Termination of Pregnancy for Mild Foetal Abnormalities: Opinions of Physicians

Author(s): Dr. Souhail Alouini, Dr. Emmanuel Curis, Dr. Federico Prefumo, Prof. Simone Benazeth, Prof. Christian Herve

Corresponding Author:
Dr. Souhail Alouini,
Centre hospitalier R & Acute, Gional d'Orleans, Obstetrics and Gynecology - France

Submitting Author:
Dr. Souhail Alouini,
Centre hospitalier regional d'Orleans, Obstetrics and Gynecology - France

Article ID: WMC001770
Article Type: Original Articles
Article URL: http://www.webmedcentral.com/article_view/1770
Subject Categories: OBSTETRICS AND GYNAECOLOGY
Keywords: Opinions of physicians, Sex Chromosome Abnormalities, Uncertain Rognosis Abnormalities, Moderate Handicap Abnormalities, Laws on Abortion


Competing Interests:
No conflicts of interest
Termination of Pregnancy for Mild Foetal Abnormalities: Opinions of Physicians

Abstract

Objective: to know physicians’ opinions in sex chromosome, uncertain prognosis and moderate handicap abnormalities and their conformity with the regional laws in case of parental request for termination of pregnancy (TOP).

Methods: we sent a questionnaire to physicians in charge of 82 maternal-fetal medicine units in 16 countries. The questions concerned the decision-making in mild congenital abnormalities and its legal aspects.

Results: 48 physicians out of 82 (59%) answered the questionnaire.

Acceptation of termination of pregnancy before fetal viability was the most frequent attitude in case of uncertain prognosis abnormalities (p = 0.003), sex chromosome abnormalities (p = 0.029) and moderate handicap abnormalities (p = 0.05).

Approximately one third to half of decisions of termination of pregnancy for mild congenital abnormalities were more permissive or restrictive than the respective laws (p < 0.05, 95% CI). 65% of the physicians did not want legislative modifications concerning termination for mild congenital abnormalities. In most cases there were no guidelines for the decisions.

Conclusion: Acceptation of termination of pregnancy before fetal viability in case involving uncertain prognosis, sex chromosome and abnormalities with moderate handicap was the most frequent attitude of physicians. These attitudes were not always in agreement with the respective regional laws but there were no wishes to modify them.

Introduction

In the 1970s, prenatal diagnosis was limited to serious polymalformative syndromes and chromosomal abnormalities such as Down syndrome (1, 2). Due to advances in technology, prenatal diagnoses have been extended to abnormalities with uncertain prognosis, sex chromosome abnormalities and abnormalities producing moderate handicaps (3).

Termination of pregnancy (TOP) is regulated by laws specific to every country. Some countries allow termination for all reasons before fetal viability and/or after fetal viability for serious or incurable fetal abnormalities (9-11); others allow TOP only for serious and incurable fetal abnormalities or in the case of a threat to the mother’s health (11-13). For fetal anomalies such as Down syndrome, TOP is generally accepted in case of parental request (13). For uncertain and “mild” fetal anomalies medical decisions to accept or to refuse TOP are less consensual (14).

We conducted a multicenter study to know the opinions of physicians in charge of fetal medicine units in case of parental request for termination of pregnancy for mild congenital abnormalities and if they were in agreement with regional laws.

Methods

We sent a questionnaire to physicians responsible for prenatal diagnosis in 82 maternal-fetal medicine units. Physicians’ addresses were found through websites of scientific associations, colleges of obstetrics and gynecology and on Pubmed. All physicians participating in the study worked in referral centres for prenatal diagnosis.

The questionnaire was accompanied by an explanatory letter describing the physicians responsible for the study, the aim of the study, a guarantee of anonymity for the respondents, and an offer of notification of the results of the study. The study was conducted between January 2004 and May 2006. This questionnaire was written in both English and French and was translated by professionals. It contained 16 questions:

Questions one to five concerned the affiliation, function, and degrees of the physicians responsible for the Maternal-Fetal Medicine Unit (MFMU), the country
of the MFMU, the level of the maternity unit, the average number of deliveries and of TOP per year, and the legislation on TOP in the country where the MFMU was located.

Questions seven to twelve concerned the physician’s decisions in the fetal abnormalities with uncertain prognosis (e.g., absence of corpus callosum, cerebral ventricular dilation), sex chromosome abnormalities (e.g., Klinefelter, Turner syndrome, 47 XXX), and abnormalities that could leave a moderate handicap: (e.g., absence of limb) in cases of parental request for termination of pregnancy.

We asked physicians for availability of guidelines in their fetal medicine unit concerning every pathology. Questions 13 through 16 concerned legal aspects of termination of pregnancy and wishes of physicians for decision making in cases of mild congenital abnormalities.

Some questions had multiple-choice responses with four to five choices, while some asked for essay answers. The questionnaire was tested with ten physicians before being sent to potential study participants. The answers to these questionnaires were not included in the results. The questionnaire was sent to potential study participants by e-mail, with a confirmation that the message had been opened, or by post. Questionnaires were sent three additional times in the absence of a response. A coding number was assigned to every completed questionnaire.

Data were entered and analysed quantitatively with XLStat software, a complementary macros package for Excel. Results were presented as number of observations and, if pertinent, as percentages, with the 95% confidence interval (CI). Homogeneity of the responses of physicians was tested using a chi-square homogeneity test, which assumed heterogeneity if $p \leq 0.05$.

Results

Forty-eight physicians out of 82 (59%) responded to the questionnaire. All physicians who responded the questionnaire were gynaecologists-obstetricians, specialised in fetal medicine. 28 were responsible of European fetal medicine units (16 French, 1 Croatian, 1 from Czech Republic, 1 Greek, 1 Italian, 1 from the Netherlands, 1 from Ireland, 1 from the UK, 1 from Sweden, 4 German), 12 of USA, 1 of Brazil, 6 of Asian fetal units (1 from China, 1 from Hong Kong, 2 from Taiwan, and 1 from Thailand), and one of South African medicine unit. Each respondent worked in a different MFMU. The 48 centres performed a total of 3,733 terminations of pregnancy for congenital abnormalities /year and 160,837 live deliveries /year on average. The mean number of deliveries per year for the 48 centres was 3,733 ± 2,059. The mean number of TOP for congenital abnormalities for the 48 centres was 83 ± 135 per year. Responses were received from 44 tertiary care centres, 2 secondary care centres, and 2 primary care maternity centres. All 48 centres were in university hospitals and made decisions in prenatal diagnosis. They are similar to other prenatal diagnosis centres in relation to their composition and competence.

Attitudes of physicians on uncertain prognosis abnormalities in case of parental request of abortion (e.g., agenesis of corpus callosum, cerebral ventricular dilation) (Table 1)

Twenty-three of forty-eight physicians (48%) accepted TOP in cases of uncertain prognosis abnormalities before foetal viability (24 weeks). Eighteen of forty eight physicians (37%) accepted TOP at any moment of the pregnancy for uncertain prognosis abnormalities. Among them, nine accepted TOP without conditions, taking into account the opinions of the parents. Nine physicians accepted TOP in cases of association with a hygroma, chromosome abnormalities, neurological anomalies, bad prognosis or after the agreement of the multidisciplinary team of fetal medicine.

Seven physicians (14%) stated that they would not allow termination of pregnancy in cases involving foetal uncertain prognosis abnormalities. Reasons for rejection of TOP included the physician’s own ethical principles and the eventuality of a normal prognosis. In case of uncertain prognosis abnormalities acceptance of termination before fetal viability is more frequent than other attitudes ($p= 0.003$).

Attitudes of physicians on sex chromosome abnormalities (e.g., Turner or Klinefelter syndromes) in case of parental request of abortion

Fifteen of forty-eight physicians (31%) accepted termination for sex chromosome abnormalities only before fetal viability. One physician explained his decision in the following way: “Prior to viability, an informed patient has a right to decide.” One physician accepted TOP before fetal viability only in cases of major anomalies, such as XXX, but never for Klinefelter or Turner syndromes. This physician said, “People can live good lives even as Turner or Klinefelter.”
Twenty of forty-eight physicians (42%) accepted TOP for sex chromosome anomalies at any moment during the pregnancy. Among them, nine accepted TOP without conditions, while eleven accepted TOP only in cases involving a diagnosis of Turner with hygroma or hydrops (one physician), lethal Turner diagnosis (two physicians), after discussion with multidisciplinary staff for prenatal diagnosis (five physicians), early diagnosis by trophoblast biopsy (one physician), or major structural abnormalities (one physician). Two physicians did not approve TOP for Klinefelter syndrome. Two physicians stated approval of TOP for SCA in cases involving psychological distress attested by a psychiatrist.

Twelve of forty-eight physicians (25%) rejected TOP for sex chromosome abnormalities. Among the reasons for refusing TOP were the probability of a quasi-normal mental development and the absence of major physical handicap (e.g., Turner syndrome).

In case of sex chromosome abnormalities acceptance of termination before fetal viability is more frequent than other attitudes (p= 0.029) (table 1).

Attitudes of physicians in case of parental request of abortion for moderate handicap abnormalities (e.g. absence of a limb) (Table 1).

Twenty-one of forty-eight physicians (41%) accepted TOP in cases of moderate handicap abnormalities before fetal viability. One physician mentioned cases of combined undetected abnormalities or late discovered abnormalities, while another physician said that consultation with other physicians (neonatologists, surgeons, and geneticists) was necessary.

Nine physicians accepted TOP for MHA in cases of parental request at any time during the pregnancy. Among them, three physicians accepted TOP requests in cases of psychological impact on the mother.

Eighteen physicians (37%) did not accept TOP for moderate anomalies. One physician stated that these abnormalities did not lead to a severe handicap that altered the autonomy in daily life. Another physician stated these were minor fetal abnormalities that did not require TOP. Another physician emphasized that refusals from multidisciplinary centers might lead female patients to have TOP in border countries.

In summary, in case of moderate handicap abnormalities acceptance of termination before fetal viability is more frequent than other attitudes (p= 0.05) (table 1).

Guidelines

The majority of physicians who make decisions regarding TOP in cases of uncertain prognosis abnormalities (41/48), sex chromosome abnormalities (41/48) or moderate handicap abnormalities (43/48) replied that there were no guidelines for the decisions. Fetal viability was a guideline for five physicians regarding uncertain prognosis abnormalities and four physicians regarding sex chromosome abnormalities.

Maternal health or parental choice was a guideline for two physicians regarding uncertain prognosis abnormalities, two physicians regarding sex chromosome abnormalities and one physician regarding anomalies with moderate handicap. Severe abnormalities in sex chromosome abnormalities were reported as a guideline for one physician.

Attitudes of physicians and regional laws (Table 1)

The physicians who answered the questionnaire provided information about laws concerning termination of pregnancy in their county. Fetal viability was defined by them as 24 weeks of gestation. In the USA, Croatia the laws authorize TOP before fetal viability for all fetal abnormalities. In Greece, Sweden, and Hong Kong, laws authorize TOP before fetal viability only for serious or incurable fetal abnormalities. In France, Thailand, South Africa and Brazil laws authorize TOP at any moment of the pregnancy for serious or incurable or lethal fetal abnormalities. In the Czech Republic, Netherlands, United Kingdom, China and Taiwan, laws authorize TOP before fetal viability for all fetal anomalies and after fetal viability only for serious or incurable fetal abnormalities. In Italy and Germany, TOP is accepted when the health of the mother is in danger. In Ireland TOP is not allowed.

Approximately one third to half of the decisions of termination of pregnancy for mild congenital abnormalities were more permissive or restrictive than the respective laws (p < 0.05, 95% CI).

Seventeen physicians out of 48 (35%) in charge of MFMU wanted legislative modifications such as an extension of indications for TOP in cases of mild congenital abnormalities.

Discussion

In spite of the variety of countries involved in our study and their different legal contexts, the most frequent attitude in case of sex chromosome, uncertain prognosis and moderate handicap abnormalities was the acceptance of termination before the fetal viability. Agreements for termination of pregnancy before fetal viability for mild disorders were within the legal boundaries in many cases. This notion of fetal viability is not only a legal criterion but corresponds to the beliefs of some physicians (15). Some health
professionals found that termination of pregnancy is less difficult to accept when the fetus is young and non viable. Nevertheless, TOP agreements before fetal viability excluded abnormalities diagnosed during the third trimester (16, 17).

In our survey, physicians’ opinions concerning mild congenital abnormalities vary from accepting termination of pregnancy under different conditions to refusal for the same pathologies. The abnormality types, the personal and ethical opinions, and the legal conditions for access to termination of pregnancy in each country could account for the heterogeneity of medical decisions. Other studies found the same heterogeneity in TOP decision-making, especially for mild disorders and uncertain prognosis abnormalities (3, 16, 18)

These attitudes were motivated by different reasons:

In cases involving uncertain prognosis abnormalities, some physicians consented to termination of pregnancy only for specific pathologies or following multidisciplinary discussions because of the inconsistency of the seriousness of the defect (19, 20). Since the scans of disorders are not always linked to a bad prognosis (e.g., agenesis of the corpus callosum, ventriculomegaly) the prognoses are difficult to establish (19-22).

A refusal of TOP was motivated by the possibility of a normal prognosis. Information to female patients should be reinforced in case of uncertain prognosis abnormalities (23).

Termination of pregnancy refusals for some sex chromosome anomalies, such as Klinefelter or Turner syndromes, was explained by the fact that these abnormalities did not always involve major physical or mental handicaps. However, for some patients, the sterility might be considered as serious. The parental choices (24), the risks to the mother’s health, the severity and the type of abnormalities account for the decisions (14, 25).

In cases of moderate handicap abnormalities, the rate of rejection of parental request of termination of pregnancy was high. TOP was not ethically acceptable and was refused by physicians as they considered that the autonomy of the child was only slightly altered.

Abnormalities with moderate handicap (e.g. absence of limb) are not considered as serious fetal abnormalities and make the decision of termination difficult in other studies (14).

This wide variety of decisions for the same disorder from one center to another and from one country to another promotes unequal access to termination of pregnancy for female patients in the European Union and in the United States. Therefore, pregnant women should have access to the knowledge of decision criteria of centers other than the one consulted, especially when they disagree with the physician’s decision.

In our survey, one third to half of TOP decisions were not in agreement with their respective regional laws. They were more permissive or more restrictive than the corresponding laws.

Differences between decisions and laws could be partially explained by new diagnosis that were unknown (uncertain prognosis, sex chromosome anomalies, absence of limb) when the laws were written. However, the majority of physicians who participated in our study did not like to change the laws concerning the access to TOP in case of mild congenital anomalies. Acceptance of TOP after fetal viability in cases in which the law permitted TOP only before fetal viability was motivated by the parental suffering or a poor prognosis.

Agreements to termination of pregnancy for sex chromosome or moderate handicap anomalies when the law permitted TOP only for serious and incurable fetal anomalies were motivated by parental suffering, which was considered the priority. These handicaps are not reversible and could possibly lead to a disorder that could be considered serious and incurable.

Termination of pregnancy refusals before fetal viability or anytime during pregnancy when the laws permitted them were motivated by personal ethical considerations, the uncertainty of the disorders in uncertain prognosis anomalies and the preservation of a rather normal quality of life in sex chromosome and moderate handicap anomalies. Other studies found that decisions of termination of pregnancy for mild and minor congenital abnormalities raised major ethical dilemmas and are not always conformed to the regional laws (14, 16).

In most cases there were no guidelines for decision-making in uncertain prognosis, sex chromosome and moderate handicap abnormalities. Nevertheless, the physicians questioned in our study thought that it was difficult to have a consensus concerning decision in case of parental request of termination. In the study of Garel et al (14), there were no protocols in the fetal medicine units interviewed to decide when a termination was justifiable.

There were limitations to the present study. Thirty-four physicians did not respond to the questionnaire, but this response rate is usual for this class of study. This study represented a segment of prenatal diagnosis
centers throughout the world but did not assume to
gauge all the medical practices of decision in mild
congenital abnormalities. However, the answers of
these 48 physicians in charge of maternal-fetal
medicine units give highlights on physicians’ attitudes
toward termination of pregnancy in cases involving
mild congenital abnormalities. These 48 centers are a
representative sample of decision-making for these
pathologies, because they are referents in prenatal
diagnosis, they performed a large number of
terminations of pregnancy for fetal abnormalities and
were not selected (beyond the inclusion criteria).
Furthermore, the range of the answers varied from the
acceptance (with or without conditions) of TOP to
refusal, thus consequently covers a wide variety of
possible attitudes.

Conclusion

Our survey found that fetal viability is the most
significant criterion to determine physicians’ attitudes
regarding abortion for mild congenital abnormalities in
spite of the wide variety of involved countries and their
different legal context.

However, physicians’ attitudes in case of parental
request of termination for mild congenital
abnormalities vary from acceptance of termination to
refusal for the same type of abnormalities. These
attitudes are not always in agreement with regional
laws but physicians do not wish to change the laws
concerning access to TOP for mild congenital
abnormalities.

In most cases, there were no ethical guidelines for
decision-making in cases of mild congenital
abnormalities.

Information on different attitudes of other physicians
should be given to women undergoing a prenatal
diagnosis for mild congenital abnormalities.

Aknowledgements

The authors thank all the physicians who responded to
questionnaire.

References

1. Nadler HL, Gerbie AB. Role of amniocentesis in the
intrauterine detection of genetic disorders. N Engl J
2. Goodlin RC. Routine ultrasonic examinations in
3. Guillem P, Fabre B, Cans C, Robert-Gnansia E,
Jouk PS. Trends in elective terminations of pregnancy
between 1989 and 2000 in a French country (the
Missouri. Supreme Court. Annu Rev Popul Law
5. Gregory v. Pembrokeshire Health Authority [31
Premiere Instance, Montpellier. Annu Rev Popul Law
7. Moutel G, Francois I, Moutard ML, Herve C. The
Perruce decree, an opportunity to question the
acceptance of a handicap and the relationship
between physicians, justice and society. Presse Med
2002;31:632-5.
8. Wright AA, Katz IT. Roe versus reality--abortion
9. No authors listed. U.S. Supreme Court on abortion.
10. Abortion policies. A global review. United nation.
Country profile
/profiles.htm
n/abortionlaws.htm
12. International Planned Parenthood Federation IPPF.
Europe Region. Abortion laws in Europe. Plan Parent
13. Mansfield C, Hopfer S, Marteau TM. Termination
rates after prenatal diagnosis of Down syndrome,
spina bifida, anencephaly, and Turner and Klinefelter
syndromes: a systematic literature review. European
Concerted Action: DADA (Decision-making After the
Diagnosis of a fetal Abnormality). Prenat Diagn
Ethical decision-making in prenatal diagnosis and
termination of pregnancy: a qualitative survey among
15. Savage W, Francombe C. Gynaecologists’ attitudes
16. Statham H, Solomou W, Green J. Late termination
of pregnancy: law, policy and decision making in four
English fetal medicine units. BJOG 2006;113:1402-1
17. Paintin D. Abortion after 24 weeks. Br J Obstet
Gynaecol 1997;104:398-400.
18. Savulescu J. Is current practice around late
termination of pregnancy eugenic and discriminatory?
Maternal interests and abortion. J Med Ethics
Illustrations

Illustration 1

Table 1.

Attitudes of physicians regarding termination of pregnancy for uncertain prognosis, sex chromosome and moderate handicap abnormalities.

<table>
<thead>
<tr>
<th>Termination of pregnancy</th>
<th>Accepted &lt;24 weeks n</th>
<th>Accepted &lt;24 weeks u.c. n</th>
<th>Accepted 0-9m n</th>
<th>Accepted 0-9m u.c. n</th>
<th>Refusal total n</th>
<th>df</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertain prognosis A.</td>
<td>23</td>
<td>9</td>
<td>9</td>
<td>7</td>
<td>48</td>
<td>3</td>
<td>0.003</td>
</tr>
<tr>
<td>Moderate handicap A.</td>
<td>21</td>
<td>8</td>
<td>1</td>
<td>18</td>
<td>48</td>
<td>3</td>
<td>0.005</td>
</tr>
<tr>
<td>Sex chromosome A.</td>
<td>15</td>
<td>1</td>
<td>10</td>
<td>10</td>
<td>12</td>
<td>4</td>
<td>0.029</td>
</tr>
</tbody>
</table>

n= number of physicians who responded for each pathology

A.= abnormalities

u.c. = under conditions
Illustration 2

Table 2. Termination of Pregnancy decisions not conform with laws (n= 48)

<table>
<thead>
<tr>
<th>Context</th>
<th>Proportion</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertain prognosis abnormalities</td>
<td>19/48</td>
<td>40</td>
</tr>
<tr>
<td>Moderate handicap abnormalities</td>
<td>18/48</td>
<td>37</td>
</tr>
<tr>
<td>Sex chromosome abnormalities</td>
<td>25/48</td>
<td>51</td>
</tr>
</tbody>
</table>
Disclaimer

This article has been downloaded from WebmedCentral. With our unique author driven post publication peer review, contents posted on this web portal do not undergo any prepublication peer or editorial review. It is completely the responsibility of the authors to ensure not only scientific and ethical standards of the manuscript but also its grammatical accuracy. Authors must ensure that they obtain all the necessary permissions before submitting any information that requires obtaining a consent or approval from a third party. Authors should also ensure not to submit any information which they do not have the copyright of or of which they have transferred the copyrights to a third party.

Contents on WebmedCentral are purely for biomedical researchers and scientists. They are not meant to cater to the needs of an individual patient. The web portal or any content(s) therein is neither designed to support, nor replace, the relationship that exists between a patient/site visitor and his/her physician. Your use of the WebmedCentral site and its contents is entirely at your own risk. We do not take any responsibility for any harm that you may suffer or inflict on a third person by following the contents of this website.