Review Article

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What homoeopathy has to offer in the rare disease scenario of India: an overview

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ABSTRACT

Incidences of rare diseases (RDs) are subsequently increasing in India. The cost of the treatment involved is exorbitant and therefore it becomes difficult for the patient to afford it. So, the need of the hour is to implement health care policies that are in favor of both, the patients and the government. Keeping in mind the current scenario of the RDs in India this article is written to mitigate this problem as far as possible using the homoeopathic system of medicine. This article delineates a newer approach to RD treatment programs available. Homoeopathy in haemophilia (HIH) research center established in the year 2007, had provided homoeopathic treatment to more than 1300 people with haemophilia i.e. 5.27% according to the annual global survey 2021, where the total number of registered haemophilia patients in India were 25384. Homoeopathy had proven over the years that it works by interacting with the genetic code of the patient. Also, it is based on the principles of symptom similarity rather than disease diagnosis. This makes it more applicable for patients of RDs because it relieves the symptoms and reduces their severity until the proper diagnosis and treatment are provided. Homoeopathy had proved itself to be a cost-beneficial therapy for patients with hemophilia and so this could be the pilot study for the other genetic diseases too.

Keywords: Rare disease, Homoeopathy, Hemophilia, Thalassemia, Sickle cell anemia

INTRODUCTION

A rare disease (RD) is one that affects a population infrequently. ¹⁻³ It is estimated that there are about 7,000 RDs, 80% of which are genetic. Only 5% of the 7,000 RDs are treatable. ⁴⁻⁶ There have so far been 450 RDs reported in India. It's expected that between 72 to 96 million people in India suffer from RDs. ⁷ Although under-reported, this number is based on the global

population prevalence of RDs, which is estimated to be between 263 and 446 million affected people worldwide at any given time or between 3.5 and 5.9%. Blood disorders, lysosomal storage disorders, primary immunodeficiency disorders, mitochondrial illnesses, neurodegenerative diseases, and musculoskeletal problems are only a few examples of RDs that have received attention in the country. The majority of these illnesses are chronic and degenerative, resulting in severe

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impairment that gets worse with age. Patients with RDs thus generally require specialized supportive care. In contrast to other diseases, RDs have substantial direct and indirect costs. The country's greater dependence on imported medications, inadequate treatment facilities, and delayed diagnosis are the main causes responsible for the high costs. Although over 95% of RDs are incurable, the existing treatments are also expensive, in part because patients need them for their entire lifespan. Also, the majority of these treatments necessitate the purchase of costly medications, whether it is biological or non-biological. This can make patients even more financially burdened. ^{10,11}

A few of the examples reported that the international price of Spinraza (Nusinersen), a drug used to treat spinal muscular atrophy (SMA) is approximately US\$ 375,000 per patient.¹² In the international market, the chemical chaperone Migalastat, which is used to treat Fabry's disease, could cost about US\$ 310,000 yearly. 13 As these drugs are not produced in India, the cost of importing such medications increases the cost of purchase, raising the entire expense of local treatments. Therefore, it is essential to create long-term regulatory frameworks that could reduce and ultimately eliminate such expenses. All patients should have equitable access to timely diagnosis, clinical management, supportive therapies, and treatments to such enablers. The need of the hour is to have in place a well-defined national policy framework with the ultimate goal of curing RDs. Until this is made possible something that can help to mitigate this problem up to some extent should be thought of. The best-supporting solution for the current scenario of a RD in today's world is homoeopathy. Homoeopathy had proven over the years that it works by interacting with the genetic code. From a mechanistic perspective, fundamental homeogenomic research has shown that homoeopathic medicines can also promote DNA methylation and other epigenetic alterations.¹⁴ This research can be the ground plan for many studies to be carried out to evaluate the role of homoeopathic medicines in treating/somewhat alleviating the symptoms. An attempt had started since 2007 in mitigating one such genetic disease-haemophilia. Several types of studies on this particular disease had been carried out by many researchers. But role of homoeopathic medicines is described by Kundu et al as yet.

DIAGNOSIS OF RARE DISEASES

Early diagnosis of RDs is challenging due to some factors, including a lack of awareness among primary care physicians and poor screening and diagnostic facilities. India, a resource limited nation (RLN) lacks the resources needed to diagnose these genetic diseases. ¹⁵ Because there aren't enough specialized clinics equipped for diagnosis. The organization for RDs in India (ORDI) believes that a genetic disorder often takes seven years on average to be detected. ¹⁶ A specialized diagnosis could be exorbitant. ¹⁷ Additionally, the dearth of clinical geneticists worsens the situation. Running specialized

clinics and training courses for specialists could therefore significantly reduce the time it takes to diagnose a patient.

TREATMENT AVAILABLE

As discussed earlier, majority of the RDs require lifelong treatment. For a considerable period, this might not aid in leading a healthy life. For example, patients suffering from haemophilia require factor infusion after any kind of internal and external hemorrhage. The continuous visits to the hospitals and clinics are also the time-consuming process. In this scenario not only, the patient suffers but also the family is involved indirectly. This condition is enhanced by the cost of the treatment. Lack of medical insurance options to pay for these expenses increases the financial strain on these patients and their families.

ECONOMIC AND SOCIAL BURDEN OF RARE DISEASES

The socioeconomic load could be analyzed in terms of direct and indirect expenses. Former imposes a disproportionate financial burden on the patients and their families as a result of the expensive diagnosis, treatments, therapies, medications, and hospitalizations as needed. A study reveals number of absenteeism from school and works by patients suffering from haemophilia. Physical activity is restricted due to acute pain and suffering if treatment is not available. There are almost 36.5% of hemophiliacs who are school dropouts and unable to attend regular school on account of bleeding and pain. 19-21

The analysis and source of this overview was based on our years of experience and published research articles.

AN ATTEMPT TO MITIGATE SOME RARE GENETIC DISEASE

An attempt was made in providing symptomatic treatment for a genetic disorder like haemophilia where the body's ability is impaired to form a blood clot, a process needed to stop the bleeding. The majority of general practitioners would see only a few cases throughout their lifetime practice.²² Doctors of HIH research center Nashik, are currently treating more than 1300 haemophilia patients using homoeopathic medicines which is 5.27% of total haemophilia patients (25384) registered in national haemophilia registry India. This is according to the annual global survey 2021. The total numbers of haemophilia camps conducted by HIH till December 2024 are 503 at 8 different centers like Nashik, Parel (Mumbai), Surat, Amravati, Thane, Nagpur, Dhule and Chatrapati Sambhaji Nagar. The total number of haemophilia awareness programs/ scientific CME/ seminars conducted are 42, and also enlisted in the Indian books of records. HIH published 15 haemophilia related research papers consisting of 7 case reports and 3 Research papers other than haemophilia consisting of Glanzmann's Thrombasthenia, afibrinogenemia, and idiopathic thrombocytopenic purpura (ITP) and etc. 23-25 Homoeopathic medicines when given based on symptom similarity to the patient with haemophilia (PWH) during the bleeding phase, successfully controlled the bleeding and prevented the complications. Similarly, few researchers in addition convincingly demonstrated the satisfactory results produced by homoeopathic medicines, one of those being-the efficacy of homoeopathic medicines in reducing the need for factor concentrates in haemophilia patients, a double-blinded placebo-controlled trial.²⁶ Management of acute bleeding with homoeopathic medicines in severe haemophilia patient showed positive results.²⁷ Hemophiliacs taking Homoeopathic medicines showed tuned parasympathetic modulations. Autonomic responses were altered and therefore alleviation of the symptoms was possible.²⁸ Homoeopathic medicines reduced pain and frequency of hemarthrosis in PWH.²⁹ Two evidence-based case reports described the effectiveness of homoeopathic medicines in scrotal hematocele and, non-healing scalp wound in a child with haemophilia.^{30,31} Homoeopathy had even shown its results in reducing the inhibitor titers in positive patients with haemophilia.³² Homoeopathy not only alleviates the suffering of these patients but also reduced the cost, involved in the management of a large number of hemophiliacs in India. 33,34 Homoeopathy also postponed the disability in the hemophilia patients and have maintained the optimum quality of life.³⁵ By doing so parental anxiety and stress is also been minimized.³³ Also, the number of absenteeism which is more due to extreme pain and discomfort is reduced.¹⁸ New approaches have also been utilized like telemedicine.³⁶ Emergency homoeopathic medicine kit provided to the PWH residing in rural areas which are devoid of modern medical amenities facilitates immediate management at home in case of emergency. Even in cases where the genetic disease is complicated with psychiatric disorder like Schizophrenia and intellectual disability homoeopathy had worked well.^{37,38} Earlier, the usage of homoeopathic medicines in genetic diseases like haemophilia was seldom but since the establishment of the HIH research center it had increased to 43.5%.³⁹ Apart from haemophilia A and B some other genetic diseases like sickle cell anemia, beta thalassemia, Duchenne muscular dystrophy and apinal muscular atrophy, von Willebrand disease, factor II deficiency, factor III deficiency, factor V deficiency, factor VII deficiency, factor IX deficiency factor XI deficiency, factor XII deficiency, factor XIII deficiency, Glanzmann thrombasthenia, afibrinogenemia like diseases are also being treated at this centre. 23,31,37,38

HOW HOMOEOPATHY CAN ASSUAGE THE DISCOMFORT CAUSED BY RDS: A NEW APPROACH

Homoeopathy-the therapeutic science is based on the principle of symptom similarity. 40-48 According to Dr Samuel Hahnemann's philosophy, Psora the fundamental miasm is responsible for the causation of these diseases. 49-51 However, cure for these diseases is not possible, only Palliation is the way left. But the genetic load of an individual carrying the hereditary character can

be reduced using these medicines.⁵⁴ Homoeopathy includes medicines from various sources with a vast literature. 52-54 Every medicine has its constellation of symptoms which forms a peculiar picture of that medicine. Single medicine (Similimum) when given for a person treats the person as a whole including his mental generals, physical generals, and characteristics disease in particulars. In addition to it, the cost incurred in the treatment using homoeopathy is cheap as compared with the standard treatment available.⁵⁵ Patients now choose the homoeopathic system of medicine that relieves the symptoms, reduces the severity of the disease and maintains the quality of life of the patient and also the family members. Adding homoeopathic treatment in the protocol management of these RDs will be beneficial for the government to cut down the cost of management required.³⁴ Complementary and alternative medicine (CAM) is growing in popularity day by day, and in India, it is advocated by the ministry of AYUSH, govt. of India. Lastly, the point, to sum up, is-homoeopathic system of medicine should be incorporated into the standard protocol for the management of rare genetic diseases. 56-61

CONCLUSION

When resources for the management protocol are limited, symptomatic homoeopathic treatment, in context of a particular patient suffering from a RD, can minimize patient's problems and government's economic burden.

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