better outcomes but there is evidence that those who continue with the pregnancy reach 'a place of peace'.
The Eighth* Amendment * The Eighth Amendment of the Constitution ensued that TOP including TOP for FFA was treated as a punishable offence, which protected the 'right to life of the unborn'.	July 5th 2016	This pro-choice article includes a piece written by Doctors for Choice. They argue 'to trust women to be able to decide what is in their best interests in their particular circumstances'. They argue that a 'pedantic or legalistic approach to terminology in this debate is not helpful in our view, and abortion services should be properly dealt with like any other health service and follow the same ethical and legal requirements'. They also argue the reasoning for the use of fatal and lethal.

The Eighth Amendment	July 6th 2016	This pro-life piece includes several pro-life voices. They argue that FFA is not accurate as there is prolonged survivors associated with all conditions. They challenge the 'Doctors for choice' and their statement that 'unborn child' is not a medical term' and that one politician is 'unsuited for office' as he votes for a bill that is not constitutional. Lastly, they question 'when did it become acceptable to describe seriously ill babies as abnormal' and how citizen assembly members and politicians are wasting time 'promoting a piece of legislation that they have been clearly advised is unconstitutional'.
Abortion not the only answer to life limiting conditions	July 14th 2016	This pro-life article describes PPC. It focuses on the positives of continuing with a pregnancy following a diagnosis of a FFA and how women should enjoy the pregnancy and that time with their baby. Within this article, they suggest that PPC is patchy and support can be poor in some maternity units. It argues that FFA is an ugly term that tells parents nothing and those babies with FFA can live for a short to longer period of time. It shares one child's life with a diagnosis of a FFA and how she attends school and enjoys life. Lastly, it references a study that

		women who TOP for FFA have a higher risk of depression than those who continue.
What is needed for prenatal diagnosis	July 25th 2016	This unbiased piece recognises the devastation parents experience following a diagnosis of a FFA despite whether they choose to continue or TOP for FFA. It includes that 'neither specialist ultrasound nor foetal medicine services are available to all pregnant women in the Republic' and that this service is first and foremost important to support prenatal diagnosis.
Bereavement teams to be placed in all maternity hospitals	Aug 10th 2016	This article is unbiased. It provides information on the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death and identifies that this standard of care will ensure that all those who receive a diagnosis of a FFA will receive PPC and bereavement care despite whether they continue with the pregnancy or terminate.

Breda O'Brien: Why terminology matters when it comes to pregnancy loss	Aug 20th 2016	This pro-life article argues against the use of FFA and 'incompatible with life'. It argues that life limiting is a more appropriate term to use, as there is uncertainty around what is a FFA and uses Wilkinson to support these statements. It provides information/examples on children with 'life limiting conditions' who have had prolonged survival. It includes Wilkinson's suggestions that healthcare professionals are medically misinformed or feel that baby diagnosed with 'life limiting conditions' do not have a 'life worth living'. It also references a study regarding how those who continue with their pregnancy have less chance of 'complicated grief and mental ill health'.
Opinion polls and the Eighth Amendment	Oct 8th 2016	This pro-choice and pro-life article is an opinion article. It includes 'that there is no such thing as a FFA as survivors are linked to all conditions referred to as FFA'. This article argued that the State needs to 'respect, and, as far as practicable, by its laws to defend and vindicate that right. The State has done this only in a negative sense. It has failed to put into place the required supports for all mothers in crisis pregnancy so that they will be assured realistically of their

		constitutional rights to full care for mother and child to the natural conclusion of pregnancy. The pro-choice ideology argued that 'removing the constitutional protection of the life of the foetus does not mean ridding the State of its interest in preserving foetal life per se' and why Stack (politician) 'believes pro-life voters outnumber pro-choice voters by a margin of two to one, why on earth would he oppose a referendum?'.
Mellet still waiting for Government response to UN ruling	Oct 25th 2016	This pro-choice article shares a personal experience of having to travel for termination of pregnancy (TOP) for FFA and how difficult that was. It reports that while this person won a case taken with the UN Human Rights Committee, against Ireland, there had been no meaningful engagement by the Government.
Harris speaks of 'frustration' at abortion laws amid Twitter campaign	Nov 10th 2016	This pro-choice article presents information on a couple tweeting their trip to the UK to TOP for FFA. The Taoiseach (Irish Prime Minister) 'refers to the deliberations of the Citizens Assembly, which is expected to report its findings on the topic next year' and voices his own opinion that 'the current situation as unsatisfactory' and 'it greatly saddens and frustrates me that women in

		this country and their partners find themselves in this situation'.
North considers allowing abortion for fatal foetal abnormality	Nov 28th 2016	This pro-choice article reports on 'a DUP Assembly member presenting the Stormont speaker Robin Newton with what he said was the largest petition ever brought before the Northern Assembly, as Northern Executive Ministers grapple with whether to permit abortion in cases of fatal foetal abnormality'.
Government will not give UN commitment to change abortion laws	Nov 30th 2016	This paper presents both pro-choice and pro-life ideologies. It presents the facts on how, following offering compensation to a woman who travelled for TOP for FFA, the 'Government will not make a commitment to change the law, but will instead describe the process it has initiated, beginning with the Citizens Assembly and moving on next year to an Oireachtas committee'. It includes representatives and their opinions on this, from both pro-life and pro-choice groups. It shares her experience and how it was agreed that Ireland violated her human rights. It does make clear how while Ireland 'ratified the international covenant on civil and political rights as far back as 1989 but has never incorporated

		it into domestic law. So while the committee's opinion has legal standing, it is not enforceable domestically'.
Fatal foetal abnormality: More State pay outs likely	Dec 3rd 2016	This pro-choice article reports on Ireland being found to violate women's human rights with their current abortion law and their requirement to pay money to a woman who had to travel for TOP for FFA. It reports that they expect there will be more state pay outs and 'that Ireland would remain in breach of its human rights obligations as interpreted by the committee until such time as the ban on abortion is relaxed'.
Complaints upheld against Ray D'Arcy show abortion coverage	Dec 21st 2016	This article reports on the Broadcasting Authority of Ireland (BAI) issuing a warning notice to RTÉ following complaints about an abortion item on the Ray D'Arcy Show on Radio 1. The broadcaster said it noted and accepted the decision of the BAI but it strongly denied accusations of bias across its programming. It includes the opinions of both pro-life campaign and Amnesty International (pro-choice).

Movement to repeal Eighth Amendment appears unstoppable	Dec 28th 2016	This pro-choice article presents that the 'momentum towards repealing the Eighth gathered such pace in 2016' and is 'unstoppable'. It mentions the 'strong voices' who have advocated for 'repeal the 8th', how the Government has come under pressure and international influence has reported a violation of women's human rights by the current abortion law. It reports that politicians have described the abortion regime as “unacceptable” and “frustrating” during the year.
Citizens’ Assembly hears ante-natal screening poses ethical issues	Jan 7th 2017	This article includes both pro-life and pro-choice ideologies. It includes the ethical concerns regarding abortion and disabilities, in particular Down Syndrome. It included the implications for Ireland in international law if no change is made in the Constitution in relation to the repeal of the eighth. Here the reported that Ireland is being found to be violating the rights of women and is ordered to pay out to women affected. It makes clear the international pressure Ireland is under and how legalising abortion will keep on coming up. The 'anti-abortion' representative shares that parents do better with perinatal hospice support than those who opt for abortion while

		the 'pro-choice' representative includes that 'those who hold to the position of equal status as an article of faith or moral belief will always be free to base their own deliberations and choices upon that view' and 'until the law changes women who hold a different view will have no such freedom'. It concludes that now the assembly will discuss what its eventual recommendations on the abortion issue might look like.
Citizens' Assembly offers 'wide views' on abortion law changes	Jan 8th 2017	This article offers both ideologies. It repeats much of the article published the day before regarding pro-life and pro-choice views and ethical considerations. In addition to this, it reports that the Citizens assembly has 'discussed for the first time what its eventual recommendations on possible changes to the law on abortion could look like' and how they require one week further to 'consider the eighth amendment'.
Radio complaint upheld after woman who had abortion called 'murderer'	Jan 31st 2017	This unbiased article provides information on how 'a woman who was called a liar and a murderer live on radio after terminating a pregnancy following a diagnosis of a fatal foetal abnormality has had a complaint to the Broadcasting

		Authority of Ireland (BAI) partially upheld'.
Citizens' Assembly hears from women affected by Eighth Amendment	March 6th 2017	This article shares both pro-life and pro-choice views. It shares women's experiences of both continuing and ending a pregnancy with a 'FFA'/'life limiting condition'. Both sides include that they have no regrets.
Citizens' Assembly shows its callousness in abortion vote	April 29th 2017	This pro-life article presents that the Citizens' Assembly is not representative at all and that there was 'a startling callousness towards even the viable baby'. It includes a title 'Act of Killing' and describes how the unborn baby is terminated. It also looks at those informing the Citizens' Assembly, who are required to be impartial experts but reports they have invested interest. Furthermore, this article refers to fostering groupthink. It also includes a Fetal Medicine Specialist reporting that 'the science has got way ahead of the ethical discussion'. It concludes that the 'Government already know what they want from the Parliamentary Committee' and eventually 'the rights of the youngest humans are being eroded'.

Minister for Health wants abortion referendum next year	June 13th 2017	This pro-choice article presents the Health Minister advocating for abortion to be legalised following the United Nation Human Rights Committee ruled Ireland's legislation on abortion violated a woman's human rights. It includes personal experiences of women affected by the eighth amendment.
Woman 'felt like a criminal' leaving Ireland for termination	June 13th 2017	This pro-choice article shares a personal experience of one woman who 'felt she could not continue with the pregnancy only to see her baby suffer and die, and she endured terrible mental suffering' through having to travel for a TOP for FFA. She shared that she had no grieving period.
Irish abortion law violated woman's human rights, UN says	June 13th 2017	This pro-choice article reports on how the Irish abortion law was found to be in violation of a woman's human rights, by the United Nations. It provides information on the personal experience of two women who travelled for a TOP for FFA who won their case against Ireland. The United Nations Human Rights Committee reports that 'Ireland needs to prevent similar violations of the rights of women by changing its laws on abortion'. It is argued that 'Women's health and wellbeing are harmed when they have to

		travel for abortion services'. They conclude that it is 'not unlikely that other women might choose to take a case against the Government on similar grounds'.
Abortion laws in Ireland should be changed, rules UN committee	June 14th 2017	This is a pro-choice article with one pro-life statement on the ruling of the UN committee that it against women's human rights not to permit abortion and the need for Ireland to change their laws. It reports on one woman's experience of travelling for a TOP for FFA, how difficult it was and how Ireland has agreed to pay this woman 30,000 following the ruling of her rights being violated. It states the number of women who travelled to the UK for abortion who gave Irish addresses in 2015. It does have a piece T the end from an 'anti-abortion' group saying that the drop in numbers travelling for an abortion demonstrates Irish laws acts as a life saving measure.
Public in the North support changes to abortion law	June 16th 2017	This pro-choice article presents information on the abortion law in Northern Ireland. It includes that a new report suggests that 'Northern Ireland public has indicated its support for changes to abortion law'. It reports that Protestants are more liberal than

		Catholics with regards abortion and that abortion should be decriminalised. It concludes by calling on politicians to take action and address the law.
'Before this happened to me, I didn't even know what pro-choice meant'	June 17th 2017	This is a pro-choice piece however pro-life ideology when discussing Down Syndrome. It shares mothers' experiences of having a child with Down Syndrome and fear of countries eradicating Down Syndrome. One woman shares how she has a son with Down Syndrome but following a diagnosis of Edwards Syndrome decide to terminate, identifying the difference of Down Syndrome and a FFA. It concludes however, that those who terminate Down Syndrome, that usually there are other complications/anomalies and shares a woman's experiences of this. It draws on the role of the State and society and that Ireland lacks the supports and services.
Human rights commission appeals NI abortion ruling	June 29th 2017	This article included pro-life and pro-choice ideologies. It describes how the board of Northern Ireland human rights commission has decided to appeal a Belfast court of Appeal ruling that the Northern Assembly will decide on abortion law and not the courts. This is because they voted against legalising

		abortion for FFA the year previous. They report that they will 'continue to seek a change to the law so that women and girls in Northern Ireland have the choice of accessing a termination of pregnancy locally in circumstances of serious malformation of the foetus, rape or incest, without being criminalised for doing so'. Representatives from both pro-life and pro-choice groups comment on the ruling.
'My daughter was dying inside me. I could not save her'	July 1st 2017	This pro-choice piece describes one mother's experience of travelling for a TOP for FFA. She describes how her daughter 'was dying inside me. She would never be born alive. I could not save her and it was killing me. The one act of mothering that I could do as her parent was to ensure that she did not suffer, and this is how we ended up in the care of the foetal medicine team at Liverpool Women's Hospital'. She expresses her anger and upset with having to travel for this service provision.
File name within Online Paper	**Date**	**Description**
Women ask consultants to support campaign to reform abortion law	May 3rd 2012	Pro-choice article which reports that 'A group of women who were required to travel abroad for abortions after being

		diagnosed with fatal foetal abnormalities have written to all consultants to ask for their support'. Included in the article is how travelling for a TOP for FFA makes an 'already horrific experience infinitely worse'.
RTÉ told to 'take greater care' after complaint over Late abortion interviews	Oct 12th 2012	This is an unbiased piece. The Broadcasting Authority of Ireland has told RTÉ's Late Show to "take greater care" when dealing with human interest aspects of political issues to ensure there is a clear and adequate separation for audiences. Complaint was made that the broadcast 'not objective and not impartial'. The complaint was 'rejected after deciding that the segment on balance, constituted a human interest rather than a news and current affairs item. Therefore, the statutory obligations on news and current affairs content did not apply'.
Alan Shatter condemns 'obscene and insensitive' anti-abortion posters	Dec 12th 2012	A pro-choice article where a politician condemns 'anti-abortion posters targeting him personally which have been erected in his constituency'. The article describes those who erected the posters (those with a pro-life ideology) as 'lacking humanity, insight and compassion'. This politician reports that termination for

		fatal fetal anomaly is the preferred choice of the people.
Group says lack of invite to Oireachtas abortion hearings "a grave injustice"	Jan 7th 2013	A pro-choice article that presents a pro-choice group (who represent couples who terminated a pregnancy following a diagnosis of fatal foetal abnormality) upset and 'extreme disappointment' 'at not being able to address a committee on the issue of abortion legislation in Ireland'. 'The members said they feel it is a grave injustice that the views of couples who have spoken out publicly despite their grief are not to be heard'. Buttimer (politician/chairman of the committee) responds that they 'facilitating as many people as they can, and those who can't take part have been asked to make written submissions. We will be as fair and as balanced as we possibly can be'.
Poll shows strong support for abortion in cases of rape, fatal foetal abnormality	Jan 27th 2013	The pro-choice article presents the findings of a poll on TOP for FFA. Included is the 'strong support for abortion to be available to women in Ireland in cases where they have become pregnant as a result of rape or where there is a fatal foetal abnormality that means the baby cannot survive'.

Medical Terminations: 'Ours is a very specific, heart-breaking and clear-cut case'	May 2nd 2013	A pro-choice article sharing their upset of TOP for FFA being omitted from a draft legislation. They share a personal experience 'of the devastating loss of a much-wanted baby girl' and how difficult receiving a diagnosis of a FFA and having to travel for a TOP for FFA was. They call that this has to change.
Letter: TFMR 'disappointed' at exclusion from abortion hearings	May 17th 2013	This pro-choice article reports that a pro-choice group are upset to be excluded from the Oireachtas committee abortion hearing. It shares their personal experiences regarding how difficult it was to travel for TOP for FFA.
Women who had medical terminations to share experiences with TDs	May 23rd 2013	This pro-choice article shares how a 'number of expert witnesses, including a former Supreme Court judge and the current Master of the Rotunda Hospital, told the Oireachtas committee on health during its hearings on proposed abortion legislation that it was disappointing and regrettable that women who travel to the UK for medical terminations because their babies are not "compatible with life" were not provided for'. It reports how members of a pro-choice group plan to share their experiences of travelling for a TOP for FFA with a number of TDs and Senators in the Dáil that afternoon.

TDs to support abortion amendment to provide for medical terminations	May 24th 2013	This pro-choice article presents 'parents trauma of having to travel to the UK' for TOP for FFA. It also shares politicians who support the legalising of TOP for FFA inclusive of two ministers who experienced a diagnosis of FFA.
Rabbitte would support fatal foetal abnormality clause in abortion bill	June 1st 2013	This pro-choice article highlights Pat Rabbitte (Politician) and how he is 'the first cabinet minister to openly support allowing abortion where there is no prospect of survival'.
Amendment to abortion bill on fatal foetal abnormalities handed to Government	June 20th 2013	Pro-choice ideology presenting information on an amendment created by a voluntary organisation who support 'termination for fatal fetal anomaly'. They indicate all parties must agree to this amendment for it to be 'voted through'. It includes that if this amendment is 'not added to the bill, the next step would be to see if TDs would submit a private members' bill from September on the issue. Another possibility is a referendum to repeal the Eighth amendment to the constitution'.
'We don't want Government empathy and compassion – give us action'	June 26th 2013	A pro-choice ideology presenting parents' stories of the 'horrible journey' undertaken when travelling for a 'termination for fatal fetal anomaly'/'terminations for medical

		reasons'. Reported, that if the proposed amendment fails to allow for terminations for medical reasons, a cross-party group have said they will bring a new Bill dealing with the issue after summer recess. Politicians argue for this amendment.
TDs vote against extending abortion bill to include fatal foetal abnormalities	July 2nd 2013	This pro-choice article presents how 'the Protection of Life during Pregnancy Bill to include a provision allowing for the termination of pregnancies where the foetus has no prospect of survival outside of the womb has been defeated at committee stage tonight'. The 'Attorney General was that it was not possible, saying there was no “constitutional certainty”'. It concludes that 'About 1,500 cases of fatal foetal diagnoses are reported each year in Ireland with about 80 per cent of the women travelling abroad for treatment. Some women shared their ‘harrowing experiences’ of travelling for a TOP for FFA at a recent press conference and in a tweet tonight, the TFMR group described the bill as it stands as “awful”'.
Amendment on fatal foetal abnormality rejected	July 11th 2013	Unbiased article describing the 'rejected' amendment on 'fatal foetal abnormality'. Politicians share their opinions in this

		articles, this is inclusive of politicians making accusations of other politicians attempting 'political opportunism'. It also describes how one politician incorrectly voted in the amendment but will have no repercussions, as it was a 'genuine mistake'.
Two senators hope to bring amendments on fatal foetal abnormalities	July 15th 2013	This pro-choice article discusses politicians wanting to make amendments to the eighth to allow for TOP for FFA. It includes politicians' names of who will and will not support this. It includes politicians' opinions on the need for women to be trusted and to avoid a reoccurrence of Savita Halappanavar (midwifery scandal where mother miscarried her baby and died of sepsis), and includes that the law needs to change.
Women who travelled to UK for terminations to bring case to United Nations	Nov 9th 2013	This pro-choice article reports how Terminations for Medical Reasons (a pro-life group) and the Centre for Reproductive Rights will file 'three petitions alleging human rights violations with the UN Human Rights Committee next week'. 'Members of TFMR were devastated of the omission from the legislation this year but vowed to take their cases to Europe and beyond' and

		that they will continue to hold another demonstration outside Government buildings.
“Amanda would have been forced to carry to term, fearing every minute”	Nov 13th 2013	Pro-choice article presenting a parent's story of a diagnosis of a fatal fetal anomaly and being 'forced to travel to the UK to terminate her unviable pregnancy'. It describes how this parent 'is filing a petition to the United Nations claiming the Irish Government violated her human rights'. It shares that this parent received 'no post abortion care' and how she felt she was doing the 'most humane thing'.
Emotional plea for change: ‘Wrap your arms around us…don’t kick us out’	Nov 13th 2013	This pro-choice article shares information on 'two women, who shared their personal experiences of losing a much-wanted child, urging the Government to ensure that women carrying unviable pregnancies can receive treatment in their home country'. They share the challenging aspects of travelling for a TOP for FFA. The pro-life group report that 'about 1,500 cases of fatal foetal abnormalities are reported each year in Ireland with about 80 per cent of the women travelling abroad for early inducement or terminations'. It concludes

		with the names of the politicians that support the pro-choice group.
Embarrassing the Government into 'doing the right thing'	Nov 14th 2013	This pro-choice article discusses the back log of cases with the United Nations Human Rights Committee and how a decision may not be legally binding. It reports on the cases already brought before the Human Rights committee and the 'cruel and inhumane treatment' this woman experienced. It also shares how a pro-choice group 'hope the Government will be encouraged to be proactive on the petition they have filed with the United Nations'.
Northern Ireland's justice minister calls for consultation on changing abortion laws	Dec 5th 2013	This pro-choice article presents the opinion of one minister. It reports that the 'justice Minister is calling for consultation process to begin on whether the abortion laws there should be changed'. He believes 'he does not think that Northern Ireland can continue to the export the problem to England, stating that he believes women who are carrying babies with fatal foetal abnormalities should be allowed a termination'.

Ireland, women and 2013: A year we dealt with our legacy issues?	Dec 29th 2013	This unbiased article reports on how 'Ireland has been dealing with a number of 'human rights' issues over the past 12 months, just many of them happen to have women at their centre'. It reports facts on how the Government is dealing with TOP for FFA. It reports on many of the maternity and church scandals; Magdalene Laundries, symphysiotomies, Michael Neary's victims, domestic violence and maternity care during 2013 and acknowledges that talking about these highlights the efforts being made.
Group campaigns for better perinatal hospice care in Ireland	Jan 22nd 2014	This paper includes pro-life ideology with a brief piece on pro-choice. It includes how a pro-life group are advocating for better PPC for children with 'life limiting conditions'. This group reports a 'disproportionate focus of abortions in cases of babies with terminal illnesses' and how 'it is really sad that some people think abortion is the obvious answer when a life shortening condition is diagnosed'. They believe 'attitudes would change considerably if more attention was given to the real life stories of women who opted against abortion and chose to keep their babies in these situations'. It finishes on how 'cruel and

		barbaric' it is for women to travel for 'TOP for FFA'.
Ireland's abortion laws to be challenged at the UN for a second time	March 13th 2014	This pro-choice article informs the public that a 'second challenge to Irish laws forbidding abortions for medical reasons has been lodged with the UN. The Centre for Reproductive Rights (CRR), which filed three petitions on behalf of an Irish woman, Amanda Mellett, alleging human rights violations with the UN Human Rights Committee in November, announced today that they are bringing another case to the committee'. It shares the experience of one of these women travelling for a TOP for FFA. This woman reports that 'I will never understand why I had to pack my bags and leave Ireland so I could access the medical care I needed. It is truly demeaning and I will never forget it'.
Irish laws 'forcing us to go to Manchester for a termination this weekend'	March 18th 2014	This pro-choice article shares a young couple's experience of travelling to the UK for a TOP for FFA. They share their 'story in order to put pressure on politicians to make necessary changes'. The dad reports 'We are forced to go to the UK for an termination – which we have been advised to do in so many words – as anything else will prolong the

		pain for my girlfriend and the baby at birth, he explained, noting that he believes the argument is not tied to one of pro-choice'. It concludes with the petitions filed with the UN Human Rights Committee against Ireland for human rights violation.
It looks like Labour's next manifesto will commit to widening Ireland's abortion laws	Aug 25th 2014	This pro-choice article shares how 'the Labour party (political party) is likely to include a commitment to legislate for abortion in cases of fatal foetal abnormality in its next election manifesto and could also include a commitment to repeal the 8th Amendment'.
Irish women with fatal foetal anomalies stuck on UK hospital waiting lists	Aug 26th 2014	This pro-choice article shares the concerns of a pro-choice group regarding Irish women being on waiting lists in the UK for TOP for FFA. The UK respond that it is a capacity issue and the paper includes 'exporting Ireland's problem. It concludes with a personal experience of being on a waiting list following a diagnosis of a FFA.
"Adverse publicity" warning over fatal foetal abnormality terminations	Oct 10th 2014	This unbiased article presents information from the Master of an Irish Maternity Unit sharing safety concerns of women who are travelling to the UK for 'terminations after receiving a diagnosis of fatal foetal abnormality are returning

		home halfway through their procedure to deliver stillborn babies in Irish hospitals'.
Opinion: Changes to abortion laws should be decided by referendum – with balanced information for voters	Oct 16th 2014	This pro-life article discusses the unpredictability of a FFA diagnosis and that no one can guarantee that the child will not be born alive. Within this article, they give examples of children who have survived, if only for a few days. This article argues against the term 'incompatible with life' and advocates that families are adequately and accurately informed. It concludes that 'changes to the abortion laws should be decided by referendum'.
'No matter what anyone says to you, you're a mammy and a daddy now'	Feb 4th 2015	This pro-choice article shares the difficulty and 'barbaric practice' of parents who had to travel for TOP for FFA. It reports on how a documentary of these parents' experiences will be presented 'ahead of the launch of Clare Daly's (politician) proposed amendment to the Protection of Life During Pregnancy Act'.
"Please don't force a woman to grow a baby that is going to die"	Feb 4th 2015	This is a pro-choice article reports on the 'Government set to oppose the latest bill on termination for medical reasons'. The politician who put the bill forward, Daly, shares that 'they (politicians that opposed

		bill) might as well wear a badge marked hypocrite. Over 50 of them have spoken on the need for this. Their shallow tears and words are an insult to the women and couples suffering from this violation of human rights. They have six days to change their minds or forever be judged for their callousness'. It includes parents' experiences and legal experts to support the amendment.
Leo: We've no mandate for abortion referendum, Mick Wallace: That's horseshit	Feb 6th 2015	This pro-choice article includes Health minister Leo Vardakas 'again opposing a proposal to legislate for abortion in cases of fatal foetal abnormality'. It includes information on Daly's (politician) bill and how it is not constitutional. Leo includes 'that the current Government has no electoral mandate to hold a referendum to repeal the amendment which guarantees the equal right to life of the unborn'. Pro-choice politicians share how 'barbaric' the abortion law is, while another feels 'that the "barbarism" of Irish abortion laws damages the country's reputation internationally'. Boyd-Barrett (politician) shares 'his own personal experience of his daughter Ella, who had a fatal foetal abnormality'.

Boyd-Barrett: 'I had to bury my daughter Ella. She was born with fatal foetal abnormalities'	Feb 6th 2015	This short piece is unbiased. It includes one politicians 'tragic' experience of having to bury his daughter who was diagnosed with a FFA.
"We can assure you, not a person on this earth wanted our babies to live more than we did."	Feb 7th 2015	This pro-choice article describes how 'campaigners seek to change the law in relation to fatal foetal abnormalities' and how they have 'written to the Taoiseach asking him to remove the whip and legislate for abortion in cases of fatal foetal abnormality', 'where the unborn baby will not be born alive'.
'A shameful abandonment': Just one Labour TD defies party as Clare Daly's abortion bill voted down	Feb 10th 2015	Pro-choice ideology presenting information on the 'abortion bill being voted down'. This article presents how politicians are restricted by the party whip and therefore silenced on their view of abortion. It presents how one politician is 'expelled' from her party as she 'defied the Government to support the proposed legislation'. Politicians use this opportunity to place blame on the Government and refer to the bill being voted down as a shameful abandonment by the Government.
Column: Why does this Government refuse to hold a referendum on abortion?	Feb 13th 2015	This pro-choice piece presents the need to legalise 'TOP for FFA/medical reasons'. It shares how a proposed bill to allow for TOP for FFA was voted down. It describes

		the eighth amendment and what the law is in application. It discusses how the Government has no mandate to call a referendum and political groups argue against each other. It concludes on how women will continue to suffer and 'repeal the eighth'.
My child was diagnosed as 'incompatible with life' but I'm glad Clare Daly's bill was voted down	Feb 15th 2015	This pro-life article reports that the proposed abortion bill was not only flawed, it was discriminatory, and it threatened the right to life of all children with disabilities. It includes examples of parents' children who had short and prolonged survival and what that meant to their parents. It included that parents are being pressured to travel for an 'abortion' following a diagnosis of a 'disability'. This article includes that 'parents felt they did not receive adequate information about other options, including palliative care after birth'. It reports that 'abortion is not a short-cut through grief' and describes abortion as a 'lethal injection straight into the heart and the mother must give birth to a dead child' which is usually a 'late-term abortion'.

Can fatal foetal abnormalities be legislated for? Politicians want to take ANOTHER look…	Feb 19th 2015	Pro-choice article that reports on the agreement of the Oireachtas health committee 'to examine the question of whether abortions in circumstances of fatal foetal abnormalities can be legislated for within the existing constitutional structures'. It includes opinions of other politicians.
Irish pro-life group want to get rid of “incompatible with life” phrase	Feb 26th 2015	This pro-life article presents information that a 'pro-life group want to get rid of incompatible with life phrase'. They all have children with 'disabilities' who have experienced this term. This article has a brief pro-choice ideology as it concludes on Daly's Bill 'that would allow for terminations for medical reasons (TFMR) voted down in the Dáil'.
I was told my daughter was incompatible with life ... she's now 8'	Mar 9th 2015	This pro-life article reports that an Irish group is 'to travel to Geneva to end the use of the term incompatible with life'. A pro-life group reports that this term 'dehumanises unborn babies with a disability'. They share personal experiences of a baby being diagnosed with an 'incompatible with life' diagnosis and short and prolonged survival. This pro-life group feel having this label affected the level of care being delivered. It includes the politician helping the

		group to prepare a bill to put forward to discontinue the use of this term.
What exactly is Sinn Féin's policy on abortion	March 4th 2015	Following Sinn Fein, a political party, 'abstaining on Clare Daly's (politician) bill providing for abortion in circumstances of fatal foetal abnormalities last month' 'questions have been raised about where exactly the party stands on the issue'. This unbiased article presents 'the party's policy could be radically overhauled at its Ard Fheis (annual party conference) this weekend'. The motion being put before Sinn Fein 'would appear to be calling on the party to adopt a firmly pro-choice stance' however the article includes that there are 'lots of different views in a party famed for taking a very collective stance on policy'.
Sinn Féin votes for abortion to be allowed in cases of fatal foetal abnormalities	March 7th 2015	This article includes both pro-life and pro-choice. It reports how Sinn Fein votes for abortion to be allowed for FFA. One Sinn Fein politician reports the lack of choice to TOP for FFA results in the woman enduring 'even more trauma'. It included opposing views from two member of the Sinn Fein Party where one shares his experience of a pregnancy with a FFA. It

		presents both ideologies protesting with placards.
Other families' bravery made me talk about my daughter Ella – Boyd Barrett	April 25th 2015	This pro-choice piece includes a politician reporting that 'bravery of other families in talking about their experiences of fatal foetal abnormality made him talk publicly about his own personal tragedy', the death of their daughter to a FFA.
Rebel TD kicked off committee after just ONE day	May 29th 2015	This is an unbiased piece. It reports how a politician who has been 'expelled from his parliamentary party yesterday, will be taken off the Health Committee despite only becoming a member of it on Wednesday' due to him going against the party whip (voting against his party) on another topic.
Parents are led to believe their babies are 'freaks of nature' – pro-life group	June 16th 2015	This pro-life article reports how a pro-life group, alongside a politician, have drafted a bill to have the term 'incompatible with life' discontinued. The pro-life group share 'the fear that this label strikes into your heart. Abortion is driven by fear and a denial of the humanity of the child. Parents are being led to believe their children are just a freak of nature, like monsters, that they're not fully human'. This politician concludes that he is 'hopeful the Government won't block the

		bill, but added he's not confident this will happen'. That he is 'never confident with this Government, especially the way they've been behaving in recent times on a whole range of matters'.
We all have dreams as young girls. Having a termination is not one of them.	June 17th 2015	This pro-choice article describes a personal experience of a woman receiving a diagnosis of a FFA as well as two miscarriages. This woman describes how she 'never knew all the things that could go wrong with a pregnancy'. She reports that TOP for FFA is something that they 'never thought when they started on (their) baby journey, that terminating a pregnancy was something that they would do'. However, she reports that they did and they 'did it for her and for us'. This article includes how 'pro-life campaigners sprout such hypocrisy in relation to supporting life but they are not 'pro-life. They are pro condemning myself and my husband. They are pro condemning those who are suicidal and those who have been raped. They lack compassion and support for women and couples whose dreams have been crushed'.

Labour and Sinn Féin want to repeal the 8th, but not everyone is on the same page	June 28th 2015	This pro-choice article presents how two political parties are for TOP for FFA but how not everyone within their party is on the same page. It includes the 'unspeakable trauma' of those who travel for a TOP for FFA and how it is 'the absolute entitlement of those women, their partners and their families" to "full care … every support and, above all, choice'. It concludes that the 'Government has come under increasing pressure of late to hold a referendum on repealing the amendment' following a' call form the UN to revise its legislation on abortion'.
'Strange': Rebel TD kicked off committee after he seeks abortion hearings	July 6th 2015	This article is unbiased. It presents the views of the politician removed from his political party following his letter to health committee and his interest in legalising TOP for FFA. His political party deny that 'there is any connection between the removal of rebel TD Michael McNamara from the Oireachtas health committee and his attempts to hold hearings on abortion' and confirms that it is due to him voting against his party with regards a different topic.

HSE hides identity of staff who suggested change to abortion document	Sept 14th 2015	The unbiased article reports that 'The Health Service Executive has refused to identify staff who suggested changes to an abortion-related document, citing fears for their safety. An official said to identify people who suggested alterations to a document dealing with management of cases of fatal foetal anomalies might endanger their safety'. It shares how this topic is 'an emotive and difficult area, arousing strong feelings on all sides'. It reports that this has developed from a HSE document, which changed its term FFA to life limiting condition, which has been criticised by a pro-choice group who have personal experience of travelling for a TOP for FFA.
'In Ireland, Helen would go to jail': Graham Linehan speaks of wife's abortion after fatal foetal diagnosis	Oct 19th 2015	In the pro-choice article, as a part of 'Amnesty International's campaign to decriminalise abortion, the couple (a writer of an Irish TV series 'Fr Ted' and his wife) describes how excited they were to learn Helen was expecting soon after they got married' and share their 'heart-breaking' and 'traumatic' experience with a fatal foetal abnormality in pregnancy.

Belfast court rules abortion should be available in cases of rape and fatal foetal abnormality	Nov 30th 2015	This pro-choice with a little pro-life article presents results of a pro-choice ruling in Belfast court. It describes how the Eighth Amendment in Ireland is against the rights of women and include the United Nations and Amnesty International to support this. It also reports that exporting women for a termination of pregnancy does not protect morals. It includes statements from an 'anti-abortion group' and 'pro-life campaign' briefly.
Paul Bradford: “There are no such babies as babies with fatal foetal abnormalities”	Dec 1st 2015	This article contains pro-life and pro-choice ideology and is in response to the previous article where the politician (Bradford) has said he ‘regrets if people feel his comments that there are no such babies as babies with fatal foetal abnormalities are insensitive'. A pro-life representative argues 'that Bradford should rethink his comments'. Bradford responds that he regrets if it was felt that his comment was insensitive, that within 'his Seanad remarks he was urging against sweeping statements that there must be a referendum to deal with issues such as fatal foetal abnormality: There are many, many cases where unborn babies have had profound medical problems, very life-limiting. Some of them live for an hour, some a day, some a month. We have met

		some of them. Our overall use of language must try to encompass all of that as well'.
'I was walking around with my baby growing inside me knowing she could die at any moment'	Dec 2nd 2015	This pro-choice piece is in response to the previous article where a senator says there is no such thing a FFA. The woman shares her experience of a diagnosis of a FFA and why she chose to travel for a TOP for FFA. It included that she will never 'get over that we had to leave the love and support of our family'. It concluded that she went on to have a little girl with disabilities and makes clear the difference between a disability and FFA.
Senator regrets if people were offended by controversial abortion comments	Dec 2nd 2015	This pro-life and pro-choice article includes a politician advocating for avoidance of terms FFA and 'incompatible with life' for children with life limiting conditions. He 'believes there are no babies with FFA' and that 'when we speak this easy phrase, fatal foetal abnormalities, we are talking about babies who have a life-limiting or life-threatening condition, they are human beings'. He concurs with another

		politician that 'what we are seeing here is the corruption of law, the corruption of the human rights community deciding that some vulnerable human beings are outside the pale for human protection'. This article also includes the 'Belfast High Court ruling that abortion laws in Northern Ireland breach human rights law'. It reports that women who experience a FFA 'entitled to exemptions in the law'.
Women shouldn't have to sell household items or take out short-term loans to afford an abortion	Jan 3rd 2016	This pro-choice article presents 'the current difficulties for Irish women attempting to access abortions' under the eighth amendment. They describe 'women crying down the phone', financially struggling to afford abortions and describe the experience as 'deeply traumatising'.
Stormont rejects allowing abortion in cases of fatal foetal abnormality	Feb 11th 2016	This article contained both pro-life and pro-choice ideology. It reports on the Northern Ireland Government, Stormont, 'rejecting a proposal to allow abortion in Northern Ireland in cases of fatal foetal abnormality'. It shares personal experiences of those who had to travel for a TOP for FFA and included that 'Medical experts advise that there is no such term as fatal fetal abnormality'. A

		pro-choice group concluded that 'its campaign will keep abortion firmly on the political agenda in the run-up to the Assembly Election'.
Irish couple on the difficult choice they faced after their baby was diagnosed with a fatal foetal abnormality	Feb 27th 2016	This unbiased article shares a personal story of a couple who continued with their pregnancy following a FFA diagnosis and the special moments they had with their son. The mother however shares how difficult the decision of whether to continue or terminate was and how every couple ' should be able to make their own choice'. This article included; 'There is no right and there is no wrong thing to do from that moment on, said Michelle, a nurse. The right thing to do is what is right for you and your unborn baby'.
This new Fianna Fáil TD wants to repeal the Eighth Amendment – but she won't convince her colleagues	Marc h 9th 2016	In a pro-choice article, one politician is advocating to repeal the eighth amendment for FFA. She includes, 'whether you be in favour of repealing it, not in favour of repealing it, [and] if you do want to repeal it, what kind of services do you want afterwards? They're questions that, as a country, we need to have a conversation about and answer those questions'. Other politicians include, that if there is a referendum they

		will allow for a free vote within their party.
Ray D'Arcy interview with Graham Linehan and wife over abortion broke broadcasting rules	May 24th 2016	This article is unbiased. It reports how a 'complaint against a show over an interview dealing with abortion has been mostly upheld by the Broadcasting Authority of Ireland'. It states that the broadcast lacked balancing views. It was argued that ' the interview was a human interest segment and the focus was the personal trauma endured by the couple' but the 'Broadcasting Authority of Ireland found that it did not agree with the characterisation of the interview as predominantly human interest in nature. It noted that the video had been created by the Linehans in support of a campaign to change the Irish Constitution'.
A mystery of our time: How do you get a TD to answer a question?	June 7th 2016	This unbiased article gives both ideologies and focuses on how controversial 'abortion' is and how politicians are reluctant to answer questions put to them on abortion by this article. The included 'humour' at the expense of the politicians. Questions being asked however are not presented.

Joan Burton has a lot to say about Enda Kenny's cop out	June 12th 2016	In this pro-choice article Joan Burton (politician) responds to the reactions following the UN ruling that Ireland was violating women's' human rights with their abortion law. 'Burton said what's going on is a "long finger exercise" by Government. Given the likely viability of the Government, it would mean that, in fact, the sub-plot is to postpone any action on the issue until after the next Government is formed. I think that is an enormous cop-out. I think it is wrong'. This politician directs blame to other politicians and political parties including that 'the Taoiseach obviously has personal issues in relation to the subject. I think, at this stage, he wants to delay it. He certainly strikes me as being quite uncomfortable around the issue'.
Bill to repeal Eighth Amendment launched	June 22nd 2016	Pro-choice article with two lines from a 'pro-life' campaign to finish article. This presents politicians arguing that there should be a free vote on the issue of 'abortion'. They argue that 'It's funny how the question of a conscience or free vote seems to come up when it relates to women, but it's never a problem when it's austerity being inflicted on whole sections of the population including women'. Both Bills brought by Wallace

		and Daly, (two politicians) to allow for TOP for FFA are mentioned.
Simon Harris has apologise to Amanda Mellet	June 30th 2016	This pro-choice article included a parent's experience of a diagnosis of a FFA and travelling for TOP for FFA. The Health Minister apologises to this mother and what she experienced and adds 'that he wants a referendum on repealing the Eighth Amendment'. The Health Minister confirms that he has to oppose the bill as it is 'not constitutional and would not be medically practicable'.
The pain and suffering is etched in my memory	June 30th 2016	This unbiased piece included an emotional plea from one of the ministers sharing her experience of a diagnosis of a congenital anomaly during a 'dail debate on a bill to legislate for terminations in the case of fatal foetal abnormalities'. 'While she commended Deputy Wallace for bringing forward the Bill, she stated her view that it would be imprudent to go against the advice of the Attorney General'.
"It's not fair, it's not right, it's not good for politics" - John Halligan isn't happy	July 3rd 2016	This unbiased article presents one politician who calls for all politicians to be given a free vote on the bill being proposed to allow for TOP for FFA. It

with the party whip system		reports the 'pressure' that has been placed on the then Health Minister 'to give members of his party and the Government a free vote on the proposed legislation when it comes up next week'. Another politician reports she does not need a free vote, as the bill is unconstitutional and it ultimately 'will get nowhere'.
Three ministers to vote for Bill allowing abortion in cases of fatal foetal abnormalities	July 4th 2016	This unbiased article presents who is voting for one politician's bill, which will allow for TOP for FFA. It discusses how independent politicians will be allowed vote freely as they are not subjected to the party whip of other political parties. It mentions who will support the bill and who will oppose it.
Taoiseach: 'Abortion bill is bad for women and medically inadequate'	July 5th 2016	This article is unbiased. It reports information on how a politician's 'bill for abortions in the case of fatal foetal abnormalities is bad for women and medically inadequate'. This article reports on what politicians are and are not supporting the bill. It also mentions 'a pro-life demonstration which was held outside Leinster House (Government).
Poll: Should TDs get to vote how they want on	July 5th 2016	This unbiased article gives a brief description of the politician's bill to allow for TOP for FFA. 'Independent alliance has

the fatal foetal abnormality bill?		asked for a free vote on the bill, meaning members can vote the way they want but Fine Gael will vote against based on the attorney generals advice', this article concludes with a poll whether politicians should be allowed a free vote.
Daly reads woman's letter: 'My son's ashes will be delivered along with Amazon and eBay purchases'	July 6th 2016	This pro-choice article includes a politician reading a woman's letter of her experience of receiving a diagnosis of a 'FFA and was incompatible with life'. This woman compares herself with her sister who had a miscarriage and how her treatment was 'cruel, inhuman and degrading' in comparison, following her decision to terminate. The politician 'hits out' at the Taoiseach (Prime Minister) for 'doing nothing'
Explainer: What is Mick Wallace's abortion bill and why is it causing so much controversy?	July 7th 2016	This article has pro-life and pro-choice ideologies included. It provides information on one politician's bill to decriminalise 'abortions in the case of fatal foetal abnormalities'. This article reports that the 'bill is causing problems at cabinet level, at constitutional level and on either side of the abortion debate' and is a 'carbon copy' of a previous bill which was voted down. Voices of both pro-life and pro-choice groups are reported within this article.

Mick Wallace's bill on fatal foetal abnormalities has been defeated	July 7th 2016	This unbiased article reports how the politician's bill has been voted down. It includes what political parties voted for and against the bill that would allow for TOP for FFA.
'No one should have to stand up in the Dáil and talk about their daughter's death to bring about change'	Aug 7th 2016	This pro-choice piece is from the view of a politician. He reports that 'occasionally you have to talk about something of which you have direct personal experience," he told the Dáil'. He refers to his daughter Ella who they 'desperately wanted … but it was an absolute certainty that she would not live'. 'He says it was not right that people should have to air their own, deeply traumatic experiences in order to bring about change'.
"The eighth amendment hasn't been voted upon in my lifetime. That's long enough"	Aug 20th 2016	This pro-choice article reports the opinion of one politician with regards the need for a referendum to repeal the eighth amendment. This politician expects that the referendum would pass if it were worded for TOP for FFA and rape.
FactCheck: What do HSE guidelines actually say about the effects of abortion?	Aug 26th 2016	This unbiased article examines a pro-life representative interpretation of a HSE document. They compared her interpretation to what the document actually said and support their findings with evidence.

'I cannot save my daughter, and it destroys me. The one kindness we can do is shield her from pain'	Sept 11th 2016	This pro-choice article shares one couples experience of a diagnosis of a FFA and what their options are currently in Ireland and what that means to them. The dad reports that 'I cannot save my daughter, and it destroys me. The one kindness we can do for this little girl, who will never know us, is to shield her from pain. If we choose to do that, we must leave our families and friends, the hospital staff we know, everyone and everything that saved us from shattering entirely'.
I cannot save my daughter, and it destroys me': The week in quotes	Sept 18th 2016	This article looks at all the quotes form the week and includes the previous article on parents experience of receiving a diagnosis of a FFA and how the kindest thing they can do, to shield 'this little girl' from the pain is TOP.
Rónán Mullen says he doesn't believe aborted foetuses are 'debris'	Oct 3rd 2016	This is a pro-life article. It describes how a senator described 'sick unborn baby being denied the dignity of being allowed to reach a natural end, illustrating how heartless abortion providers are'. He receives some backlash for his statement but confirms that he was only trying describe the abortion providers and that 'his views are not merely his own but also of other families' who are pro-life. He reports that he is merely 'speaking about

		a human right's issue and speaking up for the vulnerable' i.e. unborn baby.
Six in ten people want abortion to be decriminalised in Northern Ireland	Oct 18th 2016	This article includes pro-choice and a brief pro-life ideology. It discusses a poll, which finds six in ten people in Northern Ireland want abortion decriminalised. Amnesty International respond that 'These poll findings demonstrate an overwhelming demand for change to Northern Ireland's draconian abortion laws. This is not a small margin of support for women's access to abortion, it is a definitive landslide'. It also includes the voice of the pro-life group who respond that the poll 'has no regard for the democratic process that respects and upholds the views of the pro-life people of Northern Ireland'. It presents how a '21-year-old Northern Ireland woman was given a three-month suspended prison sentence after being found guilty of taking abortion pills to end her pregnancy'.
FactCheck: Does this pro-life leaflet stand up to scrutiny?	Nov 6th 2016	Unbiased article analysing a pro-life document on its truthfulness and providing evidence to support their results.

A couple are live-tweeting their trip to the UK for an abortion due to a fatal foetal abnormality	Nov 10th 2016	Pro-choice article presents parents experiences of travelling for a 'termination for fatal fetal anomaly'. This article reports that this is not 'by choice' but the most 'humane' thing to do. The Government are asked to comment.
Savita Halappanavar "at the core" of new care standards for bereaved parents	Aug 10th 2016	This unbiased article reports on a midwifery scandal, Savita Halappanvar, who died due to septic miscarriage. It reports that 'Savita and many other people who have had pregnancy loss were at the core of the development of these standards'. This article presents information on the new national standards for bereaved following the loss of a pregnancy or perinatal death. The article includes that parents affected by pregnancy and perinatal death get identical care following pregnancy loss, despite how that loss came about.
Government offers €30,000 to woman forced to travel abroad for abortion	Nov 30th 2016	This pro-choice article reports on the Government paying a woman €30,000 in compensation because she was forced to travel abroad to have an abortion. It shares her personal experience of travelling for TOP for FFA. The health minister apologises to this woman and reports that he is in 'favour of a referendum' and finds these cases deeply

		upsetting. 'Amnesty International has welcomed the offer made saying that it showed the Government accepted the UN committee's finding' and 'acknowledges the harm caused to women by the current law'.
Catholic Church claims some unborn babies are 'spoken of as if they were as good as dead'	Dec 9th 2016	This pro-life article shares that the Irish Catholic Bishops' Conference feels that some unborn babies are "spoken of as if they were as good as dead". They included the uncertainty regarding a diagnosis of 'a life limiting condition', that some children may live and how they have a right to life until their natural death. It also includes that people's lives have been saved by the eighth amendment.
'He hung on to see his mummy' - Mum calls for anomaly scans after losing her new-born baby	Jan 31st 2017	This unbiased paper reports on the need for anomaly scans to be delivered in all maternity units following her experience of her baby dying 30minutes after being born with a FFA. The foetal anomaly was not noticed until the 32nd week of the pregnancy.
Woman subjected to 'grossly offensive comments' on fatal foetal abnormality on 98FM show	Jan 31st 2017	This is an unbiased article reporting the facts on how 'the broadcast authority of Ireland has partly upheld a complaint against 98fm after a woman detailed her experience of carrying a child with fatal

		foetal abnormality was branded a liar on air by another caller.
'Dismay' and online anger as pro-choice TFMR Ireland excluded from Citizens' Assembly	Feb 25th 2017	This pro-choice article presents the workings of the Citizens' Assembly. It includes how one pro-choice group are not included to present to the Citizens' Assembly. This group argues that 'they are the only advocacy group that consists solely of women and couples who had their tragedies compounded by being refused the medical care of their choice purely because of the Eighth Amendment'. This article does include how women's personal experiences will be listened to however.
Citizens' Assembly recommends abortion to be allowed without restrictions up to 12 weeks	April 23rd 2017	This article includes pro-life and pro-choice ideologies. It presents figures on how many of the citizens assemble agree to abortion in what circumstances. It includes that the citizens' assembly has 'has done what it's been tasked to do' and that Amnesty International reports this as a 'truly momentous leap for the human rights of women and girls in Ireland'. It includes the opinion of a 'pro-life campaign' concern that this will lead to abortion on demand and accusing the citizens' assembly of having a 'one-sided approach'.

New poll says Irish public want abortion laws to change... but only in certain cases	May 27th 2017	This article includes pro-life and pro-choice ideologies. It identifies that the Irish public 'favours a change to the current abortion laws but differs significantly from the recommendations made by the Citizens' Assembly on the matter, according to a new poll'. Both ideologies are given an opportunity to react to this poll.
Ireland's abortion laws subjected woman to 'cruel, inhuman and degrading treatment'	June 13th 2017	This pro-choice article reports on a 'second challenge to Irish laws forbidding abortions for medical reasons being lodged with the UN'. The 'UN human right committee again calls on Ireland to reform its restrictive abortion laws claiming these laws violated the human rights of women'. It includes a personal experience of a woman who travelled to the UK for a TOP for FFA.
'Some parents have to open the coffin every two hours to put in ice-packs so remains stay cool'	June 14th 2017	This pro-choice article reports that 'for the second time in just one year the united nations Human rights committee has ruled that Ireland subjected a woman to cruel, inhuman or degrading treatment by denying her access to abortion services'. It reports that the Irish are yet again 'humiliated by our Government' and how the Government are giving vague promises for a referendum.

		Experiences of women travelling for TOP for FFA are shared and a pro-choice group reports that the Oireachtas committee (members of the Oireachtas/Irish legislature chosen to consider the subject TOP, TOP for FFA and FFA) should work in parallel with the Citizens Assembly.
Pro-choice group fears wording of abortion referendum will be too limited	June 16th 2017	This pro-choice article presents, 'ABC spokesperson Linda Kavanagh Fears that the vote on the Eighth amendment will only offer very limited abortion access and repeat the failures of the protection of life during pregnancy act'. This article includes that '3,265 girls travelled from Ireland to the UK for abortions in 2016 accounting for 67.9% of non-resident abortions in Britain'.
Citizens' Assembly publishes additional recommendations on the Eighth Amendment	June 29th 2017	This pro-choice article reports on the outcome of the Citizens' Assembly, regarding the Eighth Amendment to the Constitution. It advocates for 'The decriminalisation of abortion, including the use of the abortion pill; and recognition of and protection of female reproductive rights and autonomy; were also provided in the responses from the Members'.

Supplementary File V - Topic Guide - Volunteers' Interview

Area of Interest	Questions/Prompts
Demographics:	Ethnicity, Gender, Employment, Name of Voluntary Organisation.
Personal:	Personal experience of infant loss/diagnosis of a FFA/LLC? Did you receive any supports from a voluntary organisation?
Voluntary Role:	When did you start volunteering? What is your role? Who do you support? What has facilitated you in delivering these supports? How do you feel when supporting these parents?
Supports:	How are you supported in being a volunteer? Are there any challenges? Have you any needs? Why do you feel this way?
TOP for FFA:	What has been your experience of volunteering following the implementation of TOP for FFA in Ireland? Are there any challenges? Have you any needs? Why do you feel this way?

Supplementary File VI - Suggested members of the multidisciplinary team

Consultant Obstetrician / Fetal Medicine Specialist
Consultant Neonatologist / Consultant Paediatrician / Paediatric Palliative Care Consultant
Paediatric Radiologist
Consultant Clinical Geneticist / Genetics Counsellor Hospital
Bereavement Clinical Midwife/ Nurse Specialist Dedicated Prenatal Diagnosis / Fetal Medicine Midwife
Prenatal Diagnosis Co-Ordinator/Clinical Midwife Specialist (CMS) Midwife Sonographer Delivery Suite Senior Midwife
Neo-natal Unit Senior Midwife/ Nurse
Maternity Social Worker Chaplaincy / Spiritual care

(Institute of Obstetrics and Gynaecology and Royal College of Physicians of Ireland 2020)[52]

Supplementary file VII - Topic Guide - Fetal Medicine Specialists'

Area of Interest	Question/Prompt
Demographics:	Ethnicity, Gender, Name of Maternity Hospital/Unit employed by.
Personal:	Education/Qualifications/Training? Years of employment in prenatal diagnosis/FFA? Personal experience of a child bereavement?
FMS Role:	When do you first come in contact with the woman/parents? What is your experience with prenatal diagnosis; delivering the diagnosis of the fetal anomaly/ in counselling the woman/parents? Are there any challenges? Have you any needs? Why do you feel this way?
Supports:	What is your experience in providing supports to the woman/parents for those who: a) Those who choose to continue the pregnancy b) Those who choose to TOP How do you feel when supporting these parents? What facilitates you providing these supports? Are there any challenges? Why do you feel this way?

a) Continuing:	What is your experience of caring for the woman/parents who continue their pregnancy with a FFA diagnosis? Are there any challenges? Why do you feel this way?
b) TOP for FFA:	What is your experience of caring for the woman/parents who TOP for FFA? How has the care you deliver to women who receive a diagnosis of FFA changed since TOP for FFA has been implemented in Ireland? What is your experience with providing a termination for FFA? Are there any challenges? Why do you feel this way?
Self-Care:	What is your experience with self-care?