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Premarital Screening and Genetic Counseling program: Knowledge, attitude, and satisfaction of attendees of governmental outpatient clinics in Jeddah

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KEYWORDS

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Summary Premarital care (PMC) is a worldwide activity that aims to diagnose and treat unrecognized disorders and reduce the transmission of diseases to couples and children.

Objectives: To assess the knowledge and attitude of individuals attending governmental outpatient clinics regarding the Premarital Screening and Genetic Counseling (PMSGC) programs, to identify predictors of high knowledge scores and to determine the satisfaction and recommendations of clients of the program.

Methods: A cross-sectional study was conducted from January to April 2009. Individuals who attended three governmental hospital outpatient clinics on the day of the interview and agreed to participate in the study were recruited. The three hospitals were the two hospitals in Jeddah that offer the PMSGC programs and the King Abdulaziz University Hospital. Ethical considerations were followed and data were collected through an interview questionnaire that had been constructed for the study. The questionnaire asked for personal and socio-demographic data and for responses, on a 5-point Likert scale, to 30 knowledge items and 14 attitude statements. Individuals who participated in the PMSGC program were asked questions regarding the services and activities of the program to ascertain their satisfaction with the program and their recommendations for program improvement. The statistical analysis was performed using SPSS version 16 (SPSS Inc., Chicago, IL).

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Results: The sample included 655 participants, of whom 38.8% completed the PMSGC program. The participants' knowledge about the program was generally low. Education was the first predictor of a high knowledge score; individuals having > university degree obtained a higher score (aOR = 2.73; 95% CI: 1.77-4.20). The second predictor was the nationality of the participants, with Saudis gaining a higher score (aOR = 2.04; 95% CI: 1.002-4.16). The third predictor was monthly income. Regarding attitudes, the vast majority of participants (96.0%) strongly agreed on the importance of the program. Concerning the satisfaction levels of those who benefited from the program, 80.0% gave an excellent or very good score for program confidentiality, whereas lower scores were given for counseling. Counseling before the tests was conducted for only 11.7% of the study participants. The majority of participants recommended adding testing for other genetic diseases and STDs as well as additional topics for counseling. Conclusion: Knowledge in the general population about the PMSGC program was low. Implementation of school and university educational campaigns is important. Improved counseling and adding new topics for counseling on genetic, chronic, and psychiatric problems; building healthy families; reproduction and fertility are recommended.

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Introduction

Premarital care (PMC) involves the promotion of health and well-being of a woman and her partner before pregnancy and is considered a primary preventive approach for couples planning for conception and an important step towards protecting society and allowing people to enjoy life [1-8]. PMC includes premarital health counseling and a general medical examination [1]. Premarital examinations can particularly be important in the prevention of the spread of disease [2]. PMC can identify and modify, through prevention and management, some behavioral, medical, and other health risk factors known to impact pregnancy outcomes [1-7]. The process should educate couples and provide them with accurate and unbiased information. Premarital education and counseling seem to be effective in strengthening marriages and have clearly been shown to be beneficial [9]. Carroll and Doherty [10] conducted a meta-analytic review of 23 well-designed premarital programs and found that premarital prevention programs are generally effective in producing immediate and short-term gains in interpersonal skills and the overall quality of relationships.

The Saudi Premarital Screening and Genetic Counseling (PMSGC) program was established by law in December 2003 and implemented in February 2004 [11—16]. The program, named the "Healthy Marriage Program," is part of a national project spearheaded by the Saudi Ministry of Health [15]. By late 2003, comprehensive PMSGC program guidelines were distributed to all workers in the program. According to these guidelines, couples with

marriage proposals were required to report to the nearest health care clinic to apply for premarital certificates [16].

The PMSGC program began in 2004 as a screening program for hemoglobinopathies, particularly sickle cell anemia and thalassemias. Hemoglobinopathies are the most frequently inherited disorders worldwide. According to the WHO, approximately 240 million people are heterozygous for inherited hemoglobinopathies, including thalassemia and sickle cell disease [2]. Saudi Arabia has a high prevalence of hereditary hemoglobin disorders [16].

On January 2008, viral pathogen screening was included in the Saudi PMSGC to test participants for human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) as a prerequisite for issuing a marriage certificate [2,5,14,16]. All couples with marriage plans are required to be tested for these diseases and to have the appropriate counseling (if required) before completing their marriage plans. However, compliance with the counseling recommendation remained voluntary [16]. Premarital screening can potentially reduce the burden of inherited hemoglobin diseases by reducing the number of high-risk marriages [5,14,16,17]. In addition, the implementation of premarital infectious disease screening is an ambitious and massive project with regard to cost and impact [2,15]. Premarital programs are most successful when they address social, religious, ethnic, and cultural factors [16].

Al-Sulaiman et al. [4] conducted a study in Riyadh among three groups of participants: one representing the general population, one of

couples applying for PMSGC and one of couples who had received the results of their testing. They found a fair degree of knowledge among the three groups of Saudi participants regarding the nature of the tests and the targeted disorders. Other studies found a significant lack of knowledge, even among educated persons, about premarital care [1,2]. Some studies have been conducted to assess the knowledge of university students in Jeddah regarding the PMSGC program [2,18,19]. However, to date, few studies have been performed in Jeddah to assess the knowledge and attitude of the general population about the PMSGC program and to determine the level of satisfaction of program participants regarding the PMSGC program. Such a study regarding PMSGC is urgently needed.

The objectives of the present study were to assess the knowledge and attitudes of the attendees of governmental outpatient clinics regarding the Premarital Screening and Genetic Counseling program, to identify the predictors of high knowledge scores and to determine the satisfaction and recommendations of clients of the program.

Methodology

A cross-sectional study was conducted during the Fourth Year Field Health Survey of the Family and Community Medicine Department from January to April 2009. Three governmental hospitals were selected: the 2 hospitals which provide PMSGC in Jeddah, namely El-Mahjar King Abdulaziz Hospital and El-Mesadayah Maternal and Child Hospital, and the King Abdulaziz University Hospital. Approval for conducting the study was obtained from the Head of the Jeddah Directorate of Health Affairs, from the heads of the selected hospitals, and from the dean of the Faculty of Medicine. The team followed the ethical standards of confidentiality and freedom of participation in recruiting the subjects for the study.

The sample size was calculated using the following equation:

$$\frac{Z^2 \times p \times q}{d^2}$$

As the prevalence of knowledge regarding premarital counseling among the general population (p) was unknown, it was estimated to be 50% = 0.5, q = 1 - p = 0.5, and the value of 0.04 was chosen as an acceptable limit of precision (d). At a 95% confidence limit, the calculated size of the sample was 600 participants. This number was exceeded,

as the number of participants reached 655 during the fieldwork. All attendees of outpatient clinics (including predominantly the well-baby, hematology, and genetic clinics, among others) who were available on the day of the interviews were invited to participate in the study. The topic of the research was discussed with each attendee separately and, upon acceptance, verbal consent was obtained. Individuals who gave consent and met the requirements for the study were recruited to participate. The questionnaire for interviewing the subjects was anonymous and confidential and had been pre-constructed for the study. The validity and reliability of the questionnaire were tested.

The first part of the questionnaire elicited information regarding the respondents' personal and socio-demographic characteristics. The subjects were asked about consanguinity and a family history of hereditary diseases, such as thalassemia, sickle cell anemia and glucose 6 phosphate dehydrogenase deficiency (G6PD). The questionnaire also asked the subjects about their sources of knowledge for the PMSGC program.

In addition, questions assessing the knowledge and attitudes of participants towards the PMSGC program were asked, using the following format:

Participants' knowledge

Thirty multiple-choice questions with a single correct answer were used. These questions were used to obtain:

- General knowledge regarding the PMSGC program (5 items): these questions inquired about the starting year of the program in KSA and the hospitals in Jeddah that offer the PMSGC program.
- 2. Knowledge regarding investigations: these questions asked about investigations conducted through the PMSGC (15 items).
- 3. Knowledge regarding the infectious diseases screened in the program (2 items): these questions asked about hepatitis and AIDS.
- 4. Knowledge regarding hemoglobinopathy and enzymopathy (8 items): these questions inquired about the manifestations and complications of hemoglobinopathy, such as G6PD, thalassemia and sickle cell anemia.

Participants' attitude

These items addressed attendees' attitudes towards the PMSGC program. This inquiry was relied on participants' responses to 14 statements, using a 5 point Likert scale (range from 1 = strongly

agree to 5 = strongly disagree). Participants were asked about their attitude towards the PMSGC and about the misconception that the PMSGC violates Islamic rules. The subjects' opinions regarding whether consanguinity may increase the risk of hereditary diseases and whether the PMSGC program is expected to decrease the prevalence of some genetic and sexually transmitted diseases (STDs) were also addressed. Questions were asked regarding the importance of counseling in reducing and preventing the spread of genetic diseases or STDs and whether religious leaders should adopt the ideas of the PMSGC to be discussed on different occasions. The attendees' opinions about whether a Ma'zoon (an authorized individual who performs the religious marriage for Muslim prospective couples) should only be allowed to complete the marriage contract if the couple complete the PMSGC program was also elicited.

Participants were asked if they took part in the PMSGC program, and if so, where and when the counseling took place. The participants were also asked about the services and activities provided by the program. The questionnaire asked whether responsible health care providers took a personal or family history of hereditary diseases, conducted a physical examination, ordered laboratory tests, and provided counseling before screening. Participants were also asked about whether a health care worker provided them with knowledge regarding the screened diseases and the chance of transmission of these diseases, if present, to their partner or a baby. The participant was also asked if there was a description of the counseling and the benefits and accuracy of screening for these diseases.

Each subject was asked about the confidentiality of screening and if the health care worker checked the identification card (ID) of the person who received the test results. Participants were asked whether the results revealed the presence of any hereditary disease (in themself or their future partner) and whether this information led to the cancellation of the marriage proposal.

The study assessed the satisfaction level of the participants in the PMSCG with respect to the individuals who conducted the screening, the program itself and the provided service (i.e., place of providing the service inside the hospital, place of sample taking and waiting place in the hospital and confidentiality). The participants in the program were also asked about their recommendations for extra topics that need to be added to counseling.

After the questionnaire was completed, and only as service for the study participants, a pre-constructed, computer-based CD-ROM with multimedia interactive animated presentations was

given to and discussed with interested participants. The CD-ROM contained a lecture in Arabic on the PMSGC program. The CD-ROM was supported by attractive images related to the details of all knowledge items. The total showing took approximately 40 min. In addition, 5 brochures, each on a different theme, were given to participants. Copies of the educational CD-ROM were given to administrators in the hospitals to be used again later. In addition, hundreds of posters (consisting of five different styles with different PMSGC educational messages) were distributed throughout the visited hospitals.

A pilot study was conducted among 10 participants to pre-test the questionnaire, identify the feasibility of conducting the study, determine the difficulties that may arise during the course of the study and estimate the time required to complete each questionnaire.

Statistical analysis

The collected data were reviewed, coded, verified, and statistically analyzed. The computer program used was SPSS version 16 (SPSS Inc., Chicago, IL) [20]. A knowledge scoring system was developed for the 30 items. "Do not know" answers were treated as incorrect and given a score of "0", whereas each correct answer was given a score of "1". The total knowledge score was calculated and ranged from 0 to 30. The knowledge score was classified as poor score, <15; fair score, 15 to <20; and satisfactory score, >20. The chi-squared test was used for comparisons between proportions. The odds ratio (OR) and 95% confidence intervals (CI) were also calculated. The significant variables obtained from the bivariate analysis were used for multivariate logistic regression analysis through construction of a binary logistic regression model to identify the predictors of a high knowledge score (fair and satisfactory) versus a poor knowledge score. Adjusted odds ratios (aORs) and 95% confidence intervals (CIs) were calculated. Statistical significance was defined as P < 0.05.

Results

The total number of participants enrolled in the study was 655, and the mean age of the participants was 30.63 ± 9.1 years. There were 332 male participants (50.7%) and a male to female ratio of 1.02:1. More than four-fifths (82.9%) of the participants were Saudis. Approximately one-half of the subjects (46.7%) had a university degree or higher. Most

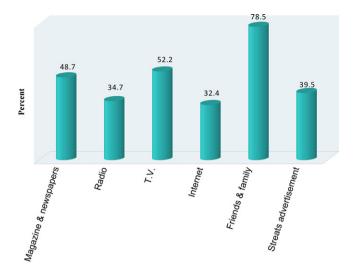


Figure 1 Sources of knowledge about pre-marital screening among attendees of outpatient clinic in Jeddah hospitals. N.B. Each question is separately asked.

of the participants (70.1%) were from the western region of Saudi Arabia. A similar percentage (71%) had a monthly income \geq 5000 SR/month. Consanguinity was reported by 44.5% of the participants (31.1% having first degree cousin consanguinity and 13.4% having other types of consanguinities).

The vast majority (93.7%) of participants had heard about the PMSGC program. Fig. 1 depicts the participants' source of knowledge regarding the program. Friends and family were cited as the most common source of information for the majority of participants (78.5%). Approximately half (52.2%) of the participants obtained their information from television, and a similar proportion (48.7%) obtained their information from magazines and newspapers. A substantial proportion of participants (39.5%) obtained their information from street advertisements. The Internet and radio were

sources of information for approximately one-third of the participants.

It is apparent from Fig. 2 that the participants' knowledge regarding the PMSGC program score was generally low. Most of the subjects (80.5%) had a low knowledge score, and only 14.0% and 5.5% had fair and satisfactory scores, respectively.

Table 1 portrays the relationship between participants' knowledge scores regarding the PMSGC and the studied variables. It is apparent from the table that participants aged <30 years had a higher proportion (22.4%) of fair and satisfactory scores when compared with those aged \geq 30 years (16.0%), with a statistically significant difference (p = 0.02). There was no statistically significant difference regarding the level of knowledge between the sexes. Saudis had significantly higher knowledge scores than non-Saudis (X^2 = 9.68, p = 0.002). Individuals who had

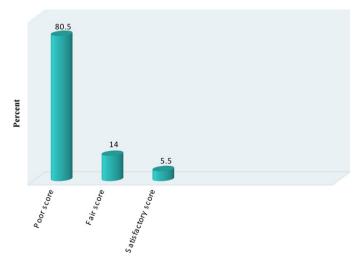


Figure 2 Knowledge score about pre-marital screening among attendees of outpatient clinics in Jeddah hospitals.

Table 1 Relationship between knowledge level about premarital screening and personal, socio-demographic characteristics of attendees of Jeddah outpatient clinics.

Knowledge level	Poor		Fair and satisfactory		Total	X^2 (P)	OR, 95% C	
Variable	No.	%	No.	%	_			
Age								
<30	281	77.6	81	22.4	362	4.13	0.66	
≥30	246	84.0	47	16.0	293	(0.02)	0.45-0.98	
Sex								
Male	270	81.3	62	18.7	332	0.32	1.12	
Female	257	79.6	66	20.4	323	(0.05)	0.76-1.64	
Nationality								
Saudi	425	87.0	118	21.7	543	9.68	0.35	
Non-Saudi	102	91.1	10	8.9	112	(0.002)	0.18-0.69	
Education								
Less than university	310	88.8	39	11.2	349	33.26	3.26	
University or above	217	70.9	89	29.1	306	(0.000)	2.15-4.93	
Income								
<5000/month	252	87.5	36	12.5	288	16.2	2.34	
\geq 5000/month	275	74.9	92	25.1	367	(0.000)	1.54-3.57	
Parental consanguinity	′							
Yes	231	82.2	50	17.8	281	0.96	1.22	
No	296	79.1	78	20.9	374	(0.33)	0.82 - 1.80	
Family history of gene	tic disease	?S						
No	95	76.6	29	23.4	124	1.44	0.75	
Yes	423	81.4	99	18.0	531	(0.2)	0.47-1.20	
Conduct the premarita	ıl examina	tion						
Yes	203	76.3	63	23.7	266	4.89	0.65	
No	324	83.3	65	16.7	389	(0.02)	0.44 - 0.95	

a monthly income $\geq 5000\,\text{SR/month}$ demonstrated significantly higher knowledge scores compared with the others (aOR=2.34; 95% CI: 1.54–3.57). Individuals who participated in the PMSGC program also had higher knowledge scores than the others.

Results of the logistic regression analysis for predictors of high knowledge scores (fair and satisfactory), after controlling for other confounders, are presented in Table 2. Education was the first predictor of a high knowledge score; individuals with a university degree or above demonstrated a higher knowledge score (aOR = 2.73; 95% CI: 1.77–4.20). The second predictor was the nationality of the subject; the score for Saudis was approximately two times higher than that for non-Saudis (aOR = 2.04; 95% CI: 1.002–4.16). The last predictor for a high knowledge score was a monthly income $\geq 5000\,\text{SR/month}$ (aOR = 1.59; 95% CI: 1.005–2.505).

Table 3 portrays the attitudes of participants towards the PMSGC. It is apparent from the table that the vast majority of participants (96.0%, 89.1% and 94.0%) strongly agreed with the importance of

the PMSGC program, that the program will contribute to a reduction in the prevalence of some genetic diseases and STDs, and on the importance of raising awareness regarding the PMSGC before marriage, respectively. Approximately two-thirds of the participants (65.2%) strongly agreed that when a genetic disease is detected, the marriage proposal should be cancelled. Another two-thirds strongly agreed that when an STD or genetic disease is discovered, the marriage decision must be left to the discretion of the couple. The majority of participants disagreed or strongly disagreed (71.1%) with the misconception that the PMSGC violates Islamic rules, whereas 11.7% strongly agreed that the PMSGC violates Islamic rules.

Among the study population, 254 individuals (38.8%) participated in the PMSGC. Genetic diseases were diagnosed in 6.7% of the interviewed persons or in a future partner. The marriage proposal was cancelled in 41.2% of cases where a genetic disease was discovered. Infectious diseases (HBV, HCV, and HIV) were diagnosed in 1.97% of the couples.

Table 2	Multiple logistic regression analysis of predictors of high knowledge score about premarital screening	
program	among attendees of Jeddah outpatient hospital clinics.	

Score and variables	β	aOR	Р	CI
Participants' knowledge				
Education (university and above)	1.003	2.73	0.000	1.77-4.20
Nationality (Saudi)	0.714	2.04	0.049	1.002-4.161
Monthly income $\geq 5000\text{SR/month}$	0.462	1.59	0.048	1.005-2.505
Constant	-4.513	0.011	0.000	
aOR, adjusted odds ratio: CI, Confidence int	erval			

Measures taken during premarital screening, as reported by the participants who completed the tests, are presented in Fig. 3. It is evident from the figure that laboratory testing was the most common conducted measure (83.1%). Determining a history of diseases, determining a family history of genetic diseases and physical examinations were reported to have been conducted in 35.1%, 34.6% and 38.5% of participants, respectively. Only 11.7% of the participants reported that they received premarital counseling before the test.

Counseling was provided regarding the screened diseases, the susceptibility of transmission, the types of testing, and the benefits of screening, in 13.4%, 14.3%, 11.3% and 16.3% of participants, respectively.

The satisfaction level regarding the program for the participants who took part in the screening is presented in Table 4. The majority (80.0%) gave an excellent or very good score for program confidentiality. More than 60% said that the place of implementation of the program inside the hospital and the place of sample taking were either excellent or very good. One-half of the beneficiaries gave excellent or very good scores regarding the waiting area in the hospital. The areas of least satisfaction were related to counseling (approximately 40% of the participants gave excellent and very good scores for the questions related to counseling).

Approximately 90% of the participants recommended adding screening for other genetic diseases and STDs to the program. A similar percentage recommended adding more genetic counseling and counseling about building a healthy family. A high percentage of participants recommended adding counseling for chronic diseases (83.7%), fertility,

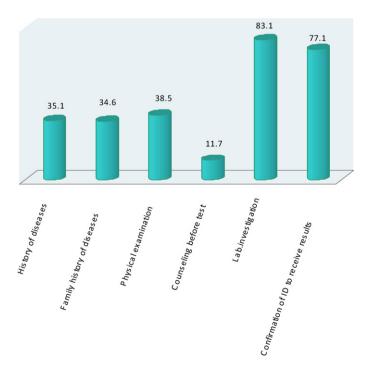


Figure 3 Activities done during premarital screening among outpatient clinic attendees who conducted screening in Jeddah's hospitals. N.B. Each question is separately asked.

Sentence	Degree of agreement									
	Strongly agree		Agree		No opinion		Disagree		Strongly disagree	
	No	%	No	%	No	%	No	%	No	%
PMS is important	545	83.2	84	12.8	15	2.3	7	1.1	4	0.6
PMS is against Islamic roles	84	7.3	29	4.4	112	17.1	141	21.5	325	49.6
Consanguinity may leads to hereditary diseases	242	36.9	288	44	71	10.8	43	6.6	11	1.7
PMS will contribute to reduction of prevalence of some genetic and STDs	424	64.7	160	24.4	47	7.2	18	2.7	6	0.9
It is important to raise awareness about PMS before marriage to reduce genetic and STDs	481	73.4	135	20.6	29	4.4	8	1.2	2	0.3
Religious people should adopt the ideas of PMS in their discussion	363	55.4	184	28.1	90	13.7	18	2.8	0.0	0.0
Ma'zoon should has the right to accept conducting marriage contract only if future couple did PMS	301	46.0	165	25.2	112	17.1	56	8.5	21	3.2
The law that obligate all future couples to do PMS is important	363	55.4	183	27.9	56	8.5	36	5.5	17	2.6
No one should obligate any person to conduct genetic testing, but only encourage to do	180	27.5	202	30.8	65	9.9	107	16.3	101	15.4
In a case of discovery having or carrying STDs, marriage decision must be left for freedom of the couple	225	34.4	202	30.8	81	12.4	64	9.8	83	12.7
In the case of discovery having or carrying inherited disease in PMS, marriage decision must be left for freedom of couple	199	30.4	246	37.6	73	11.1	67	10.2	70	10.7
Test results that shows presence of genetic diseases should change marriage decision	248	37.9	179	27.3	168	25.6	40	6.1	20	3.1
t is important to apply a law that stop marriage upon discovery presence of a genetic disease	242	36.9	132	20.2	126	19.2	108	16.5	47	7.2
PMS breaks personal privacy	49	7.5	40	6.1	67	10.2	227	34.7	272	41.5

Sentence	Opinion								
	Excellent	Very good	Good	Bad	Very bad				
Place of PMC in the hospital	30.7	29.9	23.5	10.2	5.7				
Place for taking samples	28.7	35.2	20.9	11.9	3.3				
Waiting place	21.7	28.3	23.8	17.2	9.0				
Waiting Place for laboratory sample	24.2	22.5	27.0	13.5	12.7				
Way of dealing of doctors in the program	38.3	29.6	25.1	5.3	1.6				
The confidentiality	47.9	22.1	15.0	5.4	9.6				
Place for counseling	19.3	17.6	23.3	16.1	23.3				
Dealing of staff responsible for counseling	20.7	21.6	22.1	14.0	21.6				
Doctors cooperation during counseling	26.6	17.1	24.8	13.1	18.5				

and reproduction (81.5%), and psychiatric problems (76.3%) (Fig. 4).

Discussion

Many nations have begun to realize the importance of premarital counseling as a public health measure [21–23]. PMSGC is an important means by which newly married couples can consider marriage and learn about reproductive health [1]. In the Arabian Peninsula, high proportions of consanguineous marriages and the tribal nature of marriages have resulted in a high incidence of genetically based disorders [24]. The consanguinity rate in the region ranges from 25% to 60%,

with a high incidence of first-cousin marriage [2,18,19,21,24]. This finding is in agreement with results of the present study, where the consanguinity rate was 44.5%; 31.1% of the participants had first-degree cousin consanguinity with their partner. The consanguinity rate is slightly higher than that reported in a study conducted by Abdel-Meguid et al. [25], in which the corresponding rate among the general population in Egypt was 36.8%.

The present study showed that friends and family were cited as the most common source of information regarding PMSGC, followed by television and then magazines and newspapers, which agrees with our previous findings regarding premarital counseling among unmarried female university students in Jeddah [2]. Other studies have shown that

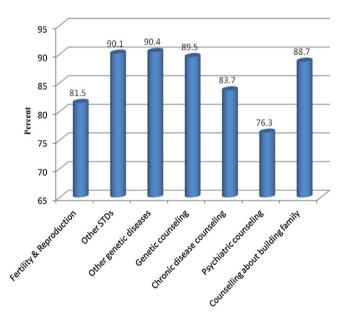


Figure 4 Recommended activities to be added to premarital screening by those who conducted tests among the outpatient clinic attendees in Jeddah.

television is the most common source of knowledge [1]. Dabbous et al. [26] found that radio and television were the most common reported means of health education (65%). The discrepancy between the current and previous studies may result from the low number of educational television programs regarding the PMSGC in KSA or from the reporting of more than one type of mass media in other studies. Therefore, the media plays a prominent role in enlightening the populace regarding the PMSGC program.

The current study showed that the participants' knowledge regarding the PMSGC was generally low; 80.5%, 14.0% and 5.5% of participants demonstrated poor, fair, and satisfactory scores, respectively. Similar rates were obtained from the pre-test in our previous study in unmarried students; the corresponding rates were 80.9%, 12.5% and 6.6%, respectively [2]. The gap in knowledge among participants demonstrates a need for more efforts to improving knowledge through the mass media or through the PMSGC program. The results of the current study also agree with those of a study conducted at King Abdulaziz University, Jeddah, that found that university students had inadequate knowledge about the program [18,19]. An older study conducted by Eshra et al. [27] in 1989 among villagers in Egypt also revealed gaps in knowledge regarding premarital screening. In contrast, a study conducted among nursing students in Alexandria revealed that 46.5% had an average score for knowledge regarding premarital counseling [6]. Another study in Syria in 2009, showed that university students had considerable knowledge about premarital testing [28]. In Nigeria, a cross-sectional survey conducted among university students in 2006 found that most study respondents (63.6%) knew the benefits of genetic counseling [29]. The discrepancy between the current and the previous studies may be attributed to differences in the target populations because the previous studies were conducted among university and nursing students rather than in the general population.

The present study showed that education was the first predictor of a high knowledge score, which coincides with the results of a study in Emirates [30]. Income was also a predictor, which agrees with our previous study that found that university students who have a higher family income have more knowledge about the PMSGC program [2].

In recent years, premarital counseling has gained acceptance [2,25]. The present study showed a positive attitude towards PMSGC among most of the general population of outpatient clinic attendees, which coincides with the findings of several other studies [4,11–13,18,19,31–34]. A study conducted

among the general population in Riyadh in 2008 showed a positive attitude toward the program and that the majority of participants agreed with the idea of applying the PMSGC program to all couples in all regions of the country [4]. An older Riyadh study indicated that 75.0% of consumers supported compulsory participation in the PMSGC program [31]. Similarly, an assessment of the attitudes of university students in Abha in 2002 showed that 70% participation in the PMSGC program [32]. El-Hazmi [11] conducted a community-based attitude study and found that 94% of the participants considered premarital testing and counseling to be important in preventing genetic blood diseases, whereas 87% thought testing should be mandatory. A study conducted among 800 university participants in Jeddah revealed that most participants favor the program. but there were concerns regarding mandating the testing and interference with individual decision making [18,19]. An educational program conducted among female students at King Saud University in Riyadh found that the students' attitudes were positive [12]. A study conducted in Iran to evaluate the attitudes of the young adult population towards premarital screening for HBV found that 73.2% of the participants agreed with HBV screening [13]. Results from Germany in 2009 found that there was an overall positive attitude toward genetic testing among respondents aged 14-95 years [33]. In 2002, Hassan et al. [34] reported that 80.9% of medical students in Alexandria, Egypt supported the idea of premarital examinations.

In the present study, few of the participants (11.7%) had religious misunderstandings regarding the PMSGC. Al-Khaldi et al. [32] also found that few students in Abha showed negative attitudes arising from religious misunderstandings and concluded that the respondents could benefit from intensive religious health education. Two older studies from Riyadh [12,31] had findings and implications similar to these studies. In a study conducted in Al-Fayoum, Egypt, the majority of participants who rejected screening believed that it interfered with God's will [1].

In the present study, the prevalence of at-risk marriages where hereditary diseases were identified was 6.7%. This finding agrees with that of Al-Hamdan et al. from 2007 [35], in which a similar rate (7.75%) was observed among 488,315 individuals screened in the first two years of the PMSGC. In Al-Hassa, Saudi Arabia, the prevalence of the B-thalassemia trait with high Hb-A2 and microcytic hypochromic anemia was determined by premarital screening to be 3.4% [36].

A recent retrospective study conducted in KSA (74,662 participants) revealed that the prevalence

of infection among couples in the PMSGC program was 1.67% (0.03%, 1.31% and 0.33% for HIV, HBV, and HCV, respectively) [14]. These results coincide with results of the present study, as these infections were diagnosed by the program in 1.97% of the couples. El-Hazmi [37] found prevalence rates of 1.4% for hepatitis B surface antigen (HBsAg) and 0.2% for anti-HCV among Saudi blood donors in Riyadh.

In the present study, the majority of participants agreed that in the case of the discovery of the presence or carrier status of an inherited disease, the marriage decision must be left to the discretion of the couple. This finding agrees with results of other studies [2,34,38]. However, approximately two-thirds of the participants (65.2%) agreed that couples contemplating a marriage with a high risk of genetic disease should change their marriage plans. This finding agrees with the results of Al Sulaiman et al. [4], who reported that more than 60% of all participants from Riyadh were in favor of canceling at-risk marriages. Approximately two-thirds of the students (67.1%) in our previous study of female university students agreed with the prevention of high-risk marriages [2].

Al-Hamdan et al. [35] found that approximately 90% of high-risk couples still married, despite knowing the risk of having a child with a genetic disease, whereas only 10% cancelled their marriage plans. They concluded at that time that the program's objective of decreasing the number of high-risk marriages was unsuccessful. Another study of a six-year outcome of the national Saudi PMSGC program for sickle cell disease and β-thalassemia reported that, of the 8925 couples who had been issued incompatibility certificates between 2004 and 2009, only 26.5% cancelled their marriage plans. The frequency of voluntary cancellation of marriage plans among the at-risk couples followed in the study showed more than a 5-fold increase between 2004 and 2009 [16]. In the present study, 41.2% of couples planning an at-risk marriage cancelled their marriage plans. This finding may indicate an improvement in the program outcome. However, the finding that 60% of planned at-risk marriages still take place indicates that a great cultural challenge remains to be addressed by the counselors. More efforts are required in providing counseling for couples contemplating at-risk marriages. Counseling is especially necessary because our religion and culture do not condone therapeutic abortions. Therefore, it is much better to prevent a high-risk marriage by providing appropriate counseling services.

Regarding the satisfaction of those who participated in the program, the majority (80.0%) gave an excellent or very good score for the level of

confidentiality of the program. More than 60% gave an excellent or very good score for the location of the program inside the hospital and for the place of sample taking, and 50% gave an excellent or very good score regarding the waiting areas inside the hospitals. In Bahrain, 70% of premarital counseling clients reported that the service was generally excellent [23].

The goal of the marriage education movement is to give contemporary individuals and couples the knowledge, skills, and virtues needed to build and sustain healthy marriages [39]. It is important to educate the population about the potential benefits of counseling, as well as the ethical dilemmas involved, so that members of the general public can make the right decisions for themselves and their families [40]. Many young women and men enter into marriage with insufficient information on sexuality, reproduction, and family planning [1,41]. Genetic counseling is the process by which individuals or families obtain information about a genetic condition that may affect them, so that they can make appropriate decisions about marriage, reproduction and health management [5,42]. Studies of patient perspectives regarding premarital examinations have revealed a need for physicians to offer counseling for various health problems before the patient asks, so they can decline unwanted help rather than bring up sensitive issues [5,42]. It was reported in Morocco that premarital counseling provided to program participants is generally not standardized and is largely dictated by physicians' priorities, capabilities, and capacity to provide counseling [44]. In the present study, counseling before screening was provided for only 11.7% of the individuals tested. In addition, only approximately 40% of the participants gave excellent or very good scores for the counseling. In an older study in 1995, Shiloh et al. [45], who studied attitudes, beliefs and decisions among counseled, non-counseled and unrelated couples in Israel, reported that counselees' appraisals of genetic counseling revealed unfulfilled expectations to obtain more definitive answers as well as mixed reactions to the nondirective approach applied by the counselors. These results disagree with results obtained from the Bahrain study, which reported that 97% of counseling clients did not face any problems during consultation with the genetics department and that the level of satisfaction with the service provided at the genetic counseling department was higher than that at health centers. This finding was attributed to the amount of knowledge provided to the couples by the specialists and to the adequate time allowed for each couple [23]. An Australian study evaluated client expectations, psychological adjustment and satisfaction with genetic counseling and found that the majority of clients attending genetic counseling reported that they were very satisfied [46]. Al-Gazali [30] assessed the level of understanding of genetic advice given in the genetic clinic in the UAE and concluded that for effective genetic counseling, it is advisable to educate the population; Al-Gazali also recommended the introduction of carrier screening and preconception diagnosis in affected families.

Addressing young couples' needs regarding information on reproductive health remains a critical area for expanded health education interventions [1,44,47]. Premarital counseling provides an opportunity to intervene according to the identified risks [48]. In the present study, the majority of participants recommended adding counseling about building a healthy family as well as reproduction and fertility issues. A high percentage of responders also recommended adding more genetic counseling, which agrees with results of Al Sulaiman et al. [49], who conducted a post-marital follow-up survey on high-risk patients who participated in a premarital screening program and found that the concept of genetic counseling was met with approval by most participants from Riyadh. One successful approach is 'solution-focused' premarital counseling. Murray and Murray [50] discussed how this approach focuses on a couple's resources and helps them to develop a shared vision for the marriage.

Strengths and limitations of the study

To our knowledge, the current study is the first large-scale community-based study conducted in Jeddah on the knowledge, attitude, and satisfaction of the general population regarding the PMSGC program. Awareness of the general population regarding the program is an important part of the effort. Client satisfaction is becoming an important public health issue in evaluating medical care, and this study represent the first time that this important issue of the PMSGC program has been studied in Jeddah. The clients' recommendations for program improvement were also studied. Educational materials regarding the program were distributed to participants and the selected hospitals, and this effort could help to increase knowledge regarding the program. The literature review provides a comprehensive summary of premarital screening programs. However, the satisfaction of the clients should be studied in more detail in a separate study.

Conclusion

This study highlights that knowledge of the general population regarding the PMSGC program was limited. However, there was generally a positive attitude towards the importance of the program. This positive attitude provides strength for the success of the program. These results indicate that there is a need for more information and education regarding the PMSGC program. Not all individuals participated in the laboratory diagnosis process, which requires further attention. Approximately 40% of couples contemplating at-risk marriages cancelled their marriage plans, whereas 60% continued with the marriages. This finding indicates that the program has been successful in preventing some at risk marriages, but large cultural challenges remain to be addressed by the counselors. The beneficiaries of counseling were satisfied with some parts of the program. However, some areas need further improvement. More attention needs to be paid to history taking, physical examination and laboratory investigations. Counseling requires marked improvement, including and the addition of some important topics to prevent at-risk marriages.

Recommendation

Public education regarding the PMSGC program is needed. Government, community and religious leaders, organizations and universities, and health personnel should cooperate in providing this education. An educational campaign needs to be implemented for the general population in high schools and universities. Dissemination of information regarding the PMSGC, through formal and informal education and media publicity, is recommended. The educational campaigns should provide information on the PMSGC, its importance, the disorders tested for, and the implications of the screening. Professionals in the fields of genetics, health education and the media can work together to increase awareness in the adult population. Television documentaries on specific diseases or videos related to the program need to be implemented. Repeated audits with quality assurance guidelines are needed in the hospitals that provide this important service. In addition, the PMSGC could be extended to include a broader spectrum of health and genetic disorder issues. Implementing counseling on genetic, chronic and psychiatric problems, building healthy families, reproduction issues and fertility is recommended. To increase the success of counseling in preventing at-risk marriages, the counseling needs to be provided by trained professionals and prior to each genetic test. It is important to add mandated genetic counseling to the current program. Knowledge could also be provided to the couples by trained specialists with adequate time for effective counseling allowed for each couple. Group counseling sessions could also be added to the program. Solution-focused premarital counseling is recommended. Certified training courses on genetic counseling methods specific for those working in the program are recommended.

There is a need for greater research on the goals of counseling and how they relate to client outcomes. Because client satisfaction is becoming an important issue in evaluating medical care, we recommend further research on the assessment of all aspects of client satisfaction.

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