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

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INTRODUCTION

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.

KEY WORDS: prenatal; abortion; attitude; Saudi; Muslim

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
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 KKUH 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 $33.4 \pm 7.5$ years, and that of informant fathers was $43 \pm 4.3$ 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.

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 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 ($33.4 \pm 8$ vs $33.5 \pm 5$, $p=0.17$, and $31.4 \pm 8$ vs $35.3 \pm 8$, $p=0.28$).

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 ($9.2 \pm 6.7$ vs $9.8 \pm 5.5$, $p=0.88$, and $7.3 \pm 5.4$ vs $10.6 \pm 7.6$, $p=0.2$) and the number of children affected ($2 \pm 1.3$ vs $2.5 \pm 1.1$, $p=0.54$, and $2.2 \pm 1.5$ vs $1.8 \pm 0.9$, $p=0.3$).

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...
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 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 recognizes, 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 ‘alaaqa’ for the same (duration), then a ‘mudgha’ (like a chewed peace 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 practicing 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 account the religious implications.
consideration the religious beliefs and education of the
target population.

REFERENCES


