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Availability and Practices of Blood Transfusion in Thalassemia Patients: Current Status with Reference to India

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ABSTRACT: Thalassemia major is a blood disorder of inheritance that is transmitted from parents to offspring, resulting in incapacity to produce an adequate quantity of haemoglobin and severe haemolytic anaemia. These conditions are extremely prevalent single-gene disorders in India. Patients with thalassemia require lifelong regular blood transfusion, typically beginning prior to being 2 years old, and die within ten-twenty years if untreated. The purpose of this investigation is to determine the prevalence and availability of blood transfusions among thalassemia patients in India. The challenge is that the illness is severely impacted by the adverse effects of transfusions, which must be assessed and managed throughout life. Blood transfusion exposes patients to adverse events like nonhemolytic cold, along with allergic, and also delayed reactions to a blood transfusion, transfusion-related lung injury, along with graft-versus-host illness, and the transfusion of pathogenic organisms including viruses, bacteria, and parasites. The prevalence of thalassemia differs as the geographical location changes and availability of blood transfusions depending on different awareness program, which is a part of management of blood transfusion for Thalassemia patients.

Keywords: Blood transfusion, Thalassemia, India, Patients, Availability, Practices.

INTRODUCTION

Thalassemia major is a severe anaemia that requires patients to receive lifelong blood transfusions for survival. A significant issue in India, it is estimated that between 8,000 and 10,000 new thalassaemic (homozygous) are born annually in India. Beta thalassemia gene is more prevalent in Punjab, Sindh, West Bengal, and Gujarat (Moirangthem and Phadte 2018).

The natural progression of the illness is severely impacted by the adverse effects of transfusions, which must be assessed and managed throughout life. Blood transfusion exposes patients to adverse events like nonhemolytic cold, along with allergic, and also delayed reactions to a blood transfusion, transfusion-related lung injury, along with graft-versus-host illness, and the transfusion of pathogenic organisms including viruses, bacteria, and parasites (Shah *et al*., 2022). This demonstrates the urgent need for enhanced awareness-raising and education programs across the nation (Colah *et al.,* 2017). The National Health Portal of the MoHFW, the Indian government is now offering statistics on thalassemia for the general public along with medical professionals. However, thalassemia is not formally taught in secondary school curricula. The main aim of this investigation is exploring the current availability and practices of transfusion of blood among Thalassemia patients in India.

MATERIAL AND METHOD

An analytical methodology was followed to analyze the data collected from various secondary sources such as Google Scholar, Websites, PubMed and many published articles, journals etc.

RESULT AND DISCUSSION

Thalassemia is an extremely prevalent genetic disorder in Inazx, dia (Shah *et al.,* 2022). With a probable incidence - 2/1,000 births along with a carrier frequency - 3 to 4%, it represents a substantial health encumbrance. An estimated 65,000-67,000 patients having beta-thalassemia exist within India, having approximately 9,000-10,000 new cases each year. Blood transfusion is the cornerstone of treatment due to the limitations of bone marrow transplantation. Recent advances in the transplant industry are enhancing the purity of blood products, while the accessibility of excellent supportive therapy has improved the survival along with elevated survivors' life quality.

A. Thalassemia control plan in India

According to (Krishna *et al.,* 2023), the multicentre Jai Vigyan programme, conducted by the ICMR on Community Control of Thalassemia, played a significant role in enhancing the capacity of medical centres, particularly those affiliated with medical colleges. This initiative aimed to establish diagnostic programmes and

assess the incidence of thalassemia along with other hemoglobinopathies in six states, namely Maharashtra, along with Gujarat, and also West Bengal, along with Karnataka, along with Punjab, and also Assam. The screening process involved the examination of college students along with pregnant women. Also, thalassemia carriers have been detected among 59 unique ethnic sets, with prevalence that vary from 0% - 9.3%. Six Assamese ethnic sets had an extremely high incidence of carriers (41–66%) (Sharma *et al.,* 2017).

B. Availability of Blood transfusion in Thalassaemic patients in India

The March of Dimes Global Report on Birth Defects estimates the incidence of blood disorders in India to be 1.2/1000 live births. On the basis of 27 million births/year in India, it is estimated that 32,400 infants with a severe haemoglobin disorder are born each year (Shah *et al.,* 2022). Although the inclusion of treatment and control for patients having thalassemia along with sickle cell disease within the 12th Five Year Plan is undertaken by the Indian government, very few of the 10,000 - 12,000 thalassaemic children born yearly in India are efficiently achieved, primarily in urban sections. Proper and frequent red cell transfusions continue to be the treatment of choice for the majority of thalassemia major patients. Colah *et al.* (2017) state that the transfusion-associated illnesses can be eliminated through secure donor selection and the implementation of improved screening techniques.

Nagar *et al.* (2015) estimated that 2 million packaged red cell units are required for transfusions of patients having thalassemia within the country. Despite the current provision of blood to patients having hemoglobinopathies without charge and the increasing availability of iron chelators in several jurisdictions, there are expenses related to the testing, along with processing, and also leucodepletion of blood. Consequently, most patients fail to receive optimal care. Patients having thalassemia major have no other cure alternative besides a stem cell transplant. The likelihood of a successful transplant is greater than 90% for patients with favorable risk factors, while the prognosis for high-risk patients remains uncertain (Colah *et al.,* 2017). The majority of families with a child who has severe thalassemia cannot also afford the exorbitant cost. Thus, prevention at delivery of an afflicted infant is a feasible and practical option.

C. Practice of Blood transfusion in Thalassaemic patients in India

A good practice research was conducted among a group with a targeted socioeconomic background of medium to low education and with the right knowledge and attitude. In the South, around 24 Parganas West Bengal districts, which happens to be a high-risk thalassemia area, only 37.93% of the population had heard of the disorder but lacked accurate knowledge about it. Only 10.07 percent of this group responded affirmatively to a question about if an average person might be a beta-thalassemia carrier (Biswas *et al.,* 2023). According to Chawla *et al.* (2017) thalassemia between a high threat group, the persons in north India being a rural part in Haryana's Rohtak constituency, along with an urban area within New Delhi demonstrated that a significant count of rural residents had never heard of thalassemia. According to this theory, the cause of this illness was attributed to orthodox emotions, such as parental crimes. In addition, greater than fifty percent of urban residents were unwilling to undergo premarital screening for thalassemia. The Indian government defines a "Blood Centre" as a location within an organisation or institution that is authorised to carry out all or any of its activities such as collection, the process of a storage, handling, and blood distribution collected from donors or even received from another licenced Blood Centre as well as planning, storage, along with blood component distribution.

Practices like blood availability along with special transfusion requirements (e.g., phenotyped red cells along with uncommon blood groups) were discussed with blood centres in advance. To address the issue of blood shortages, media campaigns were created with the aim of motivating potential donors for anyone requiring access to a transfusion facility, particularly those who must travel significant distances. Many non-governmental organisations (NGOs) also provided provisions to transfuse patients at local medical centres near their residences, which were incredibly beneficial (Shah *et al.,* 2022).

Inventory management practice proved to be one of the most difficult practices in Thalassemia because it required an elevated degree of uncertainty in planning. Depending on the types of blood shortage emergencies or persistently transfused patients who were sustaining, each blood centre devised its own protocol or plan for maintaining a buffer stock. Due to the cessation of regular blood types, the risks of a blood unit shortage and a higher rate of waste disposal were considered in this practice.

Different Institutions and social organizations in India, such as the Red Cross Society, Rotary Clubs, along with Lions Clubs, multiple NGOs, along with Thalassemia Parents-Patients people, are implementing education along with alertness plans for the previous 30–40 years (Colah *et al.,* 2017). Nevertheless, the level of knowledge of thalassemia among pregnant women in six states included in the multicentre Jai Vigyan initiative varied significantly. Specifically, the awareness rates ranged from 0.2% to 4.8% in the cities of Bangalore, along with Vadodara, and also Mumbai, along with Dibrugarh, and also Ludhiana, while in Kolkata, the awareness rate was notably higher at 20.7% (Sharma *et al.,* 2017).

D. Current status of blood transfusion system for Thalassemia patients in India

In recent years, the use of blood products for various medical purposes has increased. To meet increasing demand, administratively, India has four distinct categories of blood depots and centres. They are operated by the public (government) sector, the Indian Red Cross Society, non-profit Nongovernmental Organisations (NGOs), and the corporate or commercial sector. India has a total of 2,545, designated blood banks as of now (Krishna *et al.,* 2023).

Few reliable actions have been implemented to improve the quality of blood transfusion services, including the NABH accreditation program solely for blood banks (administered by the Quality Council of India) and the National Hemovigilance Programme for continuous gathering and analyzing information of transfusion-related adverse reactions, etc. (TGI, 2016). This initiative, which includes the growth of currently operating blood banks while the establishment of additional ones with an emphasis on equity and convenience, will aid India in attaining its intended goal.

CONCLUSION

Although substantial data on the incidence of thalassemia carriers is accessible from a few states in India, much of it is hospital-based along with selective, making it difficult to estimate the true disease burden. In India, transfusion care for Hb disorder patients should continue to emphasize education and awareness. During viral pandemics, it is essential that blood depots and transfusion facilities remain operational for the sake of other patients. During these pandemics, blood banks along with transfusion centres must devise strategies to preserve blood supply. A team-based strategy is essential for conquering the present obstacles. With the imminent implementation of a national thalassemia control program and the availability of blood transfusions, adequate centres for assessment and suitable quality control would be recognized, and a multitude of trained ancillary workers and genetic counsellors will be needed.

FUTURE SCOPE

Thalassemia major is a blood disorder of inheritance that is transmitted from parents to offspring, resulting in incapacity to produce an adequate quantity of haemoglobin and severe haemolytic anaemia. These conditions are extremely prevalent single-gene disorders in India. Patients with thalassemia require lifelong regular blood transfusion, typically beginning prior to being 2 years old, and die within ten-twenty years if untreated. Improved management of β major thalassemia patients predominates in urban sections in India and typical and safe blood transfusions will enable them to have a better standard of life

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Conflict of Interest. None.

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