

Premarital Genetic Counselling among Female Adolescents Students

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Abstract: Premarital genetic screening is one of the most important strategies for prevention of genetic disorders and congenital anomalies among adolescents. Genetic counseling has become a prominent feature in prevention and treatment of genetic diseases. Nurse play an integral role in providing genetic services that include assess genetic risk, provide information, discuss available testing options and provide appropriate supportive counseling. **Aim:** To evaluate the effect of premarital genetic counseling on the knowledge and attitudes among female adolescents' students as a quasi-experimental study **design. Setting:** Technical nursing students at Ain shams university Purposive **sample** of 100 unmarried female adolescents' students will recruited from grades I of Technical nursing students at Ain shams university. Four types of **tools** will be used for data collection which are structured interviewing questionnaire, likert scale for students' attitude towards premarital genetic screening, Counseling sessions and opinionnaire sheet. **Results revealed** that the majority of students had lack of knowledge and negative attitudes regarding premarital genetic counseling. Significant improvement was found regarding most items of knowledge and attitudes after implementation of counseling sessions. **Conclusion:** Significant improvement in students' knowledge and attitudes after implementation of counseling sessions. **Recommendation:** Involvement of community leaders and non-governmental organizations in counseling programs to youth toward premarital genetic counseling and marriage between genetically incompatible partners.

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1. Introduction:

Adolescence is considered one of the crucial periods of life in between childhood and adulthood, which accompanied by a rapid increase in the rate of physical growth and changes involving physical and cognitive development. Many serious diseases in adulthood have their roots in adolescence. Adolescents are the first generation of adults to make decisions about a wide array of genetic testing for themselves and their families. They may have opportunities to participate in various types of genetic testing especially premarital genetic screening to avoid many diseases and complications arise (1).

Genetic disorders and congenital abnormalities occur in about 2%-5% of all live births (2). Genetic disease affects as much as 5% of the world's population constituting a major public health problem in many parts of the world (3). In KSA genetic disorders are very common and highly prevalent in the general population (4). According to the WHO, approximately 240 million people are heterozygous for inherited hemoglobinopathies, including thalassemia and sickle cell disease (5). These diseases are a major public health problem in the Mediterranean area, the Middle East, the Indian subcontinent, Asia, tropical Africa and the Caribbean. Saudi Arabia has a high prevalence of hereditary hemoglobin disorders (6). Therefore it is important to

prevent this problem by early molecular diagnosis, genetic counseling and appropriate treatment (7).

Genetic diseases are hereditary in nature. Deoxyribonucleic Acid (DNA) is responsible for heredity in humans. DNA characteristically condenses to form chromosomes (8). There are 46 chromosomes in the nucleus of human cells arranged in 23 pairs. Each of the pairs consists of a chromosome of paternal origin and one of maternal origin. Each chromosome is made up of genes. Gene or set of genes control traits. The presence of defective gene in either parent and the probability of its transmission to the children can only be accessed through genetic testing (9). Therefore, information about couple's predisposition to certain diseases and the likelihood of passing on those diseases to their unborn children is necessary before marriage is consummated (10) Genetic disorders runs in blood and this accounted for why if one parent has a genetic related disease, It is very likely that 50 percent of his or her children also will develop the disease (11).

Genetic screening is a public health initiative that has been used interchangeably with genetic testing. Testing implies genetic test done on an individual basis while screening implies large scale. Genetic testing (also called DNA based tests) which involve direct examination of the DNA molecule itself. It allows for genetic diagnosis of those who are

vulnerable to inherited diseases (12). Genetic testing can be used to test for genetic disorder such as sickle cell anemia, cystic fibrosis, spinal muscular atrophy, mental retardation, epilepsy and Down syndrome (13).

Pre-marital genetic screening is one of the most important strategies for prevention of genetic disorders, congenital anomalies and several medical, psychosocial marital problems (5). WHO (7) described pre-marital genetic screening as services targeted at individuals and families which try to enable people with genetic disadvantages, and their families to live and reproduce as normally as possible, assuring access to relevant medical services and social support systems, helping them to adapt to their unique situation and providing information to enable educated and voluntary choices in health and reproductive matters. (14) Rogan opined that objectives of pre-marital genetic screening includes: early recognition of disorder for intervention that prevents or reverses the disease process; or to ensure optimal management of the patient, that is, appropriate referrals to specialists when symptoms are anticipated and, informed reproductive decisions or disease management.

Methods of preventing genetic diseases include pre-marital screening and genetic counselling, prenatal diagnosis and preconception diagnosis. (15). However, prevention of the disease through carrier identification and genetic counselling remains the only realistic approach to reduce the impact of the disease and allow better use of available resources in the low-income countries (16).

Premarital Genetic counseling is an expanding field in the age of genomic medicine. Genetic counselors provide services to clients across the lifespan, from preconception counseling to prenatal diagnosis, the diagnosis of newborns or pediatric genetic disorders, and the diagnosis of adults with inherited predisposition to diseases (17). Medical genetics and counseling are very important tools for premarital screening of unmarried females can be provided with adequate and valid information on genetic inheritance of the disease and what it means to be at risk. Premarital screening of genetic disease not only provides information about the health and wellbeing of the individual, it is also important in assessing their health-related reproductive risk. It helps people concerned to make important and major life decisions that will benefit family members either now or in the future (18).

The roles of maternity and pediatric nurses go hand in hand to help people prevent hereditary disorders and consequential morbidity and mortality. They play an integral role in providing genetic services that include assess genetic risk, provide

information, discuss available testing options and provide appropriate supportive counseling (9). In addition they ensure that the clients are aware of concerns relevant to their situation and help them make decisions that fit lifestyle and belief system (19).

Significance of the study:

In Egypt genetic disorders are very common and highly prevalent in the general population. Therefore, it is important to prevent this problem by early molecular diagnosis, genetic counseling and appropriate treatment especially for adolescents due to the absence of screening culture in Egyptian culture. Nurses can facilitate the process and offer individuals the option of support groups for families with genetic disease Professionals in the fields of genetics, health education and the media can work together to increase awareness in the premarital adolescent students. This significant issue encouraged the researchers to conduct this study to evaluate the effect of premarital genetic counselling on the knowledge and attitudes among female adolescents students that consequently help in the control and spread the diseases.

Aim:

To evaluate the effect of premarital genetic counseling on the knowledge and attitudes among female adolescents' students through:

- Assessing students' knowledge related to genetic disorders.
- Evaluating students' attitudes towards premarital genetic screening tests.
- Evaluate the effect of premarital genetic counseling on the knowledge and attitudes among female adolescents' students.

Research Hypothesis:

Premarital genetic counselling has positive effects on knowledge and attitudes among female adolescents post intervention than pre intervention.

2. Subjects and Methods:

Study Design:

A quasi experimental design was conducted.

Setting:

The study was conducted at Technical nursing students at Ain shams University.

Sampling:

A purposive sample of 100 unmarried female adolescent' students will recruited from grades I of Technical nursing students at Ain Shams University with the following criteria: age ranging from 17 to 19 years.

Tools:

Four types of tools were used for data collection and conduction of the study. These consisted of Premarital genetic structured interviewing

questionnaire, Premarital genetic likert scale for students' attitude towards screening, counseling sessions and opinionnaire sheet.

1- Premarital genetic structured interviewing questionnaire:

It was developed designated by the researchers after reviewing the related literatures. The tool included multiple choice questions, as well as open and close-ended questions and divided into three parts:

Part I (questions 1-4): this covered the general characteristics of the sample as the personal identification and demographic data, e.g. age of student, place of residence and student occupation if present.

Part II (questions 5-11): this part covered the general characteristics of the student's family as father's & mother's level of education, father's & mother's occupation, number of family, number of daughters'.

Part III (questions 11-25): this part was designated to assess student's concept and knowledge regards premarital genetic screening and counseling as students' concept, source of their knowledge and genetic screening definition, types; different screening methods used and different consequences for it. This tool was using as pre and post counseling tool.

Knowledge scoring system for structured interviewing questionnaire: It was determined through: (3) score for correct answer, (2) score for incorrect answers and (1) score for wrong answers or don't know. The total scores were graded as Poor <50%, fair 50 < 70 %, Good 70-100%).

2- Premarital genetic likert scale:

It is designed to assess students' attitudes related premarital genetic screening. It was used twice for evaluation first in the base line assessment & second after counseling. The 12-items questionnaire consists of 6 positive and 6 negative statements about premarital genetic screening.

Likert scale scores as follows: (3) score for Agree which considered positive attitude, (2) score for Neutral (neither agree nor disagree), (1) score for Disagree which considered negative attitude. The scores were summed up and converted into total percent score means and standard deviations were calculated. A higher score meant more positive attitude.

The total score level of attitude was classified into: Positive attitude: ≥ 24 -36 degree, Uncertain attitude: 12- 24 degree, and Negative attitude : < 12 degree.

Tools validity:

The tools were reviewed by jury of 5 expertises, 3 from the field of Obstetrics& gynecology and 2

from the field of pediatric to test its contents and face validity.

3- Counseling sessions:

It focus on giving vital, unbiased information in the student's decision-making process

First session "Getting Started":

It started with participants' acquaintance through everyone introduce her self to others then introduction, objective and tools of data collection of the study were explained for all participant to gain their trust and stimulate the participants' interest. The researchers took their verbal consent. Then the researchers present the plan of the counseling sessions then the study run as scheduled with them.

Second session "Pre Assessment": The aim of this session is to collect data concerning pre assessment for participants before implementing counseling sessions. Participants were asked to fill the questionnaire sheet to assess concept and knowledge regards premarital genetic screening, and then fill likert attitude scale toward premarital genetic screening. Each tool took about 20-25 minutes to fill by each participant.

Third session "Check out the myths": were educational group aiming to orient students and raise their awareness about myths surrounding premarital genetic screening, the prevalence of genetic diseases, dangers of diseases, medical and nursing management regard these diseases. This was achieved through using group-discussion and counseling technique (GATHER) and at the end of third session the research team will provide them with flyer.

Fourth session "How you protect yourself from genetic diseases ": research team implement five different scenarios through various teaching methods and media were used though demonstration and redemonstration on the doll and models in role play about genetic diseases, premarital genetic screening tests, medical referral places for doing premarital genetic screening tests, costs and how increase students' ability to defense their self and nurse role toward genetic diseases through applying problem solving technique.

Fifth sessions: "Role Play Situations" the research team implement another new five different scenarios through role play about genetic diseases and premarital screening tests and ask from each student to discuss her ability for dealing effectively in role play situations.

Sixth session "Wrap Up": the research team summarizes all the information and techniques taught and took feed back then after that asked from the students to fill the questionnaire sheet and likert scales for reevaluation participants after implementing the counseling sessions. At the end of

sessions the research team asked from the student to contact them when they are needed then distribute student opinionnaire sheet to explore their opinion and recommendation regarding study.

At the end of each session the researchers made conclusion and took feedback for every participant

4- Opinionnaire sheet:

It was used for all students to explore their opinion and recommendation, regarding study by the end of the sessions.

Ethical Considerations:-

An official approval was obtained from the Dean of Faculty of Nursing to conduct the study. The researchers assured the student freedom to withdraw from participation at any time. Informed consent was obtained from the student after explanation of the purpose and the benefits of the study. Student dignity, privacy and confidentiality were considered. The study methodology is safe with no harmful for students.

Operational Design:

Pilot study:

A pilot study was carried out on (10%) from the total sample 10 student to evaluate the clarity, and applicability of the tools. Those students were excluded from the study sample.

Field work (procedure):

An official approval will be obtained from dean of faculty. The data will be collected and analysis for 6 months. The researchers collect data for 6 months. Through data collection the counseling sessions was done through six sessions. Every student will be instructed to fill in the questionnaire as pre test, then counselling session will be applied by the researcher, then post test will be applied. DNA screening test recommended to be done for high risk student.

Each session took two hours / week which consequently changed their knowledge, attitudes and their health behavior regarding premarital genetic counselling. Each researcher used the same methods of teaching (lectures, group discussions) and media such as data show, laptop in the faculty class. Phases of counselling session include an intake phase, an initial contact phase, the encounter phase, the summary phase and a follow-up phase.

Statistical Analysis:

Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and means and standard deviations for quantitative variables. Qualitative variables were compared using chi-square test, t test. Statistical significance was considered at p-value <0.05.

3.Results:

Table (1) reveals that the mean age of students is 19.4 ± 2.1 years. As regards residence, 78% were from urban areas. In relation to previous educational level 81% of student's were diploma. Concerning Father Educational level, 91 % of their father had secondary education or less while Mother Educational level 88 % of their mother had secondary education or less.

Table (2) shows that majority of students (75 %) were accept to perform genetic screening test.

Table (3) illustrates that there are a significant highly improvement in total score level of student's knowledge regarding premarital genetic counseling post counseling than before.

Table (4) shows that there are a significant positive highly improvement in student's attitude regarding premarital genetic counseling post counseling than before.

Table (5) reveals that there were insignificant correlation between student total knowledge & attitude scores premarital genetic counseling and their age. Meanwhile significant correlation was found with residence pre and post counseling especially students from rural area.

Table (6) shows Students' recommendations regard study as reported by them

It revealed that 67.5 % of student recommended increasing duration of counseling sessions, 43.2% of them recommended Integrate topic in their nursing curriculum while 41.8 % recommended to integrate premarital genetic screening in their health assurance with suitable cost.

Table (1): Percent distribution of student regarding their demographic characteristics

Variables	n = 100	
	No	%
1- Age:		
Less than 19 yrs	89	89
19 and above yrs	11	11
Mean age \pm SD	19.4 \pm 2.1	
2-Residence:		
Urban.	78	78
Rural.	22	22
3-Previous Educational level:		
Secondary	19	19
Diploma	81	81
4-Father Educational level:		
Secondary or less	91	91
University or more	9	9
5-Mother Educational level:		
Secondary or less	88	88
University or more	12	12

Table (2): Percent distribution of high-risk students' acceptance for performing genetic screening test

Genetic screening test acceptance	High-risk students (n = 36)	
	n	%
Yes	27	75
No	9	25

Table (3): Total score level of student's Knowledge before and after counseling regarding premarital genetic counseling

Total student's knowledge score	Pre counseling (n = 100)		Post counseling (n = 100)		T-test	P value
	n	%	n	%		
Good	16	16	37	70.3	7.78	0.001*
Fair	27	27	34	26		
Poor	57	57	29	3.7		
Total mean score	1.52±0.84		3.85±1.36			

Table (4): Total score level of student's attitude before and after counseling regarding premarital genetic counseling

Total student's attitude score	Pre counseling (n = 100)		Post counseling (n = 100)		Chi square test	P value
	n	%	N	%		
Positive	21	21	52	52	3.78	0.001*
Uncertain	54	54	34	34		
Negative	25	25	14	14		
Mean attitude score.	0.872±0.67		4.98±1.06			



Figure (1): Student's opinion regarding counseling sessions

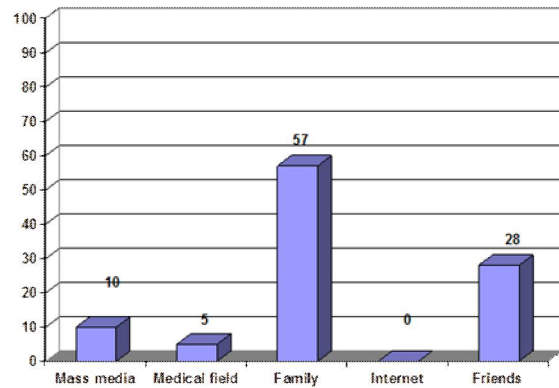


Figure (2): Student's source of knowledge regarding premarital genetic counseling

Table (5): Correlation coefficient between student total knowledge and attitude before and after counseling regarding premarital genetic counseling and their age and residence

Variables		Age		Residence	
		r	p	r	p
Knowledge	Pre counseling	-0.119	> 0.05	-0.71	0.001
	Post counseling	-0.012	> 0.05	0.89*	0.001
Attitude	Pre counseling	-0.131	> 0.05	-0.87*	0.001
	Post counseling	-0.041	> 0.05	0.84*	0.001

Table (6): Distribution of the study sample regard different recommendations regard study as reported by themselves:

Recommendations	N = 100
	%
Integrating topic in their nursing curriculum.	43.2
Increasing duration of counseling sessions.	67.5
Offering counseling sessions in summer	22.5
Integrate premarital genetic screening for high risk students in their health assurance with suitable cost.	41.8

NB: More than one recommendation was offered by each student.

4. Discussion

Genetics counseling are very important tools for premarital screening of unmarried students can be provided with adequate and valid information on genetic inheritance of the disease and what it means to be at risk (20). Premarital screening (PMS) is one of the most important strategies for prevention of genetic disorders, congenital anomalies and several medical, psychosocial marital problems (21). It can provide an opportunity to intervene according to the identified risk. This intervention include vaccination, counseling regarding behavior, nutrition, genetic counseling, advice regarding contraception, modification of chronic disease, treatment of infections and medication to decrease teratogenic risk. In addition, unlike standard marital therapies, premarital interventions (2).

Based on The WHO has repeatedly recommended several measures to prevent genetic diseases including health education and the improvement of community knowledge and attitude towards the control of hereditary genetic diseases (22). So, in respect to these concepts this study was conducted to evaluate the effect of premarital genetic counseling on the knowledge and attitudes among female adolescents' students

The present study revealed that socio-demographic characteristics are important indicators to shape the adolescents as well as their susceptibility to genetic diseases. Additionally, the present study revealed that, the mean age of students was 19.4±2.1 years, slightly more than three quarter of them were urban. These findings are plausible given the effect of education on the development of correct concepts based on sound knowledge, which consequently shapes the attitude and practices towards genetic screening tests (23).

The current study revealed that the majority of the students had lack of knowledge regarding premarital genetic screening where most of them unaware of being at risk, didn't believe on early checkup, didn't performed screening and early detection measures before counseling implementation. Their barriers or reasons of their abstinence of performing premarital genetic screening were fear from consequences of positive

results, cost of tests and fear from stigma. This finding may be attributed to that there is lack of knowledge about the importance of these premarital genetic screening tests. In addition, the coverage of premarital genetic screening is still limited in Egypt and to the absence of screening culture in Egyptian culture. These results were supported by Bennett (24). Who documented that, cultural issues are key barriers to first-generation Somali women attending premarital genetic screening. They recommended that, providing education and information orally, as well as improving access to a more culturally appropriate screening service, could lead to improved uptake among this group. On the other hand, WHO (25) cited that, the most important factor hindering the use of available premarital genetic screening was the feeling that adolescents had no medical problems.

The results of the present study mentioned that the mean scores of students lacking knowledge regarding premarital genetic screening before the counseling implementation. This knowledge deficiency was regarding most of the studied items of premarital genetic screening. This may be due to absence of designed educational program provided to these students. In addition the results revealed that the mean scores of students knowledge were significantly improved regarding most the studied items of all areas of knowledge regarding premarital genetic screening ($p < 0.001$) pre-counseling and post counseling implementation. This could be due to the effectiveness of awareness counseling sessions and that students were interested to get more information about this topic. This finding find support in the study of Al Kindi, Al Rujaiibi and Al Kendi (26) highlighted that, the majority of the study subjects were not adequately equipped with knowledge concerning premarital genetic screening. This study shows a gap between the knowledge and uptake of genetic testing and may help to guide the design of effective strategies to initiate successful genetic counseling and testing services.

Furthermore, it was evident from the results of the present study that about half of the studied students had positive attitude regarding premarital genetic screening after counseling compared to before counseling. The negative attitude before

counseling may be attributed to absence of screening culture in Egyptian culture and the horrible feeling of unknown regard premarital genetic screening. These findings not in line with Farahat, Shaheen, Mohamed and Mohaseb (27). they found that, the attitude towards screening was mainly positive (79%) and reported also the main reasons to attend were early detection of abnormalities (67%) and reassurance in case of a normal smear (22%).

Genetic screening is an important tool to control, minimize, and prevent genetic disorders. (17).started the first national premarital screening (PMS) program to control inherited hemoglobin (Hb) disorders that are the most commonly inherited genetic disorders in the Arab countries. Further more the present study revealed that most students' opinion regarding counseling sessions were very good which lead to improve students' attitude and behavior regard genetic screening and these results because most of them had their knowledge from their families

Conclusion:

Based on the study findings, it was concluded that there were lack of student's knowledge, and negative attitude regarding premarital genetic counseling. Significant improvement was found regarding most of the study items of knowledge. Positive changed behavior and consequently positive attitude were revealed among the majority of students after the counseling sessions. Also Students recommended to integrate premarital genetic screening in their health assurance with suitable cost.

Recommendations:

In the light of the study findings, the following recommendations are suggested:

1- Involvement of community leaders and non-governmental organizations in counseling programs to youth to raise awareness and change their attitude toward premarital genetic counseling and marriage between genetically incompatible partners.

2- An educational campaign needs to be implemented for the general for the General population in high schools and universities.

3- Enforce in-service training programs to be carried out for maternity and pediatric nurses to enrich their knowledge regarding the importance of premarital genetic counseling.

4- Further researches are needed to determine barriers that hinder adolescents to take their decision towards performing genetic tests.

Limitations:

1- Difficult in implementation study at first due to the absence of screening culture in Egyptian culture.

2- High cost of premarital genetic screening for high risk students.

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