Building a bridge to Bangladesh

Kate Forsyth, Rafia Khatun

Kate Forsyth recounts her experiences of a WFH twinning programme with Bangladesh and reveals that where learning is concerned, twinning is a two-way street

In any given population, around 1 in 10,000 people will be born with haemophilia. In the UK, access to the National Health Service and in particular to specialist services means that for those born with haemophilia and other inherited bleeding disorders there is funding available to provide professionals dedicated to delivering up to date care and treatment. This enables those living with bleeding disorders to lead a full and almost normal life.

Bangladesh has a population in excess of 150 million, resulting in an estimated haemophilia population of 14,000. However, given the lack of funding, supplies and the necessary professionals and knowledge, few have been diagnosed. Even fewer have access to specialist care or treatment for bleeds.

For those who are diagnosed and whose family can afford treatment, whole blood or fresh frozen plasma are the most likely treatments available for bleeds. For most, haemophilia is a life sentence. Many do not survive childhood while those who make it into adolescence and adulthood do so with much pain and disability.

This situation is reflected in many other developing countries. It is for this reason the World Federation of Hemophilia developed its Twinning Programme, now in its 16th year, under which haemophilia centres in emerging countries are twinned with centres in established countries. This two-way partnership imparts knowledge and support to enable the developing centre to deliver safe and appropriate care.

Kate Forsyth
Haemophilia Clinical Nurse Specialist (Paediatrics)
Haemophilia Centre, The Royal London Hospital
Whitechapel
London E1 1BB
Email: kate.forsyth@bartshealth.nhs.uk

Most. Rafia Khatun
Senior Staff Nurse
Dhaka Medical College & Hospital
Dhaka, Bangladesh.
Email: rofiakhatun@yahoo.com

Since the beginning of the twinning programme, the patient group in Bangladesh has established a network of hospitals. It is hoped that the partnership will provide good haemophilia care not only for those living in and around Dhaka, but also for those families travelling back and forth between London and Dhaka.

Pre-twinning care in Dhaka

Prior to the Twinning Programme, haemophilia care in Dhaka was minimal. The haematology departments struggled to cope with general haematology and haematological malignancies, leaving little if any room for haemophilia.

In the early 1990s a motivated group of parents and patients developed the Dhaka Haemophilia Society, which introduced an informal centre (essentially the ground floor of the director’s house) that provided advice, and where possible small amounts of treatment, using occasional donations of factor concentrates from the WFH. In the absence of factor treatment, bleeds were treated with whole blood or fresh frozen plasma purchased by patients from the local transfusion service. This was either self-infused or infused with help from the Haemophilia Society. With little demand, cryoprecipitate was not manufactured in Dhaka.

Since 2010, the teams in Dhaka have established a haemophilia network of three large hospitals (BSMMU, DMCH and Shishu Children’s Hospital) with additional

Figure 1: The Bangladeshi nurses and doctors together with Kate Khair and Kate Forsyth
There has also been an improvement in diagnostic techniques. Following a twinning laboratory training workshop in spring 2012, the laboratories are now performing reproducibly accurate clotting screens, as well as factor VIII and IX levels, thus ensuring the right diagnosis. Cryoprecipitate is now available for those with haemophilia A; it is clearly important that treatment is prescribed to those with a correct diagnosis. The lab is now participating in the WFH external quality assurance scheme.

The onward march of the nurse
The next part of the twinning process was to address front-line clinical care of haemophilia, which in the UK usually falls to nurses. In 2012, after much lobbying, the Bangladesh Government approved the appointment of 10 permanent haematology (haemophilia & bone marrow transplant) specialist nurses for DMCH and BSMMU. This was a big step for both haemophilia and for nurses working for government funded hospitals: previously their contracts included an obligatory rotation of practice area every 3 years.

It was decided that the next team to visit Dhaka would run a nursing workshop designed to teach the newly appointed haemophilia nurses the basics of haemophilia. The team established to run the nursing workshop in February 2013 were Dr Dan Hart, haemophilia consultant at RLH, Kate Forsyth, haemophilia nurse specialist at RLH and Dr Kate Khair, nurse consultant at Great Ormond Street Hospital.

By pooling experience from the North London Network, we brought to Dhaka a wealth of nursing experience. We hoped that by demonstrating the teamwork between doctor and nurses, we might help to break down the traditional doctor-nurse hierarchy that remains evident in many of the texts describing working relationships in Dhaka.

In Bangladesh, nursing is not a profession that many aspire to; those who become nurses have been described as "widows and destitute women who are searching for an income" in doing so they are forced into a "dirty job" with a poor social appreciation [2]. The average monthly salary is around 10,000 taka, which is less than £100. Even after allowing for the low living costs, it is not a well paid job.

By contrast, nursing in the UK and other developed countries is often seen as an admirable vocation. Ehrenreich and English [3] wrote that the Nightingale nurse was the “ideal lady, with selfless, motherly devotion to the patient” who brought “absolute obedience to the doctor.” Clearly, times have changed and nurses are no longer the doctor’s handmaiden. Nursing has moved on further with the evolution of specialist and consultant nurse roles. The necessary development of significant skill and specialist knowledge for these positions has led to a greater expectation and desire for independence that is now reflected in many haemophilia nurses in UK hospitals.

The haemophilia nursing workshop
After the introduction of the nursing degree (BSc) courses in Dhaka in 2011, nurses who held a diploma appear to be regarded as under qualified, unskilled with a poor knowledge base. Doctors are pinning their hopes on the increased numbers of degree nurses to improve the standards and the abilities of nurses. It became clear that the 10 new Dhaka haematology nurses waiting for their haemophilia workshop shared more of the aspirations and potential of new UK nurses than the more deferential and “poorly educated” Bangladeshi nurse stereotype we had been expecting.

Our workshop was initially planned to provide basic training about haemophilia based on the guidance of the senior Dhaka doctors. However, on meeting the nurses, it was apparent that their knowledge base was significantly greater than expected: their nurse training was of diploma level, which followed the UK nursing syllabus.

All 10 nurses were women, as nursing remains an almost universal female vocation in Bangladesh. With mixed religious backgrounds (Muslims, Hindus and Christians), only one of the ten was unmarried, eight of the married nurses had one or two children each, along with maids to look after them so that they could concentrate on their careers. The introduction of immunisation led to reduced infant mortality, and a growing confidence in having smaller families. This too contradicted much of our preparatory reading.

In order to establish what our nurses knew, we set them a quiz asking general questions about haemophilia and its treatment. It was important to establish a baseline from which to start teaching. They all did well, which was surprising as we’d been led to believe that their baseline
knowledge was poor!
The plans for the workshop clearly needed to be revised. Presentations on how
blood clots, bleeding disorders and treatment of bleeding were then delivered.
The nurses were then divided into three groups, with each being asked what they
felt the challenges and concerns were for people with haemophilia in three different
age groups (0 to 5 years, 5-18 years, 18 years and over). It was clear that group
work and being asked to think about how
their patients’ lives could be affected by
their bleeding disorder was an entirely
new way of learning for them (Table 1).
The concepts of nursing competencies
(soon to be made available in The Journal
of Haemophilia Practice) were discussed.
The potential for career development and
the recording of it were new concepts
soon to be made available in The Journal
of Haemophilia Practice) were discussed.
The nurses were then divided into three
groups, with each being asked what they
felt the challenges and concerns were for
people with haemophilia in three different
age groups (0 to 5 years, 5-18 years, 18
years and over). It was clear that group
work and being asked to think about how
their patients’ lives could be affected by
their bleeding disorder was an entirely
new way of learning for them (Table 1).
The concepts of nursing competencies
(soon to be made available in The Journal
of Haemophilia Practice) were discussed.
The potential for career development and
the recording of it were new concepts
about which all seemed excited. Next we
discussed the multidisciplinary team,
brainstorming every person involved in the
care of a person with haemophilia, and
focusing on the central and coordinating
role of the haemophilia nurse. This proved
an enlightening and particularly
empowering session for all 10 nurses.
On the second day, the Bangladesh
Haemophilia Society had arranged for a
number of families with haemophilia to
attend an interactive session. After
spending the morning getting to know the
visiting patients and families, the nurses
were again split into three groups, and
given five questions aimed at generating a
conversation in which to get to know the
patient. Three families were invited to sit
and talk to the nurses. The nurses found
this task difficult, with some asking the
questions and no more.
“We discussed the
multidisciplinary team,
 focusing on the central and
coordinating role of the
haemophilia nurse. This
proved an enlightening
and empowering session
for all 10 nurses”
For all three families, the cost of treating
and caring for a family member with
haemophilia was a great concern, as was
the anxiety surrounding the possibility of
having more than one child with
haemophilia. At 1200 taka (almost £10)
for an APTT test, most families lacked
sufficient funds to have their children
tested and therefore had no way of
knowing which boys would be affected
until they started to bleed.
The lack of haemophilia facilities posed
difficulties for most families: one family
had to travel over 120 km for care, but
even then there is no guarantee of
treatment. For others anxiety and
depression are common as they are
unable to fit in to the social norms,
feeling unable to care or finance further
treatment. For others anxiety and
depression are common as they are
unable to fit in to the social norms,
feeling unable to care or finance further
children who might be born with
haemophilia. Their concerns also cover
some of their worries may have been
properly explained and enabling them to
make solid decisions in areas such as
family planning.
Of the visiting families some were
unable to identify their bleeding history
and consequently were not able to relate
their current bleeding experiences with
previous ones. Had there been some
 genetic understanding and counselling
some of their worries may have been
properly explained and enabling them to
make solid decisions in areas such as
family planning.

The final teaching session of the
workshop was on genetics and
inheritance. It was a collaborative teaching
session taught by nurses and doctors. This
enabled the Dhaka teams to see how with
a break down of hierarchy, clinical teams
can work well together, with each playing a
significant role. This involved teaching
both doctor and nurse alike and it was
interesting to see the Dhaka host
professor sitting with his nurses learning
from UK nurses and doctor.

**Personal reflections on the experience**
From a personal angle, the idea of leaving
the safety of a well established, well-
equipped haemophilia centre, going to an

---

**TABLE 1: Nurses’ concerns for patients with haemophilia**

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Nurses’ concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–5</td>
<td>Cephalohaematoma, Circumcision, Teeth/gum bleeding, Umbilical bleeding, Accidents (especially road traffic accidents), Head trauma, Fractures following trauma</td>
</tr>
<tr>
<td>5–18</td>
<td>Trauma/accidents, Gums/teeth falling out, Joint swellings, Flaccid muscles, Epistaxis, Surgery, Haematuria, Melaena, Circumcision</td>
</tr>
<tr>
<td>18+</td>
<td>Sex, Internal/external bleeding, Joint bleeding and arthritis, Gum bleeds, Epistaxis, Haematuria, Trauma/accidents, Surgery, Infectious complications of blood products</td>
</tr>
</tbody>
</table>
area where the need is likely to be great, overwhelming even, with less than adequate facilities and expertise, was daunting. Added to this the anticipated reception was also quite a frightening prospect. Had we come all this way to bring some hope to an area of need, only to be dismissed because of people's social expectations and preconceived ideas? I hoped not. The published literature did not support us and yet the workshop was a success. Were we able to impart enough for these new leaders in a developing but deprived community to continue to develop, both for haemophilia and also for nursing, into the specialist nurses that we have become in the UK?

This was certainly an experience to remember. We were received gratefully: a big fuss and much work had gone to making this workshop and twinning experience a success. I returned to London, with a different outlook; we may feel the NHS is not what it once was but we too often forget just how well we care for and provide for our patients. We also forget just how far haemophilia nursing in the UK has come: once at the beck and call of a doctor, not as senior as a registrar or consultant. Now we are training them.

“We also forget just how far nursing in the UK has come: once at the beck and call of a doctor, now we are training them. The doctor’s handmaidens we are not.”

The doctor's handmaidens we are not.

But there is much also for us to learn from the developing world. Such experiences lead us to think about how we treat our patients and whether we, at times, should treat more conservatively. Is there a balance needed in order to provide good care and quality of life while at the same time not overly exposing patients to factor concentrates and the potential for inhibitor development?

Programmes such as these are a fantastic way to develop centres, both in the developing world and the developed.

Now most of them are well and out of danger. This is why I’m very happy to serve them. I have talked with nurses who attended that training course. They informed me that they have also noticed some changes among themselves and now they are able to provide nursing care to the haemophilia patients. All this became possible for the training we got from you. We all are grateful to you.

There is always much to learn and ways to refocus our approach to practice. Working collaboratively with neighbouring institutions can also build up experience for all involved by expanding our knowledge and way of practice. It is a big undertaking but with a supportive team, this is a challenge that can be taken on by any experienced or motivated member of a haemophilia MDT.

Rafia Khatun from Dhaka Medical College Hospital gives her impression of the training provided through the WFH twinning programme

Before taking part in training on haemophilia in February 2013, I was confused about this disease. Now I know many things about haemophilia.

A few days back, I got a patient at the haemophilia clinic who came from a poor family. At first, I took his history, which was similar to haemophilia. After suspecting this patient’s sign and symptoms as haemophilia, I gave him some advice to modify his lifestyle and use the emergency precaution. When I told the family about this, they became worried. I explained this disease to them clearly. Then, I sent them to the haematology department. The doctor gave some medical tests for diagnosis of haemophilia. After getting the medical report the doctor confirmed that it was haemophilia and that my suspicion was correct. My confidence developed after taking the training.

Then we admitted the patient in our ward. I served the patient appropriately. The patient is becoming well day by day. You will be happy to know about our Dhaka Medical College Hospital, Dhaka. We make an outdoor clinic for the patients of haemophilia. One day in a week, or four or five days in every month, we see patients with haemophilia and give them proper nursing care and advice.

A few days back, I got a patient at the haemophilia clinic who came from a poor family. At first, I took his history, which was similar to haemophilia. After suspecting this patient’s sign and symptoms as haemophilia, I gave him some advice to modify his lifestyle and use the emergency precaution. When I told the family about this, they became worried. I explained this disease to them clearly. Then, I sent them to the haematology department. The doctor gave some medical tests for diagnosis of haemophilia. After getting the medical report the doctor confirmed that it was haemophilia and that my suspicion was correct. My confidence developed after taking the training.

Then we admitted the patient in our ward. I served the patient appropriately. The patient is becoming well day by day. You will be happy to know about our Dhaka Medical College Hospital, Dhaka. We make an outdoor clinic for the patients of haemophilia. One day in a week, or four or five days in every month, we see patients with haemophilia and give them proper nursing care and advice.

Rafia Khatun from Dhaka Medical College Hospital gives her impression of the training provided through the WFH twinning programme

Before taking part in training on haemophilia in February 2013, I was confused about this disease. Now I know many things about haemophilia.

A few days back, I got a patient at the haemophilia clinic who came from a poor family. At first, I took his history, which was similar to haemophilia. After suspecting this patient’s sign and symptoms as haemophilia, I gave him some advice to modify his lifestyle and use the emergency precaution. When I told the family about this, they became worried. I explained this disease to them clearly. Then, I sent them to the haematology department. The doctor gave some medical tests for diagnosis of haemophilia. After getting the medical report the doctor confirmed that it was haemophilia and that my suspicion was correct. My confidence developed after taking the training.

Then we admitted the patient in our ward. I served the patient appropriately. The patient is becoming well day by day. You will be happy to know about our Dhaka Medical College Hospital, Dhaka. We make an outdoor clinic for the patients of haemophilia. One day in a week, or four or five days in every month, we see patients with haemophilia and give them proper nursing care and advice.

A few days back, I got a patient at the haemophilia clinic who came from a poor family. At first, I took his history, which was similar to haemophilia. After suspecting this patient’s sign and symptoms as haemophilia, I gave him some advice to modify his lifestyle and use the emergency precaution. When I told the family about this, they became worried. I explained this disease to them clearly. Then, I sent them to the haematology department. The doctor gave some medical tests for diagnosis of haemophilia. After getting the medical report the doctor confirmed that it was haemophilia and that my suspicion was correct. My confidence developed after taking the training.

Then we admitted the patient in our ward. I served the patient appropriately. The patient is becoming well day by day. You will be happy to know about our Dhaka Medical College Hospital, Dhaka. We make an outdoor clinic for the patients of haemophilia. One day in a week, or four or five days in every month, we see patients with haemophilia and give them proper nursing care and advice.

References

