

Knowledge and attitude toward genetic counseling and testing among parents of children with genetic disorder in the West Bank/ Palestine

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ABSTRACT

Genetic disorder is a health problem that is caused by a defect in the individual's DNA. In Palestine, there is no statistics about mortality rate of children who suffer from genetic disorders. Although, It, children, disorder is noticable that the new cases from the same family have been increased without any genetic counseling or prevention. Therefore, the study aim is to describe parents' knowledge and attitudes toward genetic counseling and testing, and to determine if knowledge affects attitudes. A cross sectional study using a questionnaire to evaluate knowledge and likert scale to evaluate attitude was used in this study. The sample size was 121 participants who were attended the two referral hospitals in West Bank from February 2016 to September 2016. The study showed that there is a significant positive relationship between parents' educational level and their knowledge regards genetic disorder (P value= 0.003). The most significant related risk factors for genetic disorder were ignoring premarital genetic testing for (99.2%); consanguineous marriage (71.1%); and family history of genetic problem for (55.4%).The study founded that most of parents of children with genetic problem had a good knowledge regards genetic disorder (63%).Whereas, the attitudes of these parents were positive for a majority of items that measure attitude level (81% for agreed answer). The relationship between knowledge and attitudes was positive and research hypothesis regards the effect of knowledge on attitude of parents had been accepted. This study recommended to increase awareness of parents about genetic testing; the important of premarital testing; and to avoid consanguinity. These are considered as a golden tool to decrease genetic problem in Palestine.

Key words: knowledge, attitudes, parents, genetic testing, genetic counseling

INTRODUCTION

In any pediatric hospital there are sick and ill innocent children, they suffer, especially those with chronic diseases which mainly caused by genetic transmission (1). But it could be preventable or limited in simple low cost criteria which completely easier and cheaper than treatment, especially when genetic sciences had been developed and genetic labs became available and achievable in Palestine.

Also, individuals affected by genetic conditions are increasingly like to seek information about inheritance and risk factors (2).

In the West Bank governmental and private hospitals especially in pediatric wards there is no statistics about mortality rate of children who suffer from genetic disorders. In some occasions, many members from the same family have been diagnosed with the same disorder. From the researcher own experience, there is a new child from the same family suffering from the same disease in the next year

without any genetic counseling or any tool of prevention.

Unfortunately, only few population epidemiological studies were conducted to discover the incidence of genetic disorders among Palestinians (1, 3, 5), Except for thalassemia and hemophiliac patients (4).

In Arab countries there is a study by Tadmori explained a data from industrialized countries showed that significant genetic diseases or birth defects that may affect approximately (3%) of all pregnancies, account for up to (30%) of pediatric hospital admissions, and cause about (50%) of childhood deaths (5).

The aim of this study is to determine parents' knowledge and attitudes toward genetic counseling and testing, and to determine if knowledge affects attitudes.

MATERIALS AND METHODS

Study design

A quantitative descriptive cross sectional survey had been used in this study using a questionnaire. This design is the most appropriate to study the knowledge and attitudes, and to discover the relationship

between the variables. The questionnaire had covered all variables of the study. It has been built based on systematic review literature (7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26). In order to meet the aim of study, which is to describe the parents knowledge and attitudes toward genetic counseling and testing, and to determine if knowledge affect attitudes There are three research questions in this study: First: Parents with high knowledge about genetic testing and counseling are expected to have positive attitudes toward it, and be more likely to use it. Second: Parents with sick children have more knowledge, and a more positive attitude toward genetic counseling. Third: Parents who have lost one or more children due to a genetic problem are more knowledgeable, and have more positive attitudes toward genetic counseling.

Setting

The study had been conducted in two hospitals in the West Bank and includes Pediatric suite (Neonate ICU, Pediatric ICU and Pediatric ward) and pediatric clinic.

Both hospitals are expected to cover cases from all cities of the West Bank because they are receiving referrals from all of governmental and private hospitals.

Population

The population is all families of children who were admitted to pediatric suites in selected hospitals as cases of genetic disorders from (15, February – 15, September, 2016).

Sampling

A consecutive sample has been used: This non-probability sample seeks to include all accessible subjects as part of the sample, it is considered as the best of all non-probability samples because it includes all subjects that are available which makes the sample a better representation of the entire population.

The researcher collected data and included all of cases which were available in both hospitals. In case the researcher found more than one file for one family it considered as one case.

Subjects that had been included in this study were 121 from both hospitals. The

total number of cases was 140 and 19 cases of them had been excluded. Ten of them excluded because they were recurrent admission cases, and nine subjects were brothers of the same family.

Analysis

The statistical analysis software, SPSS version 19, was used to analyze the data. The questionnaire included the following sections: First, Independent variables: education, address, age, number of lost children, number of sick children, income and knowledge. Second, Dependent variables: parents' attitudes toward genetic testing and counseling.

Piloting and reliability of questionnaire

The questionnaire had given to expert people in research field and genetic field to critique it and give their suggestions. After the modification, a pilot study conducted with ten families who have a child with genetic disorder or more, to clarify and evaluate the questionnaire for them and seek their feedback. This pilot sample had included in the main sample and analyzed together because there is no editing done according.

Although, the questionnaire had been translated from Arabic to English and back translation without any significance difference. The stability coefficient Chronbach Alpha was (0.72) in this study, which demonstrate the stability of tool.

Ethical and administrative considerations

The permission of conducting the study was approved by An-Najah National university's Institutional Review Board (IRB), An Najah national university and Ministry of Health. Subjects received explanation about the purpose, privacy and confidentiality of information collected and had informed that there was no potential risk from their participation. Written consent was obtained from each subject before participating in the study after full explanation about the study.

RESULTS AND DISCUSSION

Socio-demographic characteristics

Most of subjects of this study (75% n= 91) were females (mothers) while (25% n=30) were males (fathers).

Regarding place of residence, most of subjects live in villages as a percentage of (48.8%, n= 60) while (30% n=37) live in cities, (14.9% n=18) live in camps and 5.8% (n=6) was Bedouin.

Unfortunately, only few population epidemiological studies were conducted to discover the incidence and prevalence of genetic disorders among Palestinians (3).

Educational level of the participants in general had been divided as the following: (26.4% n=32) had academic education, (52% n=64) had middle and high school, and (6.6% n=8) had just primary education. Parents' educational level in this study affects their knowledge evaluation significantly and positively (P value=0.003).

Regards the monthly income of these participants: (15.7% n=19) of families live on very low income (less than 1500 shekel a month) and (27.3% n=33) of them their income from (3500-4000) shekels which considered as middle social class, but there is just (7.4% n=9) considered as a good income with monthly income as more than 4000 shekel.

In this study income has no effect on parents' knowledge (P. value: 0.29) while a study in Ohio (2014) found that there were a significant association between parents knowledge and household income (6). Arab countries are similar in demographic conditions of Palestine, but in Ohio (US) which considered as a developed country with high income on the contrary of Arab countries.

Table (1): Knowledge evaluation of participants:

	Variable	Frequency	Percent
Group1	Weak -3 or less correct answer	6	5.0%
Group2	Moderate 4-6 correct answer	38	31.4%
Group3	Good 7 -10 correct answer	77	63.6%
	Total	121	100.0%

It is clear that subjects of this study recorded good knowledge evaluation, some studies that conducted among parents (like this study) recorded better knowledge evaluation than that conducted among patients themselves or university students (9). So it is possible that being a mother or a father of a patient may lead you to search and read about the problem.

Parents' attitudes

Related risk factors

Consanguineous marriage is common and strongly popular in Arab countries , so most of parents (71% n=86) were relatives, (40% n=48) of them in first degree consanguinity , while a study by Tadmori et al, mentioned that consanguineous marriage especially the first cousin is increased to achieve (25-30%) in Arab countries (7).

Despite the well-known high levels of contagious marriages in Palestine, only one of the subjects (0.8%) underwent a genetic test before marriage, while 99.2% (n=120) did not. This is a very significant risk factor for genetic problems. Lack of laboratories, high cost and lack of awareness make barriers front families to have premarital genetic test population (2).

Parents' knowledge

Parents had been asked about the meaning of genetic testing, genetic problems, its causes, methods of transmission and how to prevent, then knowledge measured by evaluation score, which consists of ten questions. There was no cut off score for evaluation from reviewing literature. Therefore, weak evaluation was given to 3 or less correct answer, moderate (4-6) and good (7 -10).

Table (1) had illustrated the knowledge evaluation. The result showed that (5%, n=6) of parents had weak evaluation; (31.4%, n=38) of them had moderate evaluation; and (63.6%, n=77) had good evaluation.

Attitudes toward genetic counseling and testing had been studied by a Likert scale questionnaire which used five aspects: (strongly agree, agree undecided, disagree, and strongly disagree), positive attitude was determined by the items (agree and strongly agree) and the negative counted by (disagree and strongly disagree).

About (20) items from (22) of attitude evaluation questionnaire had high percentage of (agree and strongly agree) and just (2) had high percentage (more than 50%) of (disagree and strongly disagree), generally this result considered that parents' attitudes towards genetic counseling and testing are positive. This looks similar to some studies conducted before.

This results is similar to previous a cross sectional study in Netherland that used questionnaire and DNA test, to examine knowledge of patients with chronic diseases and their attitudes towards genetics and genetic testing, found that attitudes toward genetics were positive and higher levels of genetic knowledge were associated with more positive attitude towards genetic counseling (8).

Knowledge and attitudes

This section discussed the relationship between knowledge and attitudes. Knowledge evaluation classified participants into three groups: good, moderate and weak as shown in Table (1).

Attitudes had been measured by the Likert scale and considered as a positive in general. But when the three groups compared by Chi square (Table 2), it is found that some significant results determined by which group had the positive results and if knowledge affecting attitudes.

As discussed in parents attitudes, it was clear that attitudes were significantly positive (in 20 items from 22) but in correlation test it was founded that 8 items of positive attitudes had positive correlation with parent's knowledge evaluation.

So Parents whose have higher knowledge about genetic testing and counseling have also positive attitudes toward use it.

Number of sick or lost children and attitudes (experience and attitudes)

All of sample subjects had experienced a genetic problem in the family, some of

them had one sick child and some had more, while (29%) of them lost a child or more. In Table (3) results suggest that there is no significant difference in parents' knowledge and attitudes towards genetic testing and counseling based on the number of children they've lost due to genetic disorders. (P value: 0.8) also no significant relationship between the number of lost children and parents' attitudes toward that (P. value: 0.16). In Table (4 and 5) there is no significant relationship between number of sick or died children because of genetic problem and parents' knowledge about genetic counseling (P value: 0.3) also no significant relationship between number of sick or died children and parents' attitudes toward that (P value: 0.9).

CONCLUSION AND RECOMMENDATION

This study considered very valuable for the topic of genetic disorders because Palestinian researchers rarely explore this topic, so it is still a relatively young research field and will contribute on literatures especially it had deal with parents of sick children.

Also, this study will highlight the most important factors that help improve parents' knowledge about genetic counseling and testing.

According to the previous results, it is recommended to increase people awareness about genetic problems and genetic counseling especially premarital testing and prenatal prevention.

Finally, this study recommended to increase awareness of parents about genetic testing; the important of premarital testing; and to avoid consanguinity in order to overcome this problem.

LIMITATIONS OF THE STUDY

The limitation of this study includes: first, that Geographic limitations the study was conducted in two hospitals only. Second, Children with physical deformities due to genetic conditions could not be included, as they usually visit physiotherapy centers not hospitals.

Table (2): The relationship between parents Knowledge and attitudes:

Item	Answer	Weak	Moderate	Good	Total	P value
1. Couples have to do genetic testing when they plan to get marry	disagree	00.0%	00.0%	21.8%	21.8%	0.004
	I don't know	21.7%	86.6%	21.7%	129.9	
	Agree	43.3%	3024.7%	7360.3%	10788.4%	
2. Genetic counseling must be available even for families which family history free of genetic problems	disagree	32.5%	108.2%	97.4%	2218.2%	0.02
	I don't know	10.8%	21.7%	54.1%	86.6%	
	Agree	21.7%	2621.4%	6352%	9175.2%	
3. Genetic counseling had been never used for religious and social causes	disagree	21.7%	2923.9%	7057.8%	10183.4%	0.001
	I don't know	43.3%	64.9%	75.8%	1714%	
	Agree	00.0%	32.5%	00.0%	32.5%	
4. Genetic testing must be done for all of new Born baby.	disagree	21.7%	64.9%	43.3%	129.9%	0.02
	I don't know	10.8%	64.9%	75.8%	1411.7%	
	Agree	32.5%	2621.4%	6654.5%	9578.5%	
5. We have to bow to the genetic problems without interference	disagree	43.3%	337.3%	736s0%	11091%	0.01
	I don't know	00.0%	21.7%	00.0%	21.7%	
	Agree	21.7%	32.5%	43.3%	97.4%	
6. Genetic counseling must be avoided because it is increase the probability to abortion	disagree	32.5%	2520.6%	7057.8%	9679.3%	0.01
	I don't know	21.7%	75.8%	32.5%	12	
	Agree	10.8%	86.6%	43.3%	1310.7%	
7. Genetic counseling lead to avoid consanguineous marriage	disagree	00.0%	43.3%	00.0%	43.3%	0.04
	I don't know	00.0%	32.5%	21.7%	54.1%	
	Agree	64.9%	3125.6%	7561.9%	11292.5%	
8. Genetic counseling decrease the probability of having genetic problem	Disagree	00.0%	129.9%	64.9%	1814.8%	0.01
	I don't know	21.7%	32.5%	64.9%	119%	
	Agree	43.3%	2319%	6352%	9074.4%	

Table (3): Correlation of significant Items:

Item	Sig.	Person	Correlation
1.Couples have to do genetic testing when they plan to get marry	0.016	220	Positive
2. Genetic counseling must be available even for families which family history free of genetic problems	0.04	272	Positive
3. Genetic counseling had been never used for religious and social causes	0.001	-.330	Negative
4. Genetic testing must be done for all of new born baby	0.02	324	Positive
5. We have to bow to the genetic problems without interference	0.01	-.228	Negative
6. Genetic counseling must be avoided because it is increase the probability to abortion	0.01	-.296	Negative
7. Genetic counseling lead to avoid consanguineous marriage	0.04	.191	Positive
8. Genetic counseling decrease the probability of having genetic problem	0.01	.185	Positive

Table (4) The effect of number of lost children on attitudes:

Item	df	Mean Square	F	P. Value
Attitudes: Between Groups Within Groups	1119120	.190.099	1.929	.167
Knowledge: Between Groups Within Groups	1119120	.009.347	.025	.875

Table (5) The effect of number of sick children on attitudes:

Item	df	Mean Square	F	P. Value
Attitudes: Between Groups Within Groups	2118120	.002.101	.023	.977
Knowledge: Between Groups Within Groups	2118120	.364.344	1.058	.350

CONFLICT OF INTERESTS

The authors declare that they have no competing interests.

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