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Pregnant Women's Knowledge and Attitudes to Prenatal Screening for Fetal Chromosomal Abnormalities: Croatian Multicentric Survey

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A B S T R A C T

We aimed to assess opinion and preferences of Croatian pregnant women regarding the prenatal screening tests for trisomies. The study was conducted in Zagreb, Split, Čakovec, Nova Gradiška, Gospić and Zlatar. It was organized in the public primary healthcare centers, among the pregnant volunteers during their first visit to an antenatal clinic (7–12 weeks pregnant). The respondents filled anonymous questionnaire reflecting their knowledge and attitudes to the screening options. In total, 437 completed questionnaires were selected. The average maternal age and the level of education differed significantly between the respondents in the respective cities (P<0.001). Of the respondents with positive attitude towards screening, the majority would prefer the first-trimester combined test (160/219; 73.1%), while 37/219 (16.9%) opted for the second-trimester biochemical screening. The remaining 22/219 (10.0%) would accept only the ultrasound screening. Among the 224 respondents, who would accept the combined first-trimester test, 95 (42.4%) held a college and university degree, whereas among 59 women, who would choose the second-trimester biochemical screening, 14 were highly educated (23.7%). The difference was statistically significant (P=0.016). The univariate regression analysis showed that age, level of education and previous information were significant variables predictive for the choice of the test; the level of education and previous knowledge remained significant in the multivariate model. The survey has revealed some of the points that should be improved in the future concept of screening program in Croatia. Health professionals should persist to mend women's knowledge about prenatal screening, taking into consideration women's preferences as well.

***Key words**: Down syndrome screening; women's attitudes and knowledge*

Introduction

Over the recent years, continuous developments in ultrasound and biochemistry, individually or combined, have led to a progressive trend in the earlier screening for fetal chromosomal abnormalities[1–4]. Several studies have reported on the women's experience of the serum screening programs for Down syndrome, focusing on their opinions, motives, knowledge and decision-making processes[5–7]. Some of them have pointed out positive attitudes among women to earlier tests, referring to the advantages of moving the screening program to the first

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trimester[8,9]. Taking into account women's choices, the second-trimester biochemical screening is still justified on grounds of its accessibility in the prenatal care system. The second-trimester screening targeted pregnant women who were either late for an early screening or did not have sufficient time to consider the benefits and medical implications of the first-trimester screening, as well as their readiness for earlier diagnosis if necessary[6,10]. In addition, the option of prenatal screening depends to a certain degree on how the obstetrical care system is organized in a particular country or region. The reported variations in the screening uptake mirrored not only the differences in the national concepts of prenatal care, but also the demographic characteristics of the surveyed pregnant women and the timing when they were asked about the tests they would prefer[7,9,12,13].

Perhaps the inadequacy of most of the studies has been the gestational week when the surveyed pregnant women had already been in a position for an immediate decision or had already undergone the test and waited for the results [9,13,14]. In our opinion, to get an objective insight into women's knowledge, attitudes and opinions about the screening, the survey should be undertaken at the outset of the gestation, before undertaking either the screening tests or counseling about the options.

In Croatia, there are no firm regulations concerning the prenatal screening for fetal aneuploidies, although the second-trimester biochemical screening has been an option since 1996[11]. Also, caregivers have been routinely offering the first-trimester ultrasound examination to pregnant women at their first visit after getting pregnant. Since 2006, the first-trimester screening in combination with the biochemical markers and nuchal translucency measurement has been introduced as optional, though it has not been formally approved by the Croatian Ministry of Health so the costs have been borne by the patients themselves[15].

This cross-sectional study was undertaken on a prospective basis, assessing the expecting mothers' knowledge and attitudes to prenatal screening tests in different districts of Croatia. The aim was to get a better insight into pregnant women's awareness, motives and preferences about the first and the second-trimester screening in early pregnancy, before they were actually in a position to decide or choose any of the recommended tests for the screening of fetal abnormalities.

Participants and Methods

The study was conducted between August 2008 and July 2009 in six different Croatian cities. It was organized in the public primary healthcare centers, which covered particular districts. Besides in Zagreb, which is the capital of Croatia with about one million inhabitants, the survey was organized in the following cities: Split, Čakovec, Nova Gradiška, Gospić and Zlatar. Split is the second largest city, with about 200,000 inhabitants and Zlatar is the smallest town, with about 7,000 inhabitants. Our study included only pregnant volunteers, regardless of their age, prior experience and personal religious beliefs. The only selection criterion was the gestational age of 7–12 weeks of pregnancy, regardless of whether they had conceived spontaneously or using methods of assisted reproduction.

A questionnaire was offered to a randomly selected population of pregnant women at their first antenatal visit to the obstetrical practice, before undergoing any of the prenatal screening options. Each woman was given a short informative pamphlet about Down syndrome and a summary of all available screening tests in the first, as well as in the second trimester. Screening performance and screen-positive rates for each of the tests were explained on the basis of our own results[11,15]. This short review was primarily designed for women with no previous experience or knowledge about prenatal screening options. Also, it served as a kind of reminder to the experienced ones who did not think about the screening tests as a choice during the actual pregnancy. The answers to the written questionnaire were totally anonymous and did not oblige any of the participants to undergo the following screening tests for fetal chromosomal abnormalities.

The questionnaire included some general questions about the gestational age, woman's age and education. The next section involved woman's previous knowledge and sources of information. Finally, there were questions addressing the woman's decision about the ultrasound screening, combined first-trimester test and second-trimester biochemical screening. Last questions concerned woman's reasons for any of the decisions.

The women were given the opportunity to read the information pamphlet and questionnaire while waiting in the doctor's office and to complete the questionnaire at the end of their appointment. The doctors were asked to be neutral educators and not to influence the women's decision in any way. The study design did not involve participants' medical records and no identifying features about the pregnant women were recorded in the questionnaires. Also, the study did not influence the patient's and doctor's decision about the following procedures in pregnancy and the concept did not involve financial or personal interests. Still, the ethics committee of the University Hospital »Sestre milosrdnice« approved the study in order not to undermine the patients' rights.

Statistics

The data are presented as figures and percentages. The difference in percentages was compared with the chi-square test and z-test. Since the variances of median age of the respondents in subgroups across districts were unequal, the respective differences were compared with the non-parametric Kruskal-Wallis test. One way analysis of variance (ANOVA) was used to test the differences in the preferences for the test between subgroups, in relation to the age. The univariate logistic regression analysis was done to identify variables, which were predictive for the choice of the test. The variables that were significant in the univariate regression analysis were included into the multivariate modeling analysis. The regression

analysis results were presented as odds ratios (OR) and respective confidence intervals (95% CI)[16,17].

P values of <0.05 were considered to indicate significant results. All analyses were done using the MedCalc 11.2.0.0 statistical software (Frank Schoonjans, Mariakerke, Belgium).

Results

Out of the total number of 488 surveyed pregnant women, 437 filled the questionnaires completely and were selected for this study (89.5%). The rest was rejected mainly because they were beyond the 13th week of gestation (N=43) or the answers in the questionnaire were incomplete (N=8). The demographic characteristics of the respondents in different districts are presented in Table 1.

The average maternal age differed significantly between the particular districts ($P<0.001$; Kruskal-Wallis test). The women in Zagreb and Split were, on average, of similar age; the youngest were in the district of Nova Gradiška. Also, the level of education differed significantly between the respondents in particular districts ($P<0.001$; chi-square test). The highest proportion of university-educated participants was observed in Zagreb and Split, while women with secondary school education were predominant in the remaining four cities.

The answers of the respondents given in questionnaires, regarding the information and preferences about screening, are presented in Table 2.

The majority of the respondents with positive attitudes towards the options of prenatal screening answered that they would choose the first-trimester combined test (160/219; 73.1%), while 37/219 (16.9%) would prefer the second-trimester biochemical screening. The remaining 22/219 (10.0%) would accept only the ultrasound screening.

There was no difference between the maternal age of the respondents, when considering the choice of the test ($P=0.150$; one way ANOVA).

In general, there was no difference in the *pro et contra* attitudes towards the prenatal screening tests between the respondents with regards to their level of education. Out of 219 pregnant women, who would undergo prenatal screening, 93 of them (42.5) had a university degree. Out of 75 women who were unwilling to take any of the tests, 30 (40.0%) had a university degree ($P=0.812$; z-test). The remaining 143 respondents, at the time of the survey, had not yet decided about the opportunity of screening.

The most frequent answer among the decliners was »I'm going to bear my child no matter of tests« (50/75; 66.7%), while 12/75 (16.0%) respondents mentioned unreliable characteristics of a screening test as their reason for refusing the prenatal screening.

The most frequently mentioned reason for accepting a screening offer was – 'gaining knowledge about the health of the baby' (165/219; 75.3%). On the other hand, 54 of 219 (24.7%) respondents considered that a prenatal screening could be useful for earlier diagnosis of fetal health.

We analyzed whether there was a difference in preferences for a particular test between the respondents, taking their level of education as a criterion. Among the 224 respondents who would prefer the combined first-trimester test, 95 (42.4%) had a college and university degree, whereas among 56 women, who would choose the second-trimester biochemical screening, only 14 (25%) were highly educated. The difference was statistically significant ($P=0.025$; z-test).

Interestingly, the attitude towards prenatal screening for fetal chromosomal abnormalities differed between sub-groups of women, with regards to their previous knowledge about the available tests. A total of 306 women had some previous information about the screening; 186/306 (60.8%) were ready to undergo any of the available prenatal tests, while 46/306 (15.0%) felt unwilling to consider any of the screening options. The remaining 74 (24.2%) women, at the time of the survey, had not decided whether and which screening they would undergo ($P<0.001$; chi-square test). Among the 131 respondents, who were presented with the information for the first time during the survey, 33 (25.2%) would still accept some of the prenatal screening tests.

As to the question that concerned the understanding of the purpose and characteristics of various screening tests available during the first and the second trimester of pregnancy, more than half of the respondents (275/

TABLE 1
EDUCATIONAL BACKGROUND, AGE AND GESTATIONAL WEEK OF SURVEYED PREGNANT WOMEN

District	Čakovec N=95	Zlatar N=51	Zagreb N=94	Nova Gradiška N=71	Gospić N=57	Split N=69
Primary school*	8 (8.4)	2 (3.9)	–	14 (18.2)	3 (5.3)	–
Secondary school*	74 (77.8)	40 (78.5)	40 (42.5)	37 (48.1)	43 (75.4)	30 (43.5)
2-years' college*	5 (5.3)	5 (9.8)	9 (9.6)	13 (16.9)	4 (7.0)	13 (18.8)
University degree*	8 (8.4)	4 (7.8)	45 (47.9)	7 (9.1)	7 (12.3)	26 (37.7)
Maternal age (years; mean±SD)	25.1±4.5	25.9±3.5	31.5±5.5	23.9±4.8	25.2±4.3	30.6±4.4
Gestational age (weeks; mean±SD)	9.1±1.7	10.0±2.0	8.7±1.8	9.6±2.1	8.3±1.9	9.9±1.8

* Number (percentage)

TABLE 2
RESPONSES OF SURVEYED PREGNANT WOMEN TO QUESTIONS CONCERNING INFORMATION AND PREFERENCES FOR PRENATAL SCREENING FOR FETAL CHROMOSOMAL ABNORMALITIES

QUESTION	Frequency	
	N	%
Have you heard about the screening tests for Down syndrome before?		
Yes	306	70.0
No	131	30.0
Sources of information [a]		
From my doctor and/or medical staff	97	31.7
In conversation with relatives – friends	104	34.0
Press – literature – internet – books – school	105	34.3
Do you understand the purpose and performance of prenatal screening (ultrasound, biochemistry and combined ultrasound+biochemical markers)?		
Completely understandable	275	62.9
Insufficiently understandable	130	29.7
Not understandable	32	7.3
Would you accept any of prenatal screening tests in this pregnancy?		
Yes	219	50.1
No	75	17.2
I haven't think about it	49	11.2
I'd like to consult with my doctor	94	21.5
The main reason why not to undergo screening test: [b]		
Screening tests are unreliable	12	16.0
I'm going to bear my child no matter of tests	50	66.7
I don't want to refer the reason	9	12.0
Other	4	5.3
The main reason why to accept any of screening tests: [c]		
I consider the screening tests useful for earlier diagnosis	54	24.6
I want to get knowledge of child's health	165	75.3
Other	–	–
Which of the screening tests would be the most acceptable for you? [d]		
Ultrasound between 10–14th gestational week	82	22.6
Combined test between 11–13th gestational week	224	61.9
Biochemical test between 14–19th gestational week	56	15.5

[a] Only respondents with previous information about the screening tests (N=306); [b] Only respondents who would decline prenatal screening options (N=75); [c] Only respondents who declared positive attitude towards prenatal screening tests (N=219); [d] Without respondents who declined prenatal screening test (N=362)

437; 62.9%) answered that the options were completely understandable. Additionally, 130 of the respondents (29.8%) considered to be insufficiently informed about the screening, while only 32 of them (7.3%) admitted that the tests were totally indistinct.

In addition, we were interested in the source of information which contributed most to the knowledge about the options in prenatal screening for fetal aneuploidies. Of those who were informed prior to the survey, 31.7 % had got the information from the doctor and medical staff in prenatal care units, 34 % were informed by their relatives and friends, and 34.4 % had gained this information from the public media (television, books, pamphlets, education).

We performed the logistic regression analysis to identify the variables, which were predictive for the choice of the test. Age, level of education and previous knowledge about the test were significant variables predictive for the choice of the test in the univariate regression analysis, whereas only the level of education and previous knowledge remained significant in the multivariate model (Table 3).

With regards to the results of the regression analysis, previous knowledge about the characteristic of the available screening tests was the most significant positive predictor for the choice of the combined first-trimester test.

Discussion

Our study was conducted to assess the pregnant women's opinion regarding the non-invasive screening tests

TABLE 3
UNIVARIATE AND MULTIVARIATE LOGISTIC REGRESSION ANALYSIS OF THE VARIABLES POTENTIALLY PREDICTIVE FOR THE CHOICE OF THE TEST FOR THE PRENATAL SCREENING OF FETAL CHROMOSOMAL ABNORMALITIES (N=437)

Variable	Univariate analysis		Multivariate analysis	
	OR * (95% CI **)	P	OR * (95% CI **)	P
Age	0.944 (0.892–0.999)	0.048	–	–
Level of education	0.539 (0.367–0.794)	0.002	0.583 (0.393–0.864)	0.007
Previous knowledge	3.389 (1.800–6.383)	<0.001	2.950 (1.547–5.629)	0.001

* OR – odds ratio; ** CI – confidence interval

for fetal chromosomal abnormalities, both in the first and in the second trimester of pregnancy. To ensure diversity among the study population, the surveyed women were recruited from different socio-economic regions in Croatia, under the assumption that this can also attribute to the variety in their educational background and knowledge about the screening tests. This study was primarily designed to explore women's perceptions of the prenatal screening in the earliest time frame, when they had not yet decided about the screening options. Also, we were induced with a real situation, to which we have been faced frequently, when a pregnant woman came to our clinic without a clear decision what she really wished.

According to the experience of other investigators, women are usually faced with a challenging decision, which required them to balance their preferences and choose immediately which test to undergo. It was the case in most of the published studies that investigated women's opinion towards the screening while they were waiting for the results of invasive diagnostics. In Kornman's study, conducted among women attending the clinic for participating in the second trimester screening program, was shown that the majority of them would prefer the first- over the second-trimester screening[5]. Similarly, Spencer and Aitken reported that about two-thirds of pregnant women, attending six maternity units across the UK, opted for the first-trimester screening tests[7]. The results of the Weinan's study, in 160 Duch women, confirmed that the vast majority (86%) of the respondents thought that the screening in the first trimester would be an advantage[12]. One of the few investigations conducted in the earliest time of the pregnancy was that of Mulvey and Wallace who interviewed 100 women under the 14 week's pregnancy[8]. This study has shown that the majority of respondents stated the preference for as earlier screening as available, no matter that those tests identified pregnancies which were destined for spontaneous loss before 15th gestational week.

In our opinion, the strength of our study is that the survey was undertaken at six different localities across Croatia, with different local healthcare policy, socio-economic structure of inhabitants, age characteristics and education background of the respondents. Another advantage of our study is that the survey was conducted in primary healthcare centers, where pregnant women are advised for all of the prenatal procedures in the course of the pregnancy. This gave us the opportunity to get a better insight into pregnant women's preferences in early gestation, before they were actually in a position to decide or choose any of the recommended tests for the screening of fetal abnormalities.

Most of the previous studies have shown that the acceptance of prenatal screening should not depend on a passive involvement of pregnant women in the decision-making process[10,13,18–20]. On the contrary, the only plausible way should be to ensure the woman's ability to decide about the screening on the basis of an informed choice. This means that she should have relevant knowledge and that the decision should be consistent with her own values and beliefs. Equally important are her rights to have enough time to accept or decline any of the prenatal screening tests[21,22]. Knowing the fact that the screening tests are still given routinely, without offering the women the required explanation of their purpose, authors Michie and Marteau suppose that only refusing the test denotes an act of decision, while undergoing the test rather reflects the woman's routine behavior or psychological adjustment to a model »that the experts recommend«[6]. Applying the survey design described in our study, any kinds of coercion or influence on the women's attitude were avoided. In addition, we asked doctors and medical stuff at particular health centers to be absolutely neutral in assisting women to fill in the questionnaires. Healthcare providers often substitute the term 'informed consent' for 'informed choice', when dealing with screening tests. Some studies have pointed out that the physician's role in the informed choice process for any kind of screening should elicit and implement the patient's preferences, but they are sometimes in the position not to act in this manner[23–25]. Our study has clearly shown that women's education and previous information are statistically significant predictors for making an informed choice regarding prenatal screening tests. It is of importance that, due to the large sample size, this study was adequately powered to detect significant differences between the variables[26].

In a manner, our study was understated, because we did not take into consideration all the factors which could influence women's attitudes and decision about the screening options. For instance, women were not asked about the previous pregnancies, or their personal experience of congenital abnormalities and birth defects. The recent findings of Stefansdottir and co-workers confir-

med that pregnant women's previous experience of congenital anomalies or disability increased the acceptance of prenatal screening tests among 379 women attending the clinics for prenatal care[27]. Beside that, we can not discern a possible influence of personal ethical reasons or religiosity of the respondents which could oppose to prenatal screening procedures[13].

As shown in the Results, about 50% of our respondents were likely to accept the opportunity of screening, while another half of the respondents felt unwilling or had not decided for any of the screening options. For the reason that this was not the controlled trial, we can not discuss about the real screening uptake among the surveyed women. Perhaps we could rely only on the recent report of the Croatian Institute of Public Health, which showed that more than 70% pregnant women in Croatia attend the clinics for the first-trimester ultrasound screening, between 10th and 14th weeks of pregnancy[28].

One of our intentions was to conduct a survey on a district scale and to include the respondents with different levels of education. The demographic characteristics of the women surveyed in this study were somewhat different to the female population in Croatia, when it comes to their educational background. According to the latest report of the Croatian Central Bureau of Statistics in 2009, when our survey was conducted, 20% of the Croatian women were below of the age of 42 and had a 2-year college and university degree[29]. Among our respondents, there were about 30% of those with college or university education. The majority of them would prefer the first-trimester combined screening to the second-trimester biochemical screening. This is not unexpected when having in mind that the information about the prenatal tests has been extensively presented in the media available during their education (literature, internet and other). As our study demonstrates, the most significant positive predictor for the acceptance of the prenatal screening test was previous knowledge about the screening options. Still, the educational degree does not always stand for knowledge and appropriate understanding of the prenatal screening methods. More precisely, the term knowledge denotes the entire awareness of the potential implications of screening and possible proximate decision about the diagnostic procedure, if necessary[19,20]. Yet, it is important to point out that for about 60% of our respondents believed they received sufficient knowledge to make an informed decision about the screening. Maybe we should take a better look into the term of self-reported knowledge about the prenatal screening among Croatian women, because the last investigation was undertaken ten years ago[18]. We are aware that the results in the present study are insufficient to prove the contemporary awareness and knowledge of pregnant women in our country about all the issues concerning the prenatal screening and diagnosis of fetal chromosomal abnormalities. This remains to be investigated for the betterment of prenatal care in our population.

In Croatia, there are no firm regulations concerning offering prenatal screening tests to pregnant women[30]. On the one hand, there is a constant increase in the average age of childbearing women in Croatia and, coupled with the increasing involvement of pregnant women in the available screening tests for fetal aneuploidies[31,32]. The average age of women in this survey was somewhat lower than was the average age of pregnant women in the latest annual State report[29]. Still, we found no statistically significant differences between the age of respondents and the choice of the either first- or second-trimester screening tests. Some earlier studies demonstrated that older women (over 37 years of age) were significantly more likely than younger women to choose a screening test with the highest detection rate, regardless of the highest screen-positive rate[3,4]. But, those studies were undertaken among the women who were already entitled to an invasive diagnostic procedure (CVS, amniocentesis). In our opinion, in such a pre-determined condition, women were not capable of expressing their deliberated decision in accordance with their elementary beliefs. The participation in a prenatal screening test should not be burdened with the necessity of making an immediate decision.

Our study has highlighted the importance of providing the written and verbal information to all women, assuring that they have appropriate understanding of the available screening options[27,33–37]. Among our respondents, there were almost equal proportions of those who stated three main sources of information: competent gynecologist, friends or relatives and the public media, respectively. In our opinion, the effort of all specialists participating in the health services should aim at better information for each and every woman undergoing prenatal screening. The information should be tailored to suit individual learning capabilities and give the ability of free choice. Some women may simply not want to proceed with the screening or are influenced by the family, social, cultural, religious and other factors when choosing what is best for them.

In conclusion, choosing to or not to undergo a prenatal screening test for fetal aneuploidies is an important decision for both partners, which relies on a complex interrelationship between the medical indications and basic right of each women to make an informed choice. If screening procedures are to be implemented into the national policy of antenatal care, health professionals and caregivers should also determine what information pregnant women should be given to ensure the adequate and successive decision about the screening.

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ZNANJE I SKLONOSTI TRUDNICA PRENATALNIM TESTOVIMA PROBIRA FETALNIH KROMOSOMOPATIJA: MULTICENTRIČNO ISTRAŽIVANJE U HRVATSKOJ

SAŽETAK

Cilj rada bio je istražiti mišljenje i sklonosti trudnica testovima prenatalnog probira fetalnih trisomija koji se primjenjuju u Hrvatskoj. Istraživanje je provedeno u Zagrebu, Splitu, Čakovcu, Novoj Gradiški, Gospiću i Zlataru. Anketa je organizirana u centrima primarne zdravstvene zaštite, među trudnicama koje su se u ambulantu javile radi prvog pregleda u trudnoći (7–12 tjedana). Sudjelovanje u anketi bilo je dobrovoljno i anonimno, a ispitanice su pismeno odgovorile na niz pitanja o njihovom poznavanju i sklonostima različitim načinima probira fetalnih trisomija u prvom i drugom tromjesečju trudnoće. Ukupno je obrađeno 437 popunjenih upitnika. Prosječna dob ispitanica i razina obrazovanja značajno se razlikovala između anketiranih u pojedinim gradovima ($P<0,001$). Većina trudnica sklonih probirnim testovima izabrale bi kombinirani test u prvom tromjesečju (160/219; 73,1%), dok bi njih 37 od 219 (16,9%) izabrale test u drugom tromjesečju trudnoće. Preostale 22 trudnice (10%) prihvatile bi samo ultrazvučni probir. U skupini od 224 ispitanica koje su sklone probirnom testu u prvom tromjesečju, njih 95 (42,4%) imalo je višu i visoku naobrazbu, dok je 14 od 56 trudnica koje bi izabrale probir u drugom tromjesečju bilo s višim ili visokim obrazovanjem (25%). Razlika je bila statistički značajna ($P=0,016$). Univarijatna statistička analiza pokazala je da su životna dob, razina obrazovanja i ranija informiranost bile statistički značajne prediktivne varijable za izbor testa; razina obrazovanja i predznanje o testovima ostali su značajni i u multivarijatnoj analizi. Istraživanje je ukazalo na neke odrednice koje bi trebalo slijediti u budućem pristupu programu prenatalnog probira u Hrvatskoj. Zdravstveni djelatnici koji u tome sudjeluju trebali bi, s jedne strane, uvažiti znanje trudnica o prenatalnim probirnim testovima, a s druge, uzeti u obzir i različitost njihovih osobnih stavova prema preporučenim pretragama.