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Psychological effects of amniocentesis on women and their spouses: Importance of the testing period and genetic counseling

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Abstract

Objective. To evaluate both women's and their spouses' reasons for undergoing amniocentesis, their concerns relating to the procedure as well as their psychological reactions and coping mechanisms during the testing period.

Methods. Eighty-five women undergoing amniocentesis and their spouses took part in the study. The couples completed a questionnaire that provided demographic data and insights into their experiences of amniocentesis.

Results. Age was the main reason for undergoing amniocentesis. When they first learned that they were going to undergo amniocentesis, women were more concerned about the potential danger to their fetus than their spouses. Most of participants believed that their pregnancy would continue after amniocentesis. However, they also stated that they were prepared for an abortion. Uncertainty and tension were two significant emotions experienced by couples while waiting for the test results. For the majority of women (80%) and men (42.3%) the strongest support was provided by their spouses during this period. In summary, we can conclude that the test did have a major psychological impact on both women and their spouses, but did not have a negative impact on their coping mechanisms.

Conclusion. The psychological impact of amniocentesis on women and their spouses does not constitute a major obstacle to their ability to cope. However, a certain number of couples reported feelings of uncertainty, tension and anxiety about fetal injury. We strongly suggest that counseling should be given to high-risk families and that prenatal/antenatal care units must be established.

Keywords: *Amniocentesis, genetic counselling, psychological effects, spouse, women*

Introduction

Prenatal genetic testing is one of the most important and influential advances made in the identification of inherited disorders in clinical genetics. Prenatal diagnostic tests are generally offered to women who have a high risk of chromosomal abnormalities. This includes women of advanced maternal age, couples with a chromosomal abnormality and couples whose screening test results indicate an elevated risk of a chromosomal or a neural tube defect [1,2].

Amniocentesis is one of the prenatal genetic tests used to obtain prenatal information about the developing fetus/baby. Thousands of couples make critical decisions based on the results of prenatal tests, including amniocentesis. The psychological effects following a prenatal test can be devastating, leaving both women and their partners to face a decision that will affect the rest of their lives. The psychological impact of this procedure is of great importance and has been studied by many scientists. Marteau and colleagues [3] showed that women undergoing amniocentesis were significantly more anxious and less certain about their baby's health and held more negative attitudes towards the baby than women who did not undergo amniocentesis. According to Grant [4], a significant level of anxiety was present in women who underwent amniocentesis. Furthermore, these women were significantly more depressed than their partners [5] and their perceptions of pain and anxiety were significantly and positively correlated both before and after the procedure [6]. Cederholm and colleagues [7] claim that amniocentesis does not have a major psychological impact on women in general, and that only a substantial minority reacted with anxiety and distress.

On the other hand, women's concerns were focused on their worries about fetal injury as well as miscarriage and the results of amniocentesis. A study related to amniocentesis has shown that some women

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were ambivalent about the procedure [8]. Uncertainty as well as their worries about healthcare providers' attitudes towards them led some women to accept and others to refuse the test [9].

In Turkey, the way women perceive and experience amniocentesis is virtually unknown and research concerning the psychological impact of genetic testing is limited. The aim of the present study was to evaluate on a comparative basis both women's and their spouses' reasons for having amniocentesis, their concerns and psychological reactions as well as the coping mechanisms they used while waiting for their test result.

Methods

This study was based on research into the psychological effects of amniocentesis on women and their spouses living in Antalya.

Participants

This study was performed at the Department of Genetics from June 2003 to July 2004. Couples who had been referred to amniocentesis due to advanced maternal age, increased triple test, abnormal ultrasounds and elevated levels of maternal serum alpha fetoprotein were included in this study. Eighty-five couples (170 persons) participated in the study by completing the questionnaire.

Procedures

This study was approved by the Ethics Committee of the Akdeniz University Faculty of Medicine. Each spouse was required to provide written consent to participate in this study. Upon arrival at the genetic laboratory, the women and/or their spouses were given a verbal brief by the researcher, which included an invitation to participate in the study. Couples who agreed to participate in the study were required to fill out a questionnaire at home during the waiting period. The duration of the waiting period between testing and disclosure was approximately two weeks. We asked the women and their spouses to complete individual questionnaires, which featured the same questions in different forms so that they did not influence one another. The questionnaires were completed separately by couples during the reporting time of the prenatal testing and collected by the authors.

Questionnaire

The questionnaire was prepared by examining those used in earlier studies and was designed to evaluate and determine the psychological effects of amniocentesis on women and their spouses. The questionnaire provided information concerning the age, level of education, marital status, week of gestation, reason for referral and gravidity history of the participant. They also answered seven open-ended questions, three of which related to amniocentesis, two to pregnancy and abortion, one to their reactions and one to the coping mechanisms used while waiting for the test results. We conducted a pilot study in order to test the structure of the questions and clarify them. No revisions were made to questions. The results of the pilot study are not included in the results of this study.

Statistical analysis

The data was collected from the questionnaires and subsequently transferred into a computer and analyzed by the Statistical Package for Social Science. Incomplete questionnaires were excluded from the total calculation. Frequency distributions and descriptive statistics were calculated. Statistical analysis was carried out using Fisher's exact and chi-square tests for independent samples in order to compare the psychological effects on women and men after the amniocentesis procedure $-p < 0.05$ was considered statistically significant.

Results

The characteristics of participants

As shown in Table I, among the 85 couples who participated in the study, the mean age of women was 33.1 ± 5.4 years (range 20–47 years) and the mean age of men was 35.1 ± 5.7 (range 20–47 years). Mean gestational age at the time of amniocentesis was 16.3 ± 2.1 weeks (range 14–20 weeks). All participants were married (data not shown). The most common indication for amniocentesis was maternal age (50.6%). Other indications were an abnormal triple test result (38.8%) or a previous child with chromosomal abnormality (10.6%). Although most of female participants had passed a certain age (50.6%) and had already been informed about amniocentesis (60%), the majority had never thought that they would undergo amniocentesis (64.7%) (Table I).

The participants' first reactions and concerns relating to amniocentesis when they were offered the procedure are shown in Table II. We found that women were more concerned about the potential danger of amniocentesis to their fetus than men (women = 63.5%, men = 38.8%). The difference between these two groups was found to be statistically significant ($p = 0.001$). When offered amniocentesis, 28.2% of women and 32.9% of men thought that their baby had anomalies. In addition, few women (4.7%) and men (8.2%) who participated in our study worried about the procedure of amniocentesis. Another interesting finding was that 12.9% of

Table I. Characteristics of study couples.

Characteristics	Women ($n = 85$)		Men ($n = 85$)	
Age in years (M ± SD)	33.1 ± 5.4		35.1 ± 5.7	
Educational level	*n*	%	*n*	%
Illiterate	6	7.1	4	4.7
≤8 years	22	25.9	30	35.3
9–11 years	31	36.5	15	17.6
≥12 years	26	30.6	36	42.4
Weeks of gestation (M ± SD)	16.3 ± 2.1			
Reason for referral				
Advanced maternal age	42	50.6	–	–
Abnormal triple test	33	38.8	–	–
Previous child with chromosomal abnormality	9	10.6	–	–
Had you ever thought that you would undergo amniocentesis?				
Yes	30	35.3	28	32.9
No	55	64.7	57	67.1
Did you know anything about amniocentesis?				
Yes	51	60	40	47.1
No	34	40	45	52.9

Table II. Concerns expressed by couples when they were offered the test.

	Women ($n = 85$)		Men ($n = 85$)			
Ideas	*n*	%	*n*	%	χ^2	*p*
Amniocentesis can harm the fetus	54	63.5	33	38.8	10.382	0.001
The baby must have anomalies	24	28.2	28	32.9	0.443	0.506
It is routine in antenatal care	11	12.9	10	11.8	0.054	0.816
It is for the good of the baby	15	17.6	17	20.0	0.154	0.695
I am worried about the amniocentesis procedure	4	4.7	7	8.2	0.875	0.350

*There was more than one answer.

women and 11.8% of men believed that amniocentesis was a routine antenatal care. We also found that only 17.6 of women and 20% of men mentioned that it was for the good of the baby.

The participants' thoughts on a number of issues related to the test result, continuing pregnancy and their willingness to undergo abortion are given in Table III. Most women and their spouses expected very favorable outcomes related to the test result. Overall, 83.5% of women and 72.9% of men expected that the pregnancy would continue. There were statistically significant differences among women ($p < 0.05$). Among the 85 couples, 6 women and 2 men said that ''It was in God's hands'' whether or not the pregnancy would continue if an abnormal test result occurred. About half of the couples stated that if necessary, they would accept the termination of the pregnancy. However, 9.4% of women and 2.4% of men stated that they categorically refused this invasive procedure. A few women and men relied on their doctor to reach a decision concerning the processes (4.7%, 9.4% respectively). Nearly one third (31.8%) of men and 23.5% of women stated that they had ''not yet decided''. No significant differences were found in decisions related to the termination of pregnancy between men and women.

Feelings and coping mechanisms

Table IV summarizes the feelings and coping mechanisms used by couples while waiting for the test result. During this period, couples experienced different emotions. Just over half (51.8%) of women and 65.9% of men said that they felt 'uncertainty'. Most women (42.3%) reported that 'tension' was a significant emotion during this period ($p = 0.036$). In addition, some couples were secure because they had undertaken the procedure for the safety of their unborn child (women = 21.2%, men = 34.1%). Fear and curiosity about their test results were mentioned both by women and men (12.9%).

When asked about the methods they used to cope with their reactions, women stated that their greatest source of support were their spouses (80%), their mothers/fathers (55.3%) and their friends (38.8%). These findings were statistically significant ($p < 0.05$). Although men reported that they used effective coping mechanisms such as 'seeking support from their spouses, and father/mother', they also

Table III. Thoughts expressed by couples on a number of issues while waiting for the test results.

	Women		Men	
	n	%	*n*	%
Continuing pregnancy				
My pregnancy will continue	71	83.5	62	72.9
It is in God's hands	6	7.1	2	2.4
No idea	8	9.4	21	24.7
Willingness to undergo abortion				
If it is necessary, I accept	53	62.3	48	56.5
I categorically refuse	8	9.4	2	2.4
I will leave the decision to the Doctor	4	4.7	8	9.4
I am undecided	20	23.5	27	31.8
Total	85	100.0	85	100.0

Table IV. Reactions and coping mechanisms used by couples while waiting for the test results.

	Women		Men			
Feelings	*n*	%	*n*	%	χ^2	*p*
Uncertainty	44	51.8	56	65.9	3.497	0.061
Tension	36	42.3	23	27.1	4.387	0.036
Fear	22	25.9	15	17.6	1.693	0.193
Secure about the safety of the unborn child	18	21.2	29	34.1	3.558	0.059
Curiosity	11	12.9	11	12.9	0.000	1.000
Coping methods						
Support from						
Spouse	68	80.0	36	42.3	25.36	0.00
Mother/Father	47	55.3	28	32.9	8.61	0.003
Relatives	21	24.7	18	21.2	0.29	0.584
Friends	33	38.8	19	22.3	5.43	0.020
Health professionals	13	15.3	20	23.5	1.84	0.175
Experienced people	3	3.5	5	5.9	0.525	0.469
Seeking more information	11	12.9	13	15.3	0.194	0.660
Asking God for help	13	15.3	7	8.2	2.040	0.153
Positive thinking	49	57.6	31	36.5	7.650	0.006
Occupational activities	16	18.8	14	16.5	0.162	0.687
Not sharing with anyone	12	14.1	26	30.6	6.643	0.010
Feeling trapped	14	16.5	36	42.3	13.713	0.000

*There was more than one answer.

identified non-effective techniques such as 'thinking about feeling trapped' (42.3%) and 'not sharing with anybody' (30.6%) during this period. Moreover, few couples mentioned that they received support from health professionals. 'Positive thinking' was widely used both by women and men. Some couples stated that they engaged in occupational activities to cope with their negative feelings. In addition, 'asking God for help' was identified as a coping mechanism used by couples.

Discussion

This study illustrated the psychological effects of amniocentesis and the coping methods used by women and their spouses while waiting for their test result. The findings of this study showed that the main indication for amniocentesis was the maternal age of the participants. Age was the also main reason identified by other studies in the literature [7,10,11].

When couples were first told that they would undergo amniocentesis, their primary and most common concern was the potential harm to the fetus. In particular, the majority of women's concerns were centered on worries about fetal injury (Table II). Based on this finding, it can be said that our result is similar to other studies [3–7,9,12,13] and different from the finding of the study conducted by Cederholm and colleagues [14] who reported that the majority of women did not worry about the risk of fetal injury associated with the procedure.

Another negative aspect of amniocentesis pointed out by couples was fear for the baby's health. Both women and men reported that their doctor offered

them amniocentesis due to fact that their baby had genetic anomalies. Based on this finding, it can be said that women and their spouses have unrealistic expectations about prenatal screening for fetal abnormalities in line with Marteau's study [15].

Our couples identified two positive ideas about amniocentesis: that the procedure was 'routine in antenatal care' and that it was 'for the good of the baby'. The attitudes towards amniocentesis uncovered by our research are similar to those identified by some other studies [8,9,11].

These results suggest that attitudes to amniocentesis relate both to the procedure and to the perceived likelihood of the health of the unborn child as defined by Marteau et al. [3]. In Browner et al.'s study [9], several men and women refused to undergo the procedure because they feared that it could be fatal for the woman or that she could suffer from severe complications. In our study, only a few women and men stated that they were concerned about the actual procedure.

Another result that emerged from the study was that the couples had clear ideas about whether or not the pregnancy would continue, which reflects the fact that most women and men do not expect to obtain an abnormal test result; they believe that everything will be fine because they are healthy and because they personally believe that abortion is unacceptable under any circumstance. This is because, at this stage, doctors do not provide couples with information about how they will proceed following the outcome of the test. As a result, the couples gave us a spontaneous response to our question. If the outcome of the test indicates the need for an abortion, the doctor will provide them with more information and help them to reconsider their decision. Couples who are faced with the reality of having a child with an abnormality often change their initial negative reaction to the idea of having an abortion.

In addition, a few women and men stated that the decision about whether or not the pregnancy would continue was in God's hands. Based on our findings, it can be said that our result is similar to Tsianakas and Liamputtong's study [8].

When it came to abortion, most of participants stated that they would 'accept it if necessary', a response more common among women than men (Table III). Krance [16] reported that when prenatal testing detects a devastating genetic problem many couples choose to end the pregnancy. Similarly, in a study on abortion rates among CVS and amniocentesis users in Israel, it was found that in the majority of cases abortion was in fact the option chosen when fetal abnormalities were detected [17]. Another study indicates that only a small number of women said that they were certain they would have terminated pregnancy [18].

In Turkish culture, women believe that abortion is only acceptable in circumstances where the mother's life is in danger or when the fetus is abnormal. In addition, termination is considered a sin according to the Islamic faith. We concluded that this was the main reason why some women declined abortion. In this study, a few women and men stated that they would follow whatever advice they were given by their doctors. This was also associated with cultural background. The most remarkable finding of this study was that about a quarter of the participants stated that they were undecided about abortion should an abnormal test result occur. It can be concluded that if either parent is under-prepared for the possibility of an abnormal test result, then considerable stress may be caused by the ambivalence that frequently ensues. Women and their spouses who receive abnormal results face a difficult decision about whether to continue or to terminate the pregnancy. This finding is in accordance with Moyer's study [11].

In the current study, more than half of women and men stated that they felt uncertainty while waiting for the test results. This high level of uncertainty might also arise from unrealistic expectations related to prenatal testing or from the long and stressful waiting period for the test result. In addition, women experienced more fear and tension while men felt more secure about the safety of the unborn child. The defined psychological effects of amniocentesis on women found in literature are similar to those identified in our study [3,15,19–21]. The same percentage of women and men stated that they felt curious about the test result during this waiting period.

When we evaluated the methods used by couples to cope with their reactions while waiting for the test results, we concluded that women turned to different people for support including their spouse, mother/father, relatives, friends, health professionals and experienced people. For women, the strongest support was provided by their spouses during this period. Their spouse seemed to have greater importance than any other individual to whom they turned for support. This finding reflects the fact that women easily express their feelings and tend to seek support from their social network. This result was consistent with the study of Alteneder and colleagues [22]. One of the interesting findings of this study was that while women receive much support from their spouses while waiting for their test results, men have fewer resources. This is because both husbands and healthcare providers believe that women need greater support at this time. This study found that men also need social support while awaiting the test result and that this should not be neglected. As a result, support should be provided to both the husband and wife, not just to the wife. In Turkey, the best approach would be to help couples understand how important it is that they support one another and to encourage men to benefit from other sources of social support.

The findings of our study showed that health professionals were also seen as a source of information. In addition to receiving support, the participants sought information from anyone with whom they had contact, including nurses, midwives and doctors. Written and electronic media was determined to be another source of information. This result differed from the findings of Cederholm and colleagues [7] who claim that doctors and midwives in antenatal care centers served as the main source of information. A possible reason for the low level of support provided by health professionals could be the inadequacy of the antenatal care unit and of the health professionals specializing in genetic counseling in our hospital.

Positive thinking was the second most common coping method used by both men and women, although it was more common among women. In contrast, the majority of men used non-effective methods such as 'feeling trapped' and 'not sharing with anybody'. Women also stated that their husbands played an important role in their experience of amniocentesis. One possible explanation for this differing result may be that it is common for men to hide their emotions, an important characteristic of the traditional male in Turkish society.

Consequently, when we compare the coping mechanisms used by men and women, we can say that women received support from their social environment, from positive thinking (for example; 'it is safer for me and for my baby to know if there is anything wrong', 'the doctor can control it') and occupational activities (for example; knitting, cooking, planting etc.). Furthermore, women were more likely to pray for a positive test result than men. They also stressed that they believed the prayer of the pregnant woman would be granted.

Limitations

Potential limitations of this study include the small group of volunteers who made up our sample. In a study such as this, it is not appropriate to generalize the results to all couples in Turkey awaiting amniocentesis results.

Conclusion and implications

Obtaining data for a good understanding of amniocentesis and its results is critical for developing methods to decrease the negative psychological effects of this procedure on couples. Nurses, genetic specialists and doctors can broach this often-neglected topic and discuss its potential adverse effects on family relationships and health by using preventive methods.

Prenatal diagnostic procedures must become standard in obstetric care. On such a sensitive topic, both the information and the way in which it is imparted to expectant mothers and fathers are very important. We strongly recommend that counseling should be given to high-risk families. We also advocate that the physicians' and nurses' role is to support and enhance the ability of pregnant women to cope with choosing a prenatal test, with the information they receive and with making their decisions, including possible termination. Thus, unrealistic expectations and anxiety arising from feelings of uncertainty would be prevented. Providing couples with informative care may help make amniocentesis a less frightening experience.

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