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PREGNANT WOMEN'S ATTITUDES TOWARD AMNIOCENTESIS BEFORE RECEIVING DOWN SYNDROME SCREENING RESULTS

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Objectives. **We sought to evaluate pregnant women's knowledge about features of second-trimester screening for Down syndrome and to assess whether knowledge and educational level influence their attitude toward amniocentesis before receiving test results.**

Methods. **Pregnant Caucasian women (n = 300) <35 years old with no personal or family history of Down syndrome were surveyed. Women were randomized to 2 groups. One group of women (n = 150) were surveyed by questionnaire before consultation with specially trained midwives; the other group of women (n = 150) were surveyed after consultation. The questionnaire consisted of 3 sections: 1) participants' demographic data, 2) knowledge about prenatal screening for Down syndrome, and 3) readiness to undergo amniocentesis if there was an increased risk of Down syndrome.**

Results. **Women surveyed after consultation had greater total knowledge scores than those surveyed before consultation (p < .001). A statistically significant difference in knowledge scores in relation to educational levels was observed only in women who were surveyed before consultation (p = .007). Significantly more women were prepared to accept amniocentesis in the group surveyed after consultation (74%) than before consultation (53%; p < .001).**

Conclusion. **Knowledge gained during a prescreening consultation influenced pregnant women's attitudes toward further diagnostic investigation. A smaller proportion of women who were indecisive was observed in the group surveyed after prescreening consultation. Indecisiveness was not affected by poor knowledge about screening, but rather by difficulty in knowing how they will feel and what they will do if their screening result is positive.**

Second-trimester maternal serum screening for Down syndrome has become a widely accepted component of antenatal care in many countries. Women who have positive results in the screening have the option of undergoing amniocentesis, a procedure that may cause miscarriage and could lead to planned termination of affected pregnancies. Adequate prescreening education is important in enabling pregnant women to make informed decisions about Down syndrome screening and diagnostic testing (Priest et al., 1998). Many authors have studied factors that predict a woman's decision to undergo prenatal screening and amniocentesis (Markens, Browner, & Press, 1999; Marteau et al., 1991; Mavrou, Metaxotou & Trichopoulos, 1998; Michie, Dormandy, & Marteau, 2003; Santalahti, Aro, Hemminki, Helenius, & Ryynänen, 1998; van den Berg et al., 2005b; Tercyak, Johnson, Roberts, & Cruz, 2001). The most frequently mentioned reason for undergoing screening is to gain knowledge or reassurance about the health of the fetus; the most frequent reason for choosing amniocentesis is to determine

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whether the fetus has Down syndrome (Priest et al., 1998; Santalahti et al., 1998; van den Berg et al., 2005a). Factors that influence attitudes toward amniocentesis have been reported in women with age-related risk and in screen-positive women, but have not been studied in women at the time of prenatal screening before the result of the screening test is known (Hunt, de Voogd, & Castañeda, 2005; Julian-Reynier et al., 1994; Saucier et al., 2005; Tercyak et al., 2001; Vergani et al., 2002).

The aims of the present study were to evaluate pregnant women's knowledge about features of second-trimester screening for Down syndrome and to assess whether knowledge and educational level influence their attitude toward amniocentesis. The survey was administered when pregnant women had not yet learned whether they had positive or negative screening results.

Methods

Second-trimester maternal serum screening for Down syndrome has been routine since 1996 as a component of the antenatal program in Rijeka, Croatia (Brajenović-Milić et al., 1998). The screening test has been offered by gynecologists. Detailed information about features of the screening, its purpose, and its limitations were provided by specially trained midwives working at the Department of Biology and Medical Genetics, School of Medicine, University of Rijeka. The following information was presented verbally: the purpose of the screening, the likelihood of positive and negative findings, the possibility of false-positive and false-negative findings, the possibility of amniocentesis in case of a positive result, the amniocentesis procedure-related risks of miscarriage, and information about clinical features of Down syndrome.

The present study included 300 Caucasian pregnant women seen at the Department of Biology and Medical Genetics. Screening began in January 2004. Women were randomly assigned to a group ($n = 150$) that was surveyed before consultation or to a group ($n = 150$) that was surveyed after receiving information from specially trained midwives. All women were <35 years old with no personal or family history of Down syndrome, and all were being tested for the first time.

The questionnaire consisted of three sections: 1) participants' demographic data, 2) their knowledge about prenatal screening for Down syndrome, and 3) their readiness to undergo additional diagnostic procedures (i.e., amniocentesis) if there was an increased risk for Down syndrome. Knowledge about prenatal screening was measured by questions 3–6 in Table 1. The score was the sum of the number of these items that were answered correctly, so that the maximum possible total knowledge score was 4. Attitude toward amniocentesis was evaluated by responding to a concrete question about undergoing amniocentesis in the case of positive test results. We also asked the women to explain their attitude toward amniocentesis in their own words. It is important to point out that only a behavioral component of attitude toward amniocentesis was investigated (Breckler, 1984; Oppenheim, 1992). All study protocols were reviewed by the University Ethics Committee.

Table 1. Demographic Data of Women Surveyed Before and After Consultation

	Before Consultation ($n = 150$)	After Consultation ($n = 150$)	p
Women's age (mean ± SD)	28.98 ± 3.84	28.74 ± 3.81	.588
Level of education, n (%)			
Primary education	10 (7)	5 (4)	.289
Secondary education	77 (51)	92 (61)	.103
2-year college education	18 (12)	20 (13)	.862
University education	45 (30)	32 (21)	.113

Statistica for Windows 6.0 was used for statistical analysis of the data, using the statistical tests identified in the text. Statistical significance was considered at $p < .05$. Whenever the analysis showed statistical significance, odds ratios (OR) and 95% confidence intervals (CI) were calculated.

Results

The mean age of the 300 surveyed women was 28.9 ± 3.8 (mean ± SD). No significant differences in mean maternal age ($p = .59$; 1-way ANOVA) or educational level ($p > .05$; χ^2 test) were found between the 2 groups (Table 1).

Table 2 summarizes the women's answers to the survey questions. Despite the fact that >80% of women in both groups believed that they were well informed on the purpose of the testing, we found that women surveyed after consultation had greater total knowledge scores (3.83; 95% CI 3.73–3.92) than those surveyed before consultation (3.51; 95% CI 3.42–3.61) ($p < .001$; 1-way ANOVA).

A statistically significant difference in knowledge scores with respect to educational level was observed in pregnant women who were surveyed before consultation ($p = .007$; 1-way ANOVA). In contrast, no statistically significant difference in knowledge between women of different educational levels was found in women surveyed after consultation ($p = .133$; 1-way ANOVA).

Regarding their attitudes toward amniocentesis, significantly more women were prepared to undergo amniocentesis in the group surveyed after consultation (74%) than before consultation (53%; OR, 2.56; 95% CI, 1.57–4.16; $p < .001$; χ^2 test; Table 1). A post hoc

Table 2. Answers to Survey Questions Before and After Consultation

Questions	Before Consultation, (n = 150), n (%)	After Consultation, (n = 150), n (%)	p
1. The purpose of this biochemical test is			
clear.	121 (81)	133 (89)	.078
not quite clear.	29 (19)	17 (11)	
2. I heard about Down syndrome			
Before this pregnancy	132 (88)	130 (87)	.862
During this pregnancy	18 (12)	20 (13)	
3. The result of this biochemical test is 100% reliable.			
Yes	28 (19)	10 (7)	.003
No	122 (81)	140 (93)	
4. The result of this biochemical test is shown as statistical risk for Down syndrome.			
Yes	133 (89)	144 (96)	.030
No	17 (11)	6 (4)	
5. High statistical risk for Down syndrome means that			
I am carrying a child with DS	16 (11)	8 (5)	.136
It is possible that I am carrying a child with DS	134 (89)	142 (95)	
6. In the case of high statistical risk for Down syndrome amniocentesis will be offered.			
Yes	138 (92)	148 (99)	.011
No	12 (8)	2 (1)	
7. In the case of high statistical risk for Down syndrome			
I am prepared to undergo amniocentesis.	79 (53)	111 (74)	.000*
I am not prepared to undergo amniocentesis.	2 (1)	1 (1)	1.000
I shall consider amniocentesis after receiving the test result.	69 (46)	38 (25)	.000

*$p < .001$; odds ratio, 2.56; 95% confidence interval, 1.57–4.16.

test (Tukey HSD) showed that, before consultation, women who were willing to undergo diagnostic testing had a higher total knowledge score than those who would decide after receiving the screening result (p = .006). In the group of women surveyed after consultation, no statistically significant difference in knowledge scores was found in relation to their attitude toward amniocentesis (p = .713). When we compared the knowledge of women who answered that they would consider amniocentesis after receiving the test result, women from the group surveyed after consultation had a significantly higher total knowledge score than those surveyed before consultation (p = .006). For women who were willing to undergo amniocentesis if screening was positive, there was no statistically significant difference in knowledge between those who were surveyed before or after consultation (p = .151).

No correlation was found between educational level and attitude toward amniocentesis in women who were surveyed before consultation (r = .06; p = .489; Spearman Rank) nor in women surveyed after consultation (r = .09; p = .263; Spearman Rank).

Table 3 shows women's explanations of their attitudes toward amniocentesis. No statistically signifi-

Table 3. Pregnant Women's Explanations of Their Attitudes Toward Amniocentesis, Before and After Consultation

Questions	Before Consultation, n (%)	After Consultation, n (%)	p
Women who were prepared to undergo amniocentesis gave further explanations:	79 (53)	111 (74)	.000
I want to know if my baby is healthy	75 (95)	105 (95)	1.000
I would never give birth to an affected baby	4 (5)	6 (5)	1.000
Women who were not prepared to undergo amniocentesis gave further explanations:	2 (1)	1 (1)	1.000
I don't want to risk losing my baby	2 (100)	1 (100)	
Women who would consider amniocentesis after receiving the test result gave further explanations:	69 (46)	38 (25)	.000
I want to know if my baby is healthy.	7 (10)	1 (3)	.255
I am convinced that my baby is healthy.	20 (29)	18 (47)	.091
I want to consult with my gynecologist.	20 (29)	7 (18)	.331
I am afraid of amniocentesis.	8 (11.5)	10 (26)	.093
I am not familiar with the amniocentesis procedure.	8 (11.5)	1 (3)	.154
Other answers.	6 (9)	1 (3)	.417

cant differences in the frequencies of their explanations were found between the 2 surveyed groups ($p > .05$; χ^2 test).

Finally, we analyzed the actual incidence of amniocentesis in women whose screening test results indicated an increased risk for Down syndrome. Of all surveyed women ($n = 300$), 11 (3.7%) were screen positive, and only 1 (9%) refused amniocentesis. No cases of Down syndrome were found.

Discussion

Participation in screening for Down syndrome is increasing in Rijeka, Croatia, and many young women choose to undergo screening. However, many arrive at our center with poor knowledge about features of the screening. In our previous study, we observed a lack of sufficient knowledge in screened women, especially in less educated women (Paravić et al., 1999). Moreover, in that study we found a relatively high proportion of pregnant women (47%) who were prepared to consider additional diagnostic examination (amniocentesis) only after receiving the screening results. At that time, we concluded that such an attitude toward amniocentesis reflected either an attempt to avoid a difficult decision unless it becomes necessary or a misunderstanding of the prenatal testing procedure. In the present study, we evaluated knowledge of the screening test for Down syndrome among young pregnant women with different educational backgrounds and assessed whether knowledge gained during the consultation influenced their attitudes toward amniocentesis.

It has been well documented that prescreening consultations provided by health professionals improve pregnant women's knowledge about prenatal testing (Seidenfeld & Antley, 1981; Sorenson, Swazey, Scotch, Kavanagh, & Matthews, 1981). In the present study, women's knowledge before consultation depended on their educational level, whereas after consultation no significant correlation with educational level was found. Educational level had no impact on accepting further investigation in the case of a positive screening test result, either before or after consultation. Julian-Reynier et al. (1993) reported that educational level had no effect on acceptance of invasive diagnostics, although they surveyed women who had just delivered normal babies.

We asked the pregnant women to explain their attitudes toward amniocentesis using their own words. In this way, we obtained a broader spectrum of expressed opinions than we could have predicted. Women from both groups who would accept further diagnostic procedures mainly wanted to be certain that their fetus was healthy. It has been well documented that ascertaining whether the fetus had Down syndrome was the most important reason for undergoing amniocentesis (Priest et al., 1998). Only 5% of women from both groups who were willing to undergo further investigation stated that they would never give birth to an affected baby. Women who remained undecided gave several different explanations. The most frequent answer given from women in both groups was that they were convinced they were bearing a healthy baby. They also wanted to consult their gynecologists before making a final decision; some were afraid of the amniocentesis procedure. The frequencies of the provided answers were not different between the 2 groups. Only 3 women, 2 surveyed before consultation and 1 surveyed after consultation, were not prepared to undergo amniocentesis in any event for fear of losing the baby.

The actual incidence of amniocentesis in screen-positive women in the studied group was 91%, in the upper range of reported acceptance (Bekker, Hewison, & Thornton, 2004; Hunt et al., 2005; Lam et al., 1998; Mueller, Huang, T., Summers, & Winson, 2005). Mueller et al. (2005) have shown that women <35 were more likely to proceed with amniocentesis after receiving a positive screening result than were older women. This probably accounts for the high acceptance of amniocentesis in the screen-positive women in our study. It seems that after receiving a positive screening result, the fear of having an affected child overcomes the fear and indecisiveness about amniocentesis. Clearly, people need individualized risk information to make an informed decision, and this information often alters their decision (Marteau et al., 1992).

Knowledge obtained during prescreening consultation clearly influences pregnant women's attitudes toward further diagnostic testing. There was a smaller proportion of women who were indecisive in the group surveyed after prescreening consultation. The majority of adequately informed women would undergo amniocentesis if they had a screen-positive result to gain knowledge about the health of their fetus. However, we should not ignore the possibility that counseling could influence some women in a particular direction (i.e., to undergo or refuse additional diagnostic procedures). In that sense, it would be interesting to determine whether our counseling during the educational session was directive or not by surveying the participants in the current study.

The goal of the prescreening consultation was not to influence women's attitudes, but to allow them to make a more informed decision based on adequate understanding of the procedure. We also wished to eliminate any misconceptions. Women surveyed after the prescreening consultation who were indecisive about amniocentesis were not confused by poor knowledge; these women had significantly higher knowledge scores than those who were surveyed

before consultation and were undecided. Moreover, there was no significant difference in the knowledge scores of these women and women who would accept further diagnostics if indicated. Thus, their indecisiveness can be explained by their difficulty in knowing how they would feel and what they would decide if their screening result was indeed positive. This statement is based on the concept of affective forecasting, or predicting future feelings (Wilson & Gilbert, 2003). Every decision is based on the belief that the choice we make will ultimately make us happier than an alternative choice. However, people are not always able to accurately predict their emotional reactions to future events. Predicting one's future decisions is even more difficult in the field of prenatal diagnosis, when women are considering whether they might choose or refuse amniocentesis. Both options have repercussions that could affect their health or the health of their unborn child.

It is worth noting that in both groups an almost identical percentage of subjects (87–88%) had heard about Down syndrome before they were offered biochemical screening. In our previous work, published in 1999, only 56% of women were familiar with Down syndrome before participating in the screening program (Paravić et al., 1999). Recently, great efforts have been made to publicize and increase antenatal screening. However, women's knowledge about the test, mainly obtained from their obstetricians, has not improved. In many countries, information about prenatal tests is provided by obstetricians or specially trained midwives during a prescreening consultation. This is the way it should be done in our country as well. Unfortunately, the present study shows that the pregnant women we surveyed had positive attitudes, but poor knowledge, about prenatal screening. If the women are unprepared, they may accept a noninvasive test by default, not wanting to lose this option as their pregnancy progresses, rather than making an informed decision and thinking about how they will react to screening results. Therefore, obstetricians should be aware of the important role they play in helping pregnant women to make informed decisions about prenatal testing. Clearly, a better relationship between doctor and patient is needed to ensure that pregnant women have timely and accurate information to make informed decisions about prenatal screening and further diagnostics tests.

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