

The Reproductive Behavior of Families with Thalassemic Children in Hormozgan

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Abstract

Background: Thalassemic disorders are the most prevalent monogenic hereditary diseases around the world caused by decreased and altered synthesis or agenesis in one or more globin chains. Families who have a child with thalassemia major face a myriad of significant problems. Hormozgan province ranks second with thalassemic patients in Iran. Therefore, current research is aimed to analyze the reproductive behavior of such families in the southern province of Iran.

Methods: In this descriptive study 190 mothers of patients suffering from thalassemia major were included. The reproductive behavior of mothers was investigated by a questionnaire regarding the number of thalassemic infants born after their first child with thalassemia major.

Results: About 23% of these mothers had more than 1 child with major thalassemia. The findings showed that the reasons for conception among these mothers were to have a healthy child (64.2%) and to have a boy (20%). In about 92.6% of mothers CVS test was not performed.

Conclusion: This study showed that awaring mothers and families regarding the prevention of birth of afflicted infants and provision of accessible diagnostic facilities can reduce the number of children with thalassemia major.

Keywords: Mothers, Reproductive behavior, Thalassemia.

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Introduction

Thalassemia is one of the most prevalent monogenic disorders which appears due to the non- or reduced synthesis in one or more globin chains. It is classified into α and β subtypes depending on the type of chain involved. The most severe form of this disease is β thalassemia major (1). Moreover, it is considered as the most prevalent monogenic hereditary disease worldwide. Every year, about 100,000 children afflicted with a new type of this disease are born somewhere in the world (2, 3). Iran is one of the countries located in the malaria endemic areas with high prevalence of thalassemia (4). In Iran, this disease is highly prevalent in the borders of the Caspian Sea, Persian Gulf and Oman Sea which include Bushehr and Hormozgan provinces (5).

Habibzadeh et al. (2012) studied on 156 mothers of children with thalassemia in Fars province and the results showed that counselling either before marriage or after the birth of the first thalassemic child significantly reduced the number of children with thalassemia major (6). In another study by Abbaszadeh et al. (2003) on the reproductive behavior of 61 mothers of children suffering from thalassemia in Yazd city, the average number of pregnancy of these mothers was found to be 4.61, the average number of their children was 4.5 and the average number of thalassemic children was estimated to be 4.61 (*i.e* the number of average pregnancies and number of average thalassemic children born were equal) A significant correlation was observed between the education level of

these mothers, their age of marriage and the number of children (7). Considering the myriad of problems that families encounter with thalassemic children, it is expected that the birth of a sick child affects the future pregnancies of the spouses. A number of studies conducted with this aim have indicated a compensated reproductive strategy among these families (8-10) while according to Gamberrini et al. reproductive strategy is not compensated (11). Therefore, it is expected that these behaviors are, to a great extent, related to the cultural background of families. On the one hand, there is a myriad of controversies concerning this disease, and its concomitant problems for families and high diagnostic costs in the province. On the other hand, Hormozgan has the second country rank in thalassemia major with a number of 1507 thalassemia patients (12).

Therefore, in this study, an attempt was made to analyze the reproductive behavior of families who had a child suffering from thalassemia major in this southern province of Iran in 2013.

Methods

This descriptive study was designed to investigate the reproductive behaviors in families with a thalassemic child conducted in Aboureihan, Thalassemia Center of Shahid Mohammadi Hospital in Bandar Abbas in 2013. This referral center is the only place where the majority of patients with thalassemia major in Bandar Abbas are visited. Research population included all mothers who had at least one child afflicted with thalassemia major and visited the center for blood transfusion. The final participants of the study included 190 mothers. The data were collected by a questionnaire designed according to the purpose of this study. The questionnaire consisted of two sections, including demographic information (6 items) and the second section included the questions related to reproductive behavior of mothers who had a thalassemic child. It included the number of pregnancies, the desired vs. appropriate number of children, the number of children who were carriers of the disease, the number of thalassemic children, contraception before and after the birth of the thalassemic child, genetic counselling before marriage or after the birth of the affected child and the result of subsequent pregnancy. The study began after ethical and official approval from the research department of Hormozgan University of Medical Sciences as well as the consent of the official authorities of the Center for Special Dis-

Table 1. Pregnancy status among participating mothers

| Variable | Frequency | (%) |
|-------------------------------|-----------|------|
| Desired n. of children | | |
| 1-2 | 80 | 42.1 |
| 3-4 | 90 | 47.4 |
| +5 | 20 | 10.5 |
| total | 190 | 100 |
| Total n. of children | | |
| 1-2 | 76 | 40 |
| 3-5 | 88 | 46.3 |
| 6-8 | 22 | 11.6 |
| +9 | 4 | 2.1 |
| total | 190 | 100 |
| n. of pregnancy | | |
| one | 14 | 7.4 |
| two | 42 | 22.1 |
| three | 40 | 21.1 |
| four | 42 | 22.1 |
| five | 18 | 9.5 |
| +six | 34 | 18 |
| total | 190 | 100 |

eases. The collected data were analyzed by SPSS version 16 using descriptive statistics.

Results

Mothers' age ranged from 21 to 61 years. Their average age in this study was 37.1±8.3 years. About half of them had elementary or junior high school education level. About 50% of mothers had had more than 4 pregnancies. The average number of pregnancies was 3.9 (Table 1).

The findings of the current research indicated that the reason for conception among these mothers was to have a healthy child in 122 (64.2%) individuals, to have a child among 38 (20%) subjects and an inadequate number of children in 30 participants (15.8%). In about 92.6% of mothers the CVS (Chorionic villous sampling) test was not performed. This was due to lack of access to facilities among 68 (35.8) individuals, unawareness in 68 (35.8%) subjects, economic problems in 28 (14.7%) people, not taking risks and accepting the test consequences in 6 (3.2%) subjects and disagreement with abortion in 6 (3.2%) participants. Only 14 (7.4%) mothers had the CVS test.

Urban residents and those of higher education level benefited from/took the CVS test more frequently than their rural counterparts and those of lower education.

Discussion

It appears that in countries where thalassemia is prevalent, an effective way to reduce the birth rate

of these children is genetic counselling. It is estimated that the establishment of more counselling centers can raise public awareness of this issue. The findings of this study were consistent with Habibzadeh et al. in Fars province that attested to the key role of genetic counselling before marriage or after the birth of a sick child in reducing the number of thalassaemic children (6).

Moreover, in a study conducted by Zeinali et al. (2009), the primary reason for the birth of thalassaemic children in the screened families was found to be inadequate genetic counseling (13). In another research conducted by Hosseini et al. in 2007, thalassaemia-specific consultation showed to be highly effective in reducing the birth rate of children afflicted with β thalassaemia major (14). Samavat et al. indicated a genetic consultation to be efficient in preventing the birth of thalassaemic children (15). In the present research, the cause of subsequent pregnancy among mothers was giving birth to a healthy child, whereas in other studies (often in developing countries) sex preference was reported to be the main cause (16.7). This divergence could be due to the cultural and ideological differences of people in different geographical regions. According to the results, the CVS test was not performed in the majority of mothers. The key reasons were lack of access to facilities, unawareness of families and their economic problems. It appears that income of the family effected the number of visits they made to clinics for the CVS test. The medical insurance of the parents before the birth of the child was found to be correlated with a reduced birth rate of infants with thalassaemia major in Hosseini et al.'s study (14). Furthermore, Saxena et al.'s investigation in India, showed that from the 96 participating couples, 34 had not performed the tests or other diagnostic procedures due to high costs and the fact that they were not medically insured (17). According to the findings, mother's education was another influential factor in the number of afflicted children. As found in Ghanei et al.'s study, the gap between mother's and father's education was another factor influencing the birth rate of thalassaemic children (18). This implies that through raising the education level and awareness of parents, the birth of thalassaemic children can be prevented. It is, therefore, estimated that raising awareness and holding instructional classes for mothers especially for uneducated and illiterate the ones can significantly prevent the birth of afflicted children.

Increasing awareness cannot see effective on its own. Issues such as "what sort of information", "provided by whom" and "in what conditions" need to be taken into account. An effective group can be midwives who need to be adequately motivated and aware. In a similar situation, Dyson et al. investigated the awareness of midwives in England. They concluded that since this group was more in contact with mothers and women in fertile age groups, they need a wider knowledge of thalassaemia so that they can help and inform those seeking the knowledge as well (19). In the current research, few mothers had a genetic consultation before marriage. After the birth of the first afflicted child, however, there was an increase in the rate of visits for consultation. This confirms the significant role of increasing the level of awareness. The findings confirmed the effective role of genetic consultation after the birth of the first sick child in the total number of children. Moreover, those who had benefited from genetic consultation before marriage had a fewer number of afflicted children. Among the limitations of this research is the fact that, due to the limited literature sources, it was not possible to compare our findings satisfactorily with those of other researchers. Other limitations include the lack of interviews with the fathers of afflicted children in this study and the collection of data from mothers who visited Abourehan Thalassaemia Center. Therefore, it is not possible to generalize the results. Due to high prevalence of thalassaemia in this geographical region, more research is suggested to be conducted on a larger population inclusive of all the counties of the province. Further questions are suggested to be asked beyond those in our questionnaire including the order of the birth of the healthy children, sex and age of the healthy and afflicted children as well as the time interval between the birth of the healthy and afflicted children. On the other hand, due to the significance of this research topic, more longitudinal studies are suggested to be carried out in order to diagnose more of the factors involved in the birth.

Conclusion

According to the findings of this research, raising the awareness of mothers and families concerning how to prevent the birth of an afflicted child along with the provision of diagnostic and accessible facilities can significantly reduce the birth rate of thalassaemic children.

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Conflict of Interest

Authors declare they have no conflict of interest.

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