sciendo

SHORT REPORT

Processes and experiences of satellite haemophilia clinic set-ups in Uganda – a short report

Philip Kasirye, Agnes Kisakye, Annette Nakalyango, Atwiine Barnabas

Haemophilia knowledge and care are largely missing in much of sub-Saharan Africa and there is a need for concerted efforts to ensure access to care services by affected persons. Haemophilia Foundation Uganda, supported by the global haemophilia community and working with the Uganda Ministry of Health, has set up eight satellite haemophilia treatment centres (HTCs) as part of a wider initiative to raise awareness and improve haemophilia care. Setting up the HTCs has involved a six-step process involving stakeholders in government, healthcare and the community, and ranging from securing initial support to an ongoing follow-up programme of mentorship and training. Over 1,700 healthcare professionals have been trained and 186 patients have been registered at these peripheral facilities over the past five years. This is helping to improve access to care, but there are still shortcomings around diagnostic capacity, available healthcare personnel, and facilities to procure recombinant factor products. We will continue and further our advocacy for budgetary inclusion of haemophilia at political and facility levels. We also propose a continued strengthening of the haemophilia care teams through mentorship, networking, and mobilisation for diagnostic support at large public hospitals.

PHILIP KASIRYE
Mulago National Referral Hospital, Kampala, Uganda

AGNES KISAKYE
Haemophilia Foundation of Uganda, Kampala, Uganda

ANNETTE NAKALYANGO
Mulago National Referral Hospital, Kampala, Uganda

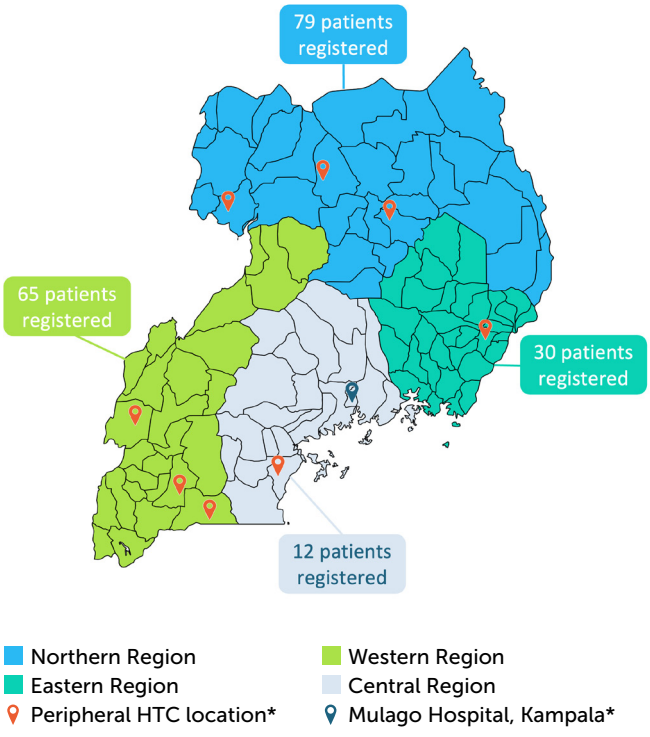
ATWIINE BARNABAS
Mbarara Regional Referral Hospital, Mbarara, Uganda

Healthcare professionals attending a training session at Nebbi Regional Referral Hospital, West Nile, Northern Region, Uganda. The training was facilitated by Dr Philip Kasirye Gitah and is part of a programme to improve haemophilia care across Uganda.

Keywords: *Haemophilia, Haemophilia treatment centre, Patient organisations, Uganda*

Haemophilia knowledge and care are largely missing in much of sub-Saharan Africa's population and healthcare setting. Haemophilia is known to be equally distributed among all ethnic groups worldwide [1], but it remains underdiagnosed in African countries [2,3,4]. There is therefore a need for concerted efforts to ensure access

Figure 1. Map of Uganda showing approximate locations of peripheral HTCs and number of patients registered with peripheral HTCs in each region



* Approximate location

to care services by affected persons. Initiatives organised by the World Federation of Hemophilia are helping this [2], as is the work of its national member organisations [5].

Haemophilia Foundation Uganda (HFU), with support from the global haemophilia community and working with the Uganda Ministry of Health, has mobilised initiatives for raising awareness and improving haemophilia care. To date, eight satellite haemophilia treatment centres (HTCs) have been set up at eight large public health facilities across Uganda, including hospitals in Gulu (Lacor), Lira and Nebbi in the Northern Region, Mbale in the Eastern Region, Masaka in the Central Region, and Kasese, Mbarara and the refugee settlement at Nakivale in the Western Region (Figure 1). Previously, haemophilia care was provided only at Mulago National Referral Hospital in Kampala. Here, we share a brief overview of the processes, experiences, and future goals.

PROCESS OF HTC SET-UP

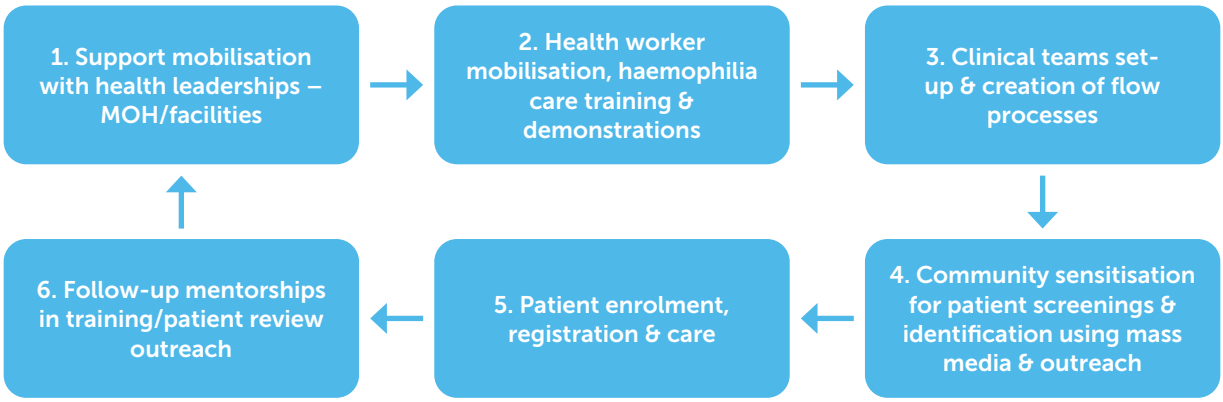
The setting up of HTCs was based on a six-step process involving stakeholders in government, healthcare and the community (Figure 2):

1. Securing the support of the Ministry of Health, health leaders and hospital facilities
2. Ensuring that nurses, clinicians and other healthcare workers at the HTC sites were equipped to provide haemophilia care. This involved a programme of training and demonstrations organised by HFU.
3. Establishing clinical teams and a clear set of processes to underpin the provision of haemophilia care
4. Raising awareness of haemophilia within the community to help improve diagnosis and facilitate access to care. This included media campaigns and community outreach programmes.
5. Ensuring that people with haemophilia were registered with their nearest HTC to enable them to access care
6. An ongoing follow-up programme involving mentorship and continued training of nurses and clinicians, and patient outreach.

EXPERIENCES

We observed great interest in developing haemophilia knowledge among healthcare staff, who attended the training sessions in high numbers at each of

Figure 2. Process of setting up peripheral HTCs



the eight HTC sites. The majority (> 95%) had never cared for a patient with haemophilia. The creation of specialised care teams has helped to increase the number of patients receiving haemophilia care. Over 1,700 healthcare professionals have been trained and 186 patients have been registered at these peripheral facilities over the past five years (Figure 1). Regionally across Uganda, this accounts for 79 patients in the Northern region (including 14 in West Nile subregion), 65 in the Western Region (54 Western, 11 Southern), 30 in the Eastern region, and 12 in the Central region (greater Masaka).

SHORTCOMINGS

Although establishing peripheral HTCs is helping to improve access to care, there is still limited diagnostic capacity for haemophilia (inability to perform coagulation tests and factors assays) and a limited number of healthcare personnel that can be allocated to haemophilia treatment. Those who are currently involved in haemophilia care have a high workload. There is also limited capacity for the facilities to procure recombinant factor products, which is related to budgetary constraints.

FUTURE GOALS

We will continue and further our advocacy for budgetary inclusion of haemophilia at political and facility levels. We also propose a continued strengthening of the haemophilia care teams through mentorship, networking, and mobilisation for diagnostic support at large public hospitals.

ACKNOWLEDGEMENTS

We thank all of our supporters for their continued engagement with training and diagnosis. Particular thanks go to the World Federation of Hemophilia for humanitarian aid and twinning projects and The Novo Nordisk Haemophilia Foundation for funding of diagnosis and healthcare professional training programmes.

This paper does not contain any studies involving human participants or animals performed by any of the authors.

ORCID

Philip Kasirye https://orcid.org/0000-0001-6620-483X

REFERENCES

1. Mehta P, Reddivari AKR. Hemophilia. [Updated 2021 Dec 31]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK551607/
2. Diop S, Haffar A, Mahlangu J, Chami I, Kitchen S, Pierce G. Improving access to hemophilia care in sub-Saharan Africa by capacity building. *Blood Adv* 2019; 3(Suppl): 1-4. doi: 1 0.1182/bloodadvances.2019GS121537.
3. Iorio A, Stonebraker JS, Brooker M, Soucie JM; Data and Demographics Committee of the World Federation of Hemophilia. Measuring the quality of haemophilia care across different settings: a set of performance indicators derived from demographics data. *Haemophilia* 2017; 23(1): e1-e7. doi: 10.1111/hae.13127.
4. Mbanya DN, Diop S, Ndoumba Mintya AN, El Kiaby M. Hemophilia care in Africa: Status and challenges. *Transfusion Clinique et Biologique* 2021; 28(2): 158-162. doi: 10.1016/j.tracli.2021.01.008.
5. Diallo YL, Poudiougo A, Drame BSI, et al. Improving haemophilia diagnosis in developing countries: the Malian experience. *J Haem Pract* 2020; 7(1): 45-53. doi: 10.17225/jhp00135.

HOW TO CITE THIS ARTICLE:
Kasirye P, Kiskaye A, Nakalyango A, Barnabas A. Processes and experience of satellite haemophilia clinic set-ups in Uganda – a short report. *J Haem Pract* 2022; 9(1): 76-78. https://doi.org/10.2478/jhp-2022-0009