

# Knowledge level, attitude, and behaviors of Turkish pregnant women about down syndrome screening

## Türk kadınlarının down sendromu taraması hakkında bilgi düzeyi tutum ve davranışları

Doğa Fatma ÖCAL<sup>1</sup>, Esengül TÜRKILMAZ<sup>2</sup>, Yasemin ÇEKMEZ<sup>5</sup>, İsmail Burak GÜLTEKİN<sup>1</sup>, Münire Funda AKDULUM<sup>3</sup>, Mehmet Fırat MUTLU<sup>4</sup>, Aydan BİRİ<sup>4</sup>

### ABSTRACT

*Purpose of this study was to investigate the level of background knowledge about Down syndrome screening tests among women in Turkey, their ability to interpret the test results, and their attitudes in deciding how to proceed based on the results. This study was performed by sending 600 questionnaires to 18 health centers throughout Turkey. The questionnaires were given to pregnant women by the practitioners who followed up their pregnancy (including doctors and midwives). The average correct answer rate of patients was found to be 1.3 out of every 6 questions (21.6%). In conclusion most pregnant women in Turkey have heard about the screening tests for Down syndrome, however they lack sufficient knowledge about the test content and the interpretation of the results.*

**Keywords:** Down syndrome, screening, knowledge level, patient

### ÖZ

*Bu çalışmanın amacı, Türk kadınlarının down sendromu tarama testleri hakkındaki bilgi düzeyini, test sonuçlarını değerlendirebilme becerilerini ve sonuçlar karşısındaki tutumlarını değerlendirmektir. Bu amaçla Türkiye genelinde 18 merkeze 600 anket gönderildi. Anketler gebe kadınlara gebelik takibini yapan kişiler tarafından uygulandı. Çalışma sonuçlarına göre hastaların ortalama doğru yanıtlama oranı %21,6 bulundu. Sonuç olarak, Türkiye'deki gebe kadınların çoğu down sendromu tarama testlerini duymuş olsa da test içeriği ve test sonuçlarını yorumlama hakkında yeterli bilgiye sahip değillerdir.*

**Anahtar kelimeler:** Down sendromu, bilgi düzeyi, hasta, tarama

### INTRODUCTION

Down syndrome is one of the most common causes of mental retardation, with an incidence of 1.3 per 1000<sup>1</sup>. In recent years various prenatal screening tests have been performed such as fetal DNA identification from maternal blood which has been rapidly become popular, with precision rates close to the diagnostic tests (sensitivity of 99% and specificity of 99%) that identify chromosomal abnormalities<sup>2-5</sup>. The screening tests that are still commonly used throughout the world are measurement of nuchal translucency by ultrasonography and beta human chorionic gonadotropin ( $\beta$ Hcg) and Plasma Associated Plasma Protein-A (PAPP-A)<sup>6</sup> from maternal serum in the first trimester and non-invasive tests on maternal serum [ $\beta$ Hcg, Alpha fetoprotein (AFP), estriol (E3)] in the second trimester<sup>7</sup>. The purpose of first trimester screening test is to identify individuals at high risk for chromosomal abnormalities, especially Down syndrome, trisomy 18, and trisomy 136. In the second trimester it is possible to detect structural abnormalities such as neural tube defects (NTD) in addition to aneuploidies<sup>7</sup>. Invasive diagnostic tests, such as chorionic

gency by ultrasonography and beta human chorionic gonadotropin ( $\beta$ Hcg) and Plasma Associated Plasma Protein-A (PAPP-A)<sup>6</sup> from maternal serum in the first trimester and non-invasive tests on maternal serum [ $\beta$ Hcg, Alpha fetoprotein (AFP), estriol (E3)] in the second trimester<sup>7</sup>. The purpose of first trimester screening test is to identify individuals at high risk for chromosomal abnormalities, especially Down syndrome, trisomy 18, and trisomy 136. In the second trimester it is possible to detect structural abnormalities such as neural tube defects (NTD) in addition to aneuploidies<sup>7</sup>. Invasive diagnostic tests, such as chorionic

**Received:** 10.01.2016

**Accepted:** 06.03.2016

<sup>1</sup>Department of Obstetrics and Gynecology, Dr. Sami Ulus Education and Research Hospital

<sup>2</sup>Atatürk Education and Research Hospital

<sup>3</sup>Gazi University, Faculty of Medicine

<sup>4</sup>Koru Hospital

<sup>5</sup>Department of Obstetrics and Gynecology, Ümraniye Education and Research Hospital

**Yazışma adresi:** Doğa Fatma Öcal, Dr. Sami Ulus Education and Research Hospital, Department of Obstetrics and Gynecology, Ankara

**e-mail:** eadoga@yahoo.com

villus sampling (CVS) and amniocentesis which are recommended to people have been found to have a high risk<sup>8</sup>. If any abnormalities are detected as a result of these tests, the situation is explained to the couple and the possible options such as termination of pregnancy are described. The level of knowledge of women about prenatal procedures affects their decision to undergo these tests. On one hand, limited understanding capacity of some women may result in rejection of prenatal screening and diagnostic procedures<sup>9-11</sup>. However, excessive information and a high level of comprehension may also cause the women to reject the investigations<sup>12,13</sup>. Previous studies have revealed that some healthcare professionals have inadequate knowledge about prenatal screening and related procedures<sup>14,15</sup>. Since the point that the healthcare professional emphasizes may be inaccurate, women are at a risk of being informed both inadequately and incorrectly. Inadequate and incorrect explanation of the pre-screening information results in an inadequate comprehension of the investigations as well<sup>16</sup>. It is of critical importance for women to understand the information presented in order to make an informed decision. The knowledge and experience of women about the screening and diagnostic tests are of paramount importance in the decision to undergo the tests, interpreting the test results, and deciding what to do based on the results.

Therefore, this study aimed to investigate the level of background knowledge about these tests among women in Turkey, their ability to interpret the test results, and their attitudes in deciding how to proceed based on the results.

## **MATERIAL and METHODS**

This study was performed in 2014 by sending 600 questionnaires to 18 health centers throughout Turkey. Approval by the local ethics committee was obtained from Gazi University. The questionnaire was prepared based on the assumption that blood and ultrasonography tests would be conducted in the first trimester for Down syndrome, blood tests for Down

syndrome and NTD in the second trimester, and amniocentesis and CVS as diagnostic tests. It consisted of 32 questions on five different domains targeted at different properties of the combined screening program: demographic data (seven questions), background knowledge about screening tests (six questions), risk assessment and interpretation of test results (seven questions), previous experience of patients with screening tests and invasive diagnostic tests (seven questions), and previous explanations provided about screening tests (five questions).

The questionnaires were given to each woman by the practitioner who followed her pregnancy. The women were not informed about the screening tests before the questionnaire survey. The women who had already undergone a screening test for their current pregnancy were included in the study. Pregnant women who were illiterate or did not have the intellectual capacity to complete the questionnaire forms were excluded from the study. Every woman completed the questionnaire only once.

The data were uploaded to the SPSS 15.0 package software (SPSS Inc., Chicago, USA) for statistical analysis. The chi-square and/or Fisher exact tests for categorical variables were used. The Mann-Whitney U test and Kruskal-Wallis test were used for variables with nonnormal distribution. A value of  $p < 0.05$  was considered statistically significant.

## **RESULTS**

From a total of 600 pregnant women 91.6% of them (552 women) who were invited to participate in the study, volunteered to take the questionnaire. The median age of the pregnant in the study was 27.3 years (range, 16-43 years).

Eighty-seven women were being followed in a private hospital. The educational levels of the women were as follows: primary school education (n=51); 107 women with a secondary school education (n=107); 207 women with a high school education (n=207); and university education (n=87).

Of the women in the study, 91.6% were monitored by a doctor, 0.7% by a midwife, and 6.5% by a doctor and a midwife. Nearly half of the women (49.3%) reported that they had been informed about the screening tests and 50.7% of them had not. Among the women who had been informed before any investigations, 75.8% of them reported that they had understood the explanation, while 24.2% had not. The results showed that for 43.3% of the women, the explanation process lasted between one and five minutes (43.3%), 10 min (21.4%), 15-20 min (21.4%), for 1% it lasted 25-35 min(1%), and 45-60 min (3.3%). Twenty-four percent of the women indicated that documents about the explanations had been given to them while 75% did not receive any documents.

The questions regarding the experience of the women with screening and invasive diagnostic tests, as well as their results, are shown in Table 1. The questions about the current knowledge of women concerning screening and diagnostic tests and their answers are shown in Table 2. On an average, 1.3 out of every 6 questions (21.6%). were responded correctly. The answers of the the women were analyzed based on their education level, whether any previous explanations were given, and their preference for type of hospital. The education level was found to be directly

proportional to the knowledge level and university graduates were found to be more knowledgeable than all other groups (Table 1). Furthermore, those who were monitored at private hospital and received previous explanations about the tests were also more successful in answering the questions (Figure 2). The questions related to the assessment of test results are shown in Table 3. Table 4 shows the distribution of attitudes in making decisions based on the test results according to educational level.

## DISCUSSION

Throughout the world, only a few countries have a national screening program for Down syndrome that includes all pregnant women<sup>17</sup>. In Turkey, there is no accepted country-wide policy on screening for Down syndrome. Although the quad test is used in some centers. the double and triple tests are most commonly used throughout the country. The majority (85.1%) of the pregnant were aware of the presence of screening tests for Down syndrome. It should be noted that, since the women completing the questionnaires had undergone screening tests, a considerable portion (14.9%) were not even aware that they had received a screening test.

**Table 1. Questions about the patients' experience related to screening and diagnostic tests.**

	Yes (%)	No (%)
Have you ever heard about a screening test for Down syndrome	85.1	14.9
Have you ever had blood collected for this test?	58.1	41.9
	Normal (%)	Abnormal (%)
If yes, what was its result?	93.8	6.2
	Yes (%)	No (%)
Have you ever heard of amniocentesis?	78.5	21.5
Have you ever undergone amniocentesis?	5.2	94.8
	Normal (%)	Abnormal (%)
If yes, what was its result?	97.1	2.9
	Yes (%)	No (%)
Have you ever heard of chorionic villus sampling or CVS?	35.0	65.0

**Table 2. Questions for measuring patients' level of information about screening tests.**

	%
What do you think about the purpose of the screening?	
To determine the people who have a high risk of having a baby with Down syndrome	21.6
To identify babies with Down syndrome	9.8
To identify all abnormal babies	10.2
To learn that my baby is fully healthy	58.4
Is it possible to definitely diagnose diseases with screening test?	
Yes	27.6
No	34
I don't know	38.4
Which diseases can be diagnosed with screening tests?	
Down syndrome	38.5
Mental retardation	17.2
Neural Tube Defects (NTD)	0.2
Kidney disease	0.2
Any disabilities	53.9
Is it obligatory to undergo screening tests?	
Yes	40.9
No	40.9
I don't know	18.2
Screening tests may also be used to identify NTD.	
Yes	12.4
No	2.2
I am not able to interpret it	85.4
When an amniocentesis is performed, only Chromosome 21 is examined.	
Yes	10.1
No	7.4
I am not able to interpret it	82.5

Even though most of the women had heard about the screening tests for Down syndrome, they did not have enough information as to why the test is done. The results indicated that 60.2% of the women defined the purpose of Down syndrome screening as "learning that my baby is totally healthy". So these women would have concluded that there were no chromosomal or structural abnormalities in their babies if they were told that their screening test risk was low.

Apart from Down syndrome the women also had little knowledge about the other pathologies that are identified by screening tests. The success rate in answering the questions the knowledge level of the participants was directly proportional to their education level which was found to be statistically significantly highest among university graduates (Figure 1). This is an indication that the ability of women to unders-

tand the information given is directly proportional to their educational level. In addition, the educational level of the people who preferred a private hospital and received prior information about the screening tests was also found to be high (Figure 2). Therefore, the rates at which these women understood the tests could be related to the greater amount of information they received, and to their possibly better developed comprehension skills. Consistent with this study, Rostant et al.<sup>18</sup> found that university graduates responded to information-related questions with greater success.

Of the women in this study, 27.6% believed that the screening tests would yield a definitive diagnosis.

One of the worrying results of this study is that more than half (53.2%) of the women did not know what they would do if faced with a high risk test result.

**Table 3. Questions about interpreting the screening test results.**

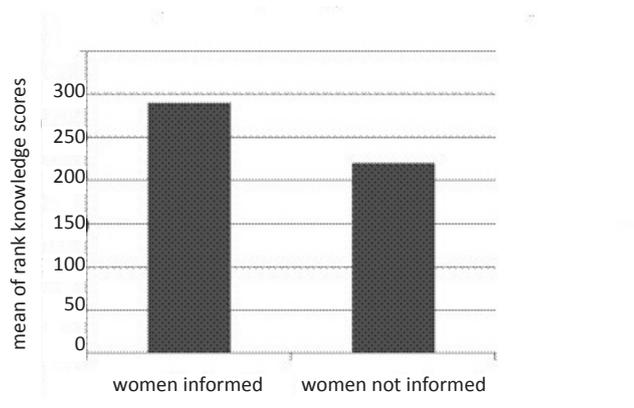
		%
Down syndrome risk is low if the risk is lower than 1/600.	Correct	7.9
	Incorrect	8.3
	I am not able to interpret it	83.8
Amniocentesis should be performed if the risk is higher than 1/270.	Correct	17.1
	Incorrect	4.2
	I am not able to interpret it	78.7
If your Down syndrome risk was found to be 1/270, your risk of miscarriage after amniocentesis is two times higher.	Correct	14.5
	Incorrect	6.3
	I am not able to interpret it	79.2
A 1/200 Down syndrome risk is lower than a 1/450 risk	Correct	13
	Incorrect	14.2
	I am not able to interpret it	72.8
Do you know what you have to do when a risk is found as a result of screening test?	Yes	46.8
	No	53.2
When a Down syndrome diagnosis is made, it is obligatory to end the pregnancy.	Yes	7.2
	No	28.6
	I am not able to interpret it	64.2
When you have a positive result after screening and diagnostic test, which one would determine whether you make a decision to end the pregnancy or not?	Opinion of the doctor monitoring my pregnancy	42.9
	My own opinion	15.6
	Opinion of my partner	15.6
	Opinion of friends/relatives	5.4
	I would not end my pregnancy under any circumstances	20.5

**Table 4. Distribution of attitudes in making decisions based on the test result, according to educational level.**

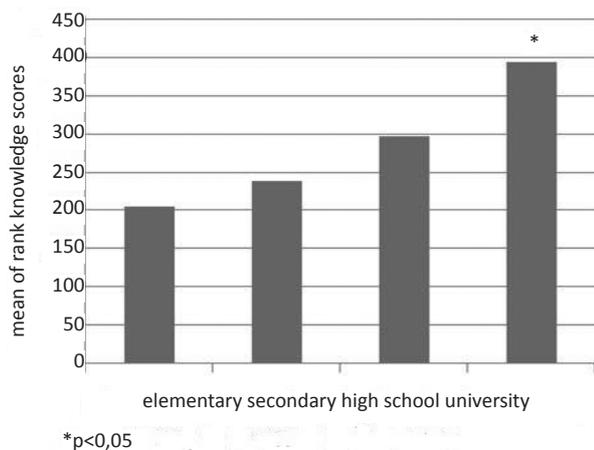
	Primary School		Secondary School		High School		University	
	n	%	n	%	n	%	n	%
My own opinion	18	11.9	15	14	32	15.5	21	24.1
Doctor's opinion	94	62.3	57	53.3	63	30.4	22	25.3
Opinion of my partner	15	9.9	10	9.3	40	19.3	21	24.1
Opinion of my friends/relatives	5	3.3	5	4.7	20	9.7	1	1.1
I Would not end my pregnancy under any circumstances	19	12.6	20	18.7	52	25.1	22	25.3

When faced with a decision regarding termination of the pregnancy, only 15.6% of the women stated that they could make a decision based on their own thoughts, while more women (42.9%) indicated that they would take into account the decision of their monitoring physician. This result is an indication of the critical role of the physician. Therefore, the

knowledge of the person offering the consultation is important for women before screening, for the evaluation of the result, and decision-making based on the result. Previous studies have also demonstrated that the physician's own ideas and opinions are important for patients when trying to understand the meaning and purpose of the investigations<sup>14,16,17-20</sup>.



**Figure 1. The knowledge level of women according to the educational levels.**



**Figure 2. The knowledge level of women according to being received previous explanation or not.**

Nearly half of the women (49.3%) enrolled in this study indicated that they were informed in detail about the screening tests. A significant proportion of the women who received an explanation (75.8%) reported that they understood the explanation. In terms of answering the questions about knowledge level, the results revealed a significant difference between people who received an explanation and people who did not (Table 4). Accordingly, it could be suggested that women have an increased ability to understand and interpret the test when properly informed.

When the quantitative data about the risks were presented to women for the purpose of interpreting the test results, the great majority of them did not

understand their meaning (Table 3). Therefore, the message is not likely to be fully grasped if the explanation of the test result is made based on the quantitative data about the risk. Taking this into account, it can be concluded from this study that explanations given should be at a level that the patient can understand and consideration of the educational level and personal interest might be a better approach. Otherwise, there is the risk of making a subject which is already hard to explain and understand, completely incomprehensible.

Regarding choices about what to do according to the test results, the study concludes that people with a high educational level would rather make their own decisions, while those with a low educational level attach more importance to the opinions of health care professionals (Table 4). In other words, there was a direct relationship between educational level and capacity to make personal decisions.

While 65% of the women did not know anything about CVS, 21.5% knew nothing about amniocentesis. Since patients cannot make decisions about a test that they are not even aware of, it is prudent to reconsider why CVS rates are so low in Turkey. These results are similar to those of Rostant et al.<sup>18</sup> who found that the percent of women who did not know about CVS was higher than the ones not heard of amniocentesis. In another study it is reported that women favored amniocentesis over CVS<sup>10</sup>.

In conclusion, most pregnant women in Turkey have heard about the screening tests for Down syndrome, however they lack sufficient knowledge about the test content and the interpretation of the results. Women have a higher capacity to understand the test and its results when they are given an explanation. Therefore, the physician who is monitoring the patient has an important role in offering information about the test and decisions based on the results. It appears that providing a verbal explanation to the patient, rather than offering numerical data, makes it easier for her to understand and interpret the test results.

Although number of this study is not sufficiently large, it is important because it offers a general impression of the knowledge level of Turkish women throughout the country.

## REFERENCES

- Mulvey S, Wallace EM. Women's knowledge of and attitudes to first and second trimester screening for Down's syndrome. *Br J Obstet Gynecol* 2000;107:1302-1305. <http://dx.doi.org/10.1111/j.1471-0528.2000.tb11624.x>
- Jean Gekas, Sylvie Langlois, Vardit Ravitsky, et al. Non-invasive prenatal testing for fetal chromosome abnormalities: review of clinical and ethical issues. *The Application of Clinical Genetics* 2016;9:15-26. <http://dx.doi.org/10.2147/TACG.S85361>
- Bianchi DW, Platt LD, Goldberg JD, et al. Genome-wide fetal aneuploidy detection by maternal plasma DNA sequencing. *Obstet Gynecol* 2012;119(5):890-901. <http://dx.doi.org/10.1097/AOG.0b013e31824fb482>
- Norton ME, Brar H, Weiss J, et al. Non-Invasive Chromosomal Evaluation (NICE) Study: results of a multicenter prospective cohort study for detection of fetal trisomy 21 and trisomy 18. *Am J Obstet Gynecol* 2012;207(2):137. e1-e8.
- Palomaki GE, Kloza EM, Lambert-Messerlian GM, et al. DNA sequencing of maternal plasma to detect Down syndrome: an international clinical validation study. *Genet Med* 2011;13(11):913-920.2
- Roth P, Bernard JP, Meyer V, et al. First trimester screening for Down syndrome at prima facie. A 6-year survey. *Gynecol Obstet Fertil* 2016;44(2):101-5. <http://dx.doi.org/10.1016/j.gyobfe.2015.11.009>
- O'Leary P, Maxwell S, Sinosich M, et al. Screening for Down syndrome in the second trimester of pregnancy. *Aust N Z J Obstet Gynaecol* 2016;56(1):19-21. <http://dx.doi.org/10.1111/ajo.12411>
- Allred SK, Takwoingi Y, Guo B, et al. First trimester serum tests for Down's syndrome screening. *Cochrane Database Syst Rev* 2015;30:11:CD011975.
- Kyle D, Cummins C, Evans S. Factors affecting the uptake of screening for neural tube defect. *Br J Obstet Gynaecol* 1988;95:560-564. <http://dx.doi.org/10.1111/j.1471-0528.1988.tb09483.x>
- Marteau TM, Johnson M, Kidd J, et al. Psychological models in predicting uptake of prenatal screening. *Psychol Health* 1992;6:13-22. <http://dx.doi.org/10.1080/08870449208402017>
- Al-Jader LN, Parry-Langdon N, William Smith RJ. Survey of attitudes of pregnant women towards Down Syndrome screening Prenat Diagn 2000;20:23-29. [http://dx.doi.org/10.1002/\(SICI\)1097-0223\(200001\)20:1<23::AID-PD746>3.0.CO;2-T](http://dx.doi.org/10.1002/(SICI)1097-0223(200001)20:1<23::AID-PD746>3.0.CO;2-T)
- Santalahti P, Hemminki E, Latikka AM, Ryyanen M. Women's decision-making in prenatal screening. *Soc Sci Med* 1998;46:1067-1076. [http://dx.doi.org/10.1016/S0277-9536\(97\)10038-7](http://dx.doi.org/10.1016/S0277-9536(97)10038-7)
- Drake ER, Engler-Todd L, O'Connor AM, et al. Development and evaluation of a decision aid about prenatal testing for women of advanced maternal age. *J Genetic Counseling* 1999;8:217-233. <http://dx.doi.org/10.1023/A:1022998415890>
- Statham H, Green J. Serum screening for Down's syndrome: Some women's experiences. *BMJ* 1993;307:174-176. <http://dx.doi.org/10.1136/bmj.307.6897.174>
- Ryder IH. Prenatal screening for Down syndrome: a dilemma for the unsupported midwife? *Midwifery* 1999;15:16-23. [http://dx.doi.org/10.1016/S0266-6138\(99\)90033-5](http://dx.doi.org/10.1016/S0266-6138(99)90033-5)
- Smith DK, Slack J, Shaw RW, Marteau TM. Lack of knowledge in health professionals: a barrier to providing information to patients? *Qual Health Care* 1994;3:75-78. <http://dx.doi.org/10.1136/qshc.3.2.75>
- Press N, Browner CH. Why women say yes to prenatal diagnosis. *Soc Sci Med* 1997;45:979-989. [http://dx.doi.org/10.1016/S0277-9536\(97\)00011-7](http://dx.doi.org/10.1016/S0277-9536(97)00011-7)
- Rostant K, Steed L, O'Leary P. Survey of the knowledge, attitudes and experiences of Western Australian women in relation to prenatal screening and diagnostic procedures. *Australian New Zealand J Obstet Gynaecology* 2003;43:134-138. <http://dx.doi.org/10.1046/j.0004-8666.2003.00041.x>
- Smith DK, Shaw RW, Marteau TM. Informed consent to undergo serum screening for Down's syndrome: The gap between policy and practice. *BMJ* 1994;309:776. <http://dx.doi.org/10.1136/bmj.309.6957.776>
- Gekas J, Gondry J, Mazur S, et al. Informed consent to serum screening for Down syndrome: are women given adequate information? *Prenat Diagn* 1999;19:1-7. [http://dx.doi.org/10.1002/\(SICI\)1097-0223\(199901\)19:1<1::AID-PD456>3.0.CO;2-S](http://dx.doi.org/10.1002/(SICI)1097-0223(199901)19:1<1::AID-PD456>3.0.CO;2-S)