

Healthcare Professionals Attitude And Knowledgeon Double Test And Pregnancy Termination For Down Syndrome**Hekimlerin İkili Test Hakkında Bilgi Düzeyi, Düşünceleri ve Down Sendromunda Terminasyon**

Nagihan SARI¹, Yaprak ENGİN-ÜSTÜN^{1,2}, Emel KIYAK ÇAĞLAYAN¹, Levent SEÇKİN¹,
Ayla AKTULAY², Ali İrfan GÜL³

¹ Bozok University Faculty of Medicine, Department of Obstetrics and Gynecology,
Yozgat, Turkey

² Department of Gynecology and Obstetrics, Zekai Tahir Burak Women's Health
Education and Research Hospital, Ankara, Turkey

³ Bozok University Faculty of Medicine, Department of Psychiatry, Yozgat, Turkey

ABSTRACT

Aim: This study aimed to evaluate the knowledge levels of physicians, who are not Gynecology & Obstetrics specialist or residents, on the 1st trimester screening test for prenatal screening and their opinions about the double test and continuation-termination of a pregnancy, a patient or their wife, with a definite Down syndrome diagnosis.

Material And Methods: A "measure of informed choice" survey was applied to physicians who are not Gynecology & Obstetrics specialist or residents. This survey was developed by Marteau et al.; to evaluate the level of knowledge of the participants on the first trimester screening test and their opinions on the test. Their decision on termination, any pregnancy or their wives' pregnancy, of the pregnancy in the presence of a Down syndrome diagnosis was assessed. Level of knowledge, opinions on the test and the decision on termination of the pregnancy were assessed.

Results: 100 physicians attended the survey and all of them completed the questionnaire. Of the 100 physicians in the study; 45% were female, 55% were male and average age was 35±4.5 (27-50 years). While 81% of the participants had sufficient knowledge on the test, 19% had insufficient knowledge. 60% of the physicians had negative and 40% of the physicians had positive attitude on conducting double test. 37% of the physicians indicated that they would want to continue the pregnancy even if the Down syndrome diagnosis was definite, 18% indicated that they would finalize the pregnancy, 45% said that they weren't sure of what their decision would be.

Conclusion: We found in this study that; 81% of the participants had sufficient knowledge on the double test, 60% of the physicians had negative attitude on conducting double test and 37% of the physicians indicated that they would want to continue the pregnancy even if the Down syndrome diagnosis was definite.

Key Words: Healthcare providers' opinions, double test, Down syndrome, termination

ÖZET

Amaç: Prenatal tarama amacıyla yapılan birinci trimester tarama testi hakkında Kadın Doğum Uzmanı veya asistanı olmayan hekimlerin bilgi düzeylerinin ve ikili test hakkındaki düşüncelerinin değerlendirilmesi, Prenatal Down Sendromu tanısı kesinleşen çiftlerin gebeliklerinde terminasyon ve gebeliğin devamı kararlarının araştırılması hedeflendi.

Gereç ve Yöntemler: Kadın doğum uzmanı veya asistanı olmayan hekimlere "bilinçli seçim" anketi uygulandı. Bu anket Marteau ve arkadaşlarının geliştirdiği, katılanların ilk trimester tarama testi hakkında bilgi düzeyini ve test hakkındaki düşüncelerini değerlendiren bir ankettir. Down Sendromu tanısının kesinleşmesi durumunda çiftlerin gebeliklerinin sonlandırılması yada devamı kararı soruldu. Bilgi düzeyi, test hakkındaki düşünceler ve gebeliğin sonlandırılması kararı incelendi. SPSS tanımlayıcı istatistik yöntemi kullanıldı.

Yazışma Adresi / Correspondence Address:

Nagihan SARI

Bozok University Faculty of Medicine Adnan Menderes Bulvarı No. 190 Yozgat - Turkey

Phone: 0 (354) 212 70 01 E-mail:opdrnagihansari@yahoo.com.tr

Geliş Tarihi/Received : 27.06.2014

Kabul Tarihi/ Accepted : 01.07.2014

Bulgular:100 hekim ankete katıldı, grubun tamamı anketi tamamladı. Çalışmaya alınan 100 hekimin %45'i kadın, % 55'i erkekti, yaş ortalamaları 35±4,5 (27-50 yaş) idi. İkili test hakkında % 81'inin bilgi düzeyi yeterli, %19'unun bilgi düzeyi yetersizdi. Hekimlerin %60'ının ikili test yaptırma konusunda tutumları olumsuz, % 40'inin olumluydu. Hekimlerimizin % 37'si Down Sendromu tanısı kesinleştiğinde gebeliğine devam etmek isteyeceklerini, %18'i gebeliğini sonlandırmak isteyeceklerini, % 45'i ise ne karar vereceğine emin olmadığını ifade etti.

Sonuç: Çalışmamıza katılan hekimlerin % 81'inin ikili test konusunda bilgi düzeyinin yeterli olduğunu, %60'ının testi yaptırma konusunda tutumlarının olumsuz olduğunu, %37'sinin Down Sendromu tanısı kesinleştiğinde gebeliklerine devam edebileceklerini saptadık.

Anahtar Kelimeler: Sağlık çalışanları düşünceleri, ikili test, Down sendromu, terminasyon.

Introduction

With the common utilization of screening tests in the early pregnancy weeks; high risk pregnancies can be detected and it is possible to diagnose Down syndrome (D.S.) through diagnostic tests during the prenatal period. The importance of informed choice for the screening tests has been emphasized by the World Health Organization in 2006, and by the National Screening Committee in 2011 (1). NICE 2010 guidelines state that; the physician has an obligation to provide support, but not inclining information for the pregnant woman for her independent decision on whether to accept the screening test or not (2). With the developments in screening tests in recent years; combined with maternal age, family medical history, biochemistry and first trimester USG; 85-90% of Down syndrome pregnancies can be detected with a 5% false positive rate, and thus the need for invasive antenatal tests are reduced (3). Among the various screening tests, the most frequently used tests are the combined (nuchal translucency, PAPP-A, free b-hCG) and integrated (nuchal translucency, PAPP-A in the 10th – 13th weeks and free b-hCG, AFP, uE3, Inhibin-A in the 14th – 20th weeks) test. Down syndrome is the most common chromosomal anomaly, at a rate of 1/750, causing mental retardation (4). If the Down syndrome is diagnosed in the antenatal period, the parents may consult the physician on whether or not to continue with the pregnancy. The physicians are usually determined not to direct the pregnant woman and her family during the decision process, but even so, the families indicate that they have obtained special comments and recommendations from physicians concerning the termination or continuation of the pregnancy (5). Our aim of this study is to evaluate the knowledge levels of physicians, who are not Gynecology & Obstetrics specialist or residents, on the 1st trimester screening test for prenatal screening and their opinions about the double test and their decision on the continuation-termination of a pregnancy for couples with a definite Down syndrome diagnosis.

Material and Methods

Physicians working in and around Yozgat province were provided information about the study, either face-to-face or by phone, and were asked if they wanted to participate. All of them responded affirmatively. Obstetrics & Gynecology specialists and residents were not included in the study. The survey was translated from English to Turkish by translators/interpreters, delivered to the participants by hand delivery or via mail, and they were returned to us upon completion between March 2014 – April 2014. An "Informed Choice" survey was applied in this study (Appendix-1). This survey was developed by Marteau et al.; to evaluate the knowledge level and attitude of the participants on the first trimester screening test. The survey we applied enables a multidimensional evaluation; risk estimation, whether the content and context of the antenatal screening test is understood or not, and sentiments and opinions about the application of the screening test. Risk estimation and the understanding of the antenatal screening test were

measured by eight questions under the "knowledge level" heading; sentiments and opinions were evaluated with the Likert scale under the "attitudes" heading. The highest score in measuring the knowledge level was 8 (on a 0-8 scale), while the highest score for attitude, behavior was 28 (on a 4-28 scale). A score of 4 and over was evaluated as sufficient knowledge and less than 4 were insufficient. Positive attitude had a score of 12 and over while a score of less than 12 points was evaluated as a negative attitude. The midpoint of the scales was used to determine the cut-off for scores. The decision of the couples, for the termination or continuation of the pregnancy in case of a definite Down syndrome diagnosis, was asked. Age and gender of the participants, whether or not they were a family physician, married and the existence of a member in the family with DS was inquired. Level of knowledge, their opinions on the test and the decision to terminate the pregnancy were assessed. Since this was a survey study, the approval of the ethical committee was not required. SPSS descriptive statistical method was used for the statistical analyses.

Results

100 physicians took the survey, it was conducted either face-to-face or by e-mail and all participants completed the survey. Of the 100 physicians in the study; 45% were female, 55% were male and the average age was 35±4.5 (27-50 years). While 81% of the participants had sufficient knowledge on the double-test, 19% had insufficient knowledge. 60% of the physicians had negative and 40% of the physicians had a positive attitude in conducting the double test. 37% of the physicians indicated that they would prefer to continue the pregnancy, even if the Down syndrome diagnosis was definite, 18% indicated that they would finalize the pregnancy, 45% said that they weren't sure of what their decision would be. 81.1% of those who decided to continue the pregnancy had a sufficient level of knowledge, and 18.9% did not. Of the participants who wanted to terminate their pregnancy, 94.4% had a sufficient level of knowledge and 5.6% did not. Among those who were not decided between continuation or termination of the pregnancy; the knowledge level was sufficient in 75.6% and insufficient in 24.4%. Answers of participants were shown in Table 1.

Table-1: The distribution of termination decision.

	n (%)	n (%)	n (%)
Married	30(37,5)	15(18,8)	35(43,8)
Single	7(35)	3(15)	10(50)
Sufficient knowledge	30(37)	17(21)	34(42)
Insufficient knowledge	7(36,8)	1(5,3)	11(57,9)
Family Physicians	9(32,1)	5(17,9)	14(50)
Physicians	28(38,9)	13(18,1)	31(43,1)
Female	15(33,3)	9(20)	21(47,6)
Male	22(40)	9(16,4)	24(43,6)

Discussion

Studies conducted so far mostly have investigated the knowledge level of antenatal screening tests, opinions and termination decisions from the parents' perspective (5, 6). In these studies; it has been assumed that the decisions to accept/refuse antenatal screening tests and termination were completely made by the parents, thus their attitudes, beliefs and decisions were evaluated. How realistic is this assumption? Although the physicians are sensitive about not playing a directing role in the decision process, parents frequently have stated that they have received special advice on whether to continue or terminate the pregnancy (7). In a study with the participation of 499 family physicians; 63% have stated that they try to be as neutral as possible while providing information on Down syndrome. % 13 have expressed that they made negative comments on the DS so that the families would make the termination decision, 10% indicated that they were oppressive for termination, 10% were targeting the continuation of the pregnancy by making positive comments, and 4% were oppressive for the continuation of pregnancy (8). In another study; 10 women had stated that they could not make a conscious decision on the continuation or termination of the pregnancy and they were informed by health professionals according to their own feelings and opinions (9). In the study we conducted with the participation of 100 physicians; only 18% of the physicians have stated that they would want to terminate the pregnancies diagnosed with prenatal D.S. 45% have expressed that they were not sure how they would decide, and 37% have indicated that they would favor the continuation of the pregnancy. In another study conducted with the participation of health professionals; 73% of the obstetrics & gynecology specialists and residents, and 43% of pediatric specialists and residents have stated that they would terminate the pregnancy in case of an antenatal D.S. The difference between the pediatricians and obstetricians has been associated with the fact that the pediatricians are in direct contact with the DS children and their families and are closely acquainted with how they live their lives (5). We think that the reason behind the fewer number of termination decisions in our study, is religious beliefs. Additionally, it should also be considered that part of the undecided (between termination and the continuation of the pregnancy) group which consists the 45%, could make the decision to terminate. Since there isn't any treatment option for antenatal diagnosed D.S, the prevailing view among the physicians is to screen the mothers who are planning to continue their pregnancy. It has been established that mothers who want to continue their pregnancy after being diagnosed with D.S. in the antenatal period are more contented than mothers with a postnatal diagnosis (10, 11). In studies conducted with mothers who had continued with their pregnancies after an antenatal Down Syndrome diagnosis; the mothers have stated that they were very pleased for having been informed of the diagnosis in the antenatal period because they could prepare themselves in the best way until the delivery (10, 11). 60% of the physicians in our study had negative opinion and attitude on the screening test while 40% had a positive attitude. The negative attitude of the physicians will be reflected on the pregnant women's behavior, thus the unpreparedness of a large group in this situation, due to postnatal diagnosis, will complicate the adaptation process. The most important handicap in surveys is whether the answers will really turn into action. We do not know if the physicians in our study will definitely put into effect their answers to the survey in case of a real antenatal D.S. diagnosis or not. Another unknown factor is the level of influence the physicians' opinions have on the pregnant women's decisions, and to what extent the physicians reflect these opinions and beliefs to the patients. In order to understand this issue better, we need to monitor and evaluate in detail,

the dialogues between the parents and the physicians in the case of an antenatal D.S. diagnosis. Further studies are needed for clarification of this issue.

Conclusion

We found in this study that; 81% of the participants had sufficient knowledge, 60% of the physicians had negative attitude on conducting double test and 37% of the physicians indicated that they would want to continue the pregnancy even if the Down syndrome diagnosis was definite.

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