

EFFECT OF EDUCATIONAL PROGRAM ABOUT GENETIC DISORDERS ON KNOWLEDGE AND BELIEFS OF HIGH RISK WOMEN

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ABSTRACT

Genetic disorders and congenital anomalies are rapidly becoming a major public health concern in Egypt. The aim of the current study was to evaluate the effectiveness of educational program about genetic disorders on knowledge and beliefs of high risk women. A quasi-experimental research design was utilized to fit the aim of the study. The study was conducted at family health center of Bani Mohamed village, Assuit governorate, Upper Egypt region. A purposive sample of 44 women who are at risk for developing genetic disorders were included in the study. Data were collected using the following tools: 1- Structured interviewing knowledge questionnaire 2- Health Beliefs Assessment Tool. The study revealed that, a highly statistically significant difference between total knowledge scores and total health belief scores among women in pre, post and follow up test. The women's total knowledge scores was increased in post and follows up test compared to pre test and women's total health belief scores was increased and they had positive beliefs in post and follows up test compared to pre test. The study results concluded that, there was an improvement in the knowledge and health beliefs to prevent genetic disorders among women after program implementation which emphasized that educational program have significant positive effect on increasing knowledge and beliefs of women about genetic disorders prevention.

KEYWORDS: Educational Program, Genetic Disorders, Knowledge & Beliefs, High Risk Women

INTRODUCTION

Genetic disorders are diseases that are not acquired or caused by infection or trauma, but rather children inherit the gene from their parents, it could be congenital, if the disease appears at birth immediately but sometimes, if they have the gene, the disease will develop later on [1]. Worldwide, about 7.9 million children annually were born with genetic disorders. Various risk factors associated with genetic disorders were maternal age, maternal nutritional status, infections, medical illnesses maternal exposure to teratogenic drugs, and consanguinity [2]. Knowledge of genetic disorders, cultural views, health beliefs, and social and economic barriers may be contributors to the lack of interest and support for genetic disorders testing and genetic counseling [3]. Primary prevention of genetic disorders process is an educational service for individuals and families who have a genetic disease or who are at risk for such a disease, it is designed to provide individuals and their families with information about their condition and help them make informed

decisions [4]. Genetic disorders and congenital anomalies are rapidly becoming a major public health concern in Egypt. The prevalence of congenital and genetic disorders among infants and young children in Egypt is estimated to range from 2.8% in urban areas to 8.4% in rural areas in Upper Egypt [5]. Many studies in Egypt have shown that, roughly 30% of admissions and about 40-50% of death occurring in pediatric hospitals are accounted for by children with genetic disorders or congenital malformations [4]. All of these genetic disorders are significant burden on healthcare systems. Their chronic nature requires life-long medical attention and expensive therapy and specialized care [6]. In Egypt genetic disorders are very common and highly prevalent in the general population, therefore it is important to prevent this problem by early genetic counseling and appropriate treatment especially for high risk group due to the absence of the importance of the screening in Egyptian culture. Nurses can facilitate the process and offer individuals the option of support groups for families with genetic disease, health education and the media can work together to increase awareness in the high risk group [7]. Therefore, this research was designed to evaluate the effectiveness of educational program about genetic disorders on knowledge and beliefs of high risk women. The current study will help in rising awareness of high risk women on possible control/ preventive measures for genetic disorders and encourage them to seek early genetic counseling and appropriate treatment.

METHODS

Aim of the Study

The aim of this study was to evaluate the effectiveness of educational program about genetic disorders on knowledge and beliefs of high risk women.

Research Hypotheses

H.1: Women who will receive health education program will have higher knowledge scores regarding genetic disorders after implementation of the program.

H. 2: Women who will receive health education program will have positive belief scores regarding genetic disorders after implementation of the program.

Research Design, Participants & Setting

Quasi-experimental design (pre / post test) was utilized in the current study. The study was conducted at family health center of Bani Mohamed village, Assuit governorate, Upper Egypt region. A purposive sample of 44 women who at risk for developing genetic disorders (those with family history), married women & women aged from (18- 45) years old.

Ethical Considerations

An official permission was obtained from the Research Ethics Committee of the Faculty of Nursing-Cairo University, and from the director of family health center of Bani Mohamed village. Participation in the study is voluntary where informed consent was signed by the participants after reading all the details; the ethical considerations include explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it will not be accessed by anyone without taking permission of the participants.

Data Collection Tools

Data were collected using the following tools: (1) Structured interviewing knowledge questionnaire that have two

parts: a) Demographic data: include women's age, educational level, occupation, family income, presence of consanguinity, consanguinity degree, number of children, presence of chronic diseases, presence of children with genetic disorders, family history of genetic disorders and available health services b) Pre/ post knowledge questionnaire to assess women's knowledge regarding genetic disorders: it includes definition, causes/risk factors, treatments of genetic disorders, how to decrease occurrence of genetic disorders, risk factors avoided during pregnancy, examination and investigation during pregnancy, precaution & measures during pregnancy, nutrition during pregnancy, vitamins & supplementations during pregnancy, important of ultrasound during pregnancy, precaution & measures during exposure to chemical, examination and investigation immediately after infant birth, risks and health problem from consanguineous marriage, aim of genetic services, places of genetic services & counseling and finally source of their knowledge (2) Health Beliefs Assessment Tool was developed by the researcher after reviewing the related literature. It is based on Champion's Health Belief Model (CHBM) which has five fundamental construct (perceived susceptibility, perceived severity, perceived benefits, perceived barriers& cues to action). The tool was classified into five parts according to five construct of CHBM.

Scoring System

Regarding knowledge scores, complete correct answer was giving "two" scores, incomplete correct answer was giving "one" score, and incorrect / unknown answer was giving "zero". The total knowledge score was (36) scores, the higher scores reflect higher levels of knowledge about prevention and control of genetic disorders. The researcher considered (zero up to <50%) score is poor knowledge while Fair knowledge was (50% up to < 75%) and good knowledge was (>75 %). The Scoring System of Health Belief Model: The five constructs included 34 items on a 5 point Likert scale ranging from (1 strongly disagree, Disagree, Neutral, Agree to 5 strongly agree). Subscale mean scores were obtained by summing and averaging the items (range 1-5). Each subscale was calculated separately. The possible total score range was (34-170), and a higher score indicated a more positive beliefs toward genetic disorders prevention. Minimum total scores for Health Belief Model equal to (34) and maximum total scores for Health Belief Model equal to (170)

Data Collection Procedure

Data collection was carried out on three phases: assessment phase, implementation phase and evaluation phase.

Assessment Phase

Women's knowledge and beliefs were assessed by using interviewing knowledge questionnaire and the health beliefs assessment tool regarding genetic disorders, assessment phase took 2 months. After acceptance from the director of family health center, co ordinations with the head nurse and other nurses in the center was done to start assessment phase and to facilitated data collection process. Interviewing the women was carried out in the waiting area beside the clinics in the family health center. Before distribution of the sheets, the researcher informed each participant about the confidentiality of the collected data, and their right to withdraw from the study at any time, and then questionnaires were distributed and each high risk women was given a code number to be used all through the program phases. The researcher was present with the participant during filling in the questionnaire sheets, to clarify the sheets and to ensure individualized response. The interviewing questionnaire sheet was filled by the participant except for those who can not read and write was filled by the researcher. The time spent to fill the questionnaires ranged between 30-45 minutes to be filled then the researcher

collected the sheets from each participant separately to check any unanswered or missed questions. The researcher collected the data two days/ week from 9 am to 2 pm.

Implementation Phase

Based on the pre-assessment data and related literature review, the researcher designed an educational program about genetic disorders to improve knowledge and beliefs of women. The designed program was conducted in the form of educational sessions; the implementation phase was carried out on the participant's home, the researcher conducted (home visit) after taking participant's home address and their acceptance to enter their homes in the assessment phase and the suitable time to visit them to implement the program sessions because of the difficulty to meet and collect the women five times in the family health centers to implement and evaluate the program also they haven't time to stay in the center because of their responsibilities.

Sessions was given to the women in the form of a teaching classes and discussion through pre-designed educational materials, duration of sessions was about 30 minutes, the number of sessions decreased to 3 sessions according women's understanding. The target group was divided into subgroup from (3-5) women; sometimes the teaching sessions was given for one participant as (individual teaching), the program was introduced for each group in the same manner. Program sessions emphasized the important point related to how to control and decrease risk factors that lead to occurrence of genetic disorders and early detection of it.

The first session was introductory one where the researcher explained the aim and objectives of the study and building a rapport as well as relaxing atmosphere. The first session included careful explanation of definition of genetic disorders, most common types of genetic disorders, causes/risk factors and treatments of genetic disorders. The second and third session included information about how to decrease risk factors that lead to occurrence of genetic disorders as risk factors avoided during pregnancy, examination and investigation during pregnancy nutrition during pregnancy, vitamins & supplementations during pregnancy, important of ultrasound during pregnancy, precaution & measures during exposure to chemical, examination and investigation immediately after infant birth, risks and health problem from consanguineous marriage, aim of genetic services, places of genetic services & counseling. The fourth and fifth session included explanation of health beliefs related to genetic disorders as perceived susceptibility for genetic disorders, perceived severity / seriousness of genetic disorders perceived benefits of counseling, examinations & follow up before, during & after pregnancy, perceived barriers for counseling, examinations & follow up before, during & after pregnancy and cues for prevention and control of genetic disorders.

Evaluation Phase

Evaluating the effectiveness of health education program about genetic disorders on women's knowledge and beliefs was done in this phase. The same tools was applied immediately post program and three months after the program with the same women that participated previously in the study in order to evaluate the degree of knowledge and change in beliefs after the program.

Tools Validity and Reliability

Data collection tools were developed after extensive reviewing of literature. Knowledge questionnaire and health beliefs assessment tool was given to a panel of five experts in community health nursing and statistical field to examine the

content validity. Modifications of the content were done according to the panel judgment on the clarity of sentences and appropriateness of content.

Statistical Design

The data was scored, tabulated, and analyzed by computer using the “Statistical package for the social sciences” (SPSS program, version 20). Numerical data were expressed as mean and standard deviation. Qualitative data were expressed as frequency and percentage. For qualitative data, comparison between two variables was done by using t test. Relations between different numerical variables were tested using person correlation. probability (P-value) <0.05 was considered significant for ANOVA test and P value less than 0.01 was considered significant for person correlation.

RESULTS AND DATA ANALYSIS

Part I: Part I: Description of the Demographic Characteristics of Women

Table 1: Percentage Distributions of Demographic Characteristics of Women Regarding their age, Educational Level & Type of Work (n= 44)

Variables	Frequency	%
Age /year		
>25	17	38.7
25 >35	15	34
35 - 45	12	27.3
X ± SD	26.64 ± 4.51years	
Educational Level		
Unable to read &write	19	43.2
Read &write	15	34.1
Secondary	6	13.6
University	4	9.1
Total	44	100
Type of Work:		
House wives	38	86.4
Farmers	4	9.1
Employees	2	4.5
Total	44	100

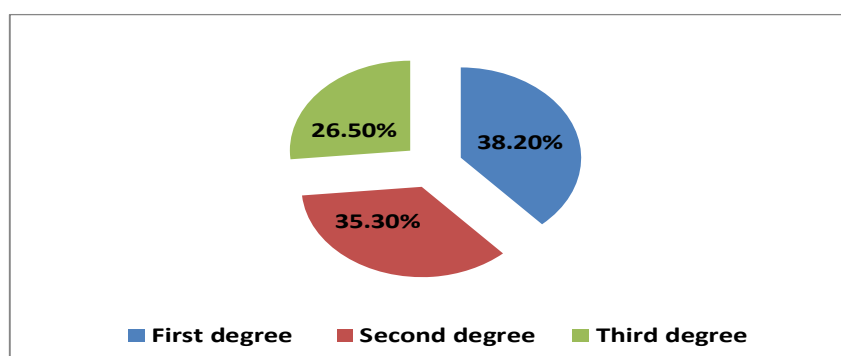


Figure 1: Percentage Distributions of Women's Consanguinity Degree (n= 44)

Table 2: Percentage Distributions of Family History for Genetic Disorders and Types of Disorders (n = 44)

Variables	Frequency	%
Family history for genetic disorders		
Yes	44	100

Types of Disorders		
Neurological disorders	18	41
Fetal, neonatal and infant deaths	6	13.6
Multiple congenital anomalies	5	11.2
Skeletal disorders/ Respiratory defects	3	6.9
Cardiac disorders / Endocrine disorders	4	9
Special senses (hearing defect, Congenital cataract, Congenital glaucoma)	2	4.5
Chromosomal abnormalities (Down's syndrome)	3	6.9
Renal anomalies	3	6.9

Part II: Knowledge of Women about Genetic Disorders Pre, Post and Follow up Tests

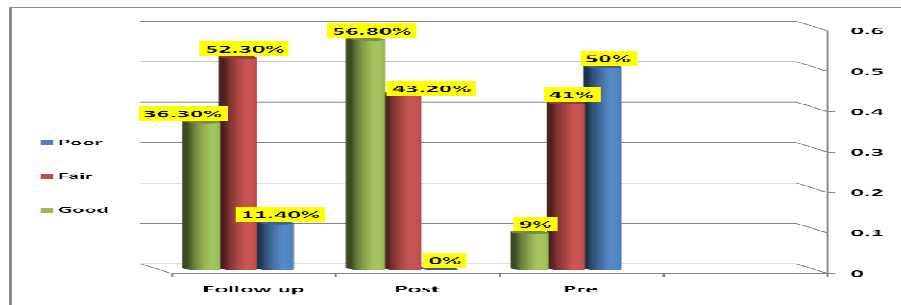


Figure 2: Percentage Distribution of Pre, Post and Follow up of Women's Level of total Knowledge Scores Regarding Genetic Disorders (n= 44)

Table 3: Differences between Women's Total Knowledge Scores in Pre, Post and Follow Up Test (n= 44)

Variables		Mean \pm SD	F	P
Total knowledge scores	Pre	3.526 \pm 2.09	41.648	0.000**
	Post	6.964 \pm 1.52		
	Follow up	5.845 \pm 1.75		

** The mean difference is significant at the 0.05 level

Part III: Health beliefs of Women about Genetic Disorders Pre, Post and Follow Up Tests

Table 4: Difference between the Mean Scores of Health Belief Model's Subscale in Pre, Post and Follow Up Tests (n= 44)

Total Health Beliefs Model Subscale		Mean \pm SD	F	P
Perceived Susceptibility	Pre	3.140 \pm .6700	2.528	0.084*
	Post	3.488 \pm .7806		
	Follow up	3.259 \pm .7576		
Perceived Severity	Pre	3.875 \pm .7108	13.880	0.000*
	Post	4.484 \pm .4711		
	Follow up	4.363 \pm .5137		
Perceived Benefits	Pre	3.590 \pm .7520	2.969	0.055*
	Post	3.977 \pm .7322		
	Follow up	3.759 \pm .7527		
Perceived Barriers	Pre	3.375 \pm .5583	5.258	0.006*
	Post	3.076 \pm .5045		
	Follow up	3.068 \pm .4474		
Cues for Actions	Pre	3.386 \pm .8555	9.269	0.000*
	Post	3.972 \pm .5431		
	Follow up	3.800 \pm .5158		

*. The mean difference is significant at the 0.05

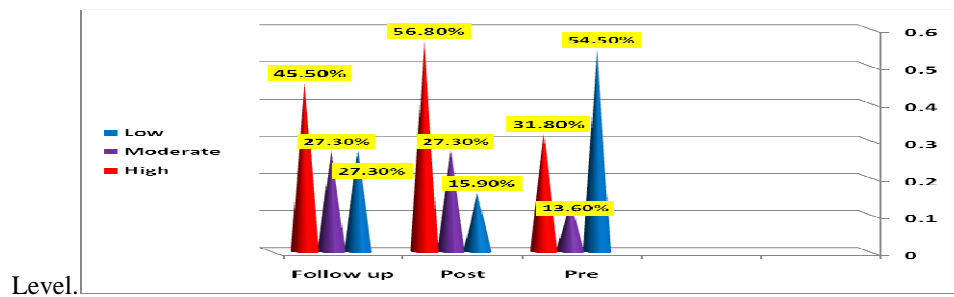


Figure 3: the Difference between Levels of Perception of Health Belief Model's Subscale and Total Health Belief Model among Women in Pre, Post and Follow Up Test (n= 44)

Part IV: Part IV: The Difference Between Total Knowledge Scores and Total Health Belief Model Scores in Pre, Post and Follow Up Test

Table 5: Difference between Total Knowledge Scores and Total Health Beliefs Scores among Women in Pre, Post and Follow Up Test (n= 44)

Variables		Mean \pm SD	F	P
Total Knowledge Scores	Pre	3.526 \pm 2.09	41.648	0.000**
	Post	6.964 \pm 1.52		
	Follow up	5.845 \pm 1.75		
Total Health Beliefs Scores	Pre	3.42 \pm .4687	5.441	0.005*
	Post	3.71 \pm .3742		
	Follow up	3.56 \pm .3542		

* The mean difference is significant at the 0.05 level. **Part V: Correlational Analysis**

Table 6: Correlations between Demographic Characteristics of Women and their Total Knowledge and total Health Beliefs Scores (n= 44)

Demographic Characteristics	Total Knowledge Scores		Total Health Belief Scores	
	r	P	r	P
Age	0.20	0.18	0.02	0.85
Education	0.45	0.00**	0.29	0.05**
Income	0.38	0.00**	0.32	0.03**

** . Correlation is significant at the 0.01 level (2-tailed).

Table 7: Correlation between Total Knowledge Scores and Total Health Beliefs Scores in Pre, Post and Follow Up Tests (n= 44)

Variables	Total Knowledge Scores	
	r	P
Total health Beliefs Scores	Pre	0.58
	Post	0.57
	Follow up	0.64

** Correlation is significant at the 0.01 level (2-tailed).

Table 8: Correlations between Total Knowledge Scores and Total Health Belief Model Subscale' Scores in Pre, Post and Follow Up Tests (n= 44)

Total Health Belief Model's Constructs	Total Knowledge Scores					
	Pre		Post		Follow up	
	r	P	r	P	r	P
Perceived susceptibility	0.54	0.00**	0.52	0.00**	0.61	0.00**
Perceived severity	0.45	0.00**	0.49	0.00**	0.40	0.00**
Perceived benefits	0.57	0.00**	0.46	0.00**	0.58	0.00**
Perceived barriers	-.314-	0.03	-0.25	0.09	-.044	0.00**
Cues for actions	0.69	0.00**	.413	0.00**	0.494	0.00**

DISCUSSIONS

Regarding demographic characteristics of women, results of the current study indicated that, more than one third of women aged less than 25 years and less than one third aged from 25 >35 while more than quarter aged from 35-45 with a mean age $26.64 \pm$ years old. This finding was in agreement with [8] who conducted a study on Four hundred and forty-three (443) pregnant women at the antenatal units of Korle-Bu Teaching Hospital Ghana and found that, the majority of women aged from 21 years to 30 years. Also [9] who conducted a study on 480 women of reproductive age at maternal child health clinics in governmental healthcare centers in Mashhad, Iran, revealed that, the mean age of the women was 27.96 ± 5.51 years. At the same line, the studies done by [10] & [11] revealed that, the majority of the women were between 21 and 30 years old and the minority was more than 41 years old. There's no doubt that this age is considered the reproductive age for women.

Results of the current study revealed that, more than two fifth of women were unable to read and write while less than one third can read and write and the minority of them had university education. This result was supported by [12] & [13] which stated that, the majority of women were illiterate or had primary education and also most of female in Egypt are less educated especially in rural area due to socio-economic and geographical factors, also gender disparities continue to affect access to primary education. Also [14] reported that among thirteen Arab states, Egypt came fourth (23.7 percent) in the highest illiteracy rates for individuals aged 15 years and above and the highest illiteracy rate was recorded in the Upper Egypt. On the contrary, this result contradicted the study done by [11], who conducted a study on 150 pregnant women in North of Iran and reported that, the majority of the women were high school graduates. This difference between the two studies could be related to the socioeconomic and cultures factors.

Concerning type of work, the majority of women were house wives. This result was in agreement with [15] who conducted a study on 3301 high risk pregnant women attending antenatal clinic of Modern Government Maternity Hospital Hyderabad- India and reported that, the majority of the women were house wives while the minority was Agricultural workers and employee. [16] who conducted a study on 300 pregnant women with fetal congenital anomalies at Fetal Medicine Unit at El-Manial University Hospital which is affiliated to Cairo University and found that, the majority of pregnant women in the consanguineous and non-consanguineous marriage groups were housewives. At the same line [9], reported that, the majority of women in his study were housewives. This results related to the majority of women in upper Egypt were illiterate or had primary education due to socio-economic and geographical factors, also socio cultural factors in which women's roles are limited to the domestic sphere and farm work, hamper their access to education which affect women's participation in the labor force.

Results revealed that, more than two third of the women had consanguinity degree between spouses. This result was in agreement with [17] & [18] who conduct a study on 8696 pregnant women at the antenatal clinic of obstetric and labour room of Women's Health Center, Assiut University, Assiut, Egypt, and revealed that, consanguineous marriage among pregnant women was (63.4%). Also [19] who conducted a study to determine the prevalence and patterns and determinants of consanguineous marriage among 1318 Saudis at Almadina Almunawwarah Area in Saudi Arabia and reported that, there was high consanguinity rate (69.15 %) especially among the younger generation. On the other hand, this result contradicted the study done by [15] who reported that, (75%) of high risk pregnant women didn't had consanguinity degree. This difference between the two studies could be related to cultural differences because consanguineous marriage is a cultural practices and still high in Arab countries and Egypt especially in rural areas where risk factors of genetic disorders include, low levels of maternal education, early age of marriage, short birth intervals, longer reproductive spans, larger family sizes and higher rates of infant and early childhood mortality all this factors affects the women health. So, specific health education and genetic counseling are needed to increase awareness about the negative health impact of consanguineous marriage on offspring.

Concerning type of genetic disorders which affect children, neurological disorders was the most common disorders followed by Fetal, neonatal and infant deaths and multiple congenital anomalies. This result was in agreement with with [18] & [17] who conduct a study on 5000 women and neonates with apparent congenital anomalies at Assiut University hospital in Upper Egypt and reported that, the commonest congenital malformations were neural tube defects especially hydrocephalus (55.3% of cases) the second commonest was multifoetal abnormalities (44.7 % of cases). At the same line, [20] who conduct a study on 109 live births had gross congenital malformations at the newborn care unit of a tertiary care rural teaching hospital in India, and revealed that, central nervous system was most commonly affected (48%) followed by musculoskeletal and gastrointestinal system.

Regarding Knowledge of women about genetic disorders, results of the current study revealed that, nine percent of women had good level of knowledge in pre test which increase to more than half and more than one third respectively in post and follow up test. Also, a highly statistically significant difference was found between women's total knowledge scores regarding genetic disorders in pre, post and follow up test. These results were supported by many studies as [21] who studied the effect of an education program based on health belief model on knowledge and behaviour of 100 couples referred to marriage counseling in health care centre of Dezful city Iran and found a significant improvement of couple's knowledge regarding marriage counseling immediately and after 3 months of program implementation, also [22] who conducted a study on 42 pregnant women at antenatal clinic at Tanta University Hospital and El Menshawy Hospital Egypt and found a statistically significant improvements in the total knowledge scores in post-test and 3 months later compared with pre-intervention scores.

Concerning health beliefs of women about genetic disorders, the study results reflected a highly statistically significant difference between total health belief subscales in pre, post and follow up tests, also there was a highly statistically significant difference between total health belief scores among women in pre, post and follow up tests, and there was improvement in health belief model subscales and total health belief scores after program implementation. This finding were in agreement with [23] who conducted a study on 90 pregnant women referred to Health Centers in South West of Iran for receiving pregnancy cares and reported that, the mean scores of all constructs of Health Belief Model after intervention and three months later were significantly higher compared with the pre intervention.

Results of the current study reflected a highly statistically significant difference between total knowledge scores and total health belief scores among women in pre, post and follows up test. The women's total knowledge scores was increased in post and follows up test compared to pre test and women's total health belief scores was increased and they have positive beliefs in post and follows up test compared to pre test. This finding were in agreement with many studies as [24], [25],[22], [26], [27],[28] & [29] which showed that educational programs have a significant positive effect in improving women's knowledge and health beliefs toward genetic disorders prevention.

Results of the current study revealed that, there was a highly statistically significant positive correlation between women's total knowledge scores and total health beliefs scores and their education. This result was supported by the studied done by [11], [29] & [25] that indicated the relation between spouse's educational level and their knowledge and belief post genetic counseling was highly statistical significant. The higher the educational level of the women the more knowledgeable they become about genetic disorders and the more positive attitude regarding genetic disorders prevention.

In the same context, the finding showed a highly statistically significant positive correlation between women's total knowledge scores and total health beliefs scores and their income. This finding was in agreement with [11] who indicated that, there was a statistically significant correlation with monthly income their knowledge and their health beliefs. With sufficient income, there will be availability of money to travel to more than one place for diagnosis, making more investigation, follow up and getting appropriate treatment and medications. Also having enough money allows women to demonstrate better healthy practices and getting more knowledge about genetic disorders and treatment from specialized doctors. While women of low socioeconomic status may find difficulty in reaching to a specialized clinics and go to the nearest general hospital which may lead to delay diagnosis and treatment.

The current study illustrated that, there was no statistically significant correlation found between women's total knowledge scores and total health belief scores and their ages. This result was in agreement with [30] & [29] who conducted a study on one hundred spouses attended the MCH centers for antenatal at in El-Qaliobia governorate Egypt reported that, no statistically significant correlation was found between women's total knowledge scores and total health belief scores and their ages.

From the current study, a highly statistically significant positive correlation was found between women's total knowledge scores and their total health beliefs scores in pre, post and follow up tests. These results were supported by [25] who conducted a study on 100 pregnant women at Outpatient Clinic affiliated to Benha University Hospital in Benha City Egypt and reported a highly statistically significant positive correlation among women's total knowledge and total health beliefs scores before and after program implementation. On the same lines [31] who studied the predictors of preventive behaviors of urinary tract infections based on health belief model among 140 pregnant women in Iran and reported that, there was a positive statistically significant correlation between women's knowledge and health beliefs before and after the program implementation.

CONCLUSIONS AND RECOMMENDATIONS

Results of the current study concluded that, there was improvement in the knowledge and health beliefs to prevent risk factors for genetic disorders among women after program implementation which emphasized that educational program have a significant positive effect in improving women's knowledge, health beliefs and attitude toward genetic disorders prevention.

Recommendations

1. Raising women's awareness through educational program in different setting as maternal and child center, family health center for prevention of risk factors of genetic disorders and mass media should be included in the programs.
2. Involvement of community leaders and nongovernmental organizations in counseling programs for high risk group to raise awareness and change their attitude toward premarital genetic counseling and effects of consanguinity.
3. Distribution of copies of educational booklet about genetic disorders based on HBM at different family health centers at Assuit governorate, upper, Egypt to improve women's knowledge and health belief.
4. Replication of this study on a large sample and in different settings is recommended for generalization of results.

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