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Review of implementation, barriers and challenges of premarital care program in the middle east countries

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ABSTRACT

Background: Many governments especially in the Middle East countries have been promoting premarital medical examinations since the first half of the 20th century. However, the prevalence of inherited disorders and consanguinity remains high **Objectives:** To explore the process of implementation of premarital care programs and highlight the possible barriers and challenges to program effectiveness in the Middle East countries. Recommendations to add momentum to current health care efforts were also outlined. Methods: Relevant works of literature were retrieved from different journals and web pages. The electronic databases were searched using the key. The review included both Arabic and English literature related to the premarital care program. Results: A review of the effectiveness of premarital screening programs in the Middle East countries indicated that the program did not achieve the stated objectives in discouraging at-risk marriages and lowering genetic disease prevalence except in some countries providing prenatal detection and therapeutic abortion. Scarcity of resources, lack of trained health professionals, lax enforcement of PMS laws, and high prevalence of consanguineous marriage were the major barriers to the successful implementation of premarital screening programs in the Middle East. Knowledge about inherited genetic disorders and the outcome of the diseases is low. Screening timing, access to prenatal detection and abortion, religious beliefs, also have a role in the success of the program. Conclusions: Efforts should be directed to policy advocacy and public education strategies. A life cycle approach to prevention, incorporation of school screening, awareness campaigns, reconsideration of therapeutic abortion are likely to improve the effectiveness of such programs in the Middle Eastern

Keywords: Premarital screening, Haemoglobinopathies, Middle east, Barriers

INTRODUCTION

Premarital Care (PMC) is an emerging concept with reproductive health to help couples to prepare for marriage. The program includes premarital health counseling, medical examination, investigations, and vaccination. It can identify and modify behavioral, medical, and other health risk factors known to impact pregnancy outcomes through prevention and management [1]. Hence, it is recognized as a step towards saving society and allowing people to enjoy life.

Since 1950, Arab countries have made progress in some health-related aspects such as infant mortality, life expectancy, and access to health care [2]. However, the Global Report on Birth Defects in 2006 stated that worldwide, about 7.9 million births occur annually with serious birth defects and 94% of these births occur in the middle and low-income countries [3]. Inherited hemoglobin disorders like thalassemia, and sickle-cell disease still constituting a major public health problem in certain parts of the world including the Middle East. It was estimated that 240 million people are heterozygous and more than 2, 00,000 lethally affected homozygotes are born annually [4]. Demographic factors and population structure as the large family size, late maternal age may contribute to the high prevalence of hemoglobinopathies. Moreover, studies demonstrated stronger evidence of the association of viral hepatitis and HIV with marital contact [5]. Viral hepatitis is highly prevalent in Middle Eastern countries than in Europe and the USA. It was estimated that 2-5 percent of Middle East populations are chronically infected with hepatitis B [6]. The prevalence of Hepatitis C in Egypt had reached 15 percent, the highest in the world [7]. Viral hepatitis is the 5th leading cause of death in North Africa and the Middle East due to associated complications mostly Hepatocellular Carcinoma and cir-

rhosis [8]. Many of these infections could have been prevented through vaccination or treatment services. HIV/AIDS is transmitted from the mother to her child during pregnancy, delivery, and breast-feeding and sexually transmitted disease as well. Although its prevalence is low (less than 0.2%) in the Middle East and North Africa (MENA), the fear of stigma makes people reluctant to seek testing for this disease [9]. Lack of reality seems to have fuelled this situation and the majority of HIV positive patients do not know they have the virus. On the contrary, antiretroviral therapy decreases greatly the risk of HIV transmission between partners and from mother to her child as well [10]. Without a shadow of a doubt, there is a necessity to introduce sexual and reproductive health education to newly engaged couples before they embark on the journey of marriage. Sociological studies indicated that consanguineous marriages increase the couple's stability, strengthen family ties, and solidarity [11]. On the other hand, it increases the risk of occurrence of recessive genetic disorders. Consanguineous marriage predates Islam, and the Quran does not encourage this practice though high prevalence (25-60)% of consanguineous marriages, particularly among first cousins in the MENA region [12]. Furthermore, the rate of divorce in new families has been reached 34.5% due to fertility problems that could be identified before marriage [13].

Prevention thus appears to be significantly more cost-effective while reducing the psychosocial implications of these chronic diseases. Premarital screening is recognized as one of the most effective strategies for reducing the burden of hereditary diseases, STD's, birth defects, divorce rates [14]. Therefore, the Ministry of Health in Arab countries has been made premarital screening mandatory before issuing a marriage certificate. The couples need to provide a certificate stamped by the Department of State of premarital screening to the court to proceed with the wedding [15]. Meanwhile, the benefits, ethical consequences of such programs have been much debated. In the year 2000, the World Health Organization reported that many governments especially in the Arabic-speaking world have been promoting premarital medical examinations since the first half of the 20th century. Yet, the little effect had been detected on hereditary diseases and consanguinity [16].

The objectives of the current review was to explore the process of implementation of premarital care program in the Middle East countries, to highlight the possible barriers and challenges to program effectiveness and to outline recommendations to add momentum to current health care efforts.

MATERIALS AND METHODS

Relevant literature was retrieved from different journals and web pages. The Science Direct, Embase, Scopus, PubMed, and Web of Science (ISI) databases were searched using keywords. The search terms of premarital testing, counseling, care, or screening, preconception care, thalassemia and sickle cell anemia testing, hepatitis testing were used. Relevant articles were identified, then screened and selected based on title and abstract from the year 1997 up to 2019. Google search was employed to collect relevant information about premarital screening programs in different countries. A review of relevant Arabic literature, booklets, and newspapers was also carried out.

RESULTS AND DISCUSSION

The high prevalence of genetic disorders specifically thalassemia was a driving force in the Mediterranean and Middle Eastern regions to implement a mandatory Premarital Screening (PMS) program. It began first in the Mediterranean region in Cyprus, Greece, and Italy in the 1970s [17,18]. The program was successful in achieving its objectives through the reduction of at-risk marriages, the provision of free Prenatal Detection (PND), and therapeutic abortion, in addition to the provision of effective health education and counseling [19]. Henceforward, this success encouraged middle east countries to implement the PMS program but it was confronted with some barriers and challenges which hinder successful implementation in several countries in the region.

Turkey

The PMS program was mandated in 1995/1998. The availability of PND and therapeutic abortion were identified as crucial factors for program success in Turkey (Table 1) [20,21]. As a result, the cancellation of at-risk marriage in 13% of couples and reduction of at-risk births was 90% [22]. Barriers identified to PND usage were a lack of social security financing, insufficient knowledge of hereditary diseases [23].

Islamic Republic of Iran

The program became mandatory in 1997. Abortion was legal only for saving the mother's life (Table 1) but in 2003, the Islamic clerics declared a fatwa permitting the abortion of homozygote β -thalassemia fetus up to 16 weeks of

gestational age. Consequently, PND initiated reforms were added in abortion-related laws [18]. The uptake of PND among at-risk couples increased from 2.8% in 2003 to 85% in 2010 [24]. Eighty percent of β-thalassemia births were terminated in 2005-2010. Hence, cancellations of at-risk marriage decreased from 50.4% in 1997 to 9.4% in 2010 [22]. This success placed the Iranian PMS program as a benchmark for other national programs.

Palestinian Territories

The PMS program was mandated in 2000 but there was limited awareness on prenatal diagnosis in Palestine, and there are no laws to guide parents toward making decisions regarding an affected fetus [25]. β -thalassemia major is not considered an indication for legal abortion in Palestine (Table 1). Cancelation of at-risk marriage was zero in 2003 and reached 73.7% in May 2005. As a result, a reduction in the number of births with beta-thalassemia major was noticed [26].

Kingdom of Bahrain

Law number 11 in the year 2004 stipulated mandatory PMS program and testing of couples for thalassemia and sickle cell anemia. The rate of at-risk marriage cancellation was 58.0%, and the incidence of sickle cell disease declined by 50% in neonates [22]. Moreover, increased awareness of the negative effects of consanguineous marriages leads to a decline in the rate of cousin marriages from 45.5% to 39.4%. Nevertheless, some of the negative implications were perceived as the labeling of carrier females, which limit or delay the chance of marriage for such females [27]. The provision of PND and abortion was useful to avoid the risk of 25% of an affected child in a carrier partner and overall program success.

Jordan

The PMS program was mandated in 2004 for thalassemia [17, 22], with PND but therapeutic abortion was only to preserve woman's health not fetal impairment [20,21] (Table 1). Marriage was canceled in more than 40% of the female carrier but some barriers were identified like issuing of fabricated negative test results by unregulated laboratories, misuse of private-sector physicians of abortion rules, general practitioners are not trained in providing genetic counseling, and family fear of the stigma of carrier status, particularly for the females [28].

Saudi Arabia

The PMS program was mandated in 2004 for Thalassemia and sickle cell disease and HIV, HVB, and HCV in 2008 [17]. Major barriers identified by Alswaidi and O'Brien, were refusal of cancelation of at-risk marriage (43%), fear of social stigma (21%), familial commitment/pressures (17%), and religious considerations (14%) [17]. Alhamdan et al., agreed that the late timing of screening is a major barrier to program success [29]. More than 50% who proceeded to marry claimed that wedding arrangements are already made with difficult cancellation. Lack of education or awareness of hereditary diseases was an additional barrier [29]. Although Islamic teaching promotes a healthy marriage and family, Muslim leaders teach people acceptance of fate and interpret it as accepting the risk of a sick child. Hence, counselors were unable to provide adequate information to at-risk couples [30]. Cousins, et al., concluded that the failure of the Saudi program was primarily due to illegal termination of the affected pregnancies [18]. Indeed, Shari'a governs all of Saudi Arabia's laws and allows abortion in case of severe risk to the woman's life or health (Table1) [20,21].

Iraqi Kurdistan

The PMS program was mandated in 2008 for thalassemia in Kurdistan, Northern Iraq, with PND and therapeutic abortion available [22]. A 5-year evaluation study since initiation of the program found that 98.1% of couples were identified and counseled as high-risk couples however they proceeded with their marriage plans. Prenatal detection was carried out in 76% of them followed by selective termination in 10 of the 11 pregnancies with an affected fetus. This study indicated a 65% reduction in the number of affected births was reported over the 5 years [31]. Al Allawi et al., reported that financial support would increase the decision of PND by high-risk couples in addition to improving the public health education and counseling programs [32].

Qatar

The premarital screening and genetic counselling program in Qatar was established by law in 2006 and implemented from December 2009. In April 2012, a decision was issued that all residents people to do this medical examination in health institutions [33]. Qatar changed its law in 1983 to allow abortion in case of harm to the woman's health or fetal

impairment (Table 1) [21]. However, lack of awareness about genetic diseases was the main barrier to the success of the program. Supreme Council of Health of Qatar stated that they do not prevent high-risk marriages and they only try to educate the couples about their possibility of having a child affected by the disease, possible preventive measures, and available treatments [34].

Table 1 Reasons for legal abortion in Middle Eastern countries with mandatory PMS programs

Countries	To save the mothers' life	To preserve the mother's physical health	To preserve the mother's mental health	Rape or incest cases	Fetal impairment
Liberal laws					
Cyprus	+	+	+	+	+
Turkey	+	+	+	+	+
Bahrain	+	+	+	+	+
Somewhat restrictive					
Iraq	+	-	-	-	+
Iran	+	-	-	-	+
Palestine	+	+	+	+	+
Jordon	+	+	+	-	+
Qatar	+	+	-	-	+
Kuwait	+	+	+	-	+
Saudi Arabia	+	+	+	-	-
Very restrictive					
Egypt	+	-	-	-	-
United Arab Emirates	+	+	+	-	-
Sudan	+	-	-	+	-
Yemen	+	-	-	-	-
Oman	+	-	-	-	-
Syria and Lebanon	+	-	-	-	-

United Arab Emirates

Premarital screening services were initiated with the Marriage Fund in 1992. Since 2009, premarital screening was mandated for thalassemia and sickle cell disease for all couples planning to get married, not only for those applying for the marriage fund [35]. The estimated prevalence of carriers among Emirati people was high though, the option of abortion is either unavailable or unacceptable to families because of social and/or religious reasons [20,36]. The screening tests were free for Emiratis, but have to be paid for by non-citizen residents. Insurance does not cover premarital testing. The program was successful in screening eligible individuals, identifying at-risk couples, and providing them with health education. However, seventy percent of the unmatched couples in the emirate of Ras Al Khaimah were going through consanguineous marriages and complete their marriage plan. Indeed, 100% of the unmatched couples get married irrespective of the risk of having a child with hemoglobinopathy [37].

Kuwait

The Premarital Law No. 31 was mandated in 2008 to protect against diseases that can be transmitted by marriage [38]. The program was targeting only Kuwaitis. The estimated prevalence of genetic blood disorders was high, ranging from (10-25)%. A higher frequency of genetic diseases was found in the first-cousin couples' offspring [39]. In 1981, Kuwait became the first Gulf States to allow abortion for physical and mental health indications and cases of fetal impairment [21] (Table 1).

Oman

A premarital carrier screening service has been in place since 1999 and was available on an optional free-of-charge basis at all governmental healthcare institutions. Consanguineous marriages are common in Oman, accounting for 58% of all marriages. Of these consanguineous marriages, 75% are first-cousin marriages [40]. Oman laws prohibit abortion except to save the life of the woman [21].

Yemen

Yemen is governed by the 1994 penal code, based on restrictive Islamic law, which prohibits abortion except to save the life of the woman [21]. Furthermore, there is no any premarital screening preventive practice in Yemen due to limited health resources [41].

Egypt

The first pre-marital check-up center opened was in July 2001. The center was located at Nasser Institute Hospital, where it provided medical checkups, Genetic Counseling for families with a history of inherited diseases [42]. The law was stipulated in 2008 and the National Council for Childhood and Motherhood has succeeded in making it mandatory for engaged couples to undergo pre-marital medical check-ups before legalizing their marriage contracts. Advocacy by of Voice of Al-Azhar "Do Not be shy, go now", and Coptic circles in which several churches conducted seminars to educate couples before marriage and convince them of the usefulness of pre-marriage medical examinations. However, health examinations were mere ink on paper due to cultural constraints. Although young women are convinced of the importance of such examinations, their suitors remain embarrassed about being seen at a pre-marital health clinic [42]. In some families in Upper Egypt, the suitor is the one who does the pre-marital medical check only but his fiancée is not allowed. Couples could get two sealed certificates listing no physical impediments to marriage and issued by the hospital [43]. Egypt's penal code prohibits the abortion of an established pregnancy. However, Article 61 stipulates: "A person shall not be punished for a crime which is in self-defense or for defending someone else against danger." This is sometimes used to condone abortion when the woman's health or life is at risk [44].

Lebanon and Syria

The PMS program was mandated in 1994 for thalassemia in Lebanon. The Chronic Care Center in Beirut was the only specialized center for the treatment and prevention of thalassemia in collaboration with the ministries of Social Affairs and Public Health. The major activities of the program included awareness campaigns, screening for thalassemia carriers, and follow-up on the mandatory premarital law [45]. During the Syrian conflict, which started in 2011, around one million Syrian individuals became refugees in Lebanon. The high rate of consanguineous marriage among Syrian refugees up to 51.9% with 17.9% of them were consanguineous for three successive generations [46]. A significant reduction in the number of new cases of thalassemia patients had been detected in Lebanon. However, the program was confronted with some barriers, mainly the illegality of abortion and improper implementation of the premarital law [16,47,48].

In summary, barriers and challenges to premarital care program in the Middle East countries operate and articulate in the following parameters:

The Availability, Accessibility, Acceptability, and Quality (AAAQ) framework

The Universal Declaration of Human Rights created a legal obligation on states to ensure access to timely, acceptable, and affordable health care of appropriate quality. Availability means a sufficient quantity of functioning health care facilities, goods, and services, as well as a program for premarital care within the country. Accessibility means these facilities should be within safe physical reach, financially affordable. Indeed, premarital screening is costly and governments should provide it free of charge, or at a discounted price. Acceptability Relates to respect for medical ethics and to be culturally appropriate, sensitive to gender requirements, and confidentiality of premarital screening results and personal health data. Finally, Facilities, goods, and services must be scientifically and medically appropriate, and of good quality [49]. However, there is a shortage of primary health care facilities to provide premarital screening and genetic counseling. Ministry of Health (MoH) succeeded in the development of standardized guidelines for PMC in a health care setting. However, there is no monitoring and evaluation of service provision [15]. Also, facilities lack the resources for the provision of continuous quality improvement of the service. Lack of capacity building and training of the health personnel to provide quality services at PHC. Even, there are no enough physicians specialized in genetics to provide genetic counseling. Furthermore, health care facilities cannot provide diagnostic tools and facilities. It is necessary, therefore, to increase the number of government-regulated facilities that provide genetic screening and counseling for all couples wishing to marry. Trained health professionals should provide counseling. Indeed, educate all members of the screening team (laboratory technicians, nurses, physicians, counselors, outreach social workers) on providing accurate advice regarding the risks and childbearing options. According to Schmidt, 'sufficient planning in the educational area before the first blood sample is drawn can avoid failures of the program [50].

Several countries have laws in place that make premarital screening programs mandatory for the entire population be-

fore couples receive their marriage certificates [17,18,22], however, screening programs are implemented differently in each country. Therefore, continuous monitoring and evaluation of the progress being made in achieving program outcomes are very important. Program evaluation in terms of percentage of consanguineous couples who have access to the screening program, rates of infectious diseases (e.g. hepatitis B, hepatitis C, and HIV/AIDS), genetic-recessive diseases (e.g. thalassemia and sickle cell anemia), and congenital malformations among children [51]. Moreover, the necessity of enacting a strict law that punishes the health workers who don't follow the guidelines for PMS along with encouraging and motivating service providers to play a positive role to enforce premarital screening law is a prerequisite.

Public Information, Education and Communication

Lack of public knowledge of the importance of premarital screening and counseling. Many young women and men enter into marriage with insufficient information on sexuality, reproduction, and family planning [52]. This is the result of a lack of communication between adolescents and their parents as well as their teachers. Although students' attitudes towards sexual matters are liberal, their knowledge about reproductive health services is still limited [53]. Mass media does not disseminate a clear message to the target audience. Men, women, and youth have incomplete and incorrect information about STDs and genetic diseases. Given the impacts of consanguineous marriages on public health, it is important to involve the community leaders and Non-Governmental Organizations (NGOs) in counseling programs for youth to raise awareness and change their attitude toward consanguineous marriage [54]. On the contrary, people with a negative attitude towards screening tests were mostly unmarried males. Eshra and colleagues suggested educational programs about the benefits of premarital examination should target unmarried males, so they can make informed choices about unmarried females and consanguineous marriages [55]. There are two models for behavior change modification, the cognitive and the contextual models. The cognitive is concerned with influencing conscious thoughts i.e. increase awareness about the benefits of screening. The contextual model, which aims to make the intended behavior more favorable under the assumption that people are affected by various factors in their environment and that their choices are therefore not always rational. A contextual change could involve adjusting the time point at which the test is performed, as this may play an important role in the outcome. Indeed, a combination of the two models should be used to change behavior towards acceptance of screening [56]. Therefore, screening programs should target people before marital and childbearing ages to allow more time to avoid or plan around high-risk marriages and births. It could be incorporated into school health packages or a requirement for university entry, along with health education on hereditary diseases and consanguineous marriages should be included in university curricula [57]. Studies indicated that those with prior knowledge of their status were less likely to proceed with at-risk marriages [31,58]. Some BCC messages should be designed to serve the objective of diminishing the stigma of carrier status of genetic diseases to ensure public cooperation with the problem.

Socio-cultural and religious constraints

Consanguinity is a deeply-rooted phenomenon in 20% of the world population mostly in the Middle East, West Asia, and North Africa. Marriages between the same tribes or extended family groups are favored in some cultures, including those between first cousins. Raising awareness about the impacts of consanguineous marriages on public health is a time-consuming process. Faulty religious beliefs restrict the success of screening programs in some communities regardless of the educational level. In the case of Islam, consanguineous marriages are also permitted, so thalassemia persists in some parts of the community, making the program redundant [59]. In Cyprus and Greece, premarital screening programs were successful because of the support from the church [60].

Lack of access to Prenatal Detection (PND) and therapeutic abortion

The traditional attitude towards therapeutic abortion should be reviewed in light of legal precedents in Bahrain, Iran, Iraqi Kurdistan, and Turkey allowing therapeutic abortion before 16 weeks of gestation for at-risk births. Moreover, national policies should ensure PND is conducted early in pregnancy to enable the completion of diagnostic testing before 16 weeks of gestation. Prenatal detection should be subsidized by the government or insurance schemes to be affordable and accessible for all population groups [61].

RECOMMENDATION

It is necessary to improve the policy environment for the successful implementation and sustainability of premarital care program. Efforts should be directed to policy advocacy for improved premarital care access, acceptability, and

quality services. Screening programs must be accessible and understood by the target population, but most importantly, they must comply with the prevailing cultural, ethnic, economic, and social values. Public education through mass media, newspapers, internet websites, awareness campaign, university symposia, incorporation into educational curricula to raise awareness and change behavior about the importance of screening [57]. Adopting a life cycle approaches for identifying health risks and intervening at critical periods during youth, prenatal, and neonatal life stages could be more successful than premarital screening alone [13]. This urge the need to capitalize on NGOs and private sector role through their clinics, role in development activities directed to youth. They could play a major role in the sustainability of demand through BCC and continuation of awareness-raising [62]. Efficient use of limited resources, social insurance, and business community support to overcome financial constraints is essential. Religious leaders should legalize therapeutic abortion in case the fetus is diagnosed with grave congenital malformation. Indeed, ensuring the contribution of different sectors and ministries can play a vital role in developing awareness among the people especially prospective life partners regarding premarital screening programs.

CONCLUSION

In conclusion, any mandatory screening program does have the potential to succeed as long as the target population is clearly identified and all ethical issues (confidentiality of results), religious, cultural, and human rights, and concerns about post-diagnostic management are fully addressed.

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