

THE ROLE OF SOCIAL MEDIA IN HEMOPHILIA IN KENYA

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Introduction and Objectives

- There is inadequate knowledge about hemophilia amongst healthcare workers and general population in Kenya.
- Efforts are being made to bridge this gap.
- An example is a group social media messaging service launched in the Coastal region of Kenya.
- The objectives are to increase hemophilia awareness, improve quality of care and accessibility to treatment for persons with hemophilia (PWH).
- The Coastal region has 1.2 million people and approximately 290 PWH.

Results

- 6 previously undiagnosed persons were tested in a period of 7 months and diagnosis of hemophilia confirmed.
- 6 PWH had bleeds, 4 mild and 2 severe (gastrointestinal). They were linked to timely appropriate care and factor availability was facilitated for them. All recovered well. Calls for blood donation were made for 2 of the patients and there was a good donor turnout.
- 2 workshops were organized and the group helped to disseminate the information and increase attendance from interested parties.
- Unfortunately, patients had to travel long distances to access the two hemophilia centers in the country located in Nairobi and Eldoret.
- There also was shortage of CFC during this time. However, emphasis on fractionated blood products use was made.



- Kenya: East Africa
- Approx. Population: 45,000,000
- Approx. number of PWH: 10,875
- Mobile phone penetration: >80% of the population
- Access to internet: >35% of the population

Materials and Methods

- The Coast Hemophilia Group, a messaging service through Whatsapp was started in May 2015.
- It has 42 members; 24 patients, 12 guardians and 6 clinicians.
- Photos of the location of the bleeds and description of the symptoms are made available while safeguarding the patient's privacy.
- Clinicians review the information and advice appropriately. Interventions may include: Referrals for diagnostic testing, sending of clotting factor concentrates (CFC), recommendation on treatments and follow-up care.
- Guardians of the PWH get education on various aspects of comprehensive hemophilia care. Information about workshops, blood donation drives and comprehensive clinics is also disseminated.



1. A parent helping his child with hemophilia with joint disease up the stairs
2. Patients being reviewed by our partners/visitors at Moi Teaching and Referral Hospital
3. Children with hemophilia getting ready for the 2016 World hemophilia day
4. Home visit to one of the members of the Coast Hemophilia Group(Family)
5. Carlos, one of PWH, who is one of the leaders of the support group

Conclusions

Accessibility to hemophilia care is a challenge in developing countries. This program shows how modern technology that is simple, cost effective and accessible can be used to enhance the dissemination of knowledge and practice on bleeding disorders and save lives.