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Thalassemia in Iran in Last Twenty Years: the Carrier Rates and the Births Trend

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Abstract

Background: Iran is one of the countries located on "the thalassemia belt" with a significant annual number of thalassemia new births. Given the importance of thalassemia prevention, a program to this effect was approved in Iran in 1995. Screening of carrier couples and prenatal diagnosis were the two main elements of this program. In the present study, the authors have tried to address the impacts of prevention efforts in Iran (1989-2009) and also the status of new birth cases of thalassemia during the time period ranging from 1989 when the Iranian Thalassemia Society was established to 1995 when the prevention program started to run and from then to 2009.

Materials and Methods: The data were obtained from the countrywide haemovigilance network. The data were then compared against the available information in the thalassemia treatment network of Iran and some other thalassemia associations. The available information had been collected through questionnaires and in some cases by phone calls and emails.

Results: The findings show that the average thalassemia carrier prevalence rate in the country is about 4% and the thalassemia prevention in Iran has been successful with the number of new born thalassemic patients falling from 1087 cases in 1989 to 239 in 2009. The success rate of the program was evaluated to be 82.3% in 2009.

Conclusion: Our results show that the thalassemia prevention program has played an effective role in lowering thalassemia births in Iran. Nonetheless, the still high number of new thalassemia cases in the year 2009 is worth considering

Keywords: Prevention of thalassemia, Iran, thalassemia, thalassemia carrier rate, success rate, screening, prenatal diagnosis.

Introduction

Based on the report of the World Bank, about 7% of the world population are carriers of blood disorders and annually 300000 to 500000 affected with severe hemoglobinopathies are born [1].

β-thalassemia major is one of these diseases in which the production of normal hemoglobin is totally or partially impaired. β-thalassemia is the common form of thalassemia caused by the lack of production of the normal chain of beta hemoglobin [2]. Although immigration has not left any regions untouched with thalassemia, it has mostly dominated the region known as "the thalassemia belt" ranging from North West Africa and Mediterranean region to South East Asia [3]. The reports show an annual number of 60000 to 70000 new birth cases of thalassemia in the world; most of them born in countries without appropriate care [4]. To enhance health in the society and to avoid the burden of thalassemia on families, thalassemia prevention has been taken into account [4]. In Canada, thalassemia prevention has also been evaluated to be justified as far as the health economy is concerned [5]. These all indicate the necessity of prevention efforts in the countries located on the thalassemia belt and Iran is one of them [4].

The countrywide thalassemia prevention program was formulated in 1995, though not nationally implemented before 1997 [6]. It was fundamentally based on screening would-be

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couples. To take care of social sensitivities and to try not to stigmatize women, at the first step men underwent screening. Just after men were tested to be positive as carriers, it would be for their female would-be partners to take the screening test [4]. After the initiation of the program across the country, a religious verdict legalized abortion for cases diagnosed at risk of thalassemia at the initial weeks of pregnancy [7]. Consequently, a few prenatal diagnosis (PND) centers were established [8].

The results of the first investigation about the efficiency of prevention program in Iran was published by Samavat and Modell in 2004 and showed significant decrease in the birth rate of thalassemic patients from 1998 to 2002 [6]. Abolghasemi et al. also reported significant decrease in new thalassemia cases after PND started to be run in the country [4].

Given the importance of thalassemia prevention program in Iran as the first experience in prevention of β-thalassemia major in Islamic countries located on the thalassemia belt, it is imperative to study it in details. Thus, in the present study we decided to collect and analyze the data of newborn cases of thalassemia at two different time periods. The first period ranges from 1989, when the Iranian Thalassemia Society was established, to 1995, before the obligatory thalassemia prevention program was initiated; the second period from 1995 to 2009. The present study also aims to evaluate the success rates of the program between the commencement of it and 2009.

Materials and Methods

This analytic cross sectional study was designed to collect the data of all new cases of thalassemia emerging after 1989. The data were taken from Iranian Blood Transfusion Organization (IBTO). The haemovigilance committees formed in all provincial blood centers of IBTO paved the ground for access to valid information of registered patients across the country. However, to increase the accuracy of the research and have access to the information of thalassemia intermedia transfusion independent patients, the above data were validated against what we received from different NGOs and what we were informed on by direct contact with thalassemia treatment centers dispersed across the country.

The statistics of geographic distribution of thalassemia gene carriers and affected births were prepared from The Genetics Office of the Disease Management Center based in Iran's Ministry of Health and Medical Education (GO-MOH).

Data sources/Measurement

Copies of the questionnaire prepared were forwarded to all provincial blood centers from where they were further extended to thalassemia treatment establishments including 207 active centers scattered across the country. The questionnaires were filled out by physicians in charge in clinics. For each one of the thalassemia affected cases born between 1989 and 2009, personal details including national code, province

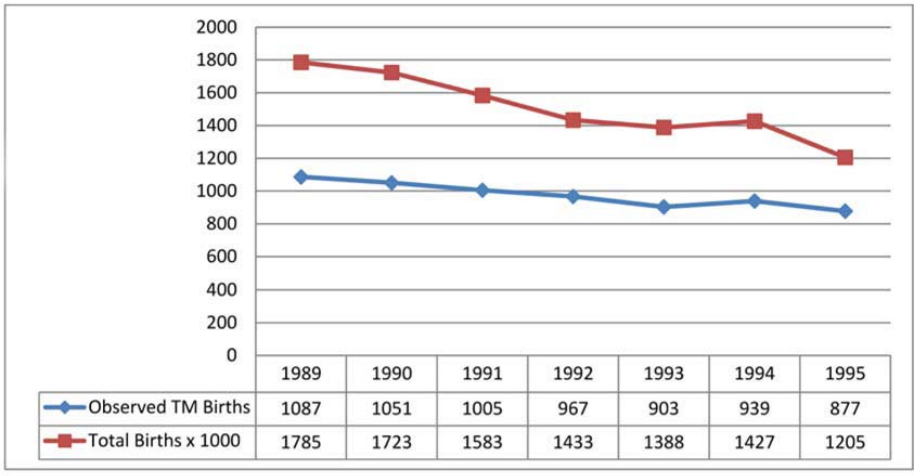

Figure 1: The trend of Thalassemia birth and total births in Iran, 1989-1995.

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of birth, province of residence, the year of birth, and gender were required to be written into the questionnaire.

There was a presumption that a number of thalassemics born during the years of study might have already passed away. To take care of this point and avoid inaccurate data, physicians were required to provide us with the information of both thalassemics being under their treatment in their own centers and those possibly having lost their lives. The final data were again reviewed by province centered NGOs and in case of further scrutiny direct contacts were made with treatment centers and physicians in charge for questionnaires to be corrected and finalized.

Bias

Our analysis of the registration process in the national thalassemia registry system showed the important fact that a number of thalassemic patients are registered just 2 or 3 years after birth and their treatment record gets open at this time. Those affected by thalassemia intermedia, comprising a significant number of thalassemics, are the main cause of this delay. So, to avoid inaccurate and unreliable data, all input about the cases born in the final 3 years prior to the study (2010-2012) were excluded.

We also faced problems in gathering the data of thalassemics born during the years of 1989, 1990, and 1991, and lost at infancy. In those beginning years of the activity of the Iranian Thalassemia Society, registration of thalassemics in treatment centers was not operational with the consequent lack of information about those who passed away before any diagnosis and registry.

The method of analysis

The data were analyzed by Statistical Package for Social Sciences Version 16.0 Software (SPSS Inc., Chicago, IL, USA). The success rate of the prevention program was estimated using the formula: [1-(observed thalassemia new cases/ estimated expectation of thalassemia new cases)] × 100.

Results

The results show that 12750 thalassemics were born in Iran during the years 1989-2009; out of this number 6829 were born during the time period after the establishment of the Iranian Thalassemia Society (1989) and before the implementation of the obligatory thalassemia prevention program in Iran (1995) (Figure 1). Out of the total number of 12750, 5921 were also born after the commencement of the program (1995) onto 2009 (Table 1).

The average number of thalassemia birth cases

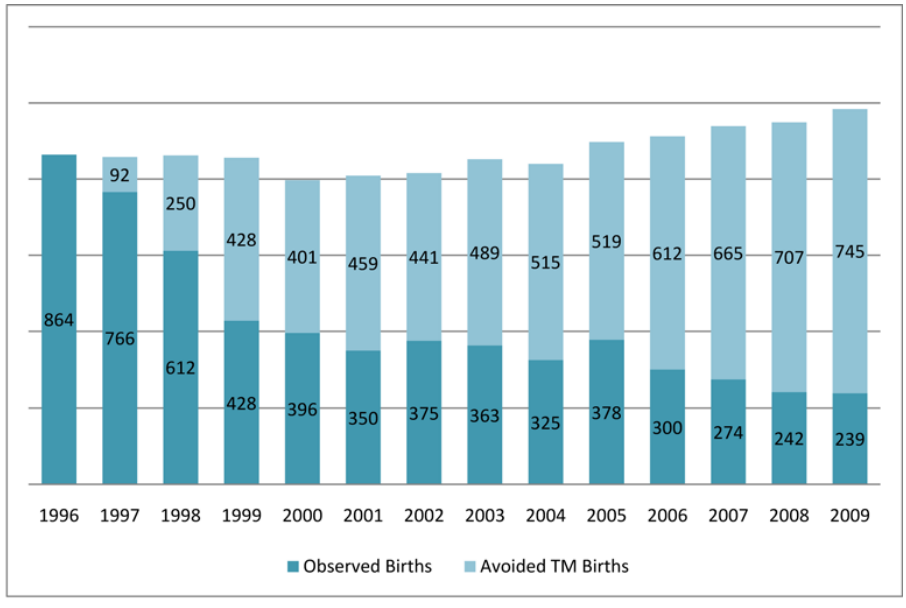

Figure 2: Number of observed *versus* avoided thalassemia births in Iran (considering thalassemia birth expectation of 0.73 per 1000 population); 1996-2009.

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during 1989-1995 was 976 and the annual average number after the commencement of the program onto 2009 was estimated to be 423.

Based on the official report of GO-MOH, the average prevalence rate of thalassemia carriers in Iran has been 4% varying at different provinces with the highest prevalence rate of 9.5% in Kerman and the lowest (1%) in West Azerbaijan (Map 1). The thalassemia affected birth rate based on the report of GO-MOH has been 1 per 1000 population that is slightly different from 0.94 per 1000 reported by Samavat and Modell [6].

Considering the GO-MOH report as the baseline, it is estimated that during the years 1996-2009 the prevention program has succeeded to prevent the birth of 324, 413, 574, 751, 699, 762, 747, 809, 829, 852, 954, 1013, 1058, and 1110 thalassemics, respectively (Table 1 and Figure 3).

If the observed birth rate of thalassemia (864 cases) in 1996, the initial time of the program, is considered to be the baseline, the annual success rate of the program will be lower than what the above estimation shows (Figure 2).

Discussion

The prevalence rate of β-thalassemia carriers in Iran is about 4% that is significantly higher than the average β-thalassemia gene prevalence (1.5%) in the world [4]. Moreover, the prevalence of minor thalassemia largely varies across Iran provinces being double the country average rate in Mazandaran, Sistan and Baluchistan, Hormozgan, and Kerman provinces while half the country average rate (less than 2%) in provinces of Tehran, East Azerbaijan, Khorasan, Hamedan, Yazd and West Azerbaijan. Concerning the distribution of thalassemia carriers, Iran is comparable with India where the average frequency is 3.3% varying from 1% to 17% in different regions, though there are doubts if the figures are precise [9].

The statistics reported by GO-MOH are somehow different from those of the previous sporadically conducted investigations in Iran. For instance, the prevalence rates of β-thalassemia carriers in the three provinces of Hormozgan, Sistan and Baluchistan, and Mazandaran in different independent investigations were estimated to be about 10% [10, 11, 12] while the figures published by GO-MOH are 9%, 8.5%, and 8%, respectively.

To have access to more precise data about the prevalence rates of β-thalassemia carriers in Iran provinces, further comprehensive countrywide studies are recommended with the help of epidemiologists, biostatisticians, health sociologists, haematologists, and geneticists.

The average β-thalassemia prevalence rate in Iran is higher than the neighboring countries like Turkey and Saudi Arabia with 2.1% and 3.22%, respectively [12, 13, 14]. However, some reports show even a lower rate in Saudi Arabia [15]. Furthermore, the rate of thalassemia carriers in Panjab state of Pakistan is estimated to be 5.6% that is higher than the average rate in Iran [16], but still lower compared to the rate in Sistan and Baluchistan, the Iranian

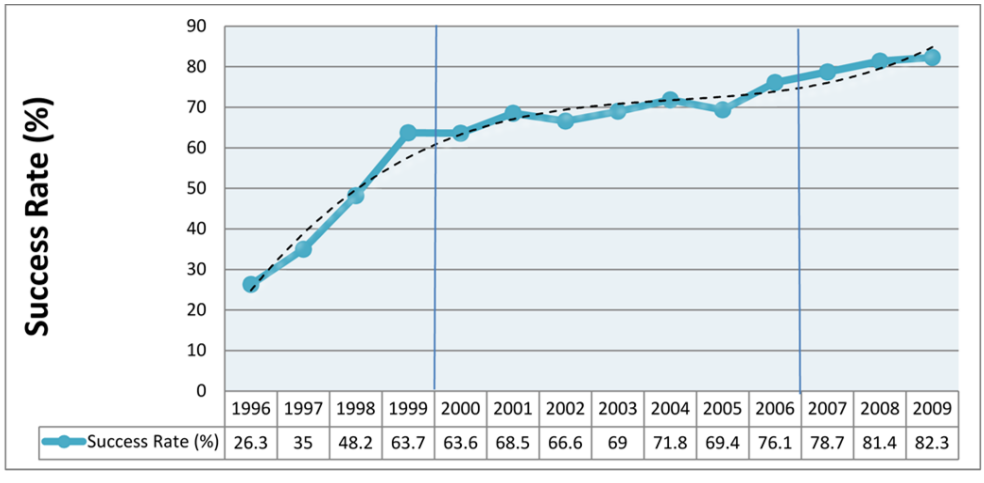

Figure 3: Trend in success rate for thalassemia prevention program (%) in Iran, 1996-2009

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province neighboring Pakistan (Map 1). It seems that the average β-thalassemia prevalence rate in Iran is closer to Malaysia with the prevalence rate of 4.5% [17].

As a matter of fact, despite the high number of registered thalassemics in Iranian treatment network [7], Iran cannot be considered as the most thalassemia prevalent country in the world. The prevalence rate of β-thalassemia carriers in Iran is less than Cyprus and Greece with the rates of 16.4% and 7.4%, respectively [18, 19].

The number of birth cases of thalassemia during the time period ranging from 1989 when the Iranian Thalassemia Society was established to 1995 when the prevention program started to run shows a declining trend. As mentioned before, although there was no full access to all birth cases of thalassemia from 1989 to 1991, it is clear to us that the falling trend of thalassemia births has not been as deep as expected. At the same time, the number of avoided cases of thalassemia during these years has followed a downward trend (Figure 1). The decrease in the annual thalassemia birth rates of 1989-1995 can be explained by resorting to the declining population growth rate and the success of birth control programs in Iran in these years (Figure 1). Thus, the idea of voluntary thalassemia prevention reported to be somehow effective in Cyprus [18] may not be valid in Iran. In this regard, the role of Iranian NGOs in persuading the government to maintain the obligatory thalassemia prevention program is more prominent than persuading the public for voluntary thalassemia prevention.

Since the beginning of the thalassemia prevention program in 1996 the rate of thalassemia births has shown a clear declining trend. At first, the birth of 741 thalassemics in 1997 was assured but later analysis clarified the presence of 25 transfusion independent thalassemics whose the records were not included in the national registry network. After the final modification to which NGOs contributed and exact ID check of the affected, the new figure in 1997 changed to be 766.

The declining trend of thalassemia births in Iran has been significant; however, considering the birth of 239 thalassemics in 2009 the responsibility



Map 1: Provincial prevalence of thalassemia carrier rates in Iran.

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Table 1: Observed versus expected births of β-Thalassemia major cases in Iran, 1996–2009.

Year	Observed TM Births	Total Births	Expected TM Births	Estimated Births Avoided	Success Rate (%)
1996	864	1187903	1188	324	26.3
1997	766	1179260	1179	413	35.0
1998	612	1185639	1186	574	48.2
1999	428	1179260	1179	751	63.7
2000	396	1095165	1095	699	63.6
2001	350	1112193	1112	762	68.5
2002	375	1122104	1122	747	66.6
2003	363	1171573	1171	809	69.0
2004	325	1154368	1154	829	71.8
2005	378	1239398	1239	852	69.4
2006	300	1253502	1254	954	76.1
2007	274	1286716	1287	1013	78.7
2008	242	1300146	1300	1058	81.4
2009	239	1348546	1349	1110	82.3

of the health authority is not over yet (Table 1).

It seems that the 14 years of thalassemia prevention can be divided into three different periods: the screening period (1996-1999); the stability period (2000-2005); and the PND success period (2006-2009) (Figure 3). In the first four years, screening for thalassemia carrier couples played an effective role in improving the success rate of the prevention program. After 2006, PND laboratory network showed its promising effectiveness in increasing the success rate [20].

Further studies should be also conducted to see if this decline still endures after 2009.

The success rate of the prevention program was estimated to be 82.3% in 2009, considering the GO-MOH expectation proportion of 1 thalassemia per 1000 births in Iran. This success rate in Cyprus for the years after 2002 was 100% [18] and in Greece for thalassemia and Sickle Cell varied from 87.5% to 88.5% (mainly attributed to thalassemia prevention)[19]. Since Iran ethnic variety and land area are more diverse and larger than countries like Cyprus and Greece, the thalassemia prevention program in Iran is considered to be a success. The success rate of the thalassemia prevention program in the adjacent Islamic country of Saudi Arabia was reported not to be as much as Iran's [15]. The comparison of the success rate of Saudi Arabia with Iran in the thalassemia prevention program is a token for Iran being superior in controlling the growth rate of thalassemia affected population among similar countries.

Our findings are compatible with the previous studies about thalassemia prevention in Iran including Samavat and Modell [6], Abolghasemi et al.[4], and Hadipour Dehshal et al. [20]. The success rate reported in a former study is higher than that of the present research; the study by Samavat and Modell was published in 2004 when the complete access to the data of the thalassemics born during

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2001-2002 considering flaws in the registry system of Iran treatment centers was almost unlikely. Thus, there is a difference between our findings and theirs in the success rate. In the study conducted by Abolghasemi et al.[4], there is no estimate for the success rate though the prevention program has been evaluated as successful.

It should not be left unnoticed that the calculation of the success rate of thalassemia prevention in Iran based on the birth of β-thalassemics in the first year of the program (the thalassemia birth expectation of 0.73 per 1000 population) should have provided a success rate lower than what is reported in figure 3. Nevertheless, as in other similar studies the baseline of the present article has been the birth expectation formula (adjusted based on the prevalence of thalassemia gene) taken from GO-MOH report.

Conclusion

The results of the present study show that the obligatory thalassemia prevention program in Iran has played an effective role in lowering thalassemia births. Nonetheless, during 2000-2009 on average an annual number of 324 thalassemics have been born. This number is worth considering as far as health economy, costs, and family problems are concerned.

Thus, it is for health decision makers to review the causes of thalassemia births and find appropriate strategies to remove obstacles, obviate problems, and rectify errors in the program so that the number of the thalassemia affected patients is reduced to the lowest limit. The ongoing dissemination of information about new thalassemia cases to which easy access of researchers is ensured would help validation of the program.

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