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REVIEW

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# Premarital screening for genetic blood disorders — an integrated review on the knowledge and attitudes of Middle Eastern university students

Jansirani Natarajan and Mickael Antoine Joseph\*

## Abstract

**Background:** Genetic blood disorders are prevalent in the Middle Eastern countries causing physical, mental, and economic handicap. Premarital screening (PMS) is actively implemented to reduce the burgeoning load of these disorders. Literature shows a low response rate for PMS in this region. This integrated review aims to identify the knowledge and attitude of university students on PMS, as they are at the verge of entering into marriage relationships.

**Main body of the abstract:** We systematically reviewed the electronic databases like MEDLINE, PubMed, CINAHL, and Scopus. Studies reporting about the knowledge and attitudes of Middle Eastern university students between 2010 and 2020 are included in the review. Twelve cross-sectional descriptive studies conducted in six countries met the inclusion criteria. Majority of the studies reported good level of knowledge on PMS among the university students, whereas not all of them agreed to undergo PMS due to various religious and cultural beliefs.

**Short conclusion:** We recommend massive health education programs at the higher secondary and university levels to create better awareness on PMS. To improve the attitude towards PMS, life cycle approach and support of the religious leaders could be sought.

**Keywords:** Knowledge, Attitude, University students, Premarital screening, Genetic screening, Middle East

## Background

Autosomal recessive disorders like sickle cell disease (SCD), beta thalassemia, and other hemoglobinopathies are considered to be the most common genetic blood disorders in the world as well as in the Middle Eastern countries [1]. The incidence of children born with sickle cell disease is expected to increase globally by 30% by 2050 [2]. Available evidence suggests that congenital and genetic disorders are responsible for a large portion of mortality and handicap leading to poor quality of life of younger adults in this region. The incidence of hereditary blood disorders is intertwined with social, cultural,

and religious practices in Middle Eastern countries [3], which makes the management of the disorders more complicated. This creates a huge burden on the individuals and families as well as on the health care systems in these countries.

The Centre for Arab Genomic Studies based in United Arab Emirates has released a list of 906 genetic pathologies, which are endemic to Arab states. Some of the commonly prevalent genetic disorders are SCD, thalassemia, Tourette's syndrome, Wilson's disease, Charcot-Marie-Tooth disease, mitochondrial encephalomyopathies, and Niemann-Pick disease [4]. Few studies have estimated that the highest prevalence rates of G6PD deficiency is ranging from 1% among Egyptians to 11.55% among Iranians [5]. On the other hand, the prevalence

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of thalassemia among adult patients in the Middle East is reported to be 43.3% [6]. Regarding SCD, sickle cell hemoglobin (Hbs) is commonly seen in all Middle Eastern countries ranging from approximately 0.04 to 2.1% [7].

Premarital screening (PMS) and genetic counseling (GC) programs can identify and modify the health risk factors known to impact genetic disorders. PMS could be the most important way to prevent the abovementioned genetic blood disorders and many medical, psychological, and social marital problems [8]. PMS and GC programs are declared mandatory in eight Middle Eastern countries. They are free of cost to reduce the at-risk marriages and the prevalence of genetic disorders [9].

The worldwide epidemiologic burden of inherited erythrocyte disorders remains high according to the recent worldwide epidemiological report [10]. In the Arab region, a greater proportion of people (25–60%) prefer consanguineous marriages [11]. Abortion is considered illegal in a majority of Arab countries, which necessitates the efforts to prevent the marriage of the disease carrier couples [12]. PMS can help the couple prepare themselves for marriage with proper premarital counseling giving them a better chance for a stable and satisfying marriage. According to the National Society of Genetic Counselors, “Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease” [13]. Though the PMS program has been widely implemented in these countries for approximately two decades, the success of the program lies in the awareness and attitudes towards PMS among the younger generation. Though Saudi Arabia has mandated the PMS program before marriage, 48% of the genetically incompatible couple have gone ahead with their marriage decision [14]. The population in Arab countries is characterized by large families, high maternal and paternal ages, and high levels of inbreeding [15]. A review conducted on the effectiveness of PMS and GC programs for beta thalassemia in Middle Eastern countries has revealed that a cancellation rate of 65% of at-risk marriage could not be achieved except in Iran, Turkey, and Iraq [9]. As an effort to identify the reason for the low response to this PMS program, we decided to review the studies conducted in this region on the aspects of knowledge and attitudes on PMS among the university students. Understanding the knowledge and attitude of this age group is crucial in developing strategies to create awareness and build positive attitudes towards PMS. University students are the target group as they are on the verge of making decisions about marriage.

## Main text

### Aims and methods

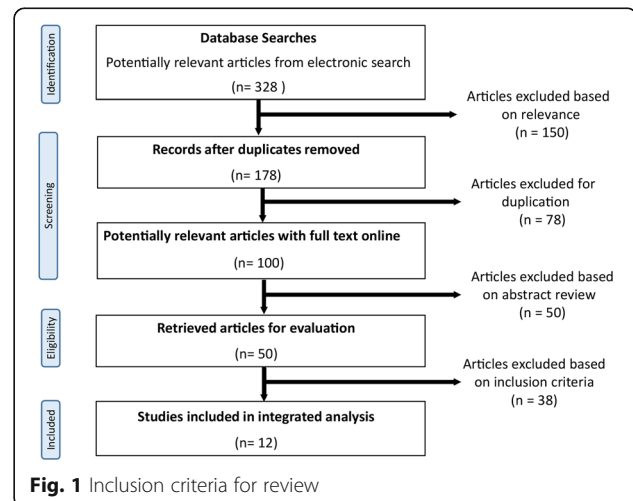
Whittemore and Knalf’s integrated review process with five steps was used. The steps involved are identification of the problem to be studied, thorough literature search, appraisal of the quality of data, examination of the data, and presentation of conclusions [16]. A systematic literature search was conducted to identify the studies exploring the knowledge and attitudes on PMS among university students. The search included databases like MEDLINE, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Scopus. Key words including knowledge, attitude, premarital screening, university students, and genetic blood disorders were used in the search. Inclusion criteria included quantitative studies that (a) assessed the knowledge of university students on PMS, (b) explored the attitude of university students towards PMS, (c) were published in peer-reviewed articles in English, (d) were published between 2010 and 2020, and (e) were from Middle Eastern countries. The final criterion was included due to international variation in culture and health policies. The search yielded 328 articles, and twelve of them met the inclusion criteria for review as depicted in Fig. 1.

### Measures

Each article was evaluated based on the revised criteria of the American Association of Critical-Care Nurses (AACN), which has six rating levels [17, 18]. All included articles in our review were quantitative descriptive studies scoring “C” for level of evidence.

### Analysis of findings

All the selected papers were reviewed carefully by two authors (JRN and MAJ) independently and finalized based on the inclusion criteria. JRN and MAJ extracted data from the literature, and discrepancies were resolved



by discussion. Data was analyzed and synthesized using the matrix table suggested by [19], and the details of the studies (author, year of publication, country, purpose, methods, and findings) with level of evidence are provided in Table 1.

## Results

A total of twelve studies conducted in six countries, including Kuwait, 1; Yemen, 1; Jordan, 1; Oman, 1; Egypt, 1; and KSA, 7, met the inclusion criteria for this review. All of the 12 studies were cross-sectional descriptive studies and have used researcher-developed self-reported questionnaires, as there are no valid standardized questionnaires available to assess the knowledge and attitude of PMS. The majority of the studies are conducted in the Middle Eastern countries where these hereditary disorders are commonly prevalent. The findings are discussed as narrative analysis under knowledge and attitudes on premarital screening of the university students in Table 2.

## Discussion

The study has reviewed the knowledge and attitudes of Middle Eastern country university students on premarital screening. Regarding knowledge of the university students about PMS, eight of the studies reported good and adequate knowledge [14, 20–26]. One study reported fair level of knowledge [27], and two studies reported low level of knowledge [28–30]. One study even reported that female students had a good level of knowledge whereas male students had insufficient knowledge. Findings cannot be conclusive about the knowledge levels of the university students, as none of the studies used valid and reliable standardized questionnaires to assess the knowledge level on PMS. Even the educated Arab population has an extremely low level of genetic literacy, which poses a hindrance for genetic counseling [31]. Many Middle Eastern countries have realized the importance of PMS as a cost-effective measure to reduce the economic burden on society. Middle Eastern countries in general have good existing programs in reproductive and other primary health services where community genetic services could easily be integrated [32]. Massive health education starting from the higher secondary curriculum advancing to the college curriculum can increase knowledge levels. Education and examinations could be targeted towards unmarried male university students, which can facilitate them in making informed choices about unmarried females and consanguineous marriages.

Ten studies explored university students' attitudes towards PMS while two studies did not. Though the majority of the students from the reviewed studies were reported to have good and adequate knowledge, it is

discouraging to note that not all of them agreed to undergo PMS due to various religious and cultural beliefs. Three of the reviewed studies reported negative or fair attitudes of university students related to PMS [21, 25, 27]. Participants of seven reviewed studies had positive attitudes towards PMS, and even held beliefs about making policies about it stronger [14, 20, 22–24, 29, 30]. One third of the participants in a study reported they would proceed with their marriage even if both partners tested positive for thalassemia, and they were unwilling to undergo PMS as it would affect their future marriage opportunities [22]. A higher level of female literacy, fear of hereditary blood disorders, urbanization, and better economic status of the families have caused a decrease in consanguineous marriages in Arab countries in recent years [33]. In a study conducted in Oman on South Batinah Governorate's adults, unwillingness to undergo PMS was associated with the following characteristics: female gender, lower education levels, younger age groups, and single populations [32]. Life cycle approaches are believed to attract a better holistic public response as a remedy to the barriers to PMS program success in the Middle East [9]. India and Canada successfully incorporated PMS into school health packages [34, 35]. Middle Eastern countries could follow this model of PMS incorporation at the higher secondary education level or make PMS mandatory for admission to the universities. Emphasis on structured health education on hereditary diseases and consanguineous marriages are needed in higher education levels.

Some participants believed that their fate is determined by God and therefore willing to accept the risk of bearing a sick child without undergoing PMS. This is similar to a study done in Oman among higher secondary school students who reported that they would accept the birth of children with genetic blood disorders as God's will [36]. Though Islam promotes healthy marriage and the role of counseling, 90% of the couples detected as carriers in KSA proceeded with their marriages. A Nigerian study conducted among religious leaders had reported good knowledge and positive attitudes towards PMS for sickle cell disease [37], and a similar study can be conducted in Middle Eastern countries to understand the viewpoints of religious leaders. Individuals with incompatible genes expressed a fear of stigma associated with the carrier status. They frequently face familial pressures with consanguineous marriages. These problems could be reduced with community health education with the support of religious authorities [38]. There is a need for intensification of health education campaigns among youth, and religious leaders could be involved to clarify and correct misconceptions about PMS [22].

**Table 1** Summary of the articles with author, country, year, participants, methods, instruments, study purpose, and main findings

SL. NO.	Author, year, and country	Participants	Methods	Instrument	Study purpose	Main findings	Major aspects	Level of evidence
1	Ibrahim et al., 2011, Jeddah, KSA	1563 students from all faculties of KAU	Cross-sectional study, multistage stratified random sample	Researcher-developed questionnaire	The present study was conducted to assess <b>knowledge and attitudes of unmarried female students in King Abdul-Aziz University (KAU)</b> towards premarital screening (PMS) programs.	Students' knowledge about the program was generally low (80 % had poor scores). Regarding attitude, almost all students (99.0%) agreed on the importance of PMS.	K, A	C
2	Al Kindi et al., 2012, Muscat, Oman	590 unmarried Omani students of both genders	Cross-sectional study	Researcher-developed questionnaire	The aim of this study was to explore the <b>knowledge and attitudes of Sultan Qaboos University students</b> towards premarital screening programs.	Most of the participants (79%) were aware of the availability of premarital screening program in Oman. The vast majority of participants (92%) thought it was important to carry out premarital screening and agreed to do it.	K, A	C
3	Ebtisam and Khalil, 2014, KSA	120 King Saud University female students	Cross-sectional study, random sample	Researcher-developed self-reported questionnaire	This study aimed at assessing the <b>knowledge, beliefs, and behavior</b> of KSU female students in Riyadh, regarding the national premarital screening program (PMS).	Most of the King Saud University's female students had fair knowledge and fair behavior towards premarital screening.	K, A	C
4	Farahat et al., 2014, Egypt	345 students from Menoufia University faculties in Shebin Elkom City	Cross-sectional study	Researcher-developed self-reported questionnaire	The aim of the study was to assess the <b>knowledge and attitudes of Menoufia University students</b> towards premarital care (PMC).	The results of this study clearly showed that 75.1% of the participants were aware of the presence of PMC services, and the participants' attitudes towards PMC were favorable (53.9%).	K, A	C
5	Al Khaldi et al., 2016, Amman, Jordan	542 students from four universities (two public and two private universities) located in North Jordan	Cross-sectional study	Researcher-developed self-reported questionnaire	This aimed to assess the <b>knowledge and attitudes of university students</b> in North Jordan towards the mandatory National Premarital Thalassemia Screening Program implemented in 2004.	Respondents had adequate knowledge of and positive attitudes towards the premarital screening program.	K, A	C
6	Al Nood et al., 2016, Yemen	516 students of the Faculty of Medicine and Health Sciences, Sana'a University	Cross-sectional study	Researcher-developed self-reported questionnaire	To assess the <b>knowledge and attitudes of Sana University medical students</b> towards premarital screening (PMS).	Most of the respondents (92%) knew that PMS reduces hereditary and sexually transmitted diseases, believed that it is important to carry out, and agreed to do it. Making PMS mandatory and legal prevention of marriage in case of positive results were accepted by 82% and 62% of the respondents, respectively.	K, A	C
7	Alghamadi et al., 2016, KSA	320 students of King Saud University	Cross-sectional study multistage sampling method	Researcher-developed self-reported questionnaire	To assess <b>knowledge</b> of premarital screening and their relation to the socio-demographic background of male university students in Riyadh City.	Students of higher academic level showed a significantly higher level of knowledge. Knowledge of male university students about the PMS program was insufficient in some areas.	K	C
8	Enezi and	809 students of	Cross-	Researcher-	The aim of the study was to	92% were aware of	K, A	C

**Table 1** Summary of the articles with author, country, year, participants, methods, instruments, study purpose, and main findings (Continued)

SL. NO.	Author, year, and country	Participants	Methods	Instrument	Study purpose	Main findings	Major aspects	Level of evidence
	Mitra, 2017, Kuwait	Kuwait University	sectional study	developed self-reported questionnaire	determine the level of <b>knowledge, attitudes and satisfaction among university students</b> regarding premarital screening programs.	premarital screening, and 85% showed positive attitudes towards PMS.		
9	Melaiabri et al., 2017, KSA	380 students of Taif University	Cross-sectional study	Researcher-developed self-reported questionnaire	To investigate the <b>knowledge, attitudes, and practices</b> of Taif University students towards the national PMS program.	Most participants (97.4%) were aware of the PMS program and (82.9%) were willing to change their decision to marry in the case of receiving incompatible results. Moreover, the majority of the participants (91.8%) demanded the implementation of a law that prohibits incompatible marriages.	K, A	C
10	Moussa et al., 2018, KSA	640 students of seven colleges of Hail University	Cross-sectional study	Researcher-developed self-reported questionnaire	To detect the degree of <b>knowledge and attitudes of the female university students</b> of Hail University towards the national mandatory premarital screening program (NPMS).	Majority of the participants were aware of the availability of the program (75.5%) and (76.2 %) knew that it was obligatory to complete it before marriage.	K	C
11	Qahtani et al., 2019, KSA	541 students of King Khalid university, Nurjan	Cross-sectional study Two stage stratified cluster sampling technique	A researcher-developed self-administered questionnaire	This study aimed to assess university students' <b>knowledge, attitudes, and practice</b> of premarital counseling (PMC) in King Khalid University.	Nearly three out of four students had a good awareness level regarding PMC. Most of the students had a positive attitude towards PMS and their readiness to adopt the counseling before marriage.	K, A	C
12	Alhowiti, et al., 2019, KSA	437 students of Tabuk University, KSA	Cross-sectional study	A researcher-developed self-administered questionnaire	To assess the level of <b>knowledge and the attitudes</b> among Saudi Tabuk University students regarding premarital screening programs.	Slightly less than half of the students (48.3%) had sufficient knowledge regarding premarital screening. Almost two thirds of the students (69.8%) had a positive attitude towards premarital screening.	K, A	C

A attitude, K knowledge

**Table 2** Themes from the review on PMS

Themes	Findings
Knowledge about PMS (12 studies)	Eight studies have reported good and adequate level of knowledge [14, 20–26] One study has reported fair level of knowledge [27] Two studies have reported low level of knowledge [28–30]
Attitude towards PMS (10 studies)	Three studies have reported negative of fair attitude towards PMS [21, 25, 27] Seven studies have reported positive attitudes towards PMS [14, 20, 22–24, 29, 30]
PMS premarital screening	

### Limitations

All of the 12 studies reviewed relied upon the researcher-developed self-reported questionnaires. The questionnaires were developed and reviewed by experts in most of the cases. Future studies could observe the practice of PMS tests among university students along with their knowledge and attitudes. Only studies published in English were included, which might have resulted in the omission of valuable studies in other languages.

### Conclusion

Various factors have contributed to the inadequate information on the extent to which these genetic blood disorders in the Middle Eastern region pose health and economic burdens; this exposes the importance of sustainable research activities in this area. The findings of this review have opened up new areas of health education needs among the yet-to-be-married couples (university students) regarding genetic blood disorders. Health education strategies involving family members, law-makers, and religious leaders could enhance the younger Middle Eastern population's compliance to PMS. Mass outreach programs through various social media platforms is the need of the hour to create awareness among the younger generation and to alleviate the burden of these genetic blood disorders on the individuals and society in the Middle East. A very exciting phase for reducing the genetic burden in the human population in this region of the world has begun, and it is hoped that this mission will succeed.

### Abbreviations

CINAHL: Cumulative Index to Nursing and Allied Health Literature; SCD: Sickle cell disease; GS: Genetic counseling; G6PD: Glucose-6-phosphate dehydrogenase; PMS: Premarital screening

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### Authors' contributions

JRN conceived and designed the study. JRN and MAJ performed the database search. JRN wrote the manuscript, drafted the studies in table form, and discussed the results. MAJ revised the literature search and reviewed and critically revised the review before submission for spelling and grammar. Both authors have read and approved the final manuscript.

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The authors declare that they have no competing interest.

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