

Factors Determining Parental Attitudes Towards Termination of Pregnancy in Prenatally Detected Down Syndrome

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OBJECTIVE: The aims of this study are to explore the rate of termination of pregnancy for Down syndrome in Turkey and to investigate demographic characteristics of the parents that may influence the parents' decision.

STUDY DESIGN: The study was conducted in Erciyes University, Department of Obstetrics and Gynecology, Prenatal Diagnosis Unit between 2009-2011. The data of 58 fetuses prenatally diagnosed as Down syndrome were analyzed retrospectively. The effects of socio-demographic features, obstetric history and educational level on termination of pregnancy for Down syndrome were compared retrospectively.

RESULTS: The mean maternal age was 33.3±7.2 years. There were no statistically significant correlation between the termination rate and any of the socio-demographic features. In case of reproductive history, the termination rate was significantly higher in women who had at least one living child than women who had no child. Contrary to our expectations, termination rate was higher in patients from rural area than in patients from urban center ($p < 0.05$).

CONCLUSION: Majority of parents choose to terminate pregnancy when the fetus diagnosed as Down syndrome. Our findings indicate that if parents have reasonable understanding of raising a child, they are most likely to terminate their pregnancy in the case of Down syndrome.

Keywords: Down syndrome, Prenatal diagnosis, Termination of pregnancy

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Introduction

Down syndrome is the most common diagnosed chromosomal abnormality among both the newborns and at the mid-trimester pregnancies.¹ Reported incidence of Down syndrome is between 1/700-1/800 at the delivery and the incidence of Down syndrome increases with maternal age.² It is a severe genetic disease with various structural anomalies, low IQ level and short life expectancy. Since it affects not only the parents but also the whole society, a considerable number of research projects focus on the detection of Down syndrome before the delivery.³

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Prenatal tests give information about the condition of the fetus, and these tests are important tools to detect Down syndrome before delivery. For instance, the detection rate of Down syndrome is reported as high as %90 if the first trimester combined test is used appropriately.^{4,5} Due to the increased rate of pregnancy in an advanced age,³ many more parents are expected to have a fetus with Down syndrome and to face with a hard decision: Whether they decide for the termination of the pregnancy or not? ⁶

Termination of pregnancy (TOP) for fetal anomalies is a sensitive issue related with numerous factors including the parents' personal beliefs, ethical views, religious beliefs and the clinicians' attitudes.⁷ Besides all these factors, termination of pregnancy is related with political issues; since the laws that regulate prenatal testing and termination of pregnancy vary across countries.⁸ The right of termination of pregnancy is protected by law in most of the developed world. For example it is legal to terminate pregnancy up to 22 weeks in most of the states of US. In Turkey, TOP after 10 weeks requires consent of a specific ethical committee consisting of specialists. This consent can be given only if maternal health is in great danger or the infant is severely disabled.⁸

Religious beliefs also play important role in the decision making processes of TOP.^{9,10} Although there are different

views, it is generally accepted that after 16th week (120th day), TOP is forbidden under the Islamic laws.¹¹ Indeed, there are various reports stating that TOP after 16th week is more difficult in the countries where dominant religion is Islam.¹²⁻¹⁴ Therefore, it can be assumed that rate of TOP for fetal anomalies in Turkey which is a predominantly Muslim country may be lower than the developed countries.

The aims of this study were to explore the rate of TOP for Down syndrome in Turkey and to investigate demographic characteristics of the parents that may influence the parents' decision. To the best of our knowledge it is the second study that seeks similar answers in Turkey but with a slightly larger sample size.⁶

Material and Method

The results of fetal chromosomal analysis that were performed with different methods including amniocentesis (AC), chorionic villus sampling (CVS) and cordocentesis (CC) between 2009-2011 in Erciyes University, Department of Obstetrics and Gynecology were retrospectively analyzed. All cytogenetic analysis was done in Erciyes University Department of Genetics. 58 of total 1024 cytogenetic results were Down syndrome. All of our patients were given genetic counseling. The reports of genetic counseling were reviewed retrospectively. Pregnancy outcomes are categorized as continued or terminated pregnancy.

Analyses were performed using SPSS version 15.0 for Windows (SPSS Inc., Chicago, IL). Descriptive statistics (n's, percentages, means, standard deviations) were calculated as appropriate for demographic variables, types of chromosomal abnormalities, and decisions to continue or terminate the pregnancy. Continuous data are presented as means \pm standard deviation or median [minimum-maximum], as appropriate. Proportions were compared using the Chi-square test or Fisher's exact test, when applicable. The level of significance was determined using the t test for normally distributed values, and the Mann-Whitney U test was used for non-normally distributed values. A p value of <0.05 was considered statistically significant.

Results

1024 cytogenetic results were reviewed. 58 results out of

1024 were Down syndrome. All of patients were reached via phone average time of 6 months after they received genetic counseling. All of our questionnaires were answered by the women themselves.

Total termination rate was 70% (41 out of 58). In 48 cases (82.7%) diagnoses were made by amniocentesis. Twelve out of those 48 patients diagnosed with AS (25%) rejected the TOP. Six out of 58 diagnoses were made by CVS, and two of these patients (33.7%) rejected the TOP. In the remaining four cases diagnoses were made by CC, and the three of these 4 (75%) patients rejected TOP. The median weeks of termination were 18 weeks (13-28 weeks). There were no statistically significant correlation between termination rate and method of diagnosis (Table 1).

Table 1: Termination rates according to diagnostic procedures.*

Diagnostic Procedures	Parent's Decision		Total n (%)
	COP n (%)	TOP n (%)	
AC	12 (25%)	36 (75%)	48 (100%)
CVS	2 (33.3%)	4 (66.7)	6 (100%)
CC	3 (75%)	1 (25%)	4 (100%)
Total	17 (29.3)	41 (70.7%)	58 (100%)

*TOP: Termination of Pregnancy, COP: Continuation of Pregnancy, AC: Amniocentesis, CVS: Chorion Villus Sampling, CC: Cordocentesis

Demographic characteristics and previous reproductive history of our patients were summarized in Table 2. The mean maternal and paternal ages were 33.3 \pm 7.2, and 36 \pm 6.5 years, respectively. All our patients had the same ethnical background as Turkish. Since the majority of our samples didn't have a college degree, patients were categorized according to their completion of compulsory 8 years education in Turkey; 70.7% of the women (41 of 58) had less than 8 year's education, 29.3% (17 of 58) had completed at least compulsory education of 8 years. %53.4 of men (31 of 58) had less than 8 year's education, and 46.6% had completed at least compulsory education of 8 years. There were no statistically significant correlation between the termination rate and any of the socio- demographic features. In case of reproductive history, the termination rate was significantly higher in women who had at least one living child than women who had no child. 34.4% (20) of couples were from a rural area and 76% of cou-

Table 2: Demographic features and previous reproductive history

	Terminated (n=41)	Continued (n=17)	p
Maternal age (mean \pm SD)	32 \pm 7.3	36 \pm 6.4	0.063
Gestational week at diagnosis (mean \pm SD)	18.6 \pm 2.6	18.3 \pm 3.7	0.671
Number of pregnancies (range)	3 (1-7)	4 (1-8)	0.092
Existing children (range)	1 (0-5)	2 (0-5)	0.031 ^a

Data were given as mean \pm SD or median (range) ^a: Terminated vs continued with mann whitney U test

ples were from an urban center. Contrary to our expectations, termination rate was higher in patients from rural area than in patients from urban center ($p < 0.05$) (Table 3).

Table 3: Termination rates according to life settings*

Life settings	Parent's Decision		Total n (%)
	COP n (%)	TOP n (%)	
Rural Area	2 (10.5%)	17 (89.5%)	19 (100%)
Urban Center	15 (38.5%)	24 (61.5%)	39 (100%)
Total	17 (29.3%)	41 (70.3%)	58 (100%)

*TOP: Termination of pregnancy, COP: Continuation of pregnancy

Discussion

There are several studies which investigate the decision-making process after prenatal diagnosis of fetal chromosomal abnormality.¹⁵⁻¹⁷ These studies establish the fact that the "severity" of diagnosis affects the parents decision after prenatal diagnosis for chromosomal abnormalities.^{15,17,18} We studied patients whose fetuses diagnosed as the Down syndrome, which was described as a severe diagnosis in previous studies, in order to investigate the other influencing factors.¹⁵

Total TOP rate for Down syndrome in the present study (70%) is lower than the previous studies.¹⁹ In their reports, Balkan et al. gave 78.9% as total TOP rate.⁶ The same rate was 92% for fetuses that diagnosed as Down syndrome in the study of Eldahdah et al.⁷ Although not statistically significant, Mezei et al. cited a decrease in termination rate over time but Schaffer et al. showed a consistent termination rate over 20 years when data stratified over four-periods.^{18,20} We believe that the difference is related to increasing patient's autonomy and informed decision process in our health care system that results in much more easily expressed objections to TOP, when compared with the clinician centered decisions process in the past.

The results of previous studies when it comes to the relation between maternal age and termination rate are conflicting. Some studies correlated the decreased rate of TOP with the maternal age,²¹ but others have not.¹⁶ We found a converse relationship between maternal age and the termination, though it was no statistically significant. This finding is consistent with the results of Shaffer et al.²⁰

The TOP rate was lower in women who had no living child than in women who had at least one living child with statistical significance. In our experience, women who raised at least one child understand more easily the implication of having a disabled child. Indeed, we encountered that reasoning in one of our interview. In one of our patient's own words: "Raising a healthy child is not a game, I cannot even think of having a disabled one" This quote indicates the urgent need for more

information about Down syndrome to reach a decision that appropriate for couples. Schuth et al. cited that the lack of information on life with a handicapped child as a restricting factor on decision-making process. Our findings confirm Schuth's conclusion.²²

We found no statistically significant relation between the methods used for prenatal diagnosis of chromosomal abnormality and the termination rate. It is important because if diagnosis is made by for example CVS, the termination would take place in earlier gestation therefore more acceptable in accord with the Islamic rules.^{11,19} If the real reason behind the continuation of pregnancy is the Islamic rules, there should have been a lower termination rate after the AC than after the CVS. Though our sample size is less than adequate, still there is no statistically significant difference in the termination rate after the method of choice for diagnosis.

The termination rate was higher among women who live in rural area than among women live in an urban area with statistical significance ($p < 0.05$). It was expected that the termination rate would be higher in urban center than rural area where religion dominates social life. On the other hand, the rural area is exactly where raising a disabled child can be difficult due to the lack of institutional support and social services.

Conclusion

In conclusion, majority of parents choose to terminate pregnancy when the fetus diagnosed as Down syndrome. Our findings indicate that if parents have reasonable understanding of raising a disabled child, they are most likely to terminate their pregnancy in the case of Down syndrome. These results show that parents need to be adequately informed to reach an appropriate decision for themselves.

Prenatal Down Sendromu Tanısı Almış Fetüslarda Ailelerin Gebelik Terminasyonu Konusunda Tutumlarını Belirleyen Etmenler

AMAÇ: Bu çalışmada amacımız Türkiye'de Down sendromu tanısı alan gebeliklerde, gebelik terminasyonu oranlarını belirleyip hastaların bu kararlarına sosyodemografik etmenlerin etkisini ortaya koymaktır.

GEREÇ VE YÖNTEM: Bu çalışma 2009-2011 yılları arasında Erciyes Üniversitesi Kadın Hastalıkları ve Doğum bölümü prenatal tanı ünitesinde yapıldı. Prenatal tanıda Down sendromu tanısı alan 58 hasta retrospektif olarak incelendi. Sosyo-demografik etkenler, obstetrik hikaye ve eğitim düzeyinin Down sendromu için gebelik terminasyonu üzerine olan etkisi retrospektif olarak incelendi.

BULGULAR: Ortalama anne yaşı $33,3 \pm 7,2$ idi. Sosyo-demo-

grafik etkenler ile gebelik terminasyonu arasında istatistiksel anlamlı farklılıklar izlenmedi. Obstetrik öyküye bakıldığında en az bir çocuk sahibi olanlarda terminasyonu kabul etme oranı çocuğu olmayanlara oranla daha yüksek bulundu. Tahminlerimizin aksine kırsal alanda yaşayanlarda terminasyon kabul etme oranları şehir merkezlerinden daha yüksek olarak bulundu.

SONUÇ: Ailelerin çoğu bebekleri Down sendromu tanısı aldığı gebelik terminasyonunu kabul etmektedir. Bizim bulgularımızın da desteklediği üzere aileler çocuk yetiştirmenin zorluklarını doğru bir şekilde kavradıklarında Down sendromu tanısı alan gebeliklerini sonlandırma eğiliminde olmaktadır.

Anahtar Kelimeler: Down sendromu, Prenatal tanı, Gebelik terminasyonu

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