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Awareness and Attitude Toward Genetic Counselling Services in South of Iran

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Abstract

Background: Genetic counseling is the process of guidance in which people understand and adjust to the psychological, clinical, and familial implications of genetic impacts on disease. As a preventive strategy, genetic counselling has an important role in increasing families' knowledge and awareness about their condition.
Objectives: The present study was conducted to assess knowledge and attitude of couples who referred for premarital laboratory testing in the south of Iran.
Methods: One hundred and twenty-five couples were recruited randomly from the premarital referrals to the Bandar Abbas Health Center in Hormozgan province, south of Iran. The questionnaire has been considered by five experts in the field. Context validity index has been calculated as 0.89. All questionnaires were filled by each partner. The collected data were statistically analyzed using statistical package for social sciences (SPSS 16.0).
Results: The total mean age was 26.7 years which among them 125 couples, 41.6% were consanguineous. There were significant relations between education, monthly income, job, religious beliefs and history of a genetic disorders in the family members and some aspects of awareness and attitude toward genetic counselling ($P < 0.05$).
Conclusions: Our present study showed the impact of socioeconomic status on attitude toward genetic counselling in marriage decision and co-operation for genetic counselling in multiple secessions. Based on our finding we suggest improvement of awareness toward genetic counselling. An educational curriculum can be designed at the school and undergraduate level besides national media in all aspects especially premarital and fertility decisions.

Keywords: Genetic Counselling, Awareness, Attitude

1. Background

Genetic counseling is the process of guidance in which people realize and adapt to the psychological, medical, and familial implications of genetic influences to disease. It is combination of family and medical histories to consider the probabilty of disease occurrence or recurrence, education about inheritance, laboratory and genetic testing, prevention, management and research, counseling to promote informed choices and adaptation to the risk or condition (1). Genetic disorders comprise a wide spectrum of diseases which arise from aberrations in a gene or multigene structures. These changes can cause many genetic disorders which range from a mild phenotype to a lethal disease (2). Genetic disorders should be controlled by comprehensive strategies with a combination of the best available treatment and prevention through social education, population screening, genetic counselling and early diagnosis (3). Due to consanguineous marriage in certain cultures, the prevalence of some genetic disorders notably autosomal recessive phenotypes is higher than other populations (4). In a study, the responses of fifty-one British Pakistani couples referred to a genetics center in southern England for counselling regarding recurrence risks for genetic problems in children have been examined. The study illustrated the diversity of responses within one eth-

nic group and challenges stereotypes about cultural and religious responses to genetic risk (5). Results of a study from Germany showed that there was an overall positive attitude toward genetic testing among the respondents aged 14 to 95 years of the German population (6). As preventive strategy, genetic counselling has an important role in increasing families' knowledge and awareness about their condition. With the aid of genetic counselling, it can be possible to choose the best option in order to future plan based on disease status, and the family's social or economic or emotional status (7).

2. Objectives

Due to lack of information about the role of genetic counseling in the south Iranian population, this study aimed to assess the status of awareness and attitude toward genetic counselling in the south of Iran.

3. Methods

3.1. Study Population

This is a cross-sectional study which was performed from 2015 to 2016. Couples were recruited from the premarital referrals to the Bandar Abbas Health Center in Hormozgan province, south of Iran. Ethics approval was obtained from the Ethics Committee, Hormozgan University of Medical Sciences (HUMS). Based on inclusion criteria 125 couples (n = 250) were participated.

3.2. The Survey

The purpose of the study, as well as the methodology was described in details. The questionnaire had been considered by five experts in the field. Context validity index was calculated as 0.89. To assess reliability, it has been filled by 20 study participants and Cronbach's α was calculated as 0.958. All questionnaires were filled by each partner. The questionnaire consisted of three parts. The first part includes demographic data related to age, education status, job, monthly income, residence, consanguinity, and the presence of any inherited disease in the 1st and 2nd degree family members. The second and third part consists of 13 questions about awareness (questions 1 to 7) and attitude (questions 8 to 12) toward genetic counselling with five different answers (very low, low, moderate, high, very high) respectively.

3.3. Data Collection and Analysis

The collected data were reviewed, coded, confirmed, and statistically analyzed using statistical package for social sciences (SPSS 16.0). Frequency distribution tables, and chi-square tests were used in the data analysis. $P < 0.05$ was considered significant.

4. Results

4.1. Personal Information

The first part of the questionnaire consisted of detailed personal and socioeconomic data as shown in Table 1. The total mean age was 26.7 years, which ranged from 15 - 41 years and 14 - 36 years in men and women, respectively. Among all subjects 52 couples had a consanguineous relationship (41.6%) from which 25.6% were firstcousins and 16% had other degrees of consanguinities. History of the most common genetic disorders such as mental disability, developmental delay, thalassemia, hearing loss and diabetes in the first (HX1) and second (HX2) degree family members were 2.4% (n = 6) and 3.6% (n = 9) respectively. Subjects' education status has been shown in Figure 1. Based on the currency unit (2015 - 2016) monthly income according to conventional labor law was less than 250$ in 82.8% (n = 207) and more than 250$ in 17.2% (n = 43), respectively.

Table 1. Demographic Information of Participants

	No. (%)
Age, y	
Male	125 (50)
Female	125 (50)
IBM, Mean ± SD	
Male	26.3 ± 9.4
Female	23 ± 9.6
Consanguinity	
First cousin	32 (25.6)
Second cousin	20 (16)
Non relative	73 (58.4)
Monthly income, $	
≤ 250	207 (82.8)
> 250	43 (17.2)
Residency	
Urban	162 (68.4)
Rural	88 (35.2)
Job	
Farmer	46 (18.4)
Employee	17 (6.8)
Self-employment	132 (52.8)
Others	55 (22)
History of genetic disorders in 1st degrees	6 (2.4)
History of genetic disorders in 2nd and other degrees	9 (3.6)

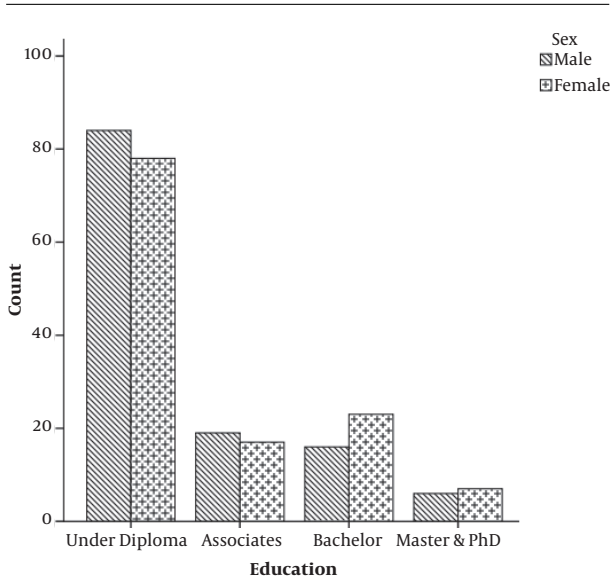

Figure 1. Frequency of participants' education according to sex

4.2. Awareness and Attitude

The 2nd and 3rd part answers showed remarkable varieties. Summary of participants' five scale answers was shown in Table 2. Regarding the second and third part, there was no significant difference between both sexes and question I - XII as well as participants' ages and residence. To indicate questions, we showed them as (QI - QXII). Attitude toward the effect of genetic counselling in marriage decision in the case of history of genetic disease (QVIII) and agreement with legal abortion of affected fetuses (QX) in two major educational groups were different significantly (P = 0.011 and P = 0.014, respectively). There was a significant impact of monthly income status on information about genetic disorders (QII, P = 0.014). Based on the presence of genetic disorder in a first-degree family member (HX 1st), participants were concerned about the role of genetics in male and female infertility (QV, P = 0.023). Furthermore, the relation between HX 1st situation with the QXII was significant (P = 0.024). Participants' awareness and attitudes towards the genetic counselling is summarized in Table 3.

5. Discussion

Many nations have begun to establish premarital counseling as a public health service (8-10). This study aimed to gain insight into the awareness and attitude toward genetic counselling in south Iranian couples. The analysis showed a range of responses that are shaped by social and cultural circumstances and moral considerations. Family history of thalassemia, hearing loss, diabetes, mental disability and developmental delay in the first and second degree family members have been shown as 2.4% and 3.6% respectively. In recent years, premarital counseling has gained positive acceptance (11). In a study it is indicated that the frequency of premarital, preconception, prenatal and postnatal counseling were 46.8%, 33.9%, 9.6% and 9.6% (12). Consanguineous marriages are witnessed even in the current era owing to its benefits like greater marital and family stability in a culturally rich heritage setting (13). In our study, about one third of couples were consanguineous (41.6%) which was close to findings of other similar studies in middle eastern countries (14-16). In a highly consanguineous population it should be considered that premarital genetic counselling is very challenging. This scheme is presented to a consanguineous Bedouin community characterized by high prevalence of genetic disorders and a religious ban on abortion. Prenatal genetic diagnosis was rejected due to religion. The result of this community and culture based study was a focus on premarital carrier testing (17). Monthly income is an important factor which may have an impact on attitude toward genetic counseling. Attitudes and behavior are distinguishable analytically. Thus, a study indicated that subjects with low income less likely to act in line with their attitudes, for a range of different reasons (18). According to Iranian conventional labor law (2015 - 2016) 82.8% of subjects' monthly income were less than 250$. In a scoping review, seven countries' genetic counselling program including Iran, Saudi Arabia, Iraq, Turkey, United Arab Emirates and Bahrain were discussed. This review reported that premarital screening and genetic counselling programs were unsuccessful in discouraging at risk marriages but effective in reducing the prevalence of affected births with the aid of prenatal diagnosis and therapeutic abortion (19). The present study showed that participants' orientation about genetic counselling ranges from very low to very high (26% - 2%) but most of them had moderate knowledge about genetic counselling (36%). Different socioeconomic levels affect the potential of genetic counselling in some populations. For instance, genetic counselling in tribals is a challenging task because of their lower literacy and poor socioeconomic status. Nevertheless, constant effort is needed with a close interface in the local language, special misbeliefs need to be removed gradually, taking into account their socio-cultural context (20). Although in this study, 35.2% were rural and 64.8% were urban, there is no overall relation between residency and awareness/ attitude toward genetic counselling. This study adds to evidence from the south of Iran that couples' status of awareness and attitudes toward genetic counselling was influenced by their socioeconomic level, religion and medical history.

Table 2. Participants' Answers About Awareness and Attitude Toward Genetic Counselling[a]

Questions	Total Answers	Very Low	Low	Moderate	High	Very High
Awareness						
I. Orientation about genetic counselling	240 (96)	65 (26)	62 (24.8)	90 (36)	18 (7.2)	5 (2)
II. Information about genetic disorders in Iran	238 (95.2)	52 (20.8)	65 (26)	79 (31.6)	31 (12.4)	11 (4.4)
III. Effect of genetic counselling in disease prevention	238 (95.2)	29 (11.8)	28 (11.2)	89 (35.6)	54 (21.6)	38 (15.2)
IV. Role of consanguineous marriage in having affected offspring	235 (94)	16 (6.4)	20 (8)	41 (16.4)	85 (34)	73 (29.2)
V. Role of genetics in male and female infertility	236 (94.4)	35 (14)	44 (17.6)	62 (24.8)	61 (24.4)	34 (13.6)
VI. Role of genetics in spontaneous abortion	235 (94)	34 (13.6)	56 (22.4)	69 (27.6)	48 (19.2)	28 (11.2)
VII. Risk of having baby with Down's syndrome at age 35 year on above	232 (92.8)	42 (16.8)	47 (18.8)	51 (20.4)	51 (20.4)	41 (16.4)
Attitude						
VIII. Effect of genetic counselling in marriage decision in the case of history of genetic disease	236 (94.4)	11 (4.4)	25 (10)	49 (19.4)	99 (39.6)	52 (20.8)
IX. Co-operation for genetic counselling in multiple secessions	233 (93.2)	24 (9.6)	40 (16)	56 (22.4)	65 (26)	48 (19.2)
X. Agreement with legal abortion of affected fetuses	234 (93.6)	33 (13.2)	50 (20)	85 (34)	43 (17.2)	23 (9.2)
XI. National media's role in informing the genetic counselling	237 (94.8)	25 (10)	54 (21.6)	89 (35.6)	50 (20)	19 (7.6)
XII. In the case of consanguinity would you like to be informed about your genetic risk?	236 (94.4)	33 (13.2)	37 (14.8)	61 (24.4)	48 (19.2)	57 (22.8)

[a]Values are expressed as No. (%).

Table 3. Association of Sociodemographic Data with Attitude and Awareness Towards the Genetic Counselling[a]

Questions	Education	Job	Monthly Income	HX1	HX2
Awareness					
I. Orientation about genetic counselling	NS	NS	NS	NS	NS
II. Information about genetic disorders in Iran	NS	NS	0.014[a]	NS	NS
III. Effect of genetic counselling in disease prevention	NS	NS	NS	NS	NS
IV. Role of consanguineous marriage in having affected offspring	NS	NS	NS	NS	NS
V. Role of genetic in male and female infertility	NS	NS	NS	0.023[a]	NS
VI. Role of genetic in spontaneous abortion	NS	NS	NS	NS	NS
VII. Risk of having baby with Down's syndrome at age 35 year on above	NS	0.039[a]	NS	NS	NS
Attitude					
VIII. Effect of genetic counselling in marriage decision in the case of history of genetic disease	0.011[a]	NS	NS	NS	NS
IX. Co-operation for genetic counselling in multiple secessions	NS	NS	NS	NS	NS
X. Agreement with legal abortion of affected fetuses	0.014[a]	NS	NS	NS	NS
XI. National media's role in informing the genetic counselling	NS	NS	NS	NS	NS
XII. In the case of consanguinity would you like to be informed about your genetic risk?	NS	NS	NS	0.024[a]	NS

Abbreviation: NS, not significant.
[a]$P < 0.05$ considered as significant level.

To improve awareness about genetic counselling, a well-designed educational curriculum with focus on genetics can be taught at the school and undergraduate level. Thus, national media can play an effective role in improvement of social awareness and knowledge about genetic counselling in all aspects especially premarital and fertility decisions.

5.1. Strengths and Limitations of This Study

This was a community-based study done in Bandar Abbas- Hormozgan province, in which the role of sociode-

mographic factors in association with awareness and attitude toward genetic counselling have been analyzed. In this survey, medical history records were not available and all data were recorded based on participants' self reports.

Supplementary Material

Supplementary material(s) is available here [To read supplementary materials, please refer to the journal website and open PDF/HTML].

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Footnotes

Authors' Contribution: Ali Mohammad Falahati: data collection and literature review; Azim Nejatizadeh: project supervisor; Soghra Fallahi, proposal editor and support; Ali Akbar Poursadegh Zonouzi: idea and writing proposal; Mohammad Shokrgozar: data collection; Marjan Masoudi: paper revision; Mohammad Mohajer-Bastami: data collection; Najmeh Ahangari: idea, literature review, data analysis, manuscript preparation and edition. The both authors including Najmeh Ahangari and Azim Nejatizadeh contributed equally.

Conflict of Interests: The authors declare that they have no competing interests.

Ethical Approval: Ethics approval was obtained from the Ethics Committee, Hormozgan University of Medical Sciences (HUMS).

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