**Termination for fetal anomaly – are women in England given a choice of method?**

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**Summary**

Choice of a medical or surgical method of termination for fetal anomaly (TFA) is advocated in national guidelines based on a similar risk profile. We investigated whether women are offered choice of method by surveying members of a UK parent support organisation.

An online questionnaire was designed to examine respondents’ experience of TFA. 351 responses were included in the final analysis. TFAs after 24 weeks gestation and selective reductions were excluded.

Mean gestational age at TFA was 17 weeks. 14% (n=50) were offered a choice of method, falling to 8% (n=19) after 14 weeks gestation. Overall, 78% (n=275) underwent medical TFA with 88% stating they chose it because it was the only method offered. 60% (n=30) of those offered a choice had a surgical TFA.

Our survey suggests women having TFA are not offered a choice of method. Service delivery should be improved to meet national guidance and women’s needs.

**Introduction**

Most developed countries offer women a range of prenatal screening and diagnostic tests for chromosomal and other major fetal anomalies. There has been a move in recent years to expand access to screening and testing, particularly within the first trimester. For example, the United Kingdom (UK) National Screening Committee now recommends that all women are offered combined screening for Down’s syndrome between 11 and 14+1 weeks of pregnancy (National Health Service Fetal Anomaly Screening Programme, Model of Best Practice 2011-14). Prenatal testing at an even earlier gestational age is set to increase with the development of accurate non-invasive techniques for detecting aneuploidy using cell free fetal DNA (Chitty et al, 2012).

Despite technological advances, there are no or few treatments available for most major anomalies that are detected prenatally. Thus, when a diagnosis of an anomaly is made, the option of termination of pregnancy is usually discussed. In Europe, the majority of women presented with a prenatal diagnosis of trisomy or major structural defects will opt for termination (Boyd et al, 2008). One of the drivers for earlier diagnosis is to enable women who choose to end their pregnancy to do so at an earlier stage. (Nicolaides, 2011). This also allows women to avoid the increase of procedure-related complications at later gestations (Cates et al 1981; Bartlett et al 2004; DH, 2012). If more diagnoses of major fetal anomalies are made through improvements in testing technologies, it follows that more women are likely to need access to termination services. It is therefore incumbent on providers to ensure services are designed to meet women’s needs.

In the UK, the Royal College of Obstetricians and Gynaecologists (RCOG) recommends that in the context of termination for fetal anomaly (TFA) women should be offered a choice of method (RCOG, 2010). Both medical and surgical methods of termination have low complication rates (Bryant et al, 2011; Kelly et al, 2010). In the second trimester, there is evidence that shows surgical termination has a lower complication rate than medical (DH 2012; Lohr et al, 2008; Lyus et al, 2013;). Neither method is associated with adverse psychological sequelae (Burgoine, 2005; Korenromp et al, 2005; Statham, Solomou & Green, 2001) nor adverse outcomes in a subsequent pregnancy (Chasen et al, 2002; Jackson et al, 2007; Kalish et al, 2002; Virk, Zhang and Olsen, 2007). In fact, recent research suggests that it can be psychologically beneficial for women to be enabled to have the procedure managed in a way that best fits their individual emotional coping style (Kerns et al, 2012).

With some complex anomalies, detailed examination of the fetus is required to confirm the diagnosis and inform counselling on the risk of recurrence (Boyd et al, 2004). In such circumstances, medical induction is generally advised. However, karyotypic and some structural anomalies can be confirmed with non-intact specimens obtained from a dilatation and evacuation (D&E), the most common method of surgical termination used in the second trimester (Bernick et al, 1990; Shulman et al, 1990; Sun et al,1999).

The UK-based support organisation Antenatal Results and Choices (ARC) was established as a charity in 1988 under the name SATFA (Support after Termination for Fetal Abnormality) in order to help address the practical and emotional support needs of parents undergoing TFA and to help health care professionals deliver high quality care in this challenging context. The organisation runs a national helpline which is accessed by approximately 6000 clients annually. ARC noted that women using the helpline reported restrictions on choice of method for TFA within their National Health Service (NHS) hospital, particularly when the diagnosis was made after 12 weeks of gestation. In addition, many women contemplating TFA after diagnosis of an anomaly made beyond 14 weeks’ gestation were unaware that D&E was an alternative and safe form of termination procedure.

In order to explore this apparent disparity between service delivery, national recommendations and women’s needs, ARC secured a voluntary sector grant from the Department of Health for England to convene an Expert Advisory Group on TFA, conduct research to better document patient experiences with TFA, and to make recommendations for improved care pathways for women deciding to end a pregnancy after a prenatal diagnosis of a fetal anomaly. This paper reports the results of an anonymous, self-administered online questionnaire which was developed with help from the Expert Advisory Group. The aim of the questionnaire was to determine if women undergoing TFA in England were offered a choice of method and what factors influenced the offer of a choice. Information on women’s experiences of TFA was also collected.

**Methods**

An 18-item anonymous, self-administered online questionnaire was created using SurveyMonkey (www.surveymonkey.com). The survey was designed to collect information on respondents’ experience of TFA, acceptability, and preferences using structured single and multiple choice questions and open-ended responses. A web link to the survey and explanatory text were emailed to 600 members of ARC, all of whom were parents bereaved after TFA and resident in England. It was also publicised in the news section on the ARC homepage (www.arc-uk.org) and in a communication from the administrator of ARC's password protected on-line support forum. Responses were invited regardless of time since the termination or gestational age at the time of termination.

A one-page summary describing the project and methods was emailed to the National Research Ethics Service (NRES) Queries line to ascertain whether ethical approval was required. The NRES advised that ethical approval was not required for this project.

The survey was open for responses from 20 January to 7 March 2012. Responses were downloaded into Microsoft Excel, cleaned, coded, and reviewed for consistency by two authors (PL and CL). Differences in interpretation of responses or coding were discussed by all four authors until an agreement was reached. Where more than one TFA was reported by the respondent, the most recent one was used in the analysis. Gestational age at diagnosis and termination were rounded down to full week (based on an ultrasound estimate of gestational age or, if not available, last menstrual period). Finally, where an initial attempt at TFA failed and completion was performed by an alternative method (e.g. a woman undergoing a medical procedure needed a surgical procedure to remove retained placenta), the intended method was used for analysis. Descriptive statistics were generated and group comparisons conducted by Chi squared tests using SPSS 21 (SPSS Inc, Chicago). Difference was considered statistically significant when the p-value was<0.05. Where required, 95% confidence intervals were calculated using Microsoft Excel 2010.

**Results**

In total, there were 430 survey responses of which 379 (88%) were complete. We excluded cases where the gestational age at TFA exceeded 24 weeks (24 cases) given that surgical management is generally not offered beyond this gestation. Four multiple pregnancy cases involving selective reduction of an affected fetus were also excluded because this is only effected medically. The total number of surveys used for analysis was therefore 351.

(Table I here)

All nine screening regions in England were represented amongst the survey respondents (Table I), with the highest proportions being from London and the South East (18.8% and 25.6% respectively). This replicates the geographical spread of the ARC membership. Most women underwent TFA in the same region as they received antenatal care. However, a small proportion of women in most regions did travel for their termination, mainly to London.

The TFAs were performed between 1969 and 2012. Most (75.7%, n=265) were performed after 2006. The great majority of TFAs were undertaken within the NHS (99.3% of medical and 73.8% of surgical procedures). Only two women (0.7%) had their medical TFA in the independent sector, while 17 (26.2%) of surgical procedures took place there (p<0.001).

The mean gestational age at final diagnosis of the anomaly was 17 weeks (range 7-24 weeks). The mean gestational age at TFA was 17 weeks (range 8-24 weeks) with a mode of 13 weeks corresponding to gestational ages at first and second trimester screening.

(Table II here)

Table II shows the indications for termination reported by respondents. The number categorised as chromosomal anomalies identified through karyotype or QF-PCR was 195 (55.6%) of which 57 (29.2%) had a termination by 14 weeks gestation.

In answer to the question: ‘which methods of termination were offered to you?’, 261 (74.4%) responded that they were only offered a medical procedure, 50 (14.2%) were offered a medical or surgical procedure, and 26 (7.4%) were only offered a surgical procedure. Fourteen women (4%) could not recall which method was offered.

The majority of respondents (275, 78.3%) had a medical induction, 67 (19.1%) had surgical management and 9 (2.6%) did not know which method applied to them. Of the 50 women offered both methods, 30 (60%) opted for a surgical termination. Of women who had a medical termination only 6.5% (n=18) were offered a choice, compared to 44.8% (n=30) who had a surgical procedure after being offered a choice of method (p<0.001).

(Table III here)

Table III shows that of the 50 women who were offered both methods of termination, 32 (64%) had a fetus with a chromosomal anomaly compared to 18 (36%) with a structural anomaly (p<0.05). Among the women who had exceeded 14 weeks gestation at time of their termination (n=248), only 15 (6.0%) were offered a choice of method. Regarding the respondents who were only offered medical, 54.4% (n=142) had a diagnosis of a chromosomal anomaly from CVS or amniocentesis.

Women were asked to list their reason(s) for choosing a particular method. Of women who had a medical procedure, 88% (n=242) responded that they chose this method because it was the only one offered. Perceived greater safety of medical induction was a factor for 25 (9.1%), and the option of having a post mortem examination was listed by 24 (8.7%). Of the women who had a surgical procedure, 39 (58.2%) said that they opted for this because they ‘could not cope with a medical termination’. Surgical termination was the only option offered to 20 (29.9%) women.

When asked how long the time period was between diagnosis and making the decision to terminate, 91.4% (n=319) stated they made the decision within a week. There were 110 respondents (31.5%) who made the decision immediately. Thirty nine (58.2%) women who had surgical management made an immediate decision, compared to 70 (25.6%) of those who had a medical induction (p<0.001). There is evidence within the open comments that time pressure was an issue for some:

*With hindsight due to the short time window for surgery the decision felt pressurised. (36)* 13 weeks gestation at diagnosis of Trisomy 13

*It was two days before Christmas. If we had left it any later a medical would have been our option which I feared even more. (285),* 12 weeks gestation at diagnosis of Trisomy 21

Once women told the hospital of their intention to terminate the pregnancy, 95.2% (n=334) had the procedure initiated within a week. For women having a medical termination, 9.8% (n=27) were accommodated immediately, whereas none of those having a surgical procedure was admitted straight away (p<0.001). Most women, (70.9% n=249) stated that the wait between decision and termination was ‘just about right’. Among women who had a surgical termination 38.8% (n=26) stated that the wait was too long compared to 17.1% (n=47) of those who had a medical termination (p<0.001).

Respondents were asked who explained the termination procedure to them. The majority said this was done by a doctor (64.7% n=227) or midwife (45.3% n=159) while others were informed by nurses (15.7% n=55) or other health care professionals (3.7% n=13). Fewer women who had a surgical termination were likely to be informed about the procedure by a midwife (22.4% (n=15) compared to 51.3% (n=141) of the women who had a medical termination (p<0.001). When asked if the explanation they received told them ‘all they wanted to know’, 45% (n= 158) of respondents answered “yes”, 41% (n=144) answered “to some extent” and 14% (n=49) answered “no”. Of the 146 who expanded on their answers, 33 (22.6%) stated that they had not realised that medical termination involved going through labour.

(Table IV here)

Table IV shows level of agreement to the statement ‘*Overall I was able to have the method of termination that best suited me’*. Just over half (52.4% n=184) agreed or strongly agreed with the statement, 28.8% (n =101) were ambivalent and 18.8% (n=66) disagreed or strongly disagreed. Few women who had either medical or surgical procedures strongly disagreed that it was right for them, 9.1% (n = 250) and 7.5% (n =5). The women who had a surgical procedure were more likely to agree or strongly agree with the statement compared to women who had a medical TFA (73.1% (n=49) versus 47.3% (n=130) (p<0.001).

**Discussion**

Understanding service requirements for women who opt to end their pregnancy after a diagnosis of a fetal anomaly is important. This study found that the majority of women surveyed were only offered and ultimately had a medical termination for this indication. Many reported that a medical procedure had best suited them but a significant proportion would have preferred a surgical procedure. Furthermore, those women who had undergone a surgical procedure were more likely to consider that it was right for them. These findings suggest that services in England may not fully accommodate choice for women in the context of method of TFA nor follow national guidance (RCOG, 2010). Although 53% of the survey respondents report experiences before 2010, the data from the remaining 47% , who had their terminations after this, do not show that their care changed to better meet the guidance.

Medical management of termination allows for post-delivery investigation of an intact fetus, which may or may not produce information of significance for future pregnancies (Boyd et al, 2004; Vogt et al, 2012). However, over half the women participating in this survey were undergoing TFA because of a chromosomal abnormality which either would not require confirmation or which could be easily confirmed using a specimen from a surgical procedure (Bernick et al 1998). Although it is still a subject of research, some studies suggest that, with a systematic approach, many structural anomalies can be elucidated from non-intact specimens (Gawron et al. LM, Hammond C, Ernst LM. 2013; Ernst LM, Gawron L, Fritsch MK. 2013). It is important that women are given accurate information as to the value and necessity of a post mortem examination in order to help inform their decision making about method of termination.

The gestational age distribution of our sample was bimodal with peaks at 13 and 17 weeks gestation reflecting the main screening periods in the first and second trimesters. Up to 15 weeks gestation surgical termination can be performed by vacuum aspiration but after this point a D&E is required (RCOG, 2011). It is acknowledged that there are a limited number of clinicians working in the NHS competent to perform D&E (RCOG, 2011; Thomas, Paranjothy and Templeton, 2003). The reasons for this are not entirely clear but may be due to a shift in the provision of second trimester termination services from the NHS to the independent sector, thus impacting caseload for training, and a decreasing proportion of gynaecologists engaged in providing second trimester abortion (Savage and Francome 2011). In our sample, one third of women undergoing termination of pregnancy for a fetal chromosomal anomaly had their termination before 14 weeks’ gestation when a vacuum aspiration would have been appropriate. So it appears there is a lack of provision within the NHS of both D&E and vacuum aspiration methods. This is reflected in Department of Health (DH) statistics for England and Wales which show a decline in the proportion of abortions performed in the NHS from approximately 13 weeks’ gestation (DH, 2013). This shortage of surgical termination services in the NHS, particularly after 13 weeks’ gestation, may explain why some women who preferred a surgical procedure expressed feeling pressured for time to make the decision to terminate. The limited provision may also account for the significant proportion of women having surgical termination who felt they had to wait too long for the procedure to be performed. In order to ensure access to termination options in a timely fashion, NHS services will need to address gaps in training and provision and in the meantime facilitate improved pathways into the independent sector where these services are already provided under contract to the NHS.

Over half our survey respondents did not feel they had all the information they required about methods of termination. For example, a number of women stated that they were unaware that a medical termination involved an induced labour and delivery of the baby. In addition, although just under half received information from midwives about methods of termination, midwives were less likely to provide information on surgical compared to medical termination. It is unclear whether this reflects the limitations of the treatment options available in the NHS services where the midwives practise, and/or some midwives’ limited knowledge about surgical TOP and therefore a lack of confidence in counselling women about this option. Nevertheless, the survey suggests that staff should be better equipped to provide women with accessible evidence-based information on options for termination methods as well as what each procedure entails.

The study has some limitations. The sample was small, self-selecting, and exclusive to ARC, one parent support organisation. Few respondents had undergone surgical termination. In addition, the questionnaire was self-administered and retrospective and therefore subject to recall bias. The sample did, however, include a wide geographical spread and three quarters of respondents had their TFA after 2006 so are recollecting recent experiences.

As prenatal testing improves, an increasing number of women and couples will find themselves making decisions about termination of pregnancy for fetal anomaly. Although national guidance recommends offering women a choice of termination method wherever possible, we did not find this to be the experience of most respondents to our survey. Moreover, many did not find the information they received to be sufficient to make an informed choice about method.

Evidence shows that having the opportunity to have the termination process managed in a way that best meets individual coping styles can help women deal with the psychological sequelae of TFA (Kerns et al, 2012). The survey results suggest a number of areas in need of improvement if services in England are to facilitate and support women’s choices; these include staff enabled to provide unbiased evidence-based information on options, greater collaboration with independent sector services and an adequately skilled workforce to accommodate method choice.

**Declarations of interest**

The authors report no declarations of interest.

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**Ethics Approval**

The corresponding author emailed a one-page summary describing the project and methods to the National Research Ethics Service (NRES) Queries line to ascertain whether ethical approval was required. The NRES advised that ethical approval was not required for this project.

**Appendix**

**Appendix 1**

**Survey questionnaire**