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Short communication

Termination of pregnancy for fetal anomaly: a population-based study 1995 to 2004

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Terminations of pregnancy for fetal anomaly (TOPFAs) were analysed over a 10-year period from a population-based congenital anomaly register covering 646 342 births. A total of 3189 cases of TOPFA were identified, prevalence of 49.3 per 10 000 registerable births. The rate of TOPFA at all gestations and at less than 16 weeks increased significantly. There were 102 cases of liveborn TOPFAs (3.2%). The proportion of liveborn TOPFAs after 22 weeks of gestation decreased significantly but below 22 weeks remains unchanged. TOPFA is increasing in frequency, occurring earlier in pregnancy. Live birth is a possible important outcome.

Keywords Abortion, congenital, fetal anomaly, live birth, termination, TOP.

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Introduction

Termination of pregnancy for fetal anomaly (TOPFA) is a rare outcome of pregnancy and a principal element of fetal medicine. It is an important option for women in the UK undergoing screening for fetal anomalies during pregnancy and commonly chosen when a lethal or seriously handicapping condition is diagnosed prenatally. The 1990 amendment to the Abortion Act has no gestation limit defined for cases of TOPFA following prenatal diagnosis (category E).

The Office for National Statistics publishes an annual reference volume of data on legally induced abortions in England and Wales. Data are collected using the notification of abortion form (Form HSA4) on cases performed under the Abortion Act 1967. Cases are categorised by the statutory grounds on which they are undertaken. Category E is the most relevant for identifying TOPFA and refers to cases '*where there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped*'. The only subanalysis of this group within the annual reference volume is to give details of the type of congenital malformation or other condition.

There is a paucity of published data on TOPFAs. Data on TOPFAs are collected within the national Confidential Enquiry into Maternal and Child Health but only for cases on or after 22 weeks gestation. Many regional congenital anomaly registers collect information on TOPFA but there is no national coverage of these registers.

Live birth following TOPFA has been the subject of discussion and debate with Royal College of Obstetricians and Gynaecologists[1] guidelines recommending feticide from 22 weeks of gestation produced in 1998.

We present data on TOPFAs from a large population-based cohort of births occurring within a 10-year period from 1995 to 2004 in the West Midland Region of the UK. During this period, TOPFA at 16 weeks onwards was undertaken as a medical procedure using oral Mifepristone followed by either Gemeprost or Misoprostol to induce vaginal delivery. A very small number of surgical TOPFAs were undertaken at lower gestations.

Methods

The West Midlands Congenital Anomaly Register (WMCAR) was setup in June 1994 and is administered by the West Midlands Perinatal Institute.

The register aims to collect information on the occurrence of suspected and confirmed congenital anomalies of West Midlands residents, detected before and after birth. The West Midlands region covers a population of approximately 66 000 births per year with notifications received from 20 maternity units.

Data are collected from multiple sources including antenatal ultrasound, fetal medicine, laboratories, labour wards, regional cardiology, paediatric inpatient admissions including surgery, and pathology departments. All anomalies are coded using the International Classification of Disease version 10 (ICD 10).

All outcomes of pregnancy are included on WMCAR: live births, stillbirths, late fetal losses, and terminations of pregnancy. The WMCAR is maintained on the same database as the regional register of perinatal deaths. In this way, data on infants with lethal fetal anomalies can be validated. From 2000 onwards, mortality data are validated against records of stillbirth and death certificates. Less than 1% of perinatal deaths arising from termination of pregnancy were ascertained via cross-matching with stillbirth and death certificates.

The study population was births to West Midlands residents delivered between 1995 and 2004.

The data set includes diagnosis (ICD 10), ultrasound derived gestation, outcome (live or stillborn), date/time of birth, date/time of death, and how the case was defined for registration purposes by the attending professionals. Notifications of liveborn TOPFA were validated using the outcome, age at death, and recording of life signs.

For the purposes of this study, a TOPFA is defined as a legally induced termination regardless of gestation or outcome following a prenatal diagnosis of a congenital anomaly.

Comparative data on abortions and data on perinatal deaths, registerable births, and conceptions were supplied by the Office for National Statistics. Registered births are live births plus stillbirths (at or after 24 weeks of pregnancy). Conception statistics include pregnancies that result in one or more live or stillbirths, or a legal abortion under the 1967 Act. Conception statistics do not include miscarriage before 20 weeks or illegal abortions. Dates of conceptions are estimated using recorded gestation for abortions and stillbirths, and assuming 38 weeks gestation for live births.

Annual rates were calculated and secular trends were examined using the chi-square test for linear trend.

Results

There were 3189 cases of TOPFA notified to the WMCAR and born to West Midlands residents between 1995 and 2004. The cohort comprised 3125 singleton pregnancies and 64 twin pregnancies. Less than 1% took place in the private sector.

The number of abortions performed under statutory grounds E (alone or with other grounds) reported by the Office for National Statistics for the same period was 1393, 43.7% of the number reported to the WMCAR.

There were 646 342 registered births and 808 236 conceptions during this period in the West Midlands. The prevalence of TOPFA was 49.3 per 10 000 (1 in 203) registerable births and 39.5 per 10 000 (1 in 253) conceptions.

Gestations of TOPFAs ranged from 8 to 40 weeks, median 19 weeks. The proportions occurring at different gestations were 20.4% before 16 weeks; 32.4% between 16 and 20 weeks; 38.3% between 20 and 24 weeks; and 8.4% at or after 24 weeks.

Thirty-nine percent of TOPFAs were for chromosomal anomaly; 25% for malformations of multiple systems; 23% for neural tube defects; 5% for renal problems; and 5% for cardiac defects.

There were 264 TOPFAs (live births and stillbirths) at or after 24 weeks gestation. Of these 94 cases occurred at or after 28 weeks and 26 at or after 34 weeks, this represents 2.9% and 0.8%, respectively, of all TOPFAs. The indications for TOPFAs at or after 24 weeks were 26% for chromosomal anomaly; 41% for malformations of multiple systems; 11% for neural tube defects; 7% for renal problems; and 12% for cardiac defects.

Analysis over time revealed that the incidence of TOPFA has increased significantly from 4.40 to 5.26 per 10 000 registerable births during the 10-year period of study (χ^2 = 9.349, P = 0.00223). There was an increasing proportion of cases occurring before 16 weeks: 12.1% of cases in 1995 increasing to 27.9% in 2004 (0.53 to 1.47 per 10 000), χ^2 = 51.587, $P < 0.00001$.

Live birth after termination of pregnancy for fetal anomaly

Of the 3189 cases of TOPFA, there were 350 registerable births, giving a prevalence of 5.4 per 10 000 registerable births. The 350 registerable births following TOPFA comprised 248 stillbirths (7.8% of TOPFA) and 102 live births with subsequent neonatal deaths (3.2% of TOPFA). There were 6304 perinatal deaths to West Midlands residents for 1995–2004. TOPFAs comprise 5.6% of perinatal deaths. Liveborn TOPFAs occurred in 18 of the 20 maternity units in the West Midlands.

There has been a significant reduction in the proportion of TOPFAs resulting in live births over time (χ^2 = 5.173, P = 0.02295) from 4.0% in 1995 to 1.7% in 2004.

There were 43 live births following TOPFAs between 2000 and 2004, these were cross-checked with death certificates. Forty-two cases were registered as live births and neonatal deaths.

Of the 102 live births, the gestation ranged from 17 to 33 with a median of 21 weeks. The survival duration for liveborn TOPFAs was a median of 80 minutes. Thirty-seven cases survived for 1 hour or less and six cases survived 6 hours or more.

The proportions of live births at different gestations were 14.7% between 16 and 20 weeks; 65.7% between 20 and 24; and 19.6% at or after 24 weeks. Within the 20- to 24-week gestation group the proportion of cases defined as 'live births' was related to gestation being 3.5%, 5.4%, 6.4%, and 9.7% for 20, 21, 22, and 23 weeks of gestation, respectively (Table 1).

Table 1. TOPFA cases 20–23 weeks, life signs by gestation: West Midlands 1995–2004

Gestation	Liveborn	Stillborn	Total	% Liveborn	95% CI
20 weeks	14	390	404	3.5	1.7–5.2
21 weeks	23	406	429	5.4	3.2–7.5
22 weeks	15	220	235	6.4	3.3–9.5
23 weeks	15	139	154	9.7	5.1–14.4

The proportion of live births at 20 and 21 weeks within each anomaly group was 5% for chromosomal anomalies (7% for trisomy 21; 2% for all other abnormal karyotypes); 3% for multiple structural anomalies; 4% for renal; and 7% for cardiac.

During this 10-year period, both the total number of cases and the proportion defined as live births in the 22- and 23-week category declined significantly ($\chi^2 = 8.561$, $P = 0.00343$) from 6.5% in 1995 to 3.0% in 2004 (Figure 1). There was no significant change in the proportion defined as live births at 20 and 21 weeks, $\chi^2 = 0.174$, $P = 0.67638$.

Discussion

This is a large population-based study with data derived from a single register. The use of multiple source notifications and cross-validation with mortality data ensures good ascertainment and reduces bias. There should be minimal selection bias, which may be present in studies based on the outcomes of referrals to tertiary fetal medicine centres.

The number of cases of TOPFA identified within this study is 2.4 times higher than that reported in national statistics for the same population. This indicates significant underreporting within national reference data on abortions for fetal anomaly, although this may be due to errors in the recording of statutory grounds rather than an under-ascertainment of all abortion cases.

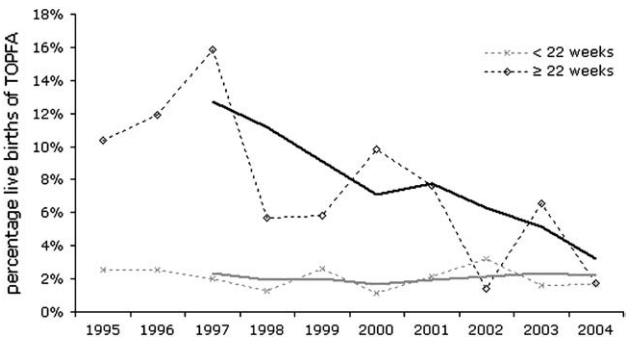

Figure 1. Annual rates of live birth in TOPFA at selected gestations: West Midlands 1995–2004 (including three year moving averages).

The rate of TOPFA reported in this study is 49.3 per 10 000 registerable births. This is comparable with the rate reported from a large population-based cohort (n = 573 417) in the North East of England[2] of 34.7 per 10 000 registerable births for a 16-year period (1985–2000). The TOPFA rate increased during the time of this study and was 47.5 per 10 000 registerable births for 1997–2000.

Evidence from Canada[3] shows a significantly increasing trend for all TOPFA during 1991 to 1998 with an initial rate of 5.2 per 100 000 increasing to 40.2 per 100 000. A study reporting TOPFA rates from congenital anomalies across five European countries[4] showed the highest rate in Paris (48.4 per 10 000 live and stillbirths) and lowest in Antwerp (9.2 per 10 000 live and stillbirths).

The rate of TOPFA at all gestations and at less than 16 weeks increased significantly during the time of our study. Evidence from the North East of England,[2] and Canada[3] also support this finding. This is likely to be due to the increasing sensitivity of screening programs for the detection of structural and chromosomal anomalies during this period. Serum screening and ultrasound imaging have both improved during this time. There have been no changes in UK legislation relating to abortion during the time of this study.

Within our study 3.2% of TOPFAs result in a live birth. The proportion has reduced significantly over the period of this study from 4.0% in 1995 to 1.7% in 2004. In particular, those of 22–23 weeks gestation have reduced significantly over the period of this study from 6.5% in 1995 to 3.0% in 2004. This is likely to be due to the impact of guidelines issued by the RCOG,[1] that feticide should be offered to ensure that live birth does not occur following TOPFA after 22 weeks. Our data show a significant chance of live birth at 20 and 21 weeks, which we have quantified as being 3.5% and 5.4%, respectively. The RCOG guidelines do not recommend feticide at these gestations.

Stillbirths and live births following TOPFA comprise 5.6% of perinatal mortality. The practice of feticide will not affect the perinatal mortality rate when carried out at 24 weeks onwards as at these gestations, cases must be registered regardless of the presence of life signs at birth. At gestations less than 24 weeks, the practice of feticide will ensure that cases do not contribute to the numbers of perinatal deaths.

The medical and legal issues are complex[5] and should not be over simplified. It has been suggested that the live birth and subsequent death from prematurity of a baby following a TOPFA could lead to the criminal accusation of murder, or the civil charge of manslaughter. We contend that this is highly unlikely within the current UK law[5] and should not be used as a means of restricting TOPFA.

A recent clarification from the RCOG[6] states that '*It is extremely important to distinguish between physiological movements and signs of life, as well as being aware that observed*

movements may be of a reflex nature and not necessarily signs of life or viability.' The process of registration of a live birth and subsequent completion of a death certificate involves the professionals in additional duties and responsibilities with the involvement of the coroner's office in some cases. The incentive therefore is very much to err on the side of not recording signs of life where any doubt exists. It is therefore important that clinicians apply rigorous objective criteria to a diagnosis of 'signs of life'.

The data suggest that the clinical staff within the West Midlands follow guidelines and do not register cases as showing signs of life unless they are convinced that these are more than physiological or reflex movements (however, these are defined).

The potential for medical staff to be the subject of investigation or legal proceedings suggests that there should be awareness that live birth is a possible outcome of termination of pregnancy. Our data clearly show there will be cases of live birth following TOPFA at 20 and 21 weeks, and the professionals dealing with the information and consent process should be aware of the likelihood of this outcome.

There is little evidence to suggest that feticide is in the best interests of the woman, or her medical attendants. Generalisation is difficult, but for universally lethal fetal anomalies, there seems little justification for insisting upon a feticide procedure being undertaken in an already difficult clinical scenario. Where the fetal prognosis is universally fatal, the early delivery and subsequent terminal care of a baby can be a satisfactory outcome. Parents facing these situations need an individualised and compassionate approach, with a full disclosure of the possible outcomes including the chance that without feticide their baby may show signs of life.

Serious handicap, in nonlethal conditions, such as Down syndrome, is different, and the expectation that the baby will not be born alive and survive is an absolute requirement of the TOPFA process. For this group, the 21-week gestation limit for feticide would seem to be entirely appropriate.

Conclusions

TOPFA is increasing in overall frequency and occurring at earlier gestations in the West Midlands of the UK between 1995 and 2004.

Live birth is an important outcome of TOPFA, occurring in 3.2% of cases. The proportion of live births following TOPFA after 22 weeks of gestation has decreased significantly during this time but has remained unchanged at 20 and 21 weeks.

We believe that these data will inform the ongoing debate regarding the optimal management of termination of pregnancy for fetal anomaly. ■

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