

The outcome of trisomy 18 pregnancies following the legalisation of termination of pregnancy

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Abstract

Aim

Termination of pregnancy (TOP) became legal in Ireland in 2019, inclusive of conditions likely to lead to the death of the fetus, making TOP for 'fatal fetal anomaly' (FFA) an option. Trisomy 18 (T18) is the second most common lethal trisomy, with associated major structural anomalies. We aimed to study T18 pregnancy decisions and outcomes following the legalisation of TOP for FFA.

Methods

Retrospective study of all pregnancies diagnosed with T18 from 2019-2022, identified through the fetal medicine (FM) referral database.

Results

We identified forty-seven T18 pregnancies. In 59.6% (28/47), TOP was performed, with median gestational age (GA) at delivery of 18 weeks (range; 17-22 weeks). Parents choosing to continue pregnancy represented 17% (8/47) of the cohort, with six women delivering at term. In 11/47 cases, intrauterine death occurred in the second trimester (range; 13.2-18 weeks). Parents choosing TOP were referred to fetal medicine services at a significantly earlier GA when compared to those who chose to continue the pregnancy (14 weeks vs. 21.5 weeks, $p < 0.010$; respectively).

Conclusions

Following a T18 diagnosis, parents may choose to continue or terminate the pregnancy, with both care options now available in Ireland. Universal access to first-trimester prenatal aneuploidy screening would facilitate wider and earlier parental choice and decision-making.

Introduction

Trisomy 18 (T18) is the second most common autosomal aneuploidy after Trisomy 21. The main clinical features of T18 include a range of major structural anomalies, characteristic craniofacial features, distinctive hand posture, and fetal growth restriction^{1,2}. The live birth prevalence of trisomy 18 is estimated as 1/6,000-1/10,000. However, the overall prevalence is higher (1/2000) due to the high frequency of fetal loss and pregnancy termination after prenatal diagnosis³⁻⁶. An older report from our region (Cork, Ireland) published in 2013 on pregnancies diagnosed with T18 demonstrated the increased risk of spontaneous miscarriage, fetal death, and short life span (median 1.5 days)⁷.

National screening programmes exist in many countries with different combinations of maternal serum biochemical markers with or without nuchal translucency [NT] measurement. Non-invasive prenatal testing (NIPT) is now available in over 60 countries and was shown to have higher sensitivity and specificity for T18 compared to the traditional combined first and second-trimester screening tests. This allows most T18 pregnancies to be prenatally diagnosed⁸⁻¹⁰.

Currently, in our settings, pregnant women are offered a first trimester visit, including an ultrasound to date the pregnancy¹¹ with no national screening programme for aneuploidies¹². The mid-trimester anomaly scan is now available to all women in Ireland with a new clinical guideline published to standardise care¹³.

The Eighth Amendment of the Irish Constitution prohibited legal termination of pregnancy (TOP) ¹⁴. Following an electoral referendum, legislation led to the introduction of TOP services in 2019. Section 11 of the legislation describes TOP for a "condition likely to lead to the death of the fetus in utero or within 28 days of birth" ¹⁵, including for so-called 'fatal fetal anomaly (FFA),' a non-medical term popularised by parent groups and the media¹⁶.

Under Irish law and in clinical practice, T18 is considered a FFA therefore, parents may choose to continue or terminate the pregnancy with no upper gestational age limit. A delay in prenatal diagnosis of T18 due to the lack of formal first trimester screening might impact the parents' informed decisions¹⁷.

Thus, in this current study, we aimed to describe parents' decisions and the outcome of T18 pregnancies following the legalisation of TOP in the Republic of Ireland.

Methods

We performed a retrospective cohort study in a single tertiary centre between 2019 and 2022. Cases were identified through the fetal medicine referral database. The institutional ethical review board approved this study.

All pregnancies diagnosed with T18 after referral to a Fetal Medicine specialist clinic were included in our study. We did not include T18 cases from miscarriages when this was diagnosed on cytogenetic testing or at a post-mortem examination. We also excluded births where T18 was diagnosed postnatally. For the purpose of this study, we compared cases where parents chose to continue pregnancy versus those who chose TOP.

Computerized files eligible for inclusion were reviewed, and the following data were obtained from the hospital's electronic maternity record: maternal demographics characteristics, gestational age (GA) at referral to a Fetal Medicine Specialist, indication for the referral, gestational age at diagnosis, non-invasive and invasive genetic testing, mode of delivery, gestational age at delivery or at TOP, birthweight and length of survival in those who were live born. The parents' decision is documented in the electronic charts following genetic result confirmation by invasive test, and approval for TOP requires the input of a multidisciplinary team meeting.

Categorical variables were summarized as frequency and percentage. Continuous variables were reported as mean, standard deviation, median, and interquartile range. The Chi-square test and Fisher's exact test were applied to compare categorical variables, while independent samples T test or Mann-Whitney test were used to compare continuous variables. P-value less than 0.05 was considered statistically significant. SPSS software was used for all statistical analyses (IBM SPSS statistic for Windows, version 28, IBM corp., Armonk, NY USA 2021).

Results

During the study period, 28,225 births occurred at Cork University Maternity Hospital (CUMH). Out of them, we identified 47 pregnancies diagnosed with T18 through the Fetal Medicine database (Figure 1). The demographic characteristics of the cohort are presented in Table 1. The average maternal age was 37.5 ± 4.2 years, with advanced maternal age > 35 years in 85% (40/47) of our cohort. Twenty-five percent of the women were primiparous, and 47.9% had a previous pregnancy loss.

TOP was performed in 59.5% (28/47) pregnancies, with median GA at delivery of 18 weeks (range; 17-22 weeks). The interval from referral to fetal medicine services to TOP was four weeks (range; 3-5 weeks). This interval encompasses the duration from the first suspicion of a concern, the referral to the fetal medicine specialist, the process of genetic testing and awaiting complete test results, the case presentation at the multidisciplinary meeting, to the approval and certification of the termination of pregnancy (TOP). Three women chose to undergo chorionic villus sampling (CVS) at 12 weeks in another institution; others waited for amniocentesis at/after 15 weeks.

Referral indications in the TOP group were: Increased NT/ cystic hygroma in 51.8% (14/28), high-risk NIPT in 21.4% (6/28), and structural abnormalities in 28.6% (8/28). In our setting, TOP was performed through medical induction without fetal monitoring.

In 23.4% (11/47) cases, parents' wishes were not documented since second-trimester miscarriage occurred before full investigations were completed. The median GA at diagnosis in this group was 13 weeks (range; 13-18 weeks) and GA at intrauterine fetal death was 15 weeks (range; 14-16 weeks), with the median interval from diagnosis to the demise of 2 weeks (range; 1-2.5 weeks).

Parents deciding to continue pregnancy represented 17% (8/47) of the cohort. The average GA at delivery was 38 weeks (range; 33-38.5 weeks), with 75% (6/8) of pregnancies reaching term.

In Table 2, we compared women who had TOP (n=28) versus those who chose to continue with pregnancy (n=8). The GA at referral to fetal medicine services occurred significantly earlier in the TOP group compared to those who decided to continue with pregnancy (14 vs. 21.5 weeks, $p < 0.010$, respectively). The indication for referral differed significantly between the groups ($p = 0.034$). In the group that decided to

Maternal age (years)	37.5±4.2
Advanced maternal age>35 years old, n (%)	40/47 (85.1)
Primiparity, n (%)	12/47 (25.5)
BMI	25.9±3.2
Previous pregnancy loss, n (%)	23/47 (48.9)
Smoking, n (%)	1/47 (2.1)
ART, n (%)	2/47 (4.2)
GA at 1 st FMS clinic (weeks)	14.5 (13-20.5)
<u>Indications for referral</u>	
Increased NT/ cystic hygroma	24/47 (51)
High Risk NIPT	8/47 (17)
Structural abnormalities	15/47 (31.9)

continue with the pregnancy, 75% were referred due to structural anomalies detected at the anatomy ultrasound scan, compared to only 28.6% in the TOP group.

The details of the outcomes of the pregnancies delivered at term are presented in Table 3.

Table 1- Characteristics of the 47 study participants

Data presented as mean ± standard deviation (SD), or number (rate) as appropriate. BMI- body mass index; ART- assisted reproductive technology; FMS- fetal medicine specialist; GA- gestational age; NT- nuchal translucency; NIPT- non-invasive prenatal testing.

	TOP n=28	Continue pregnancy n=8	P value
Maternal age	37.6±4.2	37.1±4.2	0.768
AMA>35 years old, n (%)	24 (85.7)	7 (87.5)	>.99
Primiparity, n (%)	7 (25)	3 (37.5)	0.658
Previous pregnancy loss, n (%)	17 (60.7)	3 (37.5)	0.422
GA at 1 st FMS clinic (weeks)	14 (13-16.5)	21.5 (18.5-21.5)	0.010
Referred from anomaly scan	5 (17.8)	6 (75)	0.005
Structural indication for referral	8 (28.6)	6 (75)	0.034

Table 2- Comparison between women choosing to continue pregnancy and women choosing termination of pregnancy

Data presented as mean ± standard deviation (SD), or median (interquartile range) or n (%) as appropriate. TOP- termination of pregnancy; AMA- advanced maternal age; GA- gestational age; FMS- fetal medicine specialist.

Table 3- Outcomes of trisomy 18 term deliveries

Case	Year	Gestational age at referral (weeks)	Indication for referral to Fetal Medicine	Pregnancy outcome	Neonatal outcome

1	2019	22+2	Fetal growth restriction + Bilateral choroid plexus cysts	Induction and vaginal delivery at 38 weeks	Boy- 2240 grams Neonatal death at 1 day
2	2019	30+5	Fetal growth restriction + polyhydramnios	Induction and vaginal delivery at 38 weeks Pregnancy induced hypertension	Boy- 1900 grams Intrapartum death
3	2019	21+4	Multiple anomalies	Induction and vaginal delivery at 38 weeks	Boy- 1800 grams Intrapartum death
4	2020	22+5	Fetal growth restriction+ cardiac anomaly	Elective Caesarean delivery at 38 weeks	Girl- 1840 grams Neonatal death at 6 days
5	2021	13+1	Cystic hygroma (later, multiple anomalies)	Spontaneous breech delivery at 39 weeks	Girl- 2280 grams Intrapartum death
6	2021	19+4	Multiple anomalies	Spontaneous vaginal delivery at 37 weeks	Girl -1670 grams Neonatal death at 2 days

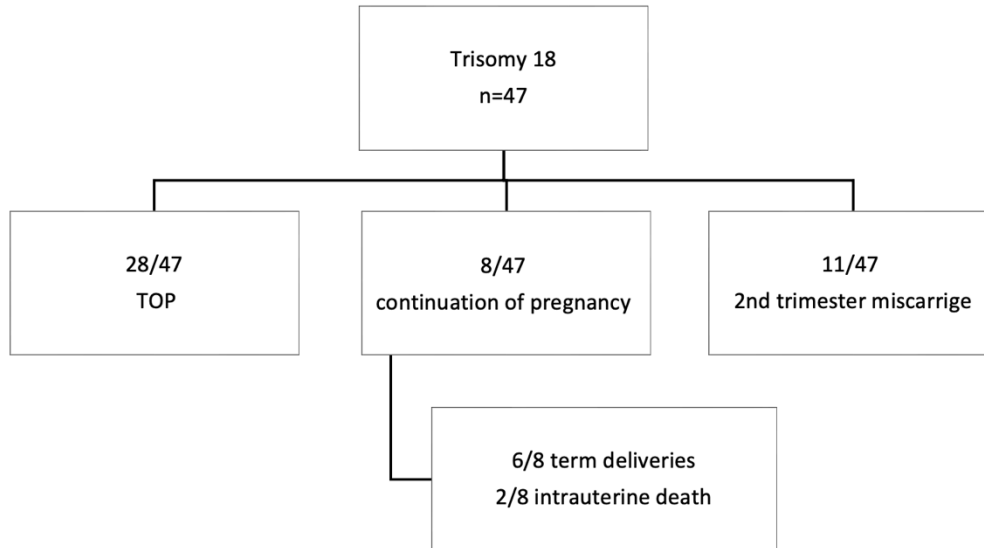


Figure 1- Flowchart of the study participants

Discussion

In this study, we identified pregnancies diagnosed with Trisomy 18 following the legalisation of termination of pregnancy in the Republic of Ireland. Our cohort consisted of forty-seven pregnancies, with 59% of parents choosing TOP, while the proportion choosing to continue pregnancy represented 17% of the cohort. Of these, we had six-term deliveries with 50% live births. In contrast to other studies^{18,19} that reported longer lifespans but similar to our previous report⁷, the most extended survival was one week.

The American College of Obstetrics and Gynecology (ACOG)¹⁰ recommends that prenatal genetic screening options be discussed and offered to all pregnant women regardless of age or risk for chromosomal abnormality. However, it is essential to remember that a screening test also requires extensive pre-and post-test counselling and informed consent from parents²⁰. Other professional bodies and organisations provide guidance and recommendations on topics such as patient selection, pre-test counselling, test performance characteristics, and the integration of NIPT into existing prenatal screening programmes²¹⁻²⁵.

There is no national first trimester aneuploidy screening programme in Ireland²⁶.

Women in Ireland can choose to pay for private aneuploidy screening tests²⁷, which is an apparent inequity in access to care. Moreover, most Irish pregnant women would choose testing if it was available^{28,29}. A recent publication studied the perspectives and awareness of pregnant women regarding prenatal screening for fetal trisomy in Ireland. The study demonstrated that while pregnant women possess a reasonable grasp of how to interpret screening test outcomes, they had limited awareness of the prenatal screening choices available to them. It is important to prioritise efforts to ensure that pregnant women receive equal and comprehensive information about and, ideally, access to NIPT at an early stage in their pregnancy³⁰, so they may make an informed choice about NIPT. Some will opt out of screening, and this can be influenced by personal beliefs, risk perceptions, access, affordability and cultural or religious beliefs. Within our cohort, we do not have full detail on the information given to women about screening, and whether they had had access to private funding or declined screening.

The decision to terminate a pregnancy following a FFA diagnosis is a personal and complex decision influenced by various factors, including the severity of the diagnosis, cultural and religious beliefs as well as access to prenatal care and genetic diagnosis³¹⁻³⁴. In our study, parents who decided to continue pregnancy were diagnosed later in gestation, primarily due to structural anomalies identified at the second-trimester anatomy ultrasound. It is, therefore, reasonable to speculate that the relatively late GA at diagnosis could influence parents' decisions, and it has been previously shown how GA at diagnosis substantially affects maternal-fetal attachment³⁵. Further, it is important to consider the medical consequences of late gestation in cases of TOP^{36,37}.

Our findings contrast with a similar study published recently³⁸ that presented the outcomes of trisomy 18 in a public hospital in South Africa. In their study, no significant difference in gestational age at diagnosis was demonstrated between those who did and did not terminate their pregnancies (23.1±5.1 vs. 24.7±5.3 weeks; $p = 0.067$). However, in their study, both groups received the diagnosis at a later GA.

A qualitative analysis of parental decision making following the diagnosis of suspected anomaly identified that parents have a nonlinear three-phase process: "information seeking," reflecting the way parents-to-be face the uncertainty associated with a fetal diagnosis and related prognosis; "implications," where consideration is given to future consequences of the decision; and "decision making," which reflects how the decision is made (head- or heart-led)³⁹. Another recent qualitative study⁴⁰ described the care

experiences of Irish parents whose pregnancy was diagnosed with FFA (mainly trisomy 18). This study described parents' need for consistent, well-communicated, and comprehensive care, irrespective of decisions made, which encourages a perinatal palliative care approach that is individual to the parents. Both studies highlight the need to improve the communication between healthcare professionals and patients and to allow enough time and provide adequate information for parents facing this decision.

Our study is not without limitations. The retrospective design and our data collection are based on cases referred to Fetal Medicine services, thus potentially under-representing the pregnancies where a diagnosis was made only postnatally. We also excluded cases where T18 was suspected but confirmed only postnatally. The strength of the study is in a relatively large cohort over four years from a single referral centre, as well as the novelty of the study looking at parental decisions following the legalisation of TOP in Ireland.

In conclusion, following the diagnosis of trisomy 18, parents may choose to continue or terminate the pregnancy, with both care pathways available in Ireland's maternity services since 2019. We should provide the choice to access universal first-trimester prenatal screening alongside expanded early anatomy ultrasound for all pregnant women to facilitate wider and earlier parental decision-making.

Declarations of Conflicts of Interest:

None declared.

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References:

1. Cereda A, Carey JC. The trisomy 18 syndrome. *Orphanet Journal of Rare Diseases*; 7. Epub ahead of print 2012. DOI: 10.1186/1750-1172-7-81.
2. Becker DA, Tang Y, Jacobs AP, et al. Sensitivity of prenatal ultrasound for detection of trisomy 18. *Journal of Maternal-Fetal and Neonatal Medicine*; 32. Epub ahead of print 2019. DOI: 10.1080/14767058.2018.1471460.
3. Dolk H, Loane M, Garne E. The prevalence of congenital anomalies in Europe. *Adv Exp Med Biol*; 686. Epub ahead of print 2010. DOI: 10.1007/978-90-481-9485-8_20.
4. Irving C, Richmond S, Wren C, et al. Changes in fetal prevalence and outcome for trisomies 13 and 18: A population-based study over 23 years. *Journal of Maternal-Fetal and Neonatal Medicine*; 24. Epub ahead of print 2011. DOI: 10.3109/14767051003758879.
5. Rasmussen SA, Wong LYC, Yang Q, et al. Population-based analyses of mortality in trisomy 13 and trisomy 18. *Pediatrics*; 111. Epub ahead of print 2003. DOI: 10.1542/peds.111.4.777.
6. Forrester MB, Merz RD. Trisomies 13 and 18: Prenatal diagnosis and epidemiologic studies in Hawaii, 1986-1997. *Genet Test*; 3. Epub ahead of print 1999. DOI: 10.1089/gte.1999.3.335.
7. Houlihan OA, O'Donoghue K. The natural history of pregnancies with a diagnosis of Trisomy 18 or Trisomy 13; a retrospective case series. *BMC Pregnancy Childbirth*; 13. Epub ahead of print 2013. DOI: 10.1186/1471-2393-13-209.
8. Gregg AR, Skotko BG, Benkendorf JL, et al. Noninvasive prenatal screening for fetal aneuploidy, 2016 update: A position statement of the American College of Medical Genetics and Genomics. *Genetics in Medicine*; 18. Epub ahead of print 2016. DOI: 10.1038/gim.2016.97.
9. Audibert F, De Bie I, Johnson JA, et al. No. 348-Joint SOGC-CCMG Guideline: Update on Prenatal Screening for Fetal Aneuploidy, Fetal Anomalies, and Adverse Pregnancy Outcomes. *Journal of Obstetrics and Gynaecology Canada*; 39. Epub ahead of print 2017. DOI: 10.1016/j.jogc.2017.01.032.
10. Rose NC, Kaimal AJ, Dugoff L, et al. Screening for Fetal Chromosomal Abnormalities: ACOG Practice Bulletin, Number 226. *Obstetrics and gynecology*; 136. Epub ahead of print 2020. DOI: 10.1097/AOG.0000000000004084.
11. Mohamed M, McCormick CA, Foo A, et al. Dating Ultrasounds are Fundamental to Modern Obstetric Care. *Ir Med J*; 115.

12. Petch S, Clinton S, Roche D, et al. Non-Invasive Prenatal Testing (NIPT) - We Need a National Programme. *Ir Med J*; 115.
13. Fleming A, Corbett G, McParland P. *The Fetal Anatomy Ultrasound*, <https://www.rcpi.ie/faculties/obstetricians-and-gynaecologists/national-clinical-guidelines-in->.
14. de Londras F. Constitutionalizing Fetal Rights: A Salutary Tale from Ireland. *Mich J Genet Law*. Epub ahead of print 2015. DOI: 10.36641/mjgl.22.2.constitutionalizing.
15. *Report of the Joint Committee on the Eighth Amendment of the Constitution, December 2017*. 2017.
16. Power S, Meaney S, O'Donoghue K. An assessment of the general public's knowledge of fatal fetal anomalies. *Prenat Diagn*; 38. Epub ahead of print 2018. DOI: 10.1002/pd.5348.
17. Choi H, van Riper M, Thoyre S. Decision Making Following a Prenatal Diagnosis of Down Syndrome: An Integrative Review. *Journal of Midwifery and Women's Health*; 57. Epub ahead of print 2012. DOI: 10.1111/j.1542-2011.2011.00109.x.
18. Meyer RE, Liu G, Gilboa SM, et al. Survival of children with trisomy 13 and trisomy 18: A multi-state population-based study. *Am J Med Genet A*; 170. Epub ahead of print 2016. DOI: 10.1002/ajmg.a.37495.
19. Gunne E, Lynch SA, McGarvey C, et al. Fatal fetal abnormality Irish live-born survival—an observational study. *J Community Genet*; 12. Epub ahead of print 2021. DOI: 10.1007/s12687-021-00534-3.
20. Biggio JR, Ralston SJ. Counseling About Genetic Testing and Communication of Genetic Test Results. *Obstetrics and Gynecology*; 129. Epub ahead of print 2017. DOI: 10.1097/AOG.0000000000002011.
21. Dondorp W, De Wert G, Bombard Y, et al. Non-invasive prenatal testing for aneuploidy and beyond: Challenges of responsible innovation in prenatal screening. *European Journal of Human Genetics*; 23. Epub ahead of print 2015. DOI: 10.1038/ejhg.2015.57.
22. Bakkeren IM, Kater-Kuipers A, Bunnik EM, et al. Implementing non-invasive prenatal testing (NIPT) in the Netherlands: An interview study exploring opinions about and experiences with societal pressure, reimbursement, and an expanding scope. *J Genet Couns*; 29. Epub ahead of print 2020. DOI: 10.1002/jgc4.1188.
23. Royal College of Obstetricians & Gynaecologists. Non-invasive Prenatal Testing for Chromosomal Abnormality using Maternal Plasma DNA. *RCOG Scientific Impact Paper*.

24. MacVillem M, Van Der Meij K, Sistermans E, et al. National implementation of genomewide non-invasive prenatal testing as a first-tier screening test in the Netherlands: The TRIDENT-2 study. *Prenat Diagn*; 40.
25. Hui L, Ellis K, Mayen D, et al. Position statement from the International Society for Prenatal Diagnosis on the use of non-invasive prenatal testing for the detection of fetal chromosomal conditions in singleton pregnancies. *Prenatal Diagnosis*. Epub ahead of print 2023. DOI: 10.1002/pd.6357.
26. Petch S, Clinton S, Roche D, et al. Non-Invasive Prenatal Testing (NIPT) - We Need a National Programme. *Ir Med J*; 115.
27. Kennedy Sarah, Miremberg Hadas, O'Donoghue Keelin. Non-invasive prenatal testing: Assessing the availability and accessibility of information available to the pregnant population within the Republic of Ireland Special Issue: British Maternal and Fetal Medicine Society and MacDonald Obstetric Medicine Society conference abstracts 2022; April 2023, Volume 130, Issue S1, Page:52. *BJOG* 2023; 130: 4–129.
28. Kelly Kristin, Leito Sara, Meany Sarah, et al. Evaluation of women's opinions on prenatal screening tests for fetal trisomy. *Top Scoring Abstracts of the RCOG World Congress 2022, London 13-15 June 2022 BJOG: An International Journal of Obstetrics & Gynaecology* 2022; 129: 212–213.
29. Ononeze BO, Gaffney G, Morrison JJ. Attitudes towards routine prenatal diagnostic investigations in obstetrics practice in the Republic of Ireland. *Ir Med J*; 96.
30. Kelly K, Leitao S, Meaney S, et al. Pregnant people's views and knowledge on prenatal screening for fetal trisomy in the absence of a national screening program. *J Genet Couns*. Epub ahead of print 18 September 2023. DOI: 10.1002/jgc4.1769.
31. Schechtman K, Gray D, Baty J, et al. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies.[Erratum appears in *Obstet Gynecol* 2002 Apr;99(4):678]. *Obstetrics & Gynecology*; 99.
32. Asplin N, Wessel H, Marions L, et al. Pregnant women's perspectives on decision-making when a fetal malformation is detected by ultrasound examination. *Sexual and Reproductive Healthcare*; 4. Epub ahead of print 2013. DOI: 10.1016/j.srhc.2013.02.001.
33. Benute GRG, Nomura RMY, Liao AW, et al. Feelings of women regarding end-of-life decision making after ultrasound diagnosis of a lethal fetal malformation. *Midwifery*; 28. Epub ahead of print 2012. DOI: 10.1016/j.midw.2011.06.011.

34. Guon J, Wilfond BS, Farlow B, et al. Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18. *Am J Med Genet A*; 164. Epub ahead of print 2014. DOI: 10.1002/ajmg.a.36298.
35. Yarcheski A, Mahon NE, Yarcheski TJ, et al. A meta-analytic study of predictors of maternal-fetal attachment. *International Journal of Nursing Studies*; 46. Epub ahead of print 2009. DOI: 10.1016/j.ijnurstu.2008.10.013.
36. Hendrix T, Roncoroni J, Magdamo B, et al. Stigma, Social Support, and Decision Satisfaction in Terminations of Pregnancy for Medical Reasons. *Women's Health Reports 2023*; 4: 271–279.
37. Abiola L, Legendre G, Spiers A, et al. Late fetal demise, a risk factor for post-traumatic stress disorder. *Sci Rep*; 12. Epub ahead of print 1 December 2022. DOI: 10.1038/s41598-022-16683-5.
38. Stewart C, Owusu-Bempah A, Boutall A, et al. Survival rates and outcomes of pregnancies with prenatal diagnosis of trisomy 18: A 16-year experience from a public hospital in South Africa. *Prenat Diagn*; 42. Epub ahead of print 2022. DOI: 10.1002/pd.6270.
39. Lotto R, Smith LK, Armstrong N. Diagnosis of a severe congenital anomaly: A qualitative analysis of parental decision making and the implications for healthcare encounters. *Health Expectations*; 21. Epub ahead of print 2018. DOI: 10.1111/hex.12664.
40. Jackson P, Power-Walsh S, Dennehy R, et al. Fatal fetal anomaly: Experiences of women and their partners. *Prenat Diagn*. Epub ahead of print 29 January 2023. DOI: 10.1002/pd.6311.