

Original Research Article

An online cross sectional survey study regarding awareness of thalassemia in students of homoeopathic medical college in rural area of Gujarat

Vijay Patel¹, Nidhi Joshi^{2*}, Sneha Agrawal³

¹Department of Homoeopathic Materia Medica, Jay Jalaram Homoeopathic Medical College, Morva (Rena), Godhra, Gujarat, India

²Department of Forensic Medicine and Toxicology, Jay Jalaram Homoeopathic Medical College, Morva (Rena), Godhra, Gujarat, India

³Department of Pathology and Microbiology, Jay Jalaram Homoeopathic Medical College, Morva (Rena), Godhra, Gujarat, India

Received: 04 October 2024

Revised: 07 November 2024

Accepted: 08 November 2024

*Correspondence:

Dr. Nidhi Joshi,

E-mail: dr.nidhijoshi21@gmail.com

Copyright: © the author(s), publisher and licensee Medip Academy. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ABSTRACT

Background: Thalassemia is one of the significant public health concerns as the carrier rate and disease numbers are increasing worldwide. The increase in number is because of cognate marriage which has a deep-rooted norm among many people globally. The objective of this study was to identify knowledge and awareness among the fresher students of homoeopathic medical college in rural area.

Methods: An online cross-sectional survey was undertaken in the homoeopathic college in rural area of Gujarat. The questions were in the questionnaires analysed to identify differences with sociodemographic variables. Responses to the questions on thalassemia awareness were analysed to identify differences in the domains.

Results: Out of the 171 responses received over 5 days, 200 were included for analysis. Awareness regarding thalassemia in college fresher is seen in more from rural area 59%, urban area 39% and tribal 2%. In this survey, as per the questionnaires 83.6% students knew about the disease. When asked about cause of disease i.e. genetic disease 99.4% students knew that. 89.4% students know about thalassemia is transmitted by parents to offsprings.

Conclusions: In this survey, it was observed that college students have knowledge about thalassemia but certain myths or misconceptions were also present, and it is also evident that use of screening survey in medical is needed due to lack of awareness of its usefulness in wide range of diseases and disorders.

Keywords: Thalassemia, Fresher student's, Awareness, Screening

INTRODUCTION

Thalassemia is one of the significant public health concerns as the carrier rate and disease records are extending worldwide. This proliferation in number is because of consanguineous marriage which has a deep implanted norm among several people universally. Besides several clinical and psychological problems associated with thalassemia, a lifelong treatment aspect

makes it much more problematic for a person to sustain with thalassemia or thalassemia affected children. Though the government has come up with a screening programme for thalassemia, given the fact that its elective, people tend to ignore it.

We suggest that it should be general to have a prenatal screening programme to prevent thalassemia related deaths.¹

Genetic blood disorders are considered to be the most common causes of physical and mental disabilities in babies and children.² Sickle cell anaemia and thalassemia is the most common genetic hemoglobinopathies worldwide.³

Thalassemia's are a mixed alliance of genetic disorders that affect from a decreased synthesis of alpha or beta chains of haemoglobin (Hb). Hb serves as the oxygen-carrying element of the red blood cells. It comprises of two proteins, an alpha, and a beta. If the body does not manufacture enough of one or the other of these two proteins, and if defect in any one of the protein the blood cells cannot carry sufficient oxygen this causes anaemia that begins in early age and lasts throughout life.

Thalassemia is an inherited disease, that means at least one of the parents must be a carrier for the disease. A genetic mutation or a deletion of certain key gene fragments might be the reason of it. Alpha thalassemia is occurred by alpha-globin gene deletion which results in reduced or absent production of alpha-globin chains. Alpha globin gene has 4 alleles and disease severity ranges from mild to severe depending on the number of deletions of the alleles.¹² Four allele deletions are the most severe form in which no alpha globin is produced and the excess gamma chains (present-day during the fetal period) form tetramers. It is conflicting with life and results in hydrops fetalis. One allele omission is the mildest form and is generally clinically silent. Beta thalassemia caused by point mutations in the beta-globin gene. It's divided into three groups based on the zygosity of the beta- gene mutation. A heterozygous mutation (beta-plus thalassemia) results in beta-thalassemia minor in which beta chains are under produced. It's mild and generally asymptomatic. Beta thalassemia major is caused by a homozygous mutation (beta-zero thalassemia) of the beta-globin gene, follow-on in the entire absence of beta progressions. It manifests clinically as jaundice, growth retardation, hepato-splenomegaly, endocrine abnormalities, and severe anaemia taking life-long blood transfusions. The condition in between these two manners is called beta- thalassemia inter media with mild to moderate clinical symptoms.

One mutated gene

Mild signs and symptoms. The condition is called thalassemia minor.

Two mutated genes

Signs and symptoms will be moderate to severe. This condition is known as thalassemia major, or Cooley anaemia. Babies born with two mutated beta Hb genes are usually healthy at birth but disease starts to manifest after 6 months of life when fetal Hb (Hb-gamma) disappears and is exchanged by adult Hb.

The excess unpaired alpha-globin chains in beta-thalassemia combined and form precipitates that damage

red cell membranes and outcome is intravascular hemolysis. This premature death of erythroid precursor cells leads to ineffective erythropoiesis and later results in extramedullary expansion of haematopoiesis.⁴⁻⁶

Etiology

Thalassemia is autosomal recessive, that means both the parents must be affected with or carriers for the disease to the next generation. It is caused by mutations or deletions of the Hb genes, resulting in under production or absence of alpha or beta chains.

There are over 200 alterations identified as the culprits for causing thalassemia. Alpha thalassemia is caused by deletions of alpha-globin genes, and beta-thalassemia are caused by a point mutation in splice site and promoter regions of the beta-globin gene on chromosome 11.^{7,10}

METHODS

Study period, design and participants

The study was carried out from 02 May 2024 to 06 May 2024 in Jay Jalaram Homoeopathic Medical College, Morva (Rena), Gujarat, India. A web-based cross-sectional study design was used by e-questionnaire using Google form.

Stratified sampling technique was applied in this study. Those who were in 1st year students included and 2nd to 4th year, internes and others were excluded in this study.

Survey population

A cross-sectional online survey was conducted from 02 May 2024 to 06 May 2024. The survey questionnaire prepared and was circulated on the social media site (WhatsApp®) to homoeopathic college fresher students. Students from second, third, final and interns currently pursuing bachelor's degree and non-homoeopathy qualified persons were excluded. However, the survey was fixed for the duration of 5 days, irrespective of the number of responders.

Data collection with questionnaire

A thalassemia carrier screening questionnaire was created on Google forms comprising three parts. The first section was a brief about the objectives of the survey and the consent of the participants. The second section was socio-demographic information including age, gender, address, contact number, educational qualification, Aadhar card number, academic year, religion, socio economic status diet, habitat and date of birth.

The third section was on thalassemia awareness questions. The face validity of the questionnaire was assessed by head of institute and two homoeopathic researchers.

RESULTS

Responses received

A total of number capacity of first year (senior and junior) batch is 200. Out of which registered students were 171 and 171 responses were received. 29 students were denial for consent so, not a part of survey. The survey was conducted from 02 May 2024 to 06 May 2024. Over a period of 5 days, the response rate was on first day 92, second day 46, third day 27, fourth 1 and fifth day 5 responses received.

Preliminary profile

Age of the participants was between 17 to 23. Here 11 participants (6%), 49 participants (29%), 65 participants (38%), 32 participants (19%), 12 participants (7%), 1 participant (1%), 1 participant (1%) have 17 years to 23 years respectively (n=171). In this, total male was 88 (51%) and female were 83 (49%) (Figure 1).

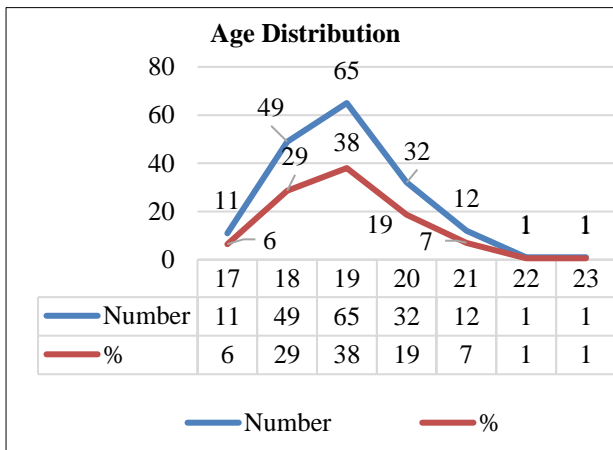


Figure 1: Age distribution.

Place of city

Responses were received from whole first year students they are belonging to different cities/district from Gujrat and Madhya Pradesh (Table 1).

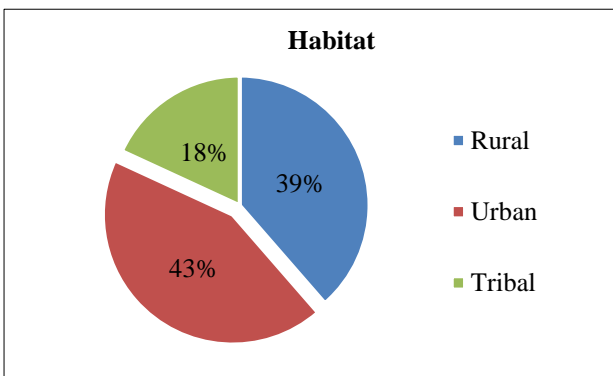


Figure 2: Demographic distribution.

Demographic distribution

On the basis of demography, students were belonging from 66 (39%) from rural area, 74 (43%) number of participants from urban area where as 31 (18%) participants from tribal areas (Figure 2).

Religion wise distribution

A large number of participants were Hindu 87.7%, and Muslim 11.1% whereas Jain 0.6% and Sindhi 0.6% (Figure 3).

Table 1: Place of city.

Name of district or city	Number (171)
Ahmedabad	5
Anand	4
Ankleshwar	1
Arvalli	2
Banaskatha	2
Bayad	4
Bharuch	1
Bilimora	1
Chotaudepur	5
Dahod	29
Godhra	31
Jhabua, MP	1
Kalol	4
Kheda	10
Mahisagar	6
Mehsana	1
Modasa	8
Narmada	2
Navsari	1
Palanpur	1
Patan	1
Panchmahals	22
Rajkot	8
Sabarkatha	3
Surat	8
Surendranagar	1
Tapi	2
Vadodara	7

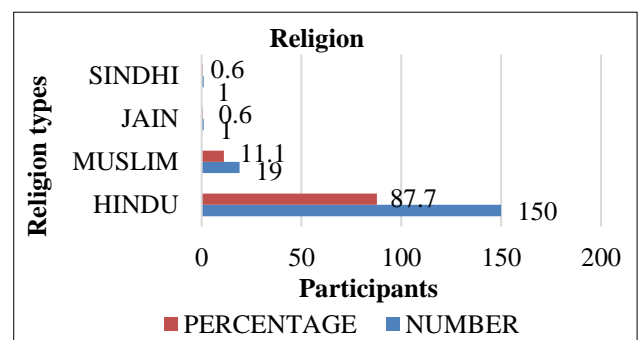


Figure 3: Religion wise distribution.

Table 2: Response to knowledge questions (n=171).

Questions	Responses			
Do you know about thalassemia?	Yes, I know (143) (83.6%)	No, I don't know (28) (16.3%)	-	-
Thalassemia is a	Bacterial disease (1) (0.58%)	Genetic disease (170) (99.4%)	-	-
Thalassemia is transmitted by	Blood transfusion (18) (10.52%)	Parents to offspring (153) (89.4%)	-	-
Thalassemia may be treated by	Do not worry it is easily curable (2) (1.16%)	I don't know (128) (74.85%)	Medicine (22) (12.8%)	Surgery (19) (11.11%)
Past history of any disease condition/ medical condition?	Yes (1) (0.58%)	I don't know (3) (1.75%)	No (167) (97.6%)	-
Do you have any history of thalassemia in family?	May be (5) (2.92%)	No (165) (96.49%)	Yes (1) (0.58%)	-
Any other medical condition in your family?	No (164) (95.9%)	Yes (7) (4.09%)	-	-

DISCUSSION

In many countries, patients who suffered with thalassemia major suggestively increased in recent years, as reported by several groups. Though, complications are there and affect the patients' quality of life. In recent research by Borgna-Pignatti said that in article survival and complications in thalassemia, in United Kingdom it was found that 50% of the patients had died before age 35.⁸

As per history, the prevalence of β -thalassemia has been highest in the Mediterranean region, the Middle East, and Southeast Asia and lowest in Northern Europe and North America. the lesser information about India is available. As per WHO report in 2008, more than 40000 newborns seen with β -thalassemia every twelve months. approximately 1.5% of people are β -thalassemia carriers globally.⁹ There are >40 million carriers of β -thalassemia (β -thal) in India with 10,000–12,000 affected births every year.¹¹ Western part of India is aware about this disease condition or not is not available. So, there is need to know that how much beginner of medical students aware about these genetic disorders.

The need of a universal screening programme is strongly recommendable as mentioned, since its future suggestions. Communication needs to be enhanced for all the families to accept the risk of them having a thalassaemic child. There is also a need to make the screening more readily available and to motivate high-risk groups through awareness-raising programmes.¹

Homoeopathic college students in this cross-sectional survey presented a high response rate, expressing their willingness to participate in the survey. These fresher students have been able to maintain a high level of knowledge, purely on their own accord. Level of disease-based knowledge and awareness is highly satisfactory, although a better understanding of the disease in the family is needed.

In this survey, as per the questionnaires 83.6% students knew about the disease. When asked about cause of disease i.e. genetic disease 99.4% students knew that 89.4% students were know about thalassemia is transmitted by parents to offsprings.

The survey had a mass outreach by electronic media, and the medical students were easily available and ready to complete the survey. Perhaps we could include more students but here we only included first year batch. The strengths of the study are that real time data could be collected in a short period of time on digital platform.

Limitations

The study limitations are that the survey was conducted only for a period of 5 days. The students who were active on social media are, therefore, more likely to be responders, rather than those who had limited activity on social media. Furthermore, although participants were from first year batch so, knowledge and awareness might be limited about disease condition.

CONCLUSION

In this survey, it was observed that college students have knowledge about thalassemia but certain myths or misconceptions were also present, and it is also evident that use of screening survey in medical is needed due to lack of awareness of its usefulness in wide range of diseases and disorders. As the survey was done on a small population in a region, it is very difficult to generalize about the general awareness; a nationwide survey is needed to be done to exactly know about the status of awareness about thalassemia in general population across the country.

ACKNOWLEDGEMENTS

Authors would like to acknowledge the contribution of Jay Jalaram Homoeopathic Medical College and Hospital

superintend and trustees, who permitted and guide the authors for this cross-sectional survey. They are thankful to homoeopathic college fresher students who were willingly ready to be part of survey.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. Thiagarajan A, Bhattacharya S, Sharma N, Srivastava A, Dhar DK. Need for a universal thalassemia screening programme in India? A public health perspective. *J Family Med Prim Care*. 2019;8:1528-32.
2. Basu M. A study on knowledge, attitude and practice about thalassemia among general population in outpatient department at a tertiary care hospital of Kolkata. *J Prev Med Holistic Health*. 2015;1:6-13.
3. Al-Farsi OA, Al-Farsi YM, Gupta I, Ouhtit A, Al-Farsi KS, Al-Adawi S. A study on knowledge, attitude, and practice towards premarital carrier screening among adults attending primary healthcare centers in a region in Oman. *BMC Public Health*. 2014;14:380.
4. He LN, Chen W, Yang Y, Xie YJ, Xiong ZY, Chen DY, et al. Elevated Prevalence of Abnormal Glucose Metabolism and Other Endocrine Disorders in Patients with β -Thalassemia Major: A Meta-Analysis. *Biomed Res Int*. 2019;2019:6573497.
5. Vichinsky E, Cohen A, Thompson AA, Giardina PJ, Lal A, Paley C, et al. Epidemiologic and clinical characteristics of non-transfusion-dependent thalassemia in the United States. *Paediatric Blood Cancer*. 2018;65(7):e27067.
6. Ahmadpanah M, Asadi Y, Haghghi M, Ghasemibasis H, Khanlarzadeh E, Brand S. In Patients with Minor Beta-Thalassemia, Cognitive Performance Is Related to Length of Education, But Not to Minor Beta-Thalassemia or Haemoglobin Levels. *Iran J Psychiatry*. 2019;14(1):47-53.
7. Jalil T, Yousafzai YM, Rashid I, Ahmed S, Ali A, Fatima S, et al. Mutational Analysis of Beta Thalassemia by Multiplex Arms-Pcr in Khyber Pakhtunkhwa, Pakistan. *J Ayub Med Coll Abbottabad*. 2019;31(1):98-103.
8. Borgna-Pignatti C, Cappellini MD, De Stefano P, Del Vecchio GC, Forni GL, Gamberini MR, et al. Survival and complications in thalassemia. *Ann N Y Acad Sci*. 2005;1054:40-7.
9. Kattamis A, Forni GL, Aydinok Y, Viprakasit V. Changing patterns in the epidemiology of β -thalassemia. *Eur J Haematol*. 2020;105(6):692-703.
10. Ali S, Mumtaz S, Shakir HA, Khan M, Tahir HM, Mumtaz S, et al. Current status of beta-thalassemia and its treatment strategies. *Mol Genet Genomic Med*. 2021;9(12):e1788.
11. Vachhani NA, Vekariya DJ, Colah RB, Kashiyani HN, Nandani SL. Spectrum of β -Thalassemia and Other Hemoglobinopathies in the Saurashtra Region of Gujarat, India: Analysis of a Large Population Screening Program. *Hemoglobin*. 2022;46(5):285-9.
12. Lal A, Viprakasit V, Vichinsky E, Lai Y, Lu MY, Kattamis A. Disease burden, management strategies, and unmet needs in α -thalassemia due to hemoglobin H disease. *Am J Hematol*. 2024;99(11):2164-77.

Cite this article as: Patel V, Joshi N, Agrawal S. An online cross sectional survey study regarding awareness of thalassemia in students of homoeopathic medical college in rural area of Gujarat. *Int J Res Med Sci* 2024;12:4630-4.