ORIGINAL ARTICLE

Knowledge of Prenatal Screening, Down Syndrome, Amniocentesis, and Related Factors among Iranian Pregnant Women: A Cross-Sectional Study

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Received: 1 September 2018 Revised: 10 December 2018 Accepted: 16 December 2018

ABSTRACT

Background: The primary goal of prenatal aneuploidy screening is the early detection of pregnancies at high risk of Down syndrome (DS). The present study aimed to assess the knowledge about the prenatal screening test (PST), DS, and amniotic fluid test (AFT) among Iranian pregnant women.

Methods: The present cross-sectional study was conducted from April 2013 to July 2014 in Mostafa Khomeini Educational Hospital, Tehran, Iran. The participants were recruited among pregnant women referred to the Obstetrics and Gynecology Clinic of the hospital for their routine medical evaluations. A total of 471 consecutive women fulfilling the inclusion criteria were enrolled in the study. The data collection instruments included a 9-item socio-demographic information form and a 23-item knowledge questionnaire. The latter included 9 items on DS, 10 items on PST, and 4 items on AFT. The data were analyzed using the SPSS software (version 20.0) with the Kruskal–Wallis and Mann-Whitney tests. P<0.05 was considered statistically significant.

Results: The mean score of total knowledge, PST, DS, and AFT was 9.93 ± 4.86 , 5.26 ± 2.19 , 3.25 ± 2.42 , and 1.41 ± 1.39 , respectively. There was a significant correlation between the mean score of total knowledge and the age of the mother (P=0.019), gestational age (P=0.001), educational level of the mother and spouse (P=0.001), history of birth abnormality (P=0.03), history of birth abnormality in the family (P=0.02), and sources of information (P=0.001).

Conclusion: The results showed that the mean score of knowledge in pregnant women was less than half of the total scores, and total score was related to various parameters. Intervention factors that could contribute to improved knowledge and informed decision-making among pregnant women should be considered.

Keywords: Amniocentesis, Down syndrome, Pregnancy, Prenatal, Screening

Please cite this article as: Rabiee M, Jouhari Z, Pirasteh A. Knowledge of Prenatal Screening, Down Syndrome, Amniocentesis, and Related Factors among Iranian Pregnant Women: A Cross-Sectional Study. IJCBNM. 2019;7(2):150-160. doi: 10.30476/IJCBNM.2019.44886.

INTRODUCTION

Prenatal aneuploidy screening was utilized in the mid-1960s, based on maternal age risk estimation, for the early detection of pregnancies at high risk of trisomy 21.¹ This condition, also called Down syndrome (DS), is the most common trisomy disorder among live births. The test involves measuring biochemical markers in maternal serum to detect DS. The same markers are also used to detect trisomy 18 and trisomy 13. However, prenatal screening test (PST) is mainly focused on DS since both prevalence and long-term survival are much higher in cases with trisomy 21.²

Prenatal aneuploidy screening is an essential part of prenatal care and pregnant women should be provided with reliable information about the test.^{2,3} The first-trimester combined screening test is performed at 11 to 13 weeks of gestation with a maximum delay of 6 days based on a combination of maternal age, nuchal translucency (NT) thickness, and two biochemical markers (serum-free human chorionic gonadotropin [B-HCG] and the pregnancy-associated plasma protein A [PAPP-A]). Using a 5% screen-positive rate, this test would detect 82-87% of fetuses with DS. Such an early diagnosis of abnormalities is a reassurance to anxious parents^{4, 5} and information on the risks involved allows them to make an informed decision on subsequent invasive tests.⁶ Invasive testing includes amniocentesis, also known as the amniotic fluid test (AFT), and cell-free fetal DNA test. These tests are performed in women of advanced maternal age based on the ultrasound findings and previous pregnancy loss influenced by chromosomal aberration.⁷ It is in this context that it is necessary for pregnant women at the early stage of pregnancy to have sufficient knowledge about the advantages, risks, and side effects of different available screening tests in order to facilitate an informed choice.8

A previous study conducted in England reported that performing DS screening is directly associated with the level of knowledge and attitude of the pregnant women as well as the quality of the information provided by health care professionals. However, despite their awareness, pregnant women did not proactively pursue a screening test for DS.9 Another study in The Netherlands revealed low participation and low awareness among pregnant women in the Dutch DS screening program. They concluded that sufficient knowledge about PST is a prerequisite for making informed decisions about participation in the national screening program.¹⁰ In an attempt to measure the extent to which the choices are information based, some studies showed that PST was considered routine and performed in all public hospitals or private obstetrics ultrasound clinics.¹¹⁻¹³ Nonetheless, women had inadequate knowledge about PST. They also showed that education by health care providers (obstetricians, midwives, perinatal nurses) tend to increase women's knowledge about PST. Furthermore, a significant postconsultation improvement on the level of knowledge about the tests was reported.

A survey conducted in England indicated that while most pregnant women were offered PST for DS, approximately 10% inclined to undertake the test. The authors concluded that, compared to Caucasian women, Asian women were less likely to report being offered or to undertake DS screening test.¹⁴ A study in The Netherlands, among pregnant women from different ethnic backgrounds, reported that 71% of the Caucasian, 5% of Turkish, and 26% of Surinamese women were able to make an informed decision on undertaking a DS screening test. The difference in the results was mainly attributed to the education level between different ethnicities.¹⁵ The above-mentioned studies underline two fundamental issues. Firstly, a large number of women had poor knowledge about the DS screening test and its importance. Secondly, the decision-making process on PST was influenced by complex ethical and social aspects.^{13, 14} Consequently, as the first step for a successful implementation of screening programs in each community, it is important that all women from different ethnicities have a sufficient level of knowledge about the DS screening test.

The guideline issued by the Iranian Ministry of Health and Medical Education (#25013.302, dated 8 November 2011) requires health care providers to offer PTS to all pregnant women to determine possible fetal abnormalities, including chromosomal abnormalities and neural tube defects. The program covers both the combined ultrasound and biochemical tests as well as the more invasive tests. Additionally, the cell-free DNA test is also provided on a need basis. Despite the existence of such an elaborated program, regretfully, the staff of both the public and private health care centers are overworked, resulting in less attention being paid in enhancing the knowledge of the pregnant women. Moreover, the implementation of the program does not accommodate cultural and religious sensitivities.¹⁶

To the best of our knowledge, there are limited studies that determine the extent of the knowledge and awareness about PST among Iranian pregnant women. Considering the above shortcomings, the present study aimed to address two main topics. Firstly, to assess the knowledge about PST, DS, and AFT among Iranian pregnant women. Secondly, to determine those factors contributing to the acquisition of such knowledge.

PARTICIPANTS AND METHODS

The present cross-sectional study was conducted from April 2013 to July 2014 in Mostafa Khomeini Educational Hospital, Tehran, Iran. The participants were recruited among pregnant women referred to the Obstetrics and Gynecology Clinic of the hospital for their routine medical evaluations.

As a pilot study, the convenience sampling method was used to calculate the σ value. For this purpose, 20 available participants were selected among the studied population. The selected group did not receive any information about PST nor DS. Subsequently, the sample size was calculated based on the following

formula (considering α =0.05, d=0.05, σ =0.55).

$$n = \frac{z_{\frac{\alpha}{2}}^2 \sigma^2}{d^2}$$

The inclusion criteria were pregnancy, aged ≥ 18 years, and literacy in the Persian language. The exclusion criterion was the unwillingness to participate in the study. Eventually, a total of 471 consecutive women fulfilling the inclusion criteria were enrolled in the study.

The study was approved by the Research Ethics Committee of Shahed University of Medical Sciences, Tehran, Iran (code: p-550.86). The participants were personally informed about the goals of the research, methodology, and confidentiality of any disclosed information. Verbal informed consent was obtained from all participants.

The data collection instruments included a socio-demographic information form and a knowledge questionnaire. The sociodemographic characteristics included age, gestational age, education level of both the participant and spouse, number of children, consanguineous marriage, the source of information during pregnancy, and a history of birth abnormalities in the participant, spouse, and their families. The gestational age was calculated from the last menstrual period (LMP) as reported by the women.

The 23-item knowledge questionnaire comprised of a list of structured questions based on previous studies.^{15, 17} It included 9 items on DS, 10 items on PST, and 4 items on AFT. In consultation with an expert researcher, the questionnaire was fine-tuned to include Iranian cultural sensitivities. The items of the questionnaire were answered based on 3 choices; *correct* (1 score), *incorrect* (1 score), and *do not know* (0 scores). The total test score ranged from 0 to 23. Note that the item on "*source of information about PST*" was in the form of a multiple-choice question.

To confirm the reliability of the questionnaire, 15 pregnant women filled out the questionnaire two times (at first and after

one month). The test-retest method was used. Subsequently, the results of PST, DS, AFT and total knowledge of the questionnaire were r=0.68, r=0.71, r=0.73 and r=0.711, respectively. Hence, the reliability of the questionnaire was confirmed. To confirm the face validity of the questionnaire a total of 15 pregnant women reviewed the questions and their comments were used to shorten, clarify, or omit redundant questions. To confirm the qualitative content validity of the questionnaire, the questions were initially reviewed by 10 experts (i.e. oncologists, midwives, public health education specialists, community medicine specialists). Based on their feedback, two questions were omitted and two other questions were modified for clarity. To confirm the quantitative content validity, Content Validity Index (CVI) and Content Validity Ratio (CVR) were performed based on Lawshe's table CVR was calculated (0.63), which was higher than the acceptable value (0.62). In addition, CVI for each question ranged from 0.6 to 0.9 and for all questions was 0.79. Subsequently, all questions with acceptable CVR were used in the present study. Based on the Kuder-Richardson method, the internal consistency value was 0.78.

In order to determine the construct validity of the questionnaire, the knowngroups method was used. This method allows determination of the degree of isolation of different subgroups by a questionnaire.^{18, 19} The parameters used to define the subgroups of pregnant women were education level, sources of information, and history of having a child with abnormalities. A comparison of the known-groups was performed using the Kruskal-Wallis and Mann-Whitney tests. In terms of the knowledge of the mothers, the results showed a significant difference between the respective subgroups, which in turn indicated construct validity of the questionnaire. (P=0.001, P=0.03, P=0.001 and total P<0.05).

Statistical Analysis

The data were analyzed using the SPSS

software (version 20.0). Descriptive statistic was used to present socio-demographic characteristics. The normality of quantitative variables was investigated using the Kolmogorov-Smirnov test. The Kruskal– Wallis and Mann-Whitney tests were used to assess the role of baseline characteristics of the participants on knowledge. P<0.05 was considered statistically significant.

RESULTS

The mean age of the participants was 29.09±4.67 years (range: 19-43 years). The majority of the participants 415 (88.10%) and their spouses 398 (84.50%) had a high school or university education. A high proportion of the participants 303 (64.30%) obtained information about PST, DS, and AFT from health care professionals. Detailed socio-demographic characteristics of the participants are described in Table 1. The results of the knowledge questionnaire for PST, DS, and AFT are shown in Tables 2, 3, and 4, respectively. The results showed that 221 (46.93%) participants believed that PST would comprehensively confirm fetal health and only 121 (25.69%) believed that it indicates fetal abnormalities. The majority of the participants 351 (74.52%) were not aware of the risks of pregnancy loss. Furthermore, 122 (25.90%) of the participants believed that AFT could cause a miscarriage.

The mean score of total knowledge, PST, DS, and AFT was 9.93±4.86, 5.26±2.19, 3.25±2.42, and 1.41±1.39, respectively. As shown in Table 5, the mean score of PST, DS, AFT, and total knowledge was significantly different for some demographic characteristics.

The older mothers at a gestational age of about 12-25 weeks were better informed. Those women and their spouse who had university degree were better informed than those with elementary education. Pregnant women who had a previous child with anomalies, or the occurrence of birth abnormality in their family or their spouse, had more information. When health care professionals were their source of information, the mothers were better informed.

participants			
Variables	n (%)		
Age of the mother (years)			
≤25	92 (19.50)		
26-30	177 (37.60)		
31-35	118 (25.10)		
≥36	36 (7.60)		
N.A. ^a	48 (10.20)		
Gestational age (weeks)			
1-12	31 (6.60)		
13-25	61 (13.00)		
25-40	331 (70.20)		
N.A.	48 (10.20)		
Education level			
Mother			
Elementary	24 (5.10)		
High school	209 (44.40)		
University	206 (43.70)		
N.A.	32 (6.80)		
Spouse			
Elementary	40 (8.49)		
High school	224 (47.55)		
University	174 (36.95)		
N.A.	33 (7.01)		
Number of children	. ,		
0	207 (43.94)		
1	170 (36.09)		
2	25 (5.31)		
≥3	8 (1.69)		
N.A.	61 (12.97)		
History of birth abnormality			
Mother			
Yes	8 (1.69)		
No	456 (96.81)		
N.A.	7 (1.50)		
Mother's family			
Yes	16 (3.39)		
No	448 (95.11)		
N.A.	7 (1.50)		
Father's family			
Yes	25 (5.30)		
No	427 (90.70)		
N.A.	19 (4.00)		
Consanguineous marriage			
Yes	86 (18.30)		
No	378 (80.20)		
N.A.	7 (1.50)		
Sources of information			
Internet	35 (7.40)		
Books	17 (3.60)		
Health care professionals	303 (64.30)		
Friends	42 (8.90)		
Others	35 (7.40)		
N.A.	39 (8.40)		

 Table 1: Socio-demographic characteristics of the participants

a: None Answered

DISCUSSION

The mean score of PST was found to be higher than that of DS and AFT. This finding could be primarily associated with the fact that the Iranian Ministry of Health and Medical Education had issued a guideline promoting the tests. Obviously, health care providers (obstetricians, midwives, perinatal nurses) were obliged to offer PST in order to prevent legal consequences. The education level of the participants and their spouses (the majority had a high school education or university degree) also contributed to a high PST score. This finding was supported by those results indicating a significant correlation between the education level and knowledge about PST, DS, and AFT. Concurrent with our study, similar results were reported in other studies.^{10, 20} A positive attitude toward risk assessment, particularly regarding DS, among pregnant women in other countries has been reported.²⁰⁻²⁶ It should be noted that, despite awareness of PST, a high percentage of women were apprehensive to undergo the test and did not consider it necessary.5, 9, 13 Seemingly, the level of knowledge about the exact nature of the test played an important role in their decision. A study reported that the concern of the mothers' drive to protect fetal health was the main reason for not undertaking PST or any other similar test.⁷

Our results showed that a large number of the participants believed that all congenital abnormalities could be diagnosed by PST. Moreover, they felt that their neonates would certainly not have DS when the results of the first- and second-trimester screening tests were negative. Interestingly, many of the participants were unaware of the physical and mental disabilities associated with DS. Half of the participants were relevant literature under the impression that DS could be treated, and the majority had no knowledge of the risks associated with a fetus having DS. Similar to other studies^{10, 11}, we also found that the participants had less knowledge about PST diagnosis than about the test itself. A few studies reported that despite an increase in

Questions	n (%)			
	Yes	No	Do not Know	N.A. ^a
Is a blood test required?	440 (93.42)	8 (1.70)	16 (3.40)	7 (1.48)
Is an ultrasound scan required?	417 (88.53)	22 (4.67)	25 (5.32)	7 (1.48)
Is a combined blood test and ultrasound required?	414 (87.89)	33 (7.00)	13 (2.76)	11 (2.35)
Can a normal screening test fully confirm fetal health?	221 (46.93)	138 (29.29)	83 (17.63)	29 (6.15)
Can a normal screening test rule out DS? ^b	112 (23.77)	169 (35.88)	151 (32.06)	39 (8.29)
Can PST diagnose fetal abnormalities?	121 (25.69)	158 (33.55)	158 (33.54)	34 (7.20)
Should AFT be done subsequent to unfavorable PST? ^c	296 (62.84)	3 (0.65)	142 (30.15)	30 (6.36)
Is fetal abnormality confirmed with unfavorable AFT? ^d	122 (25.91)	38 (8.06)	270 (57.32)	41 (8.71)
Is fetal abnormality confirmed with unfavorable PST?	125 (26.55)	92 (19.53)	217 (46.07)	37 (7.85)
Do you know the meaning of nuchal translucency?	223 (47.30)	214 (45.50)	0 (0.00)	34 (7.20)

Table 2: List of questions related to the knowledge about the prenatal screening test

a: None Answered; b: Down syndrome; c: Prenatal screening test; d: Amniotic fluid test

Table 3: List of questions related to the knowledge about Down syndrome

Questions	n (%)			
	Yes	No	Do not know	N.A. ^a
Is DS ^b a chromosomal abnormality?	290 (61.57)	25 (5.32)	128 (27.17)	28 (5.94)
Does a child with DS always suffer from physical disability?	117 (24.85)	35 (7.44)	289 (61.35)	30 (6.36)
Does a child with DS always suffer from intellectual disability?	173 (36.74)	38 (8.06)	225 (47.77)	35 (7.43)
Can a child with DS be cured?	209 (44.37)	11 (2.33)	225 (47.77)	26 (5.53)
Does a baby with DS die at birth?	183 (38.85)	4 (0.85)	258 (54.77)	26 (5.53)
Does abortion of a fetus with DS present a higher risk than a normal fetus?	12 (2.55)	159 (33.75)	263 (55.85)	37 (7.85)
What is the prevalence of DS in 1000 live births?	120 (25.48)	169 (35.88)	182 (38.64)	0 (0.00)
Is DS associated with maternal age?	163 (34.63)	89 (18.89)	177 (37.57)	42 (8.91)
Are women aged \geq 36 years at greater risk of having a child with DS?	265 (56.26)	25 (5.32)	146 (30.99)	35 (7.43)

a: None Answered; b: Down syndrome

Table 4: List of questions related to the knowledge about the amniotic fluid test

Questions	n (%)			
	Yes	No	Do not know	N.A. ^a
Can DS ^b be diagnosed using AFT? ^c	199 (42.26)	10 (2.12)	230 (48.83)	32 (6.79)
Would a fetus be certainly abnormal if the result of AFT is unfavorable?	122 (25.90)	38 (8.06)	270 (57.33)	41(8.71)
Does AFT involve removing a sample of amniotic fluid using a needle through the abdomen?	224 (47.60)	7 (1.48)	202 (42.88)	38 (8.04)
Does removing a sample of amniotic fluid result in a miscarriage?	122 (25.90)	52 (11.04)	259 (54.98)	38 (8.08)

a: None Answered; b: Down syndrome; c: Amniotic fluid test

Variables	PST ^a DS ^b		AFT ^c	Total knowledge
	(0-10)	(0-9)	(0-4)	(0-23)
	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Age of mothers (years)				
≤25	4.92±1.97	2.52±2.17	1.13 ± 1.24	8.58±4.28
26-30	5.33±2.22	3.43 ± 2.48	1.39±1.36	10.16 ± 5.00
31-35	5.41±2.19	3.48±2.42	1.57±1.44	10.47±4.73
≥36	5.52±2.38	3.38±2.55	1.75±1.59	10.67±5.37
P value*	0.31	0.017	0.1	0.019
Gestational age (weeks)				
1-12	2.97±2.65	3.29±2.56	1.19±1.49	7.45±5.65
13-25	6.02±2.22	3.85±2.54	1.62 ± 1.37	11.49±5.10
25-40	5.44±2.22	3.25±2.37	1.44±1.39	10.13±4.62
P value*	0.001	0.285	0.213	0.001
Education level				
Mother				
Elementary	3.83±1.73	1.08 ± 1.03	0.5±0.83	5.42±3.32
High school	5.10±2.03	2.79 ± 2.28	1.42±1.37	9.33±4.56
University	5.82±2.29	4.25±2.32	1.6±1.46	11.69±4.8
P value*	0.001	0.001	0.001	0.001
Spouse				
Elementary	4.35±1.00	1.82±1.91	0.66±0.95	6.85±3.95
High school	5.22±2.00	3.09 ± 2.37	1.45±1.38	9.77±4.65
University	5.76±2.45	4.03 ± 2.41	1.62 ± 1.46	11.43±4.99
P value*	0.001	0.001	0.001	0.001
History of birth abnormality		0.001	0.001	0.001
Mother				
Yes	10.42±2.69	4.5±2.64	3.00±1.00	13.88±4.45
No	8.72±2.77	4.12±2.38	1.49 ± 1.40	9.86±4.84
P value**	0.07	0.16	0.007	0.03
Mother's family	0.07	0.10	0.007	0.05
Yes	6.75 ±2.71	4.37±1.76	2.75±1.16	12.36±4.17
No	5.23±2.70	3.24 ± 2.43	1.38 ± 1.39	9.84±4.83
P value**	0.83	0.07	0.001	0.02
Father's family	0.05	0.07	0.001	0.02
Yes	5.56±2.25	4.25±2.17	2.81±1.16	12.08±4.94
No	5.26±2.19	4.25±2.17 3.21±2.41	1.37 ± 1.38	9.80±4.81
P value**	0.28	0.04	0.03	0.02
Consanguineous marriage	0.20	0.04	0.05	0.02
Yes	5.72±2.05	3.62±2.27	1.59±1.42	10.94±4.74
No	5.18±2.20	3.18 ± 2.45	1.37 ± 1.38	9.74 ± 4.84
P value**	0.11	0.09	0.17	9.74±4.84 0.06
Sources of information	0.11	0.09	0.17	0.00
Internet	6.06±1.99	4.62±2.39	1.76 ± 1.30	12.47±4.26
Books	6.00 ± 1.99 6.25 ± 2.07	4.85 ± 1.95	1.76 ± 1.30 2.10±1.33	12.47 ± 4.20 10.27 ± 4.68
Health care professionals Others	10.91±1.88 4.71±2.28	5.81±1.72 3.13±2.12	2.35±1.15 1.13±1.19	13.20±4.02 8.98±4.25
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Table 5: Comparison between the mean score of the prenatal screening test, Down syndrome, and amniotic fluid test with respect to the socio-demographic characteristics

a: Prenatal Screening Test; b: Down Syndrome; c: Amniotic Fluid Test; *Kruskal-Wallis; **Mann-Whitney

the participation of pregnant women in DS screening, the majority had poor knowledge about different aspects of the test and many had minimal baseline knowledge about the nature of PST, diagnosis, and outcomes.^{27, 28} A number of studies have reported that most of the patients stated that physicians requested a blood test without providing any background information.^{10, 17, 29-31} Although the majority of our participants indicated that their information was provided by health care professionals, it was noted that those who obtained their information from relevant literature had a higher level of knowledge about PST.

One of the main objectives of the present study was to determine the factors that contributed to the acquisition of knowledge about PST, DS, and AFT. In this regard, in addition to knowledge and education level, we found that parameters that also played an important role were the age of the mother, previous congenital abnormality in the family, and two sources of information; namely health care professionals and the internet. In a previous study, similar factors were reported. In descending order, they were: personal experience, consultations with health care professionals (physicians, obstetricians, midwives), and public media (literature, television, internet). In addition, they reported that younger women had a lower level of knowledge than older women.³² Another study concluded that patients' knowledge about DS screening was associated with the experience from previous tests and/or information. Consequently, the authors recommended improvement of the knowledge, particularly among first-time young pregnant women.³³

Concurrent with a previous study,³⁴ we also believe that in order to gain sufficient knowledge on PTS, access to an appropriate source of information is vital and a prerequisite to adequate awareness. Our results on the knowledge score showed that those who used the internet as a tool to obtain information on PST were ranked lower than those who reviewed the relevant literature.

Therefore, the choice for an appropriate source of information is essential. It is recommended that pregnant women should obtain the necessary information from health care providers. These organizations should play a central role in providing information and creating awareness about DS.5, 16, 33 Prenatal care providers should also ensure that pregnant women fully understand that DS is associated with intellectual disability and PST is only indicative of low DS risk, but it does not guarantee fetal health due to probable congenital aneuploidy.³³ Obviously, comprehensive pre-screening education permits pregnant women to make an informed decision on PST, DS, and AFT.²⁰ Therefore, it is of paramount importance that counseling sessions are designed to provide short, sharp, and clear information to facilitate an informed decision-making process.35

The main limitation of the present study was the recruitment of the participates from a single center. However, the relatively large sample size and pro-active participation of the participants outweighed the limitation.

CONCLUSION

The results showed that the mean score of pregnant women was less than half of the total scores, and their score was related to various parameters (e.g., the age of the mother, gestational age, education level of the mother and spouse, history of birth abnormality in the family, and sources of information). Intervention factors that could contribute to improved knowledge and informed decision-making among pregnant women should be considered. Moreover, appropriate information should be provided to facilitate the informed decisionmaking process. Further studies are required on a larger sample size with greater diversity to obtain comprehensive results.

ACKNOWLEDGMENT

The present study was supported by Shahed University of Medical Sciences, Tehran, Iran (code: p-550.86). We would like to express our gratitude to the participants for their active participation. We also would like to thank the personnel at the Mostafa Khomeini Educational Hospital for their cooperation.

Conflict of Interest: None declared.

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