WOMEN'S EMOTIONAL PROFILE AND THE PSYCHOLOGICAL STRESS ASSOCIATED WITH WAITING FOR THE PRENATAL DIAGNOSTIC TESTING RESULTS

MELANIA ELENA POP-TUDOSE[1], PETRU ARMEAN[2], VICTOR IOAN POP[3]

[1,3]"Iuliu Haţieganu" University of Medicine and Pharmacy, Cluj-Napoca [2]"Carol Davila" University of Medicine and Pharmacy, Bucharest

Keywords: *Down syndrome, prenatal diagnosis, psychological stress, pregnant women*

Abstract: *Prenatal Diagnostic Testing for Down's syndrome suspicion can have multiple physical and psychological implications. Women going through this process experience negative emotions both at the time of the invasive procedure and while waiting for the results. The aim of this study was to outline the emotional profile of women while waiting for the results and to assess the psychological disturbance experienced by them. It included 40 women who completed the Profile of Mood States questionnaire and a demographics, experience, and knowledge questionnaire. Two-thirds of the women surveyed experienced anxiety, almost a quarter of them depression, a third anger, confusion, acute distress, and 15% total distress. The level of knowledge was medium and the perception of risk far from reality. The emotional profile obtained highlights the disturbance of the women's psycho-emotional state. For better awareness and diminishing negative emotions, women who go through this process should benefit from adequate individualized information as well as genetic counselling.*

INTRODUCTION

The age of the reproductive woman, with the least risk, is considered by specialists between 20-30 years. The woman of the 3rd millennium tends to defer it more and more, most likely in favour of a career path.(1) According to Eurostat, in 2016 the average age of European women at the first birth was 29 years old and average age of mothers at birth was up to 33.8 in Greece.(2) Increasing maternal age also raises the risk for Down syndrome (DS) and implicitly increases the rate of referral and access to prenatal testing.(3) DS or Trisomy 21 is the chromosomal aberration most compatible with survival and, implicitly, the most commonly encountered in pregnancies and in the general population. DS is the result of the triplication of chromosome 21 or only of the critical region 21q22 and is recognized by characteristic facial phenotype and the association of moderate to severe mental retardation.(4) Classical DS assignment follows a route based on first-trimester screening, and/or second trimester. A high risk leads to the recommendation of Prenatal Diagnostic Testing (PDT) through Amniocentesis (AC) or Chorionic Villus Sampling (CVS), invasive procedures that involve a risk of miscarriage.(5) The emergence and promotion of the NIPT (Non Invasive Prenatal Test) has lowered the rate of these procedures (6), but has not removed their supremacy in the diagnosis of chromosomal anomalies. NIPT, according to the American College of Obstetricians and Gynecologists (ACOG), can be used as the second contingent of screening for pregnant women identified at high risk.(7,8) AC has become increasingly safer with a 0.1% risk of miscarriage (lower than a 1% overall risk in general population) (9,10) and a 99.4% detection rate for 0.1- 0.6% false positives, being preferred to CVS which is less conclusive due to placental mosaicism.(11,12)

AC associates a degree of anxiety related to the procedure itself, the adjacent complications, and also to the results that may require a longer period to be released.(3,13,14,15,16) AC is applied at an advanced age of pregnancy when we are talking about an actual fetus, and so the possibility of a positive result followed by a potential abortion may trigger strong negative emotions as well as ethical dilemmas.(17,18) Studies have shown that the anxiety related to the procedure itself disappears shortly after, but the anxiety related to the possible outcome and the potential need to make a quick and radical decision remains for a long time, and sometimes even until birth.(3,14) The wait period may be as long as three weeks, thus favouring anxiety intensification and even the development of antenatal depression that may influence the neuropsychological development of the fetus with the possible psycho-behavioral alteration of the future child.(19,20) Maladaptation and lack of adequate information and support may have irreversible effects. The attitude of psychologically rejecting pregnancy and discontinuing communication with the fetus during the wait period identified in women who decide to interrupt the pregnancy if the suspicion will be confirmed is extremely dangerous in case the suspicion is not confirmed. The fetus's psycho-emotional status may have already been affected.(21,22) This study is based on the hypothesis that women waiting for the diagnosis result for increased DS risk experience negative emotions of such intensity that they cause a disturbance of their general psychological state and alter their Emotional Profile.

MATERIALS AND METHODS

This study was conducted between January and December 2016 and included 40 pregnant women who performed PDT for suspicion of DS in maternity hospitals in Bucharest. A questionnaire containing 14 demographic and experience items, 33 items for knowledge and perceived risk were used, and the Profile of Mood States-Short Version (POMS-SV) questionnaire was used to assess the psychological status. The perceived knowledge and risk test was based on three "yes", "no" and "don't know" responses, and the quantification was done by giving 1 point for the appropriate

[1]Corresponding author: Melania Elena Pop-Tudose, B-dul. N. Bălcescu, Bl. Camelia, Ap. 16, Buzău, România, E-mail: melaniaelena_tudose@yahoo.ro, Phone: +40721 751540
Article received on 11.02.2019 and accepted for publication on 29.03.2019
ACTA MEDICA TRANSILVANICA March 2019;24(1):4-7

response and 0 points for the inappropriate answer and the "do not know" answer. The original POMS version was developed by McNair et al. (23) and consisted of 65 items. POMS-SV has 47 emotional items and contains six subscales with related scores: Anxiety (Ax), Depression (D), Anger (A), Vigor (V), Fatigue (F) and Confusion (C). To assess the women's overall psychological status we used The Total Mood Disturbances (TMD) score obtained by subtracting the score obtained in the subscale V from the sum of the scores obtained in the five subscales measuring negative emotions.(24) Previous studies on the Romanian population have shown that POMS-SV can be used successfully to assess psychological distress.(25) In this study, POMS-SV showed a good internal consistency with a .95 Alpha Cronbach coefficient and the knowledge and perceived risk test obtained a coefficient of 0.74. The data was processed using the IBM SPSS 20.0 0 statistical program (IBM Corp., Armonk, NY, USA) and the graphs were executed with Microsoft Excel. A descriptive, frequency analysis was performed and for the correlation we applied the correlation coefficient of Spearman's Rank-Order Correlation. Each questionnaire has had attached an information sheet and the consent form.

RESULTS

The data were collected from 40 pregnant women, who were waiting for results after the procedure for harvesting genetic material. The vast majority (92.5%,n=37) had performed AC, were of Romanian ethnicity, Christian-Orthodox religion, had medium and high studies and came from an urban environment. The average age of the participants was 32.7 years (SD =5.7, min 22 - max 45). More than half of the women were under the age of 35 and had no children and only one third had experienced miscarriage (table no. 1). For two-thirds of the women (67.5%,n=27) the reason for taking PDT was an increased risk for DS in screening testing, for 15% (n=6) the age over 35 years, for 12.5% (n = 5) the family history and 5% (n=2) performed this procedure at their request. Most followed-up with an obstetrician, almost three quarters exclusively and a little over a quarter in collaboration with the family doctor. Half of the women turned to private services, more than a quarter to state provided services, and nearly a quarter to both types. More than half have heard and received most of the information about PDT from the obstetrician, for one third, the main source of information was the Internet and informative material was only received by one quarter of the participants (table no. 2). For half (52.5%,n = 21) of the participants NIPT was unknown and more than one third (37.5%, n= 15) had not heard about CVS.

Table no. 1. Demographic characteristics of the participants

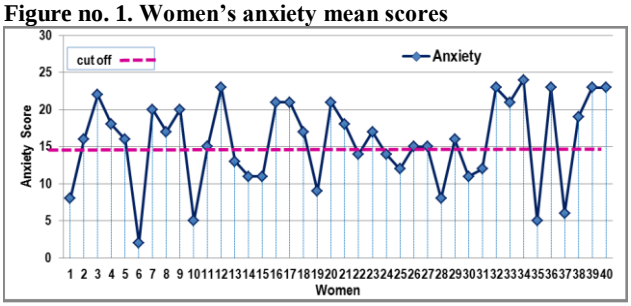
	Number	%
Age (years)		
18-24	4	10
25-34	20	50
35-44	16	40
Ethnicity		
Romanian	37	92.5
Other	3	7.5
Religion		
Christian	36	90
Other	4	10
Education level		
Low	1	2.5
Medium	13	32.5
High	26	65
Residence		
Urban	32	80
Rural	8	20
No. of children		
0	25	62.5
1	9	22.5
≥2	6	15
Miscarriage		
Yes	15	37.5
No	25	62.5

Table no. 2. Data related to follow-up and experiences

	Number	%
Follow-up by		
Obstetrician	28	70
Obstetrician and Family Doctor	12	30
Where		
Private Services	21	52.5
State Services	11	27.5
Both	8	20
Using teaching aids		
Yes	10	25
No	27	67.5
Don't know	3	7.5
They heard about amniocentesis from		
Internet	8	20
Family doctor	3	7.5
Obstetrician	21	52.5
Others	8	20
The most information was provided by		
Internet	13	32.5
Obstetrician	22	55
Others	5	12.5

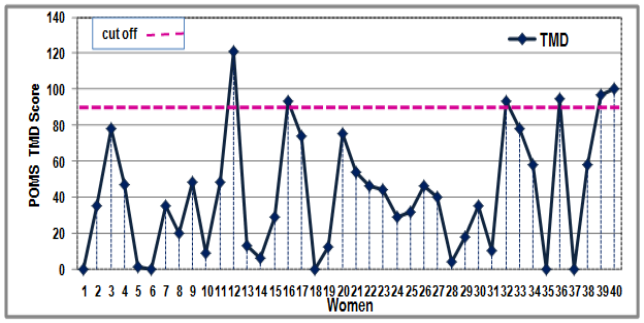
In terms of emotional profile, two thirds (62.5%, n=25) experienced anxiety (figure no. 1), one third (32.5%, n=13) confusion and anger, almost a quarter (20%, n=8) depression and almost one-third (27.5%, n = 11) acute distress.

Figure no. 1. Women's anxiety mean scores



15% (n=6) of the participants achieved a high TMD score (figure no. 2), which indicates a disturbance in the general psycho-emotional state, equivalent to a total distress experienced by them during the expectation of the results.

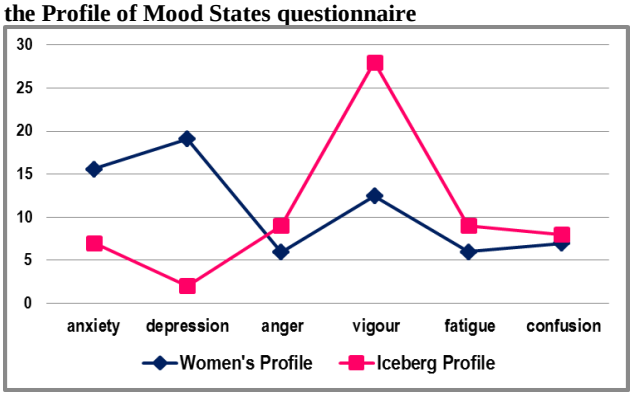
Figure no. 2. Total Mood Disturbance (TMD) mean scores



The emotional profile of women included in the study compared to the „Iceberg" profile was outlined in terms of

emotional state. The "Iceberg" profile, the ideal psychological profile, illustrates a positive condition (positive disposition profile) characterized by low scores on the subscales Ax, D, A, F and C and high scores at V.(23) The POMS analysis for women pending post-diagnostic results revealed that they showed a reverted profile compared to the ideal "Iceberg" profile for the Ax and D subscales with a much diminished peak for the V subscale (figure no. 3).

Figure no. 3. Scores related to the observed dimensions in the Profile of Mood States questionnaire



The average of the scores obtained by the participants in the knowledge test related to prenatal testing and DS was 14.65 (SD=4.1) of the maximum possible score of 23, showing a medium level. Only 37.5% (n=15) said they had received sufficient and clear information about the diagnosis procedure and results, 45% (n=18) abstained and 17.5% (n=7) were unsatisfied with the information received. The perception of the risk of having a pregnancy with DS was far from reality, the average score obtained in the perceived risk test was 4.23 (SD=2.2) of the maximum possible score of 10. Nearly three quarters (72.5%, n=29) did not know that, statistically, after PDT, only "two out of 100 pregnant women with increased risk of screening receive a positive result for DS". Most (92.5%, n=37) knew that the procedure itself involved a risk of miscarriage, but almost half (47.5%, n=19) considered that PDT investigates only the responsible genetic modification for DS and more than two thirds (65%, n=26) were convinced that a negative result guarantees the birth of a perfectly healthy baby. However, we identified no correlations between the participants' emotional profile and the demographic or knowledge and information variables. Only one positive influence was identified, namely those who had the experience of miscarriage, had the tendency to obtain higher scores for distress (0.37, $p < 0.05$). In terms of risk perception, it appears that those with a higher level of knowledge tended to perceive the risk closer to reality (0.48, p=0.002). Nearly half (47.5%, n=19) were of the opinion that children diagnosed with DS may not have a quasi-normal future and 42.5% (n=17) that they cannot attend normal schools, but nearly three-quarters (70%, n=28) agreed that these children could be integrated into society if they benefit from special education.

DISCUSSIONS

As we expected, our study highlighted the fact that a significant percentage of women waiting for the PDT results experienced negative emotions. The emotional profile obtained, different from the ideal profile, highlights the disturbance of the participants' psycho-emotional state. Most of them reported anxiety and acute distress. The knowledge of the participants regarding prenatal testing proved to be insufficient to provide them with an adequate view of this type of testing and the related adjacent implications, and misunderstanding the significance of the calculated risk could explain the distorted perception of risk. It was unexpected that for most NIPT was unknown, thus eliminating from the start the possibility of opting for it as a second screening contingent. Unlike previous studies, our study did not identify a link between the lack of knowledge and the intensity of distress, but given that the level of knowledge was predominantly medium and below average, this deduction is questionable. Guides recommend complete pre-screening information, regarding all prenatal tests, benefits, drawbacks, accuracy of results, limits, path and possible consequences. Particularly in the diagnostic stage, the woman should benefit from all the information from the moment of recommendation: the procedure, the associated risks, the possibility of detecting other abnormalities, and the potential scenarios.(26,27) Participants in this study did not understand that there is the possibility of identifying another chromosomal syndrome and that the negative result cannot guarantee the overall health of the fetus. However, half of the participants refrained from appreciating the delivery and the quality of the information provided by the specialists, although most were monitored by an obstetrician. Previous international studies also suggested the maintenance of high distress levels during this period, but a comparison was difficult to asses because the measurement tests and the moment they were applied were different.(3,16,28,29) All, however, concluded that the psycho-emotional disorder pre and post procedure is influenced by ignorance or misinformation, and the lack of psychological support and counselling, largely due to poor quality services. The limits of this study, the first in Romania on this issue, are related to the small number of these procedures as well as the difficult accessibility to this type of subjects in terms of the sensitivity created by the situation itself. In 2016 in state maternities in Bucharest, according to INS (30), 114 AC and only 11 CVS were made. This study provides the opportunity for another larger, representative, nationwide study with a more focused analysis of possible distress factors and effective practices to reduce or eliminate them. Moreover, starting from the conclusions of this study, it would be important to explore the attitude, knowledge and the communication model practiced by the professionals on this matter.

CONCLUSIONS

Prenatal Diagnostic Testing is an invasive procedure both physically and psychologically. Due to this double aggressiveness it cannot be compared with other routine tests or investigations during pregnancy. In this context, individualized pre-procedural information and continued psycho-emotional counselling until the outcome is crucial for the psychological status of the pregnant woman concerned also for her future child. Also, the special training and education of those who perform information and counselling is essential in order to acquire the necessary advanced skills given the sensitivity and complexity of this period as well as the possible irreversible effects on the mother-child binom.

REFERENCES

1. Bellieni C. The Best Age for Pregnancy and Undue Pressures. J Family Reprod Health 2016 Sept;10(3):104–107.PMID:28101110.
2. Fertility statistics https://ec.europa.eu/eurostat/statistics-explained/index.php/Fertility_statistics.Accessed on 2.02.2019.
3. Nakić Radoš S, Košec V, Gall V. The psychological effects of prenatal diagnostic procedures: maternal anxiety before and after invasive and noninvasive procedures. Prenatal Diag. 2013;33:1194-1200. DOI:10.1002/pd.4223.

4. Online Mendelian Inheritance in Man, OMIM (TM). Down syndrome. Baltimore: Johns Hopkins University. Number:#190685: Updated 15 February 2017. Available from: http://omim.org/entry/190685 Last accessed 27 Jan 2019
5. ACOG Committee on Practice Bulletins. ACOG practice bulletin no. 88: invasive prenatal testing for aneuploidy. Obstet Gynecol. 2007 Dec;110(6):1459-67.
6. Carlson LM, Vora NL. Prenatal Diagnosis: Screening and Diagnostic Tools. Obstet Gynecol Clin North Am. 2017 June;44(2):245–256.doi:10.1016/j.ogc.2017.02.004.
7. Gil MM, Quezada MS, Revello R, Akolekar R, Nicplaides KH. Analysis of cell-free DNA in maternal blood in screening for fetal aneuploidies: updated meta-analysis. Ultrasound Obstet Gynecol. 2015;45:249–266.DOI:10.1002/uog.14791.
8. ACOG Committee on Practice Bulletins. ACOG practice bulletin no.163:Screening for fetal aneuploidy. Obstet Gynecol. 2016 May;127(5):108-22.
9. Akolekar R, Beta J, Picciarelli G, Ogilvie C, D'Antonio F. Procedure-related risk of miscarriage following amniocentesis and chorionic villus sampling: a systematic review and meta-analysis. Ultrasound Obstet Gynecol. 2015;45:16-26.
10. Zinaman MJ, Clegg ED, Brown CC, O'Connor J, Selevan SG. Estimates of human fertility and pregnancy loss. Fertil Steril. 1996;65(3):503-9.
11. Anderson CL, Brown CE. Fetal Chromosomal Abnormalities: Antenatal Screening and Diagnosis American Fam. Physician. 2009;79(2):117-123,124.
12. Binns V, Hsu N. Prenatal Diagnosis. eLS. 2002 Jun;1-17.doi:10.1038/npg.els.0002291.
13. Tursinawati Y, Thain S, Choi C, Yeo GSH. Amniocentesis increases level of anxiety in women with invasive prenatal diagnosis of Down Syndrome. Univ Med. 2015;34:112-120.
14. Durand MA, Stiel M, Boivin J, Elwyn Glyn. Information and decision support needs of parents considering amniocentesis: interviews with pregnant women and health professionals. Health Expect 2010;13:125-138.Doi:10.1111/j.1369-7625.2009.00544.x.
15. Sahin NH, Ilkay G. Congenital anomalies: parents' anxiety and women's concern before prenatal testing and women's opinion towards the risk factors. J Clin Nurs. 2008;17:827-36 doi:10.1111/j.1365-2702.2007.02023.x.
16. Sjogren B, Uddenberg N. Prenatal Diagnosis and Psychological Distress: Amniocentesis or Chorionic Villus Biopsy? Prenat Diagn. 1989;9:477-87.
17. Ng CC, Lai FM, Yeo GSH. Assessment of maternal anxiety levels before and after amniocentesis. Singapore Med J. 2004;45(8):370-4.
18. Kowalcek I, Mühlhoff A, Bachmann S, Gembruch U. Depressive reactions and stress related to prenatal medicine procedures. Ultrasound Obstet Gynecol. 2002 Jan;19(1):18-23.
19. Sanhal CY, Ozekinci IM, Simsek M, Bozkurt S. Comparison of pre-procedural anxiety and depression scores for patients undergoing chorion villus sampling and amniocentesis: An alternative perspective on prenatal invasive techniques. Pak J Med Sci. 2015;31(5):1038-42.doi:10.12669/pjms.315.7477.
20. Goodman J, Guarino A, Chenausky K, Klein, Lauri Prager J, Petersen R et al. Calm Pregnancy: results of a pilot study of mindfulness-based cognitive therapy for perinatal anxiety. Arch Womens Ment Health. 2014 Oct;17(5):373-387.Doi: 10.1007/s00737-013-0402-7.
21. Allison SJ, Stafford J, Anumba D. The effect of stress and anxiety associated with maternal prenatal diagnosis on feto-maternal attachment. BMC Women's Health. 2011;11(1):33-40. Doi:10.1186/1472-6874-11-33.
22. Georgsson Ohman S, Saltvedt S, Waldenstrom U, Grunewald C, Olin-Lauritzen S. Pregnant Women's Responses to Information About an Increased Risk of Carrying a Baby with Down Syndrome. Birth-ISS Perinat C. 2006 Mar;33(1):64-73. Doi:10.1111/j.0730-7659.2006.00075.x.
23. McNair DM, Lorr M, Droppleman LF. Manual for the Profile of Mood States. EDITS. 1992:1-40.
24. DiLorenzo TA, Bovbjerg DH, Montgomery GH, Valdimarsdottir H, Jacobsen PB. The application of a shortened version of the profile of mood states in a sample of breast cancer chemotherapy patients. Br J Health Psychol. 1999;4(4):315-325.doi:10.1348/135910799168669.
25. David D, Montgomery GH, Macavei B, Bovbjerg DH. An empirical investigation of Albert Ellis's binary model of distress. J Clin Psychol. 2005;61:499-516. doi:10.1002/jclp.20058.
26. NICE guidelines CG62. Last updated: December 2018.Available from: http://www.nice.org.uk/guidance/cg62/chapter/Woman-centred-care Last accessed 27 Jan 2019.
27. Wilson KL, Czerwinski JL, Hoskovec JM, Noblin SJ, Sullivan CM, Harbison A et al. NSGC Practice Guideline: Prenatal Screening and Diagnostic Testing Optionns for Chromosome Aneuploidy. J Genet Counsel. 2013;22:4-15.Doi:10.1007/s10897-012-9545-3.
28. Hewison J, Nixon J, Fountain J, Cocks K, Jones C, Mason G, Morley S, Thornton J. Amniocentesis results: investigation of anxiety. The ARIA trial. Health Technol Assess. 2006 Dec;10(50):1-78.
29. Leithner K, Maar A, Fischer-Kern M, Hilger E, Löffler-Stastka H, Ponocny-Seliger E. Affective state of women following a prenatal diagnosis: predictors of a negative psychological outcome. Ultrasound Obstet Gynecol. 2004;23:240-246.Doi:10.1002/uog.978.
30. Adress no. 7539/07.06.2018. National Center of Public Health Statistics and Information.