Evaluating The Deciding Factors For Termination Of Pregnancy With Fetal Anomaly – Experience From Two Centers In Malaysia

Nazimah I[1], Noor Sham Y L[2], Khairun Niza C N[3], Mohd Ikhsan S[2], Nadzratulaiman N[2], Juliana Y[2]

Objective: To evaluate the factors that contributes to the decision for termination of pregnancy in prenatally diagnosed fetal anomaly cases.

Methods: A retrospective analysis of all cases of prenatally diagnosed fetal anomaly who delivered between 1 January 2007 and 30 June 2009 in two tertiary hospitals in Malaysia.

Results: A total of seventy-two (72) prenatally diagnosed pregnancies with fetal anomalies were identified. Mean maternal age was 29.8 ± 5.5 years and mean parity 1.47 ± 1.8. 70.8% of patients were ethnic Malay, 15.3% Chinese and 12.5% ethnic Indian. 22 (30.6%) fetuses were lethally abnormal. The overall pregnancy termination rate was 29.2%. 50% of pregnancies with lethally abnormal fetuses were terminated compared to 20% of pregnancies with non-lethal abnormality ($p<0.05$). There were no significant differences seen in the decision for pregnancy termination with regards to mean maternal age, parity and between mothers of different ethnic backgrounds.

Conclusion: Severity of fetal anomaly is the main determinant in the decision for pregnancy termination. Maternal age, parity and ethnic background did not significantly influence the decision.

IeJSME 2010: 4(2): 41-46

Key words: Prenatal diagnosis, Fetal anomaly, Termination of pregnancy, Determining factors

Introduction

Termination of pregnancy for fetal anomaly (TOPFA) is a rare outcome of pregnancy and carries with it ethical, moral and legal dilemma for practicing physicians. Advances in ultrasound technology and prenatal diagnosis have contributed tremendously to the diagnosis of fetal anomalies and provide information that can influence the decision to continue or interrupt a pregnancy.

Many factors could potentially contribute to the decision for TOPFA. Among the factors that have been studied include maternal characteristics such as age, ethnic background and education level as well as the types and severity of fetal anomaly diagnosed. Schechtman et al showed that the severity of structural anomalies, especially when it involves the central nervous system, directly correlated with abortion rates of anomalous fetuses.[1] Other studies have also reported that the number of defects and the severity of structural anomalies are factors associated with decisions to interrupt a pregnancy.[2,3]

In the local Malaysian setting, published data on TOPFA is seriously lacking. Malaysia is a pluralistic society with a predominantly Malay population which made up 55% of total population, 25% ethnic Chinese and 8% ethnic Indian. Termination of pregnancy (TOP) is an available but restricted option in Malaysia. The Malaysian Penal Code (Amendment) Act 1989 (Act 727) states that "*Abortion may be carried out if the practitioner is of the opinion, formed "in good faith", that continuation of the pregnancy would constitute a risk to the "mental and physical health of the pregnant woman greater than if the pregnancy were terminated*". In cases of fetal anomalies, it is the effects of the diagnosis on the mother's well-being, including that of mental or psychological well-being that is being taken into consideration when exploring the option of pregnancy interruption.

To date, there is no national congenital anomaly registry and hence data regarding termination of pregnancy for fetal anomaly is not readily available. We present data collected from two state hospitals in the country where fetal anomaly was diagnosed prenatally and termination of pregnancy was one of the options explored with the prospective parents. We evaluated factors that may have contributed to the decision for pregnancy termination in a multiethnic multi-religious society of Malaysia.

[1]Department of Obstetrics & Gynaecology, International Medical University, Seremban, Negeri Sembilan, MALAYSIA
[2]Faculty of Medicine, University Teknologi Mara, Shah Alam, Selangor, MALAYSIA
[3]Department of Obstetrics & Gynaecology, Hospital Tuanku Jaafar, Seremban, Negeri Sembilan, MALAYSIA

Address for Correspondence:

Nazimah Idris, Department of Obstetrics & Gynaecology, International Medical University, Clinical School Seremban, 70300 Seremban, Negeri Sembilan, MALAYSIA

Email: nazimahidris@hotmail.com

Methods

This is a retrospective study. The patients sample was pregnant women who were diagnosed with fetal anomaly prenatally and delivered consecutively in two tertiary public hospitals in Malaysia, Hospital Tuanku Jaafar Seremban and Hospital Selayang, between 1 January 2007 and 30 June 2009. Institutional approval was obtained prior to the commencement of the study.

As with many public hospitals in Malaysia, there is no routine fetal anomaly screening programs in the centres involved in this study. The patients were referred to the maternal-fetal medicine specialist when an earlier ultrasound done for other indications detected or suspected fetal anomaly. The diagnosis was made following the ultrasound examination performed by the maternal-fetal medicine specialist. Prior to the sonographic examination, patient and her partner were counselled on the indication of the examination, the expected findings and subsequent management based on the results of the examination. Where chromosomal anomaly was suspected, fetal karyotyping was offered and done with the patient's consent. The sample was obtained from an amniocentesis performed by the same specialist. After the results were obtained, pregnancy management options including fetal therapy (where feasible), expectant management and neonatal intervention and termination of pregnancy were discussed.

Data were collected from multiple sources including antenatal ultrasound records, laboratories and labour wards birth registry. All anomalies were classified using the International Classification of Disease version 10 (ICD 10) and further classified in order of severity into lethal and non-lethal anomaly. For non-lethal anomaly, a distinction was made between the normal and abnormal karyotypes, physical and mental handicap.

For this study, termination of pregnancy was defined as a legally induced termination regardless of gestation or outcome following a prenatal diagnosis of a congenital anomaly. Live birth is defined as birth of a baby showing signs of life after at least 22 weeks gestation or weighing at least 500gm. Stillbirth is defined as birth of a baby with no signs of life after at least 22 weeks gestation or at least 500gm in weight. Early neonatal death is defined as death occurring within seven days of life in a baby born after 22 weeks gestation or weighing at least 500gm at birth. Perinatal death is stillbirth or death within seven days of birth.

Statistical analysis: For comparison of categorical variables, we used chi-square or Fisher exact test (for small sample). The level of significance was set at $p<0.05$.

Results

A total of seventy-two (72) prenatally diagnosed pregnancies with fetal anomalies were identified, all in a singleton pregnancies. The mean maternal age was 29.8 ± 5.5 years and mean parity 1.47 ± 1.8. 70.8% of patients were ethnic Malay, 15.3% Chinese and 12.5% ethnic Indian. Of the 72 pregnancies, 22 (30.6%) fetuses were lethally abnormal. A total of 21(29.2%) pregnancies were terminated, with only 4 performed before the age of viability, taken as from 22 weeks onwards. The mean gestational age when the pregnancy termination was performed was 26.6 ± 5.8 weeks, which is above the gestational age for viability. The overview of the outcome of the 72 pregnancies studied is shown in Table 1.

The diagnosis of the 72 fetal anomalies were made according to ICD 10 Classification and further classified in order of severity according to the classification by Statham et al.[4] Table 2 shows the classification of anomalies and the number of pregnancies that were terminated in each class.

The overall pregnancy termination rate in our study was 29.2%. We look into the decision for TOP based on severity of anomalies i.e. whether the anomalies were lethal or non-lethal and found significantly more pregnancies with lethally abnormal fetuses were terminated compared to those with non-lethal abnormality ($p<0.05$) (Table 3).

There were no significant differences seen in the decision for pregnancy termination with regards to maternal age (29.7 ± 5.5 vs 29.9 ± 5.7 years; p=0.9 or p>0.05), parity (1.4 ± 1.5 vs 1.6 ± 2.4; p=0.7 or p>0.05) and between mothers of different ethnic backgrounds. These findings are summarized in Table 4.

Discussion

We present the data on pregnancies that were diagnosed with fetal anomaly prenatally and evaluated the factors that could have contributed to the decision of pregnancy interruption or termination. The option of pregnancy termination is a sensitive but necessary option to be discussed with the prospective parents in order to allow them to make an informed decision about how the pregnancy is to be subsequently managed.

Of the 72 pregnancies, 21 (29.2%) were terminated. Our TOPFA rate was relatively lower when compared to TOPFA rates of 43.7% in a population-based study in the West Midland regions of the United Kingdom[8], 34.6% (for pregnancies above 24 weeks gestation) in France[9] and 33% in New Jersey.[10] Nearer to home, a study done in predominantly Chinese Hong Kong assessing the attitudes towards termination of pregnancy found that their women who attended the prenatal diagnostic clinic had an open mind towards TOP for fetal abnormalities in general with 90% expressing desire for TOP for lethal abnormalities and Down's syndrome.[11] There have been suggestions that women from different socio-cultural or religious backgrounds would view the issue of TOP differently.[12]

We found that the rate of termination differs based on the severity of anomaly. We have shown that fetuses with lethal anomaly were more likely to be terminated (50%), followed by fetuses with the likelihood to have mental as well as physical handicap (33%) and fetuses with multiple anomalies (30%). This result is consistent with what has been previously reported by other authors. For lethal anomaly, rates of 56.0%, 64.9% and 77.6% has been reported.[1,10,13] Between the organ systems, we found that when the anomalies involved the CNS, which would have resulted in mental and physical handicap, the pregnancies were more likely to be terminated. Pryde et al reported that the severity of sonographic anomalies identified in the CNS and other organs correlated positively with the decision to terminate a pregnancy and Schechtman et al concurred with this when he reported TOP rate of 72.5% for non-lethal CNS anomalies compared to 37.1% for non-CNS anomalies.[1,2]

One important finding of this study is the late gestation at which the TOP was performed, at the mean gestation of 26.6 ± 5.8 weeks, beyond the period of viability, where in this country is taken as 22 weeks onwards or birth weight of at least 500gm. Only 4(19.0%) pregnancies were terminated before the age of viability. This could be attributed to late diagnosis since both hospitals did not offer routine first trimester screening or the 18-22 weeks morphology scans that can ensure earlier detection and diagnosis. There are several implications of late diagnosis and hence late pregnancy terminations. The process of TOP would carry higher risk of complications to the mother, particularly the increased amount of blood loss at delivery compared to earlier gestation and procedure failure with risks for operative delivery. There is also a risk of babies surviving leading to new and complex management dilemma. Statistical wise, due to the late TOP, the perinatal mortality rate would not have been much altered despite the TOP.

The issue of live-birth after TOP warrants a special mention because it is a particularly distressing issue to the parents and presents complex management dilemma to the medical professionals as to the extent of medical care that should be provided to the baby. There may also be medico-legal issues involved when parents who have expected to 'put the painful episode behind' now have to contend with caring for a significantly disabled child. The Royal College of Obstetrician and Gynaecologists advised that beyond the gestational age of 21 weeks and 6 days, feticide should be done to ensure that fetus is born dead.[14] We did not encounter such complications in the pregnancies that we evaluated.

Legally, there is no limit to the gestation for TOP according to the Malaysian legal system, as indicated in the Malaysian Penal Code. Similarly, The Human Fertilization and Embryology Act (1990) in the United Kingdom placed no upper gestational limit on TOP when there is 'substantial risk of serious handicap' (fetal disability ground) or if it is necessary to prevent 'grave permanent injury to the physical or mental health of the pregnant woman' (maternal health ground).[5] In comparison, in the United States, TOP for any reason after viability is legal only in the states of Oregon, Ohio and New Jersey.[6] TOP when the fetus has severe anomalies is legal after viability in Texas, New Mexico, Colorado and Kansas.[6,7] Note that the TOP under the Malaysian Penal Code do not take fetal disability as a ground for termination of pregnancy, only that of the mother's and therefore all TOP in this country has to justify the maternal risks before the procedure can be performed.

With regards to the pluralistic nature of Malaysian society, we found no difference in their acceptance or request for TOP between the different ethnic groups. Maternal parity and age were not contributory either. Other studies has evaluated maternal education level and found that when the anomalies were severe, education level had no effect on the TOP. These findings further strengthen the fact that across the board, it was the fetal status that were the main determinant for TOP and not maternal background.

One limitation of this study, beside the relatively small number of cases for analysis, is that perinatal autopsy is rarely performed in both hospitals. Fetal karyotyping is available in this country but mostly limited to the private sector and cost was a hindrance to many patients. Therefore, final diagnosis was based mainly on prenatal ultrasound and external examination at birth. We observed that for each cases of fetal anomaly diagnosed prenatally, there would be at least a similar number that was not, and the parents would have missed the opportunity to make an informed decision about the pregnancy management and outcome.

From the findings of this study, we would like to make several recommendations. Screening for fetal abnormality should be made available to all pregnant women. Although this may result in substantial cost implications to the healthcare services, an effort should made by the authority to move in to this direction. At the very least, routine ultrasound for fetal morphology between 18 to 22 weeks gestation should be offered to all patients to ascertain the fetal structural normality. If any anomaly is detected, counseling by a feto-maternal specialist is advised and options for further pregnancy management should be explored with both parents. This will enable an earlier TOP with less inherent risks to the mother and avoid the issue of survival after TOP. Fetal karyotyping services should be made available when needed and where cost is a hindrance, a mechanism exists where patients can be assisted with the financial issues. The need for more qualified sonographers and feto-maternal specialists can not be over-emphasized. As the procedure of TOP has both medical and legal implications, physicians should familiarize themselves with the law of the country to avoid untoward legal liabilities.

In conclusion, termination of pregnancy for fetal anomaly is a likely option chosen by our patients and severity of anomaly is the main determinant for the decision. Maternal background in our multiethnic multi-religious population was non-contributory to the decision.

Conflict of interest

The authors wish to declare that there are no conflicts of interest to disclose.

REFERENCE

1. Schechtman KB, Gray DL, Baty JD, Rothman SM. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. Obstet Gynecol 2002; 99: 216-22.
2. Pryde PG, Isada NB, Hallak M, Johnson MP, Odgers AE, Evans MI. Determinants of parental decision to abort or continue after non-euploidy ultrasound-detected fetal anomalies. Obstet Gynecol 1992; 80: 52-6.

3. Mansfield C, Hopfer S, Martesu TM. Termination rates after prenatal diagnosis of Down's syndrome, spins bifida, anencephaly, and Turner and Klinefelter syndromes: a systemic literature review: European Concerted Action DADA (Decision-making after the Diagnosis of a fetal Anomaly). Prenat Diagn 1999; 19: 808-12.
4. Statham H, Solomou W, Green J. Continuing a pregnancy after the diagnosis of an anomaly: Parents' experiences. In: Abramsky L, Chapple J, eds. Prenatal Diagnosis: The Huma Side. 2nd ed. Cheltenham, UK: Nelson Thornes, 2003:164-77.
5. Human Fertilization and Embryology Act 1990. London: HMSO, 1990.
6. Linton, PB. Enforcement of state abortion statutes after Roe: a state by state analysis. University of Detroit Law Review 1990; 67: 157-259.
7. Manchester D, Clewell W, Mancho-Johnson M, et al. Management of pregnancies with suspected fetal anomalies: clinical experience and ethical issues. In: Nomrod C, Griener G, editors. Biomedical ethics and fetal therapy. Waterloo (Ontario): Wilfred Laurier University Press; 1988:67-79.
8. Wyldes M, Tonks A. Termination of pregnancy for fetal anomaly: a population-based study 1995 to 2004. BJOG 2007;114: 639-642.
9. Guillem P, Racinet C, Leynaud A, Benbassa A, Cans C. Evaluation of maternal morbidity after drug-induced termination of pregnancy (TOP) after 12 gestation weeks. *J Gynecol Obstet Biol Reprod* 2003;32: 227-38.
10. Rauch, ER, Smulian JC, DePrince K, et.al. Pregnancy interruption after second trimester diagnosis of fetal structural anomalies: The New Jersey Fetal Abnormalities Registry. AJOG 2005;193:1492-7.
11. Leung TN, Ching MM, Chang JJ, et al. Attitudes towards termination of pregnancy among Hong Kong Chinese women attending prenatal diagnostic counseling clinic. Prenat Diagn 2004;24:546-51.
12. Drake H, Reid M, Marteau T. Attitudes towards termination for fetal abnormality: comparisons in three European countries. Clin Genet 1996;49:134-140.
13. Hassed SJ, Miller CH, Pope SK, Murphy P, Quirk JG Jr, Cunniff C. Perinatal lethal conditions: the effect of diagnosis on decision-making. Obstet Gynecol 1993;82:37-42.
14. RCOG. Further issues relating to late abortion, fetal viability and registration of births and deaths. RCOG Publications, 2001.

Table 1: Outcome of pregnancy (n=72)

Outcome	n
TOP	**21**
- <22 weeks (mean 18.5 ± 1.0)	4
- ≥22 weeks (mean 28.5 ± 4.7)	17*
No TOP	**51**
- Livebirth	40
- Early neonatal death	17
- Stillbirth	11
- Perinatal death	28
Total	**72**

**all patients delivered vaginally without complications, all babies died within the early neonatal period*

Table 2: TOP and Classification of anomalies (72 anomalous fetuses)

Type	Description	TOP n=21
1	Lethal (n=22) (anencephaly=12, renal agenesis=2, Trisomy 13 and 18=2, lethal skeletal dysplasia=4, others=2)	11 (50%)
2	Non-lethal, normal karyotype (n=13) A: likely physical handicap only e.g limb abnormality, skeletal deformity (n=4) B: likely physical and mental handicap e.g neural tube defect, Dandy-Walker malformation (n=9)	 1 (25%) 3 (33%)
3	Non-lethal with abnormal karyotype e.g Trisomy 21, Turner's syndrome (n=1)	0 (0%)
4	Structural anomaly with option to repair (n=26) A: with significant mortality risk e.g cardiac defects, diaphragmatic hernia (n=11) B: without significant mortality risk e.g talipes, some renal tract anomalies (n=15)	 3 (27%) 0 (0%)
5	Suspicious (multiple markers/anomalies with normal karyotype) (n=10)	3 (30%)

Table 3: TOP and severity of anomaly

	TOP (n)	No TOP (n)
Lethal (n=22)	11	11
Non-lethal (n=50)	10	40
Total	**21**	**51**

p <0.05

Table 4: Maternal Background and TOP

	TOP n=21	NO TOP n=51	P value
Mean maternal age (years)	29.7 +-5.5	29.9 +-5.7	>0.05
Mean parity	1.4 +-1.5	1.6 +-2.4	>0.05
Ethnic Malay (n=51)	15	36	>0.05
Ethnic Chinese (n=11)	4	7	>0.05
Ethnic Indian (n=9)	2	7	>0.05