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A review of usage of telemedicine for management of acute bleeding episodes in haemophilia

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Abstract

Introduction and background: Haemophilia is an X-linked inherited genetic disorder that impairs the body's ability to make blood clots. It results in spontaneous uncontrolled bleeding. Maximum of its manifestation are acute and require immediate intervention. Therefore this study is aimed at focusing on impact of telemedicine in emergency management of haemophilia in remote areas.

Materials and methods: At Multicentric HIH centres the patients are prescribed with homeopathic medicines as per the symptom similarity which is the base for homeopathic treatment, and given constitution medicines in Fleiss kappa manner, on monthly basis. Patients are provided with emergency kits which consist of around 30 medicines which have been formulated considering haemorrhagic diathesis, and articulation problems, oedema, ecchymosis, pain, inflammation, bleeding, tenderness etc. This tool employed in telemedicine in remote areas to manage acute conditions on the proper time.

Result: Total number of interactions of these patients with a team of HIH is 22926, out of which 43.59% was telephonically managed emergencies. In Thane, Surat and Amravati, around 75% of interactions are dealt with the use of social media that is 17722 emergencies have been managed telephonically.

Conclusion: Telemedicine has efficiently helped to manage and control acute episodes of people with haemophilia and thereby increasing their quality of life as well as the quality of healthcare with homeopathic medicines.

Keywords: Usage, telemedicine, management, bleeding, haemophilia

Introduction

Haemophilia is a hereditary recessive coagulation defect which means love (“philia”) of blood (“haemo”). It is associated with prolonged, excessive and uncontrolled bleeding episodes. This disorder of haemostasis occurs in one in 5000 men (prevalence of 10 in 1,00,000 people) and is caused by a deficiency of clotting factor VIII (in haemophilia A) or factor IX (in haemophilia B) as a result of defects in the *F8* and *F9* genes^[1,2].

Telemedicine is a rising tool in the treatment of haemophilia. Haemophilia usually presents itself as acute emergency and on spot management is the most essential need. Such situation is overcome through telemedicine. Most of the PWH reside in remote areas where immediate care centres are seldom available. Moreover emergencies that occur during night are the difficult to manage. Use of Telemedicine in such areas has enabled and eased the management of bleeding and related symptoms of haemophilia.

Homeopathy in Haemophilia (HIH) is a self governing charitable organisation whose foundation was laid in December 2007. Persistently and consistently since then, it is rendering its service to the people with haemophilia (PWH). The organization runs with the scientific support of the Department of Immunohaematology, K.E.M Hospital, Parel, Mumbai.

The sole purpose of HIH is to improve QOL of PWH, and to scale back the amount of bleeding and swelling episodes, thereby reducing the cost of management of the disease which has been scientifically established in our previous publications^[3-8].

Mode of treatment

At Multicentric HIH centres, which has been working in service of PWH since December 2007, thorough history taking is done and all reports of the patient are viewed and degree of disability if any are noted. After which everything is noted down sequentially and charted as

per requirement. Thereafter they are prescribed with homoeopathic medicines as per the symptom similarity which is the base for homoeopathic treatment, and given constitution medicines in Fleiss kappa manner, on monthly basis. They are also guided for add on physiotherapy for improvement of ROM (Range of Motion) of joints.

On their follow-ups, appropriate scales are applied to monitor perfectly improvement in condition as well as in day to day activities. Accordingly, repeat dose or next required medicine is prescribed.

Along with this patients are provided with emergency kits which consist of around 50 medicines which have been formulated considering haemorrhagic diathesis, and articulation problems, oedema, ecchymosis, pain, inflammation, bleeding, tenderness etc and provided to the patients. This tool is employed in telemedicine in remote areas to manage acute conditions on the proper time.

In case of any minor ailments like cold, coryza, GIT disturbance, bowel irregularities, etc to a major illness like spontaneous bleed, tooth fall, joint bleed, fall, ecchymosis muscle bleed, etc, is informed to the team of doctors at HIH Centre, they then advise medicines as per symptom

similarity to the patients, totally on basis of communication with the assistance of social media apps like Whatsapp, Facebook or mail wherein photos, video or activity of the patient during ailments are recorded, conveyed which is quick and time-saving, and treatment is done which is well accessible and effective.

This not only turns out to be life-saving, also saves the time, reduced the panic and fear in the mind of the patient as well as their relatives. Thereby making homoeopathic medicines more reliable and making the patients more stress-free.

The utility of Telemedicine in the treatment of Haemophilia

- Easy access and coverage of health care to remote areas. (Table no .1 and image no.1)
- Using telemedicine in peripheral Homoeopathy in Haemophilia centres have reduced significantly the time and costs of patient transportation
- Improved communications between health providers separated by distance
- It has facilitated continuing medical education and clinical research

Table 1: Tabular Representation of No. of Telephonically Managed Patients, No of Total Patients Checked.

SR NO		Nasik	Mumbai	Surat	Amravati	Thane	Nagpur	Dhule	Total
1	Date of Establishment	21/12/2007	04/2011	03/2013	8/3/2015	6/8/2016	13/8/2016	21/7/2019	
2	Emergency Telephonically Prescribed	6928	3061	2350	2022	944	2321	96	17722
3	Total No. of Interactions With Patients	16296	3647	1163	648	370	776	26	22926
4	Total No. of Telephonic And Personal Interactions	23224	6708	3513	2670	1314	3097	122	40648
5	% of Telephonically Handled Patients	29.831%	45.63%	66.89%	75.73%	71.84%	75.45%	78.68%	43.59%
6	Total No of Patients Registered At These Centres.	530	377	104	84	16	105	16	1232

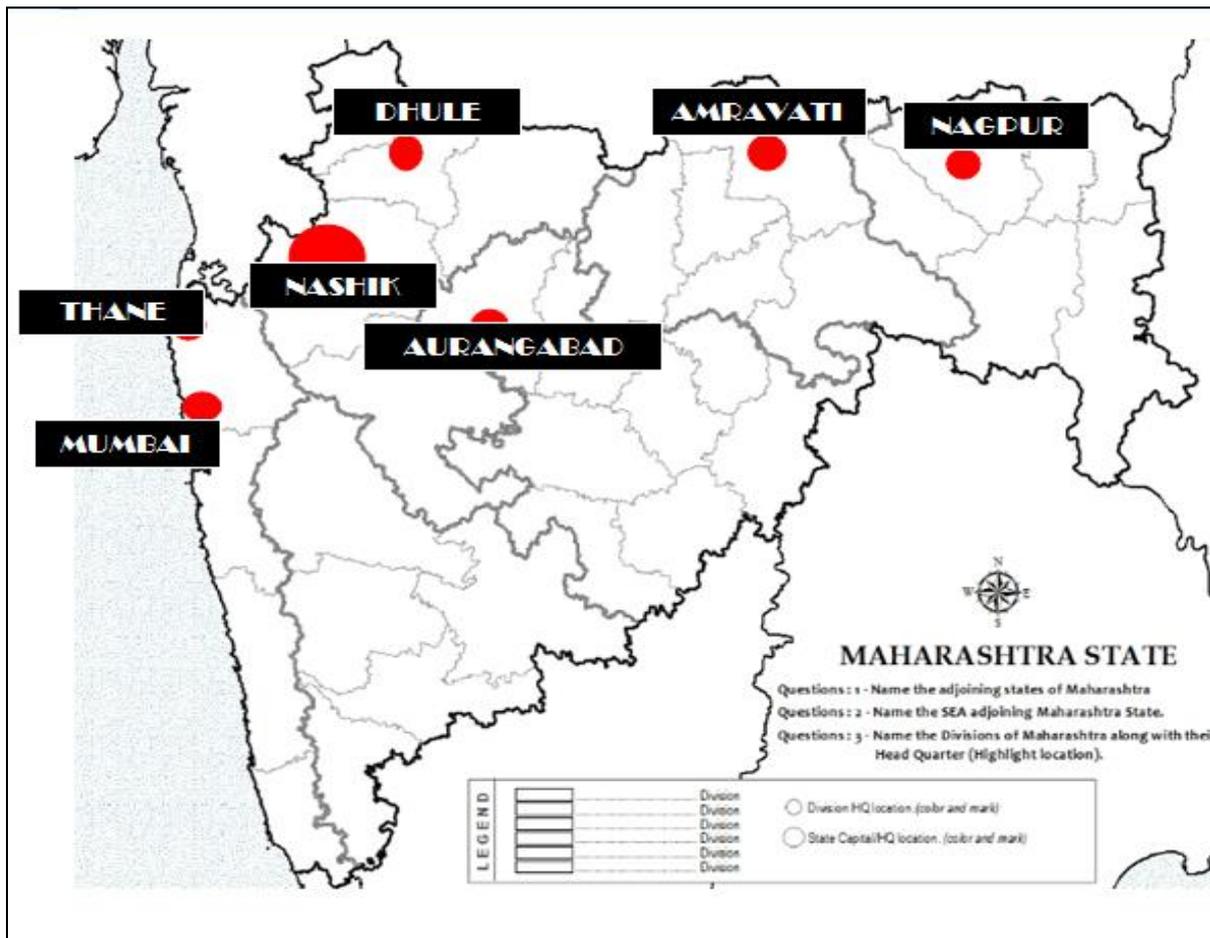


Image 1: Graphical Representation of Centres of Hih

Table 2: Information of Patients From Outside Maharashtra

Sr. No	Registration No	Mode Of Communication	Residence Of Patient
1	H-409	Telephonic	Punjab
2	H-322	Telephonic	Pakistan
3	H-207	Telephonic	Usa

Discussion

Telemedicine has a variety of applications in patient care, education, research, administration and public health^{9, 10}. The method implemented by HIH is rational use of telemedicine in management of haemophilia which is discussed in this article.

As shown in table no.1, the number of patients attending monthly HIH camps and are registered patients are 1232, the total number of interactions of these patients with a team of HIH 22926, out of which 43.59% was telephonically handled emergencies, As per data suggested by ICMR, 1330 children are born every year and there are 5,00,000 patients of haemophilia A of whom less than 5% have access to medical facilities. The commonest of the disorder is haemophilia A or clotting factor VIII deficiency. Haemophilia B or factor IX deficiency is one fifth less common than haemophilia A^[11, 12]. If we go by this calculation, the population covered by HIH is 1/4th of Indian haemophilic population who is taking treatment and are seeking the benefits of taking homoeopathic treatment as on add on therapy for the treatment of haemophilia, reducing the number of bleeding and swelling episodes, thereby improving their QOL. As per data shown in table no 1, in some centres of HIH, especially in the city areas, where people are more oriented to technology, maximum interactions have been done by use of social media e.g., in Thane, Surat and Amravati, around 75% of interactions are dealt with the use of social media. 17722 emergencies have been managed telephonically, which itself is suggestive of the number of times, travelling time, anxiety, cost of treatment, etc was saved and patients could have cost-friendly non-invasive treatment without rushing to the emergency Centre and with ease. Just using the faster mode of communication and social media. A study suggests typically a severely affected person with haemophilia Bleeds 35 times a year on an average necessitating supplement of factor 1000 unit per bleed.4 So the question arises is, is it possible for them to reach the government centre for 35 times whenever they have these episodes of bleeding? Is it economically possible for them to access

factor supplement and also bear travel expense to the nearest haematological centre? So many of them opt to add on therapy and alternative mode of treatment like homoeopathy which is easily palatable, non-invasive, effective even for the management of acute bleeding episodes, cost-effective and easily accessible. This has become more possible due to social media which is helping in creating awareness and making it easy for patients to have a clear, and open discussion without hesitations, which is providing space to discuss medical conditions outside healthcare provider's clinic. Not only that but also it helps in sharing experiences, and their findings, location and other material, the live activity of patients can be recorded and sent within minutes wherein the whole idea of the patient's condition can be obtained, especially in cases where migrating transporting can be a risk to life, in cases of patients with severe haemophilia they can have a risk to their life if a spontaneous bleed occurs, and they don't receive timely treatment. But the team of doctors have reduced the risk by more than 80% where patients immediately communicate and receive treatment with help of emergency medicines and social media apps. This not only enables to save time and have a brief idea of the condition of the patient to the treating physician within minutes and gets the effective treatment, without creating a situation of panic and anxiety.

Conclusion

Telemedicine has efficiently helped to manage and control acute episodes of people with haemophilia and thereby increasing their quality of life as well as the quality of healthcare with homoeopathic medicines.

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Conflicts of Interest: The Authors declare no conflicts of interest.

Few feedback from PWH

Feedback H-322

Dr. Kundu/Inbox

4 Nov at 7:56 pm

Print Raw message

Dr. Kundu/Inbox

9 Nov at 7:34 pm

Print Raw message

H-322
Hello Sir,
I joined Homoeopathy in Hemophilia, from Pakistan in 2-3-2015. As I am from Pakistan and Homoeopathy in Hemophilia is in India so I have to contact Dr Omkar Sir via Whatsapp. He asked me for my details (case taking method) and I gave him my life history according to my symptoms he prescribed me medicine. And the results were wonderful. First I use to take allopathic medicine for bleeding episodes and pain killers but now I am using only homoeopathy for pain and swelling some time I have to take factor injection and every one can understand that it's normal for any Hemophilia person. Using whatsapp is wonderful any time if I feel to consult Dr they are always available and willing to help. It's so helpful not only in Hemophilia but also in other minor issues. The most important and interesting thing is that I got admission in Homeopathy and start learning here just only the results that I got from it. (Dr Omkar and Afroz Sheikh) was inspiration also there treatment and behaviour is wonderful. Now I am in final year and I love to learn more and want to be like team Homoeopathy in Hemophilia.

I want to thanks all the members of Team Homoeopathy in Hemophilia for such wonderful support and help for me to get better life with Homoeopathy.

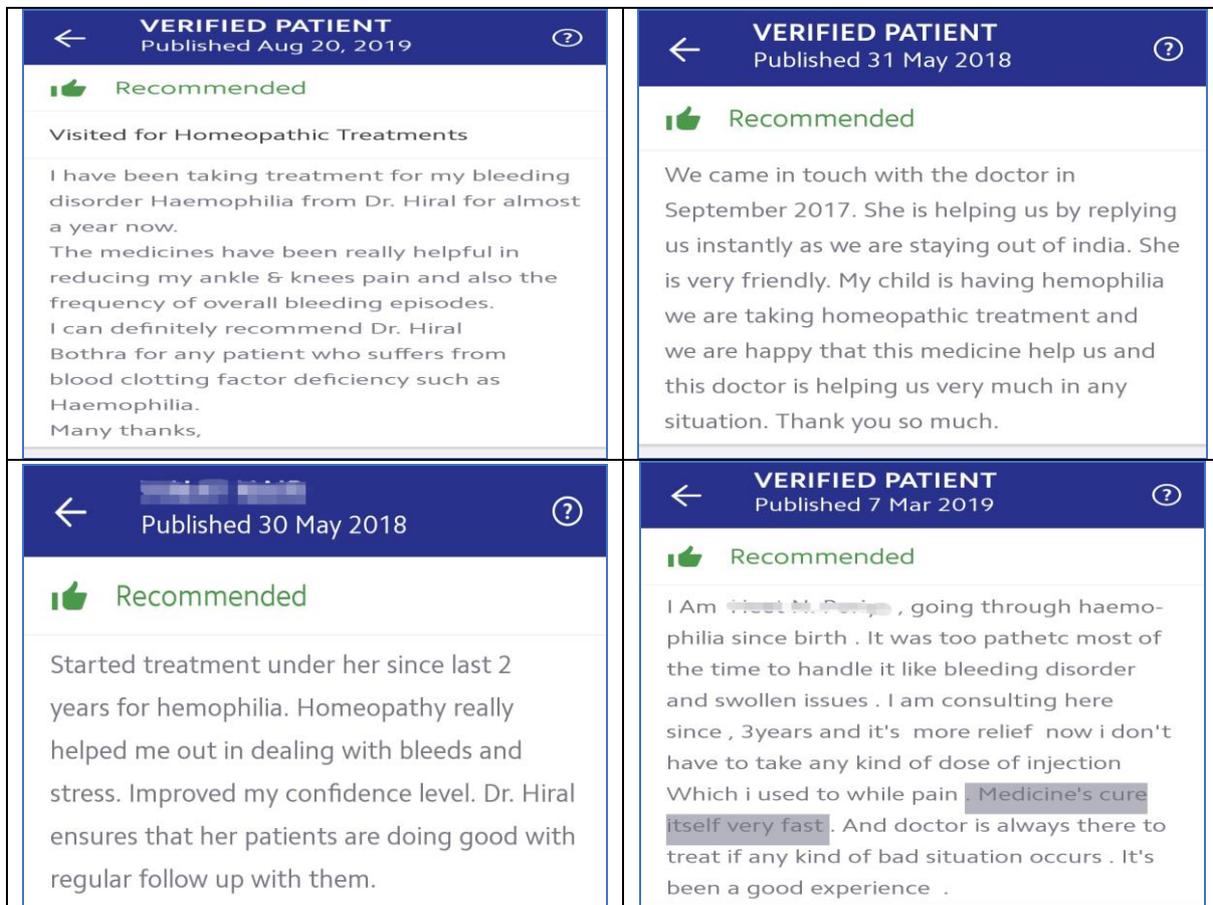
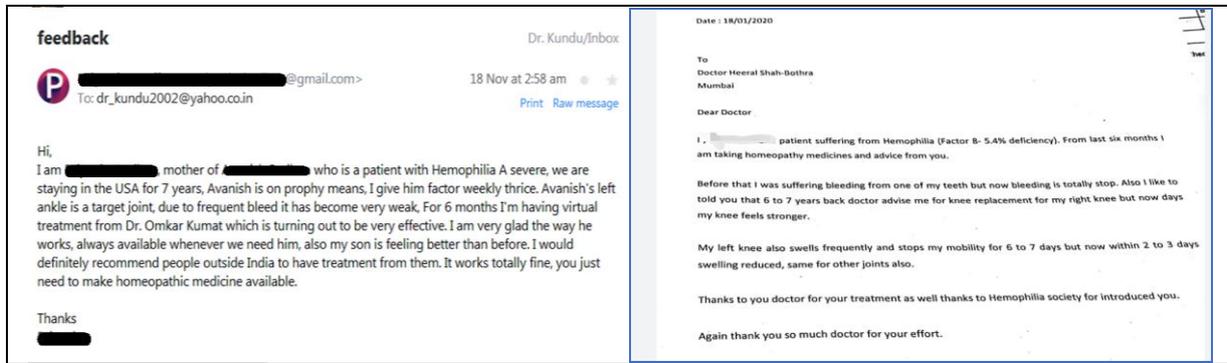
Kind regards,
Pakistani.

Dear Dr. Kundu,

This is the feedback regarding telephonic Homoeopathic treatment for Haemophilia patient. My son (a severe Haemophilic) has been under your care since he was 10 months old. Your treatment has proved extremely beneficial for him. He is now 4.5 years old, and growing up to be a normal child with normal joint functions.

We are presently living in Canada. But the distance has not impacted the care and treatment we have received from you. Earlier when we lived in Punjab, India, we used to visit your centre only once a year and most of his treatment was carried out telephonically. I must highly appreciate the efficiency and dedication of your team that is always ready to help at any hour, may it be day or night. Even as we moved to Canada, I never felt that we are miles away. Even the day night difference has not affected my son's treatment. Sir, you and your team are always there to stand by us and listen to our problems and provide solutions. Be it general care or an emergency, you have handled every case with utmost dedication and success. I look forward to a long lasting association and hope that you continue your noble deed and help many more patients who require your expertise.

Kind Regards,
(Mother)



Few Whatsapp Interactions





Dissemination Of Research



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