



Identification of Common Ways for Thalassemia Awareness in Medical and Non-medical Professionals

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Abstract

To identify the common ways of thalassemia awareness in medical and non-medical professions. A simple random sampling technique was used for 130 (N) participants. A designed questionnaire with multiple sections (Demographics, Awareness about Diagnosis, Management and Prevention) for the study was used. The data was analyzed for frequency in terms of percentages by using SPSS version 23. Participants that were asked about have they ever heard about thalassemia, 95% (n=123) of selected participants said yes while 5% (n=7) of selected participants said they had never heard about thalassemia before, in which non-medical employees and non-medical students were included. When those participants were asked where did they heard about thalassemia, participants that were related to medical profession either they were medical students and doctors or were from para-medical students and employees mostly heard about thalassemia from literature as thalassemia is present in their curriculum while for participants from non-medical profession either employees or students had mostly heard from Television, Friends and Social Media. When participants were asked about the kind of disease, majority 85% (n=110) knew that it is hereditary but some participants 5% (n=6) said thalassemia is caused due to dietary deficiency and 3% (n=4) said they do not have any information about its kind while remaining 2-3% of participants said that thalassemia is contagious or occurs due to an allergic reaction. The commonest information media was television, for spreading awareness regarding health related problems such as Thalassemia. Participants related to medical profession either doctors or para-medical staffs are well aware as compare to the participants from non-medical profession.

1 Introduction

Thalassemia is a common hereditary autosomal disease that is cause by mutation in genes responsible in hemoglobin production. It is subdivided into α -Thalassemia and β -thalassemia (Minor, Intermediate and Major) others are Cooley's anemia and Mediterranean anemia^{1,2}.

It is a prevalent disease throughout the world and its prevalence is increasing each year. In Pakistan around 5,000 child births are effected with β -thalassemia and its prevalence is about 6% and about 50,000 patients are registered all over the Pakistan³. According to WHO, In Iran around 8000 pregnancies are at risk

each year and Mediterranean basin, Italian, Greek, Middle Eastern, Asian and African, Transcaucasus, Cyprus (14%), Sardinia (12%)^{4,5} have thalassemia more prevalent^{1,2,6}. approximately 240 million people worldwide are heterozygous and approximately 200,000 affected homozygotes are b-thalassemia and are born annually, respectively^{7,8}. approximately 4.5% of Malaysians are carriers of b-thalassemia, and the affected births annually are estimated at 2.1 per 1,000 with an estimated 5,600 patients with transfusion dependent b-thalassemia in Malaysia⁹.

Affected annual conceptions, worldwide with thalassemia major are around 56000 in which 42409 and 13466 are β and α thalassemias, respectively. That include 30000 patients that need regular transfusions and around 5500 patients die prenatally. Estimated β thalassemia births worldwide are about 40618 (about 25511 are dependent on regular transfusions). Around 97630 patients are on living with regular transfusions (while 37866 are on iron chelation therapy and about 3000 patients die annually due to iron overload¹⁰.

On 118th meeting of WHO Executive board call upon the major affected countries, WHO formed resolution on thalassemia and on 63rd World Health Assembly held in May 2010 a resolution on prevention and management of birth defects, including thalassemia^{1,2}.

Thalassemia is a preventable disease and could be controlled with the help of preventive health services. Education by family planning services to the thalassemic carrier couple to inform risks in conceiving a child. Thalassemia could be diagnosed at any stage of life with the help of various laboratory investigations like in prenatal life it can be diagnosed by Chorionic villous sampling at 18-22 weeks of gestation. After birth it could be initially suspected with signs and symptoms of patient with simple complete blood picture followed by Hb-Electrophoresis. Premarital screening should be done to decrease the incidence of thalassemia and genetic counseling to the thalassemic carrier couple, both of these strategies have numerous benefits in decreasing incidence of thalassemia in newborns¹¹.

In Pakistan, due to cultural and religious values most common issue that may lead to cause thalassemia is consanguineous marriages and due to lack of knowledge premarital screening and genetic counseling has not been practiced especially to couple with strong suspicion to have thalassemic newborn. According to a study previously done that we can only control and decrease the incidence and mortality rate by educating our population through various ways, strategies and campaigns¹². This study is done to identify the level of awareness and common ways of thalassemia awareness in medical and non-medical professions.

2 Materials and Methods

A descriptive cross sectional study, done over the period of 2 months from 15th May 2015 to 15th June 2015 at Al-Nafees Medical College & Hospital, after taking approval from the institutional ethical review board committee of Al-Nafees Medical College & Hospital.

Sample Size of 130 (N) Participants were selected by simple random sampling technique from 2 major categories

(Employees & Students), and 3 Sub Categories (Medical, Para Medical & Non-Medical) from Al-Nafees Medical College & Hospital, who fulfilled the inclusion criteria and after getting a written consent. Non willing candidates were excluded from the study.

After reviewing previously done study's authors of the current study designed the Questionnaire^{13,14}. Questionnaire consist of multiple sections, and was then distributed among the selected participants to get filled. The identity of each participant was kept anonymous throughout the study.

After collecting the filled questionnaire, the parameters of questionnaire then were entered in a specifically designed software i.e. statistical package of social science (SPSS) version 23, and was used to calculate the frequencies in terms of percentages were commented the quantitative variables for statistical inference.

3 Results

When participants were asked that have they ever heard about thalassemia 95% (n=123) of selected participants said yes while 5% (n=7) of selected participants said they had never heard about thalassemia before, in which non-medical employees and non-medical students were included, as shown in Figure-1.

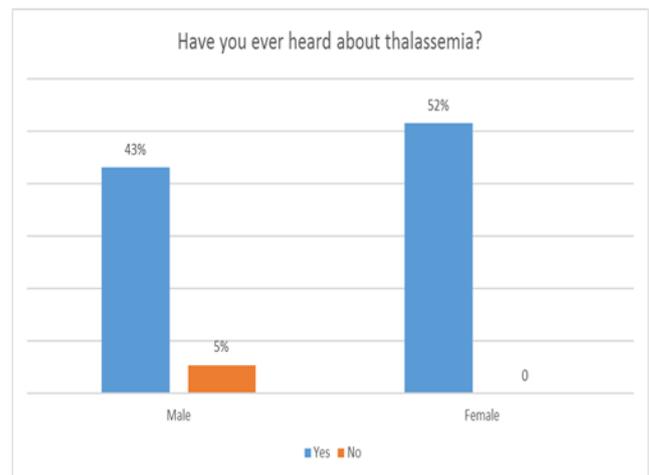


Fig 1: Awareness about Diagnostic Modalities of Thalassemia (N=130)

When participants that have heard about thalassemia before were asked where did they heard about thalassemia, participants that were related to medical profession either they were medical students and doctors or were from para-medical students and employees mostly heard about thalassemia from literature as thalassemia is present in their curriculum while for participants from no-medical profession either employees or students had mostly heard from Television, Friends and Social Media, as shown in table 1.

Table 1: Awareness about Thalassemia Management (N=130)

Enrolled Participants	Where did you hear about thalassemia?					
	TV	Social Media	Newspaper	Friends	Family	Literature
Medical Employees	4% (n=1)	12% (n=3)	4% (n=1)	4% (n=1)	0	92% (n=23)
Non-Medical Employees	36% (n=9)	24% (n=6)	12% (n=3)	32% (n=8)	8% (n=2)	16% (n=4)
MBBS Students	8% (n=2)	16% (n=4)	4% (n=1)	4% (n=1)	12% (n=3)	76% (n=19)
DPT Students	28% (n=7)	32% (n=8)	4% (n=1)	20% (n=5)	36% (n=9)	24% (n=6)
Para-Medical Staff	0	20% (n=3)	13% (n=2)	7% (n=1)	0	67% (n=10)
Nursing Students	13% (n=2)	27% (n=4)	13% (n=2)	7% (n=1)	0	60% (n=9)
Total	16% (n=21)	22% (n=28)	8% (n=10)	13% (n=17)	11% (n=14)	55% (n=71)

When participants that have awareness about thalassemia were asked about the kind of disease that whether it is hereditary, due to dietary deficiency, contagious, allergy or have no idea, majority 85% (n=110) was right about the kind of disease that it is hereditary but some participants have confusion about the kind of thalassemia disease 5% (n=6) said thalassemia is caused due to dietary deficiency and 3% (n=4) said they do not have any information about its kind while remaining 2-3% of participants said that thalassemia is contagious or occurs due to an allergic reaction, as shown in figure 2.

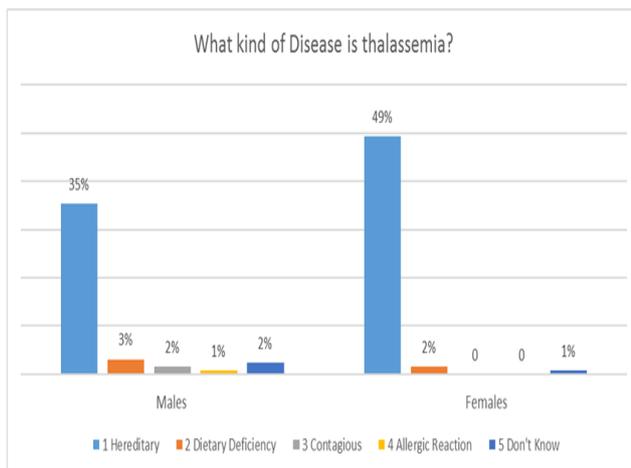


Fig 2: Awareness about Thalassemia Prevention (N=130)

4 Discussions

In our study 93% of total participants had heard about thalassemia, previously. Which is on higher side than a Malaysian study in which 76.4% participants had heard about thalassemia, previously in which majority were of females and from rural area¹⁵. Which is also much on higher side than a study done in turkey in which 57.7% participants had heard about thalassemia, previously¹⁶. A previous study done in

Pakistan shows less result i.e. 54.5% participants had heard about thalassemia, previously¹⁷.

In our study mass media plays an important role in spreading awareness among non-medical population in which we consider television, social media and newspaper while among medical population literature is the main source and then friends and family plays role in spreading awareness among population as shown in table 1. Opposite results were noted in a study done in Malaysia in which mass media (83.3%), family and friends (15.2%), and health care providers (8.9%) plays role as a source of information about thalassemia¹⁵. Another study done in turkey have different results than previously discussed studies, Turkish study shows TV (22.4%), internet (27.6%), newspaper (62.1%), friends and family (57.7%), and school/health services (29.4%) plays role as a source of information about thalassemia¹⁶. Similar results were noted in a study done in Pakistan in which Print and Electronic media 25.5%, family 16.8%, school/university 16.3%, friends 12.6%, β -thalassemia subject 6.6%, others 1.3% plays role in providing information about thalassemia¹⁷. It was noted in a study done in Lahore, Pakistan where 71.2% parents got information about the disease from doctors, others being paramedics 1.8%, electronic media 8.7%, print media 3.5%, seminars 2.6%, internet 0.9% and relatives 3.5%¹⁸. And in a study done in Denizli, which shows that half of the couples gain information about thalassemia is T.V, internet, and newspaper were noted as the most common source of information, followed friends and family¹⁶. Another study shows that the main sources of information on genetic diseases were friends and family¹⁹. Another study reported that nearly one third of the participants' source of information on PMS was media²⁰. Another study The most common source of knowledge was TV^{21,22}. In a study of India it has been noted that the most common sources of information regarding thalassemia were health care professionals and electronic media i.e. 37.38% and 31.77%, respectively, then

other sources were friends and relatives, Print Media, Seminars and Periodical notes i.e. 29.21%, 19.16%, 6.77%, 1.87%, respectively²³.

In our study 85% of participants knew that thalassemia is a hereditary disorder while 5%, 2%, 1% said that thalassemia is a dietary deficiency disorder, contagious or due to allergic reaction and 3% of participants said they have no information regarding kind of thalassemia disease. These results are on higher side than another study done in Lahore, Pakistan where 44.6% participants knew that thalassemia is a hereditary blood disorder while 55.6% didn't know about the kind of thalassemia disease¹⁸. In a study done in India 60.05% participants knew the hereditary nature of thalassemia²³. In a study done in India 57.94% participants had adequate knowledge about thalassaemia which have similar results as stated by Pausri at Srinagarind hospital²⁴.

However, Indian study results were far higher than study at Guilan university²⁵ and at Iran²⁶, where only 12.17% and 14.7% respectively had adequate knowledge about the disorder. Unlike the study from Myanmar²⁷, rural Bengal²⁸ and Lahore²⁹ where 28%, 22.27% and 44.6% respectively knew that thalassemia is a genetic disorder. In a study done in Malaysia in which medical and non-medical participants were asked whether thalassemia is a contagious disease, hereditary Disease, sexually transmitted disease or it occurs due to an allergic reaction; 32.35%, 66.33%, 25%, 24.13% medical participants responded that yes it is a contagious disease, hereditary Disease, sexually transmitted disease or it occurs due to an allergic reaction, respectively; whereas 67.65%, 36.67%, 75%, 75.87% non-medical participants responded that yes it is a contagious disease, hereditary Disease, sexually transmitted disease or it occurs due to an allergic reaction, respectively³⁰. In Denizli study, 17.5% of participants said thalassemia is a contagious disease while 82.5% of participant had no idea that whether it is a contagious disease or not (46.3% said NO to contagious character while 36.2% don't know about its character)¹⁶.

In a study done in India shows that 53.27% participants stated, thalassemia is a result of consanguineous marriages, while in a study done in Denizli shows decreased results where more than half of the population knew that consanguineous marriages increases genetic disease but nearly half of the population knew that risk of having thalassemia could be increased by consanguinity, these results are much on lower side than previously done studies in Saudi Arabia where 84%, 89.6% of participants agreed that consanguinity increases the risk for genetic diseases like thalassemia^{19, 31}.

5 Conclusion

The commonest information media was television, for spreading awareness regarding health related problems such as Thalassemia. Participants related to medical profession either

doctors or para-medical staff are well aware as compare to the participants from non-medical profession.

6 Recommendations

- Social Media should start certain awareness campaigns for thalassemia awareness so that the miseries of thalassaemic patients and near ones can be reduced.
- The social media should focus on starting campaign for pre-marital counseling, Chorionic Villous Sampling.

7 Limitations

This study is done on a less number of participants and was conducted in an institute which is medical college and hospital to generalize on general population.

8 Conflicts of interests

There are no conflicts of interests regarding publication of this manuscript.

9 Author's contributions

DA: Provoking the idea of manuscript, Abstract, Results and Discussion writing; HZ: Corresponding author, Compiling and formulating the entire manuscript; KTB: Supervising entire study for all technicalities; MNN: Sample collection, Introduction writing, data recording on SPSS; MA: Sample collection, Methodology writing, data recording on SPSS

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