

Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa)

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Hemoglobinopathies are common inherited disorders in Saudi Arabia. Prenatal diagnosis for such diseases is specific and sensitive but not yet implemented in Saudi Arabia. Saudis are Muslims with a very high rate of consanguinity and inherited genetic disorders. To examine the attitude of Saudi families affected with hemoglobinopathies towards prenatal diagnosis and abortion, and to evaluate the effect of education on religious ruling on such attitudes, 32 families were interviewed using a pre-structured questionnaire. The majority accepted prenatal diagnosis (81.3%). The attitude towards abortion was greatly affected by religious values. Education about religious ruling significantly affected parents' attitude towards accepting abortion and prenatal diagnosis. No other factors were found to influence the outcome. Although the majority of families received some kind of formal genetic counseling [23/32 (71.9%)], none of them was informed about the possibility of prenatal or preimplantation diagnosis prior to the interview. Therefore for prevention of genetic disorders, the emphasis in countries with a vast majority of Muslims such as Saudi Arabia has probably to be placed on public awareness about genetic risks, the risk of consanguinity, availability of services, and so on, while at the same time taking into consideration the religious beliefs and education of the target population Copyright © 2001 John Wiley & Sons, Ltd.

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INTRODUCTION

Sickle cell anemia (SCA) and thalassemia (Thal) are the most important hemoglobin disorders in Saudi Arabia (Al-Saleh and Hussain, 1992). In such life-long diseases where no cure is generally available, prevention is the most appropriate approach (Tuzmen *et al.*, 1996). This entails proper education, identification of carriers and reproductive counseling, in addition to prenatal diagnosis. With its increasing applicability, several organizations recommend prenatal diagnosis as a means of prevention of hemoglobinopathies, with differences regarding the individuals to target (American College of Obstetricians and Gynecologists, 1993; Canadian Task Force on the Periodic Health Examination, 1994). Naturally, a prerequisite to the application of any screening procedure is its acceptance by the involved parties, particularly when the screening procedure is closely linked to decision-making issues like termination of pregnancy in cases of an affected fetus. Acceptance of such an approach may vary from one country to another, depending on the health system, religious beliefs, and cultural and educational background of the population screened. Studies on the acceptance of prenatal diagnostic procedures have been mostly conducted in the West (Lippman *et al.*, 1985; McGovern *et al.*, 1986; Cao *et al.*, 1987; Spencer and Cox, 1988; Julian-Reynier *et al.*, 1993; Hietala *et al.*, 1995; Haddow and

Palomaki, 1996) and showed a higher level of uptake than did the limited studies performed in the Middle East (Zahed and Bou-Dames, 1997; Zahed *et al.*, 1999). The rejection of prenatal diagnosis among Muslim Lebanese was related to rejection of abortion due to religious convictions (Zahed and Bou-Dames, 1997; Zahed *et al.*, 1999). However, the effect of an intervention such as education about religious ruling was not previously addressed. Therefore, the present study was conducted in order to shed some light on the attitude of Saudi families towards such diagnostic procedures, and to examine the effect of an intervention such as education about religious ruling on such attitudes.

PATIENTS AND METHODS

We interviewed parents attending the outpatient clinic or accompanying their child in the ward. Cases were taken from King Khaled University Hospital (KKUH), and from two Ministry of Health (MOH) hospitals in Riyadh. Only Saudi parents with one or more children affected by Thal, SCA, or both were enrolled. Data were collected by personal interviews that were conducted by the same person (one of the authors) who filled in the data in a pre-structured questionnaire especially designed for the study. Interviews were taken in a private setting for 45–60 min. The concepts of prenatal and preimplantation diagnosis were explained to the participants. Every effort was taken to ensure consistency of data collection. The questionnaire was designed such that it covered the following areas: sociodemographic data, degree of

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suffering, prior genetic-related knowledge, attitude towards prenatal diagnosis and factors influencing it, attitude towards abortion, practice of family planning, and finally attitude towards consanguinity. We then examined the effect of knowledge about religious ruling (Fatwa). The Fatwa implies that abortion is permissible if a diseased fetus is diagnosed in the first 120 days, i.e. before the soul breathing (Albar, 1991; El-Hashemite, 1995). Parents were not aware of this Fatwa and were educated about it at the end of the first questionnaire. They were then asked the same questions pertinent to their attitude towards prenatal diagnosis and abortion.

We considered the attitude towards prenatal diagnosis and abortion as the main outcome measures.

Statistics

Student's *t*-test and chi-square test were used as appropriate.

RESULTS

Parents accompanying their affected child(ren) who were either inpatients or outpatients were interviewed. A total of 32 families were enrolled in the study: 26 from KKHU and six from MOH hospitals. The informant was the mother, father, or both in 26 (81.3%), five (15.6%) and one (3.1%) occasions, respectively. All participants were Muslims. The age of the informant mothers was 33.4 ± 7.5 years, and that of informant fathers was 43 ± 4.3 years. The level of education of informants was primary school or lower in 19/27 (70.4%) mothers and in 4/6 (66.7%) fathers. The diagnosis of the child(ren) was SCA, Thal or sickle-Thal in 26 (81.3%), four (12.5%) and two (6.2%) families, respectively. The average family monthly income was $\text{US}\$1317 \pm 1032$. [The average monthly income of a Saudi family comprising five members is $\text{US}\$596 \times 5 = \text{US}\2980 (NUSACC, 2000)]. Consanguinity was noted in 23 families (71.9% vs 57.7% in the Saudi Arabian general population) (El-Hazmi, 1995). Although the majority of families [23/32 (71.9%)] received some kind of formal genetic counseling, none of them was informed about the possibility of prenatal or preimplantation diagnosis. However, this concept was discussed during the interview.

Most participants accepted the idea of prenatal diagnosis [26/32 (81.3%)], whereas four rejected the idea (12.5%) and two were not sure (6.3%). Similarly, 20 participants (62.5%) agreed to preimplantation diagnosis.

Four participants (12.5%) would abort the affected fetus regardless of gestational age and even before we discussed the Fatwa with them. In all, 28/32 (87.5%) participants refused the idea of abortion as an initial response to the question and 27/32 (96.4%) of them stated religious reasons for their rejection of abortion. Of these 28 participants, 13 (46.4%) changed their minds after they were given the Fatwa on abortion, 14

(50%) participants did not change their attitude and one (3.4%) was not sure. All (13/13) participants who changed their minds after Fatwa agreed to prenatal diagnosis as compared to 64.3% (9/14) of those who refused the idea of abortion even after Fatwa ($p=0.017$). Similarly, four (100%) of those who agreed to abort prior to learning about the Fatwa agreed to prenatal diagnosis. Of interest is that Fatwa education resulted in more participants accepting abortion but did not increase the overall number of those who accepted prenatal diagnosis (Table 1).

There was no significant difference between those who accepted or rejected prenatal diagnosis or abortion as regards their monthly income ($\text{US}\$1446 \pm 1113$ vs $\text{US}\$878 \pm 425$, $p=0.21$, and $\text{US}\$1380 \pm 1158$ vs $\text{US}\$1347 \pm 990$, $p=0.94$), the level of education or ages of participating parents (33.4 ± 8 vs 33.5 ± 5 , $p=0.17$, and 31.4 ± 8 vs 35.3 ± 8 , $p=0.28$).

The degree of suffering was not significantly different between those who accepted and those who rejected prenatal diagnosis ($p=0.66$). On the contrary, more of those who described their sufferings as miserable rejected abortion ($p=0.025$). Similarly, there was no difference in the degree of suffering measured indirectly by the number of years since the first affected child (9.2 ± 6.7 vs 9.8 ± 5.5 , $p=0.88$, and 7.3 ± 5.4 vs 10.6 ± 7.6 , $p=0.2$) and the number of children affected (2 ± 1.3 vs 2.5 ± 1.1 , $p=0.54$, and 2.2 ± 1.5 vs 1.8 ± 0.9 , $p=0.3$).

Of the four families who refused prenatal diagnosis, two attributed their refusal to the fact that it is all in the Hands of God and they should not interfere with God's Will. The reason given by the other two was they don't want to be worried. All four families continued to reject abortion even after the Fatwa.

Seventeen (53.1%) participants stated a negative attitude towards consanguinity. Among them five (15.6%) participants maintained their negative attitude towards consanguinity and 12 (37.5%) participants changed their attitude towards consanguinity from positive or equivocal to negative or less positive after their experience with their affected children, i.e. they no longer encourage consanguineous marriages. Eleven (34.4%) participants stated a positive attitude towards consanguinity. Four (12.5%) encourage consanguineous marriage provided premarital screening is done. Four (12.5%) participants retained their equivocal attitude.

Thirteen families elected not to change their reproduction plans, whereas 15 families decided to stop reproduction and two families decided to limit the number of future pregnancies in an attempt to avoid begetting affected children. The question was not applicable in two cases where the husbands were dead and there were no plans to remarry.

DISCUSSION

Prenatal diagnosis is a highly sensitive and specific method of early diagnosis of both SSA and Thal (Benz, 1995; Tuzmen *et al.*, 1996). A common belief

Table 1—Attitude towards prenatal diagnosis and abortion prior and after education on Fatwa

	Pre-Fatwa education			Post-Fatwa education			<i>p</i> value
	Accepted (%)	Rejected (%)	Not sure	Accepted (%)	Rejected (%)	Not sure	
Prenatal diagnosis	26 (81.3)	4 (12.5)	2	26 (81.3)	5 (15.6)	1	0.76
Abortion	4 (12.5)	28 (87.5)	0	17 (53)	14 (43.8)	1	0.0004

among Saudi health care providers is that it is still too early to start a prenatal diagnosis service because of the great lack of genetic knowledge among afflicted families and the religious unacceptability of abortion. This partly explains the near absence of such services in the University and MOH hospitals in the Kingdom. This is, however, only partly true because this limited study shows that the majority of the index families are willing to accept prenatal diagnosis even when they strictly refuse the idea of abortion. Indeed, Petrou and Modell (1995) stated that the reason why the number of prenatal diagnoses actually performed falls far short of expectations of health care systems in view of available resources is the failure to deliver information, screening and counseling to the populations at risk, rather than rejection of prenatal diagnosis. Nevertheless, as was shown in previous studies, the present study shows that attitude towards abortion and prenatal diagnosis are closely related (Wertz, 1992) since those who agree with abortion are more likely to go for prenatal diagnosis.

Islam looks at the growing embryo and fetus as passing through different stages of sanctity. The inception of life occurs with the union of a sperm and an ovum, forming a zygote. From the moment a zygote settles inside a woman's body, it deserves a unanimously recognized degree of respect, and a number of legal stipulations, known to all Muslim scholars, apply to it. When it arrives at the spirit-breathing stage, the fetus acquires greater sanctity, as all scholars agree, and additional legal stipulations apply to it (IOMS, 1985). Islam recognize, respect and protect human life in all its phases including the intrauterine stage, and therefore abortion is not to be permitted except under the most direct medical indication (IOMS, 1982).

It was authentically reported from Prophet Mohammed 'peace be upon him' that soul breathing 'ensoulment' occurs at 120 days of gestation from conception. The Prophet said, "The creation of each of you in his mother's abdomen assumes a 'nutfa' (male and female semen drops) for 40 days, then he becomes 'alaqa' for the same (duration), then a 'mudgha' (like a chewed piece of meat) for the same, then God sends an angel to it with four instructions. The angel is ordered to write the Sustenance, life span, deeds and whether eventually his lot is happiness or misery, then to blow the Spirit into him." (Albukhari, 1987). Based on this, the Islamic Jurisprudence Council in its twelfth session in Makkah 10–17 February 1990 deduced a ruling (Fatwa) that abortion is allowed in the first 120 days of conception if it was proven beyond doubt that the fetus is affected with a

severe malformation that is not amenable to therapy and if his life after being born will be a means of misery to both him and his family and if his parents agree (Albar, 1991).

As was expected, this Fatwa did change the attitude of almost half of those who initially refused the idea of abortion, which was the initial response of the great majority of participants. Most of them stated religious reasons for their rejection. It is of interest that those who rejected prenatal diagnosis are those who continued to reject prenatal diagnosis and abortion even after the Fatwa. Perhaps in their minds prenatal diagnosis is aimed at abortion. Since abortion is not a choice for them, they possibly have rejected prenatal diagnosis because they oppose abortion.

No significant relation was found between the attitude towards either prenatal diagnosis or abortion and the different sociodemographic factors. Similarly there was poor correlation between the families' attitude towards prenatal diagnosis or abortion and the degree of suffering. On the contrary, more of those who described their sufferings as miserable rejected abortion. Despite the degree of suffering and its effect on the families' willingness to accept prenatal diagnosis and abortion, religious beliefs prohibit them from accepting such decisions. This signifies the critical role of religion in such decisions among the Saudi population. Such an impact of religious convictions on acceptance of prenatal diagnosis procedures has been previously demonstrated to a lesser degree among the Muslim Lebanese, where 26% of 90 couples at risk for genetic disorders opposed the procedure. In 87.5%, religious conviction against termination of pregnancy was the reason behind their refusal of prenatal diagnosis (Zahed and Bou-Dames, 1997; Zahed *et al.*, 1999).

The unique finding of the present study is that it demonstrates the positive role of intervention by religious education on attitudes of parents toward those issues. Another potential target for such educational intervention is the attitude towards consanguinity. The present results should encourage researchers to conduct further studies on such sensitive issues that were once believed to be irrelevant to the Saudi and Muslim communities. Until then, it is the duty of practising physicians to properly educate and counsel the involved families. In countries such as Saudi Arabia, where there is a high rate of consanguinity and genetic disorders, it is the duty of the health authorities to place more emphasis on public awareness about genetic risks, the risk of consanguinity, and availability of services, while at the same time taking into

consideration the religious beliefs and education of the target population.

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