Development, implementation, evaluation and validation of a haemophilia nurses’ education program in South Africa

Jill Smith
The University of Notre Dame Australia

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APPENDICES
Appendix A

The HRF and HNEP curriculum

Information can be found in the attached thumb drive.
Appendix B

HNEP Summative examination

Name: _______________________________ Date: _________________

Hospital: _____________________________________
Province: _____________________________________
Country: _____________________________________

Marks: Marks shown for each correct question. Total: 100

1. **Definition of haemophilia.** Tick the correct answers:
   a) haemophilia is curable
   b) haemophilia A is a deficiency of clotting factor XII
   c) haemophilia B is a deficiency of clotting factor IX
   d) severe haemophilia has < 1% clotting factor
   e) moderate haemophilia has 1%-5% clotting factor
   f) mild haemophilia has 5%-25% clotting factor
   g) All females born to fathers with haemophilia will be carriers of the disorder

   (7)

2. Show how each of a mother’s XX and father’s XY sex chromosomes unite to form male and female offspring.

   (4)
3. Draw a pedigree (genogram) of the following family.

a. Thomas Huma (18 months) presented at casualty with a limp and swollen knee. On testing he was found to have a factor 8 level of less than 1%.

b. His parents, Mary and Joseph Huma have two children: Thomas and one daughter, Lucy aged 5.

c. Mary Huma has a brother Bobby Jonas

d. Bobby Jonas also has haemophilia A.

e. Mary and Bobby’s parents died in a car accident in 1995.
4. Name two common sites that people with haemophilia bleed into.

Tick the correct answers:

a) Fingertips
b) Muscles
c) Liver
d) Joints

5. What are the four most important things to do to treat a bleed?

Tick the correct answers:

a) Replace factor
b) Ice
c) Immobilize
d) Rehabilitate
e) Hot packs
f) Pain relief

6. Listed below are some signs and symptoms of a joint bleed.

Tick the correct answers:

a) Heat
b) Pain
c) Stiffness
d) Tingling
e) Swelling
f) Increased movement
g) Decreased range movement
7. Signs and symptoms of muscle bleeds –

Tick the correct answers:

a) Discomfort/Pain  □
b) Pins and needles  □
c) Threatened limb  □
d) Tingling  □
e) Cool to the touch  □
f) Painless  □
g) Swelling  □

(5)

8. Tick four complications of untreated and un-rehabilitated bleeds to joints and muscles.

Tick the correct answers:

a) Crippling deformities  □
b) Arthritis  □
c) Contractures  □
d) Stiffness  □
e) Increased mobility  □

(4)


a) Develops muscle strength to protect joints so fewer bleeds  □
b) Rehabilitates to maintain a range of motion  □
c) Restores flexion to limbs  □
d) Not restoring extension to limbs  □
e) Stops infections in bones  □
10. How can you immobilize a person with a joint bleed?

Tick the correct answers:

a) Splints
b) Crutches
c) Sedation

11. Why do we immobilise limbs during a bleed?

Tick correct answers.

a) To prevent further bleeding into the joint
b) To decrease the pain caused by the bleed
c) To increase movement of limb

12. Why do we use ice on a bleed? How do we apply ice to a bleed?

Tick the correct answers:

a) To promote vasoconstriction
b) To limit the extent of the bleed
c) Apply for 20 minutes twice per day
d) Apply for five minutes on and 10 minutes off
e) Apply ice to the circumference of bleed
13. The most important measures to be taken for a Haemophilia A patient who is to have a tooth extraction are:

Tick the correct answers:

a) Liaison between haemophilia centre and dentist
b) Check for inhibitors
c) Give clotting factor and Tranexamic acid prior to the procedure
d) A quick-dissolving suture should be used
e) Tranexamic acid mouthwash “swish & swallow” for 1 week
f) Do not rinse on 1st day but then rinse regularly to maintain hygiene

14. A person with haemophilia presents with persistent headaches, nausea, vomiting, irritability and slurred speech. What could be wrong with him and how would he be managed?

Tick the correct answers:

a) He has a head bleed
b) Give factor as for a major bleed
c) Give anti-inflammatory medication to relieve pain
d) He requires a CAT scan
e) He needs to be admitted with bed rest for one week
f) Neurological observations should be carried out

15. Von Willebrands Disease.

Tick the correct answers:

a) Is an inherited bleeding disorder
b) Is a deficiency of VWF
c) Factor VIII may be low on the blood test
d) Children grow out of it □

e) Only affects males □

f) May be a qualitative disorder □

g) May be a quantitative disorder □

16. Signs and symptoms of von Willebrand Disease _____
Tick the correct answers:

a) mucous membrane bleed □

b) fever □

c) epistaxis □

d) heavy/prolonged bleeding post-partum □

e) menorrhagia □

f) easy bruising □

(5)

17. Inhibitors.
Tick the correct answers:

a) Inhibitors are antibodies to factor VIII or IX □

b) Inhibitors need to be checked following the first few infusions of factor □

c) Inhibitors are infectious □

d) Immune tolerance is used to attempt to clear the inhibitor □

e) FEIBA and Recombinant factor VIIa are products used to treat bleeding in haemophiliacs with inhibitors □

(4)

18. These functions form part of the role of the Haemophilia Nurse.
Tick the correct answers:

a) Link between team members □
b) Clinically evaluate and treat

c) Financial manager

d) Clinic co-ordinator

e) Maintains accurate records

f) Educator

g) Advocator

19. Home therapy: the advantages of infusing factor products in the home are:

Tick the correct answers:

a) Treatment is begun more quickly

b) Costs are reduced

c) Fewer long-term complications

d) Freedom in lifestyle

e) Increases the amount of factor used

20. Tick the correct answers:

a) Continuous infusion is given via a pump continuously to allow factor levels

b) to remain constant

c) Primary prophylaxis prevents bleeds in people with haemophilia

d) Secondary prophylaxis is given after recurrent joint bleeds have occurred in a target joint

e) On demand therapy is given once a week
21. Preparation for surgical procedure

Tick the correct answers:

a) No need to check for inhibitors
b) Notify the lab prior to procedure
c) Bring factor level up to 80-100%
d) Repeat factor in one week
e) Sutures may be removed on day 5

(2)

22. Laboratory

Tick the correct answers:

f) All coagulation tests are sent in a citrated tube (blue top)
g) Tubes must be filled to correct level
h) All specimens must reach the lab within 4 hours
i) Arrangements must be made for specialised testing
j) All laboratories in South Africa can process tests for haemophilia
k) Factor levels are tested at every clinic visit

(4)

TOTAL

100
Appendix C

Nurse participant evaluation of the HNEP

Evaluation Form
Post haemophilia Nurse training Evaluation Form
Training received July 2002
Evaluation forms March 2003

Name of Trainee:

Hospital/ Institution where employed:

We would like to evaluate the effectiveness of the Haemophilia Nurse Training course you attended in July 2002.
Please assist us by filling in the following information as accurately as possible
This information will assist the Department of Health in assessing the effectiveness of the training in rolling out the Haemophilia program countrywide
Please fax this form to:
Anne Gillham fax number (011) 787 6710

1. Since your training have you treated or been involved with the management of any People with haemophilia (PWH) in your area
   - Yes
   - No

2. If yes how many
   - 0
   - 1 – 5
   - 6 – 10
   - > 11
   Comment / explanation

3. Have you identified any new PWH in your area?
   - Yes
   - No

4. If so how many?
   - 0
   - 1 – 5
   - 6 – 10
   - > 11

5. Have you referred any PWH to the Nearest Haemophilia Treatment Comprehensive Care centre (HCCC)
   - Yes
   - No
   - N/A
6 If yes how many?
   0
   1 – 5
   6 – 10
   ▶ 11
Comment/explanation

7 Have you followed up any PWH in your community
   Yes
   No

8 If yes how many
   0
   1 – 5
   6 – 10
   ▶ 11
Comment/explanation

9 Have you been involved with any negotiating and advocating for haemophilia care within your hospital?
   Yes
   No
   N/A
   Comment/explanation

10 Is Anti Haemophilia factor (Factor VIII or IX as required) available at your hospital?
    Yes
    No
    If no, comment/explanation

11 Does your hospital recognise your role as haemophilia trained nurse?
    Yes
    No
12 Are you allocated to the correct area to undertake your duties as a haemophilia nurse?
   Yes
   No

13 Do the Nursing administration of your hospital and Medical staff support your role?
   Yes
   No

14 Have you been moved from your area since training disabling you from managing PWH?
   Yes
   No

15 Have you been moved from your area since training enabling you to manage PWH?
   Yes
   No

16 How many weeks night duty have you worked since training?

15 If you have worked night duty has this disabled you from undertaking your duties in treating PWH?
   Yes
   No

17 Have you trained any other staff members in Haemophilia care in your hospital?
   Yes
   No
   If yes comment /explanation

18 Have you identified any barriers, which have prevented you from taking an active role in the management of haemophilia patients, or identification of haemophilia patients in your area?
   Yes
   No
   Comment /explanation
Appendix D.

Questions for haemophilia coordinators.

1. Creation of HNEP

- What prompted the creation of the HNEP?
- Describe any barriers to the formation of the HNEP.
- Who were the essential participants in the formation of the HNEP?
- How long did it take to progress from planning to implementation?
- What do you see as the most important elements in the curriculum?
- Can you tell me about the preparation of the curriculum materials.
- What factors were considered to ensure the curriculum was appropriate for the level of education standard of the participants?
- Were there any other considerations taken into account to create the HNEP?

2. Implementation of the HNEP

- What are the most important measures needed to organise an HNEP?
  - Advertising, including criteria for targeting participants, lead in time
  - Venue, catering, transport
- What financial resources are required to support the implementation of the HNEP?
- What human resources are required to support the implementation of the HNEP?
- How important is the support of the local health providers: local hospital, local doctors, and provincial government health department?
- Does poor infrastructure, such as roads, power failures, influence the implementation of the HNEP?
- Have many changes been made the implementation of the HNEP over the years? Are there any major changes that you would like to make in the program?
- What do you think would happen to PWH in SA if there was no HNEP offered?
- What do you personally gain from being involved with the HENP?
- What do you think would happen to the HNEP without you? Can you tell me about the succession planning for the HNEP?
Appendix E

Focus Group Questions

Good morning, you may remember me from your haemophilia nurses education program (HNEP). My name is Jill Smith, one of the trainers and you all know Anne. I am here today to collect some data about the program so that we can judge how well the education has benefitted PWH. I wrote to you a few weeks ago to ask if you would participate in this focus group so we could have some conversations about the nurse training and the PWH that you care for. Please note that although I would ask you not to repeat what you have heard from others in this session, I cannot personally guarantee absolute confidentiality

a) I would like it if you would go round the room so you can tell us who you are, where you work, how long you have been an RN and when you completed the HNEP.

b) Tell me about how satisfied you were with the HNEP immediately after you finished the course and now.

Can you also describe the support network you have?

c) Take me through the process of what you do when a PWH comes to your clinic/ward/department?

Do you think the HNEP has improved your practice and if so, can you tell me how?

d) How do you go about putting together a care plan for a PWH?
What do you think are the key things to consider?

e) Can you describe ways that the Haemophilia Nurses’ Education Program has helped you provide haemophilia nursing services to the PWH and family members?

f) Do you share your haemophilia knowledge with other health care workers?
   Can you describe how and in what settings does this happen.

g) Tell me about an episode with a PWH which sticks in your mind – before and after.

h) How many PWH have you instructed with Home Therapy?
   How did they react?
   Did it help them?

i) Have you seen an improvement in the lives of PWH? If so, tell me about it.
Appendix F

Participant Information Form for Nurse Participants

If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943.

SCHOOL OF NURSING

PROJECT TITLE: Creation, implementation, evaluation and validation of a haemophilia nurses’ education program in South Africa.

CHIEF INVESTIGATOR: Jill Smith

STUDENT'S DEGREE: PhD Nursing

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

The Haemophilia Nurses’ Education program was created to inform nurses about haemophilia and the necessary knowledge and skill to care for PWH. This program now requires evaluation and this is my undertaking as part of my Doctor of Philosophy at the University of Notre Dame, Fremantle, Western Australia (School of Nursing and Midwifery). Participating in a focus group and interview will provide the opportunity to express your opinions about the Haemophilia Nurses Education Program and how this may have helped you to care for PWH.
Who is undertaking the project?

This project is being conducted by me and will form the basis for the degree of PhD at The University of Notre Dame Australia, under the supervision of Dr Catherine Ward and Professor Richard Berlach. I am a recipient of a grant from the West Australian Department of Health.

What will I be asked to do?

This study will use focus groups and one-to-one interviews to evaluate the Haemophilia Nurses’ Education Program in South Africa. The sample group will consist of nurses who have completed the Haemophilia Nurses’ Education Program in South Africa, currently care for PWH and are fluent in English. Participants are based in Nelspruit in the Mpumalanga province, the second in Johannesburg, the third in Cape Town and the fourth in George in the Western Cape Province. No individual will be identified in the results and thesis.

How much time will the project take?

Your participation will only require an hour or so of your time which does not include travel time to the place of interview.

Are there any risks associated with participating in this project?

No risks are foreseen by the researcher.

What are the benefits of the research project?

The benefits of the study are to validate a teaching package which has been developed for RNs to manage haemophilia care competently and confidently. The benefits are therefore not only to the individual RN but also haemophilia patients in their care and nursing colleagues in the context of a developing country.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences.

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals. All data generated will be kept in a locked filing cabinet drawer in School of Nursing and Midwifery, The University of Notre Dame Australia. Data will be entered onto a password protected computer. As stated all hard copies of data will be stored
in a locked drawer and the names of the experts and participants will be kept confidential. It is anticipated that the study will be published in a peer-reviewed nursing journal.

**Will I be able to find out the results of the project?**

The results or a summary of the results will be made available to the participants by letter at the completion of the study.

**Who do I contact if I have questions about the project?**

Jill Smith or Dr Catherine Ward at the University of Notre Dame Australia School of Nursing, Fremantle campus: phone number +61 9433 0223.

**What if I have a complaint or any concerns?**

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (approval number 013128F). If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

**I want to participate! How do I sign up?**

Once you have agreed to participate in the evaluation of the teaching package, you will be emailed a copy of the Consent form. When have signed the form and had your signature witnessed, you can return the form to me by email.

Yours sincerely,

Jill Smith, RN, B.Nurs., PhD candidate
Appendix G

Consent form for participation in focus group or interview

I, (participant’s name) _________________________________ hereby agree to being a participant in the above research project.

a) I have read and understood the Information Sheet about this project and any questions have been answered to my satisfaction.

b) I understand that I will be required to answer questions that will be audio-taped.

c) I understand that I may withdraw from participating in the project at any time and free to withdraw any unprocessed identifiable data previously supplied.

d) I understand that this study is being undertaken for research purposes.

e) I understand that all information gathered by the researcher will be treated as strictly confidential. There are legal limitations to this confidentiality as it is possible that data may be subject to subpoena, freedom of information requests or legal reporting obligations.
f) I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed. However, as the sample size is small, this may have implications for protecting the identity of the participants.

g) This agreement will be retained by the researcher once it is signed and returned.

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<td>RESEARCHER’S FULL NAME:</td>
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Appendix H

Participant Information Form – Expert Panel

SCHOOL OF NURSING

PROJECT TITLE: Creation, implementation, evaluation and validation of a haemophilia nurses’ education program in South Africa.

CHIEF INVESTIGATOR: Jill Smith
STUDENT'S DEGREE: PhD Nursing

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

The research project presents the contents of a Haemophilia Resource File for validation by expert nurse educators. The contents of the File were written by the facilitators of the Haemophilia Nurses’ Education Program (HNEP) and are designed to accommodate the challenges of delivering quality nursing care in the context of a developing economy. The evaluation of the file contents will establish whether this model of education would be of benefit to other sub-specialty nursing education programs in developing countries.

What am I being asked to do?

1. You are one of seven expert nurse educators who have been invited to evaluate the lectures contained in within the teaching package and the package as a whole to assess whether the package offers teaching and learning strategies appropriate for adult learners (in this case Registered Nurses).

2. The contents of the file contain copies of all the lectures that are delivered at each HNEP. A thumb drive containing the corresponding power point presentations will
also be included in the package which will help you to appreciate how the lecture is delivered. A short survey is enclosed with each lecture for your evaluation.

3. The evaluation asks you as an expert, to respond to eight open ended questions and which will require a time commitment of approximately 6 hours. There will be no follow-up requirements.

Who is undertaking the project?

This project is being conducted by Jill Smith and will form the basis for the degree of PhD at The University of Notre Dame Australia, under the supervision of Dr Catherine Ward and Professor Richard Berlach. The candidate is the recipient of a grant from the West Australian Department of Health.

What time commitment is being asked of me?

It is estimated that it will take approximately 6 hours to complete the evaluation of the curriculum resource.

Are there any risks associated with participating in this project?

No risks are foreseen by the researcher.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences.

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken in instances of legal requirements such as court subpoenas, freedom of information requests, or mandated reporting by some professionals. All data generated will be kept in a locked filing cabinet drawer in School of Nursing and Midwifery, The University of Notre Dame Australia. Data will be entered onto a password protected computer. As stated all hard copies of data will be stored in a locked drawer and the names of the experts and participants will be kept confidential. It is anticipated that the study will be published in a peer-reviewed nursing journal.

Will I be able to find out the results of the project?
The results or a summary of the results will be made available to the participants by letter at the completion of the study.

Who do I contact if I have questions about the project?

Jill Smith or Dr Catherine Ward at the University of Notre Dame School of Nursing, Fremantle Australia: phone number +61 9433 0223.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (approval number 013128F). If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943, research@nd.edu.au Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up?

Once you have agreed to participate in the evaluation of the teaching package, you will be emailed a copy of the Consent form. When you have signed the form, you can return the form to me by email.

Yours sincerely,

Jill Smith, RN, B.Nurs., PhD Candidate

Researcher
Appendix I

Experts’ consent form for assessment of an education program

Construction, implementation, evaluation and validation of a haemophilia nurses education program in South Africa

Principal Researcher: Jill Smith

Research Supervisors: Dr Catherine Ward and Professor Richard Berlach

INFORMED CONSENT FORM TO PARTICPATE IN THE ASSESSMENT OF THE HAEMOPHILIA NURSES EDUCATION PROGRAM

I, (participant’s name) _________________________________ hereby agree to being a participant in the above research project.

h) I have read and understood the Information Sheet about this project and any questions have been answered to my satisfaction.

i) I understand that I will be required to answer survey questions.

j) I understand that I may withdraw from participating in the project at any time and free to withdraw any unprocessed identifiable data previously supplied.

k) I understand that this study is being undertaken for research purposes.

l) I understand that all information gathered by the researcher will be treated as strictly confidential. There are legal limitations to this confidentiality as it is possible that data may be subject to subpoena, freedom of information requests or legal reporting obligations.
m) I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed. However, as the sample size is small, this may have implications for protecting the identity of the participants.

n) This agreement will be retained by the researcher once it is signed and returned.

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Appendix J

Letter of introduction to expert nurse educators

If participants have any complaint regarding the manner in which a research project is conducted, it should be directed to the Executive Officer of the Human Research Ethics Committee, Research Office, The University of Notre Dame Australia, PO Box 1225 Fremantle WA 6959, phone (08) 9433 0943.

Dear

Firstly, let me introduce myself, my name Jill Smith and I am a Registered Nurse (RN) working in the Haemophilia Centre of Western Australia, beginning there in 1995. I was invited by members of the South African Haemophilia Nurses’ committee to help develop a haemophilia training program for RNs. The result of this meeting was the creation and implementation of the Haemophilia Nurse Education Program (HNEP). Four expert haemophilia nurses (the researcher and three South African nurses) were involved in the development of the program. The time has now come to evaluate the HNEP.

As an expert nurse educator you will appreciate that a formal evaluation of the HNEP is essential to determine its educational merit, and its value in relation to the context in which it will be taught, that is South Africa. As part of my Doctoral studies I am in the process of evaluating the HNEP and as such I am seeking your assistance as an expert to be involved in this process. Since the program will be taught within SA I have attached a description of the context to provide a more detailed overview of the nurse education and the context in which the program operates (see attached).

The contents of the HNEP teaching package includes all lecture material, activities, booklets outlining the management of a PWH, pharmaceutical products used in the treatment of haemophilia, clinic forms and product information about factor replacement. Power point presentations which accompany specific lectures have been downloaded to the...
attached thumb drive for easy assessment. On completion of the program the participants of
the HNEP will be encouraged to take the resource file to their workplace to be used as a
haemophilia information resource.

Should you consent to be part of this evaluation process, you are asked to respond to
eight questions (question four is directed at SA evaluators only as it is context-specific) and
complete a 9-item survey (see attached). The eight questions pertain to the overall HNEP
content and teaching strategies used in the delivery of the program and the short survey will
be attached to each lecture in the resource file to enable you to score each individual lecture.
If you agree are to undertake this evaluation I will despatch the complete file and survey
questions to you by courier, including a pre-paid envelope for you to return the file to me by
courier.

In recognition of the time involved in the examination of the Haemophilia Resource
File, a gratuity of AU$ 200.00 will be paid upon return of the file and review comments.

I am very grateful to you for considering my request. If you should require further
information you can call me on +61 408980708 or via email jsmith@highway1.biz.
Alternatively you can contact my research supervisor Dr Catherine Ward on +6194330223.

Yours sincerely,

Jill Smith RN., B. Nurs., PhD candidate
Appendix K

Context statement of the HNEP for expert nurse educators

This overview will provide you with the background in which the Haemophilia Nurses’ Education Program (HNEP) operates and from this review you will understand why this program evaluation is necessary.

The HNEP is offered in a location where it has been demonstrated that people with haemophilia (PWH) have been poorly managed. The RNs who will attend this program are selected by the Directors of Nursing at their workplaces to attend the program following them being advised by the Haemophilia Nurses’ Association that a training program will take place in their province. Each of the participants will be funded by the Provincial Department of Health.

The HNEP was designed to be culture-specific and take into account the work difficulties that some South African nurses experience. These RNs often lack access to equipment and facilities that nurses in a developed country take for granted and some of these nurses work in health care facilities far from the major cities (and therefore Haemophilia Treatment Centres). Often these areas have poor road access, unreliable communication and power supplies and limited access to electronic equipment such as computers. The patient population frequently comes from several different cultures and many are poorly educated or illiterate.

The Oxford Dictionaries online define the word context as “the circumstances that form the setting for an event, statement or idea, and in which the terms of which it can be fully understood”. In order to understand the context of the HNEP, it requires some explanation of the setting to fully appreciate the challenges of implementing such an education program within South Africa (SA).

Haemophilia is a lifelong, incurable bleeding disorder whereby blood does not clot. This occurs because one of the clotting proteins, either factor VIII or factor IX is missing. In
its severest form, people with haemophilia (PWH) will not survive past adolescence. Recurrent bleeding into muscles, organs and especially joints, can result in crippling and severe pain. If the PWH does not receive treatment, significant morbidity and mortality are frequent outcomes. The intent of treatment is to replace the missing clotting factor by intravenous injection, which is expensive and therefore unavailable in many low income countries. Prompt treatment of a haemophilic bleed, even if conservative first aid measures are all that is available, can improve outcomes (Chandy, 2005).

Lack of education of healthcare staff about haemophilia contributes to a low index of recognition which means that PWH are often undiagnosed and therefore untreated. Those PWH who are diagnosed and live in areas with poor access to a haemophilia treatment centre, are frequently poorly managed, suffering increased morbidity and mortality. The HNEP was created in the hope of addressing some of these issues. This five day program is aimed at Registered Nurses (RNs) working in areas where haemophilia bleeding episodes have been reported to be mismanaged. Thus educating these RNs about haemophilia recognition, diagnosis, genetic patterns, treatment and management of specific episodes such as surgery will assist to enhance the management of PWH and improve outcomes.

The World Bank ranks SA as an upper middle income economy, which has a high rate of poverty and a low GDP per capita (South Africa – World Bank ), and is regarded as a developing nation in various aspects, with some essential services such as education and health at a level consistent with a developing economy. In other ways, services reflect the standards one would expect to find in developed economies. It is within this context that the HNEP will be conducted.

In contrast to nurses in Australia, for many of the participants in the HNEP, choice about whether they would attend the program was not an option: they were simply directed by nursing management at their workplace to attend. Often the RNs were given only a few days’ notice that they would be away from their workplace and homes for five days. These RNs work in hospitals and health clinics predominantly in SA but they may originate from Lesotho, Kenya, Zimbabwe and other sub-Saharan nations. All the RNs have received nurse education through university or a college of nursing. A problem confronting these RNs is the lack of access to electronic devices such as computers, laptops, email and internet either at work or at home - conveniences that are taken for granted in Australia. This situation in SA obviates the need for a paper-based resource manual such as the one
provided by the HNEP as the access for electronic-based information for nurses in SA is frequently unavailable. The Haemophilia Resource File becomes the property of the RNs at the completion of the HNEP and they are encouraged to take the resource file back to their place of work: therefore it becomes a resource to all clinicians at that workplace, including doctors.
Appendix L

Experts’ Survey for evaluating the content of each presentation in the HNEP teaching package.

The following questions are designed to determine suitability of the teaching programme. Please respond to each item by ticking the relevant box - strongly agree to strongly disagree.

<table>
<thead>
<tr>
<th>Category</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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<tbody>
<tr>
<td><strong>Content</strong></td>
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<tr>
<td>the objectives are appropriate</td>
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<tr>
<td>the content is relevant to caring for a person with haemophilia</td>
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<tr>
<td>the content is evidence-based</td>
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<tr>
<td>the purpose of the program is clearly stated</td>
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<tr>
<td>instructional outcomes are realistic, measurable and achievable</td>
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<tr>
<td><strong>Instructional design</strong></td>
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<tr>
<td>the information is presented logically</td>
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<tr>
<td>the format of the program is appropriate for the participants (RNs in South Africa)</td>
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<tr>
<td>the teaching strategies would actively engage the learner</td>
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<td>summative evaluation material is provided</td>
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<tr>
<td><strong>Technical production</strong></td>
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<td>Power point presentations</td>
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<td>a) the sound is clear and intelligible</td>
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<td>b) there is no distracting background noise</td>
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<tr>
<td>c) the pace of the narration is appropriate for the participants</td>
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</table>

<table>
<thead>
<tr>
<th>Teaching package</th>
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<tbody>
<tr>
<td>the presentation of the package is user-friendly</td>
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<tr>
<td>The “handouts” within the teaching package are/would be a valuable resource in the clinical setting</td>
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<tr>
<td>the package is a valuable teaching and learning resource.</td>
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</table>

1. The topics within the teaching package represent the breadth of the information required to understand haemophilia and how to care for these patients. In what ways do you think this has been accomplished?

2. Do you believe that the information provided complies with evidence-based requirements and if so, how?

3. Anticipated learning outcomes are stated at the beginning of the program. How do these outcomes reflect the content of the package?

4. Please comment on whether the content is pitched at an appropriate level for the educational status of RNs in developing countries.
5. The HNEP has introduced new terminology. Do you perceive that this would be an issue for these nurses and if so, in what way?

6. The program is designed to be progressive in that foundational learning is presented first followed by more complex topics. Do you perceive this has been successful and if so, how?

7. How does or does not the resource manual provide sufficient information to allow the learner to reach learning goals?

8. Can you comment on the appropriateness of the teaching strategies and tools within this package. For example, are they pitched to maintain interest?
Appendix M

Ethics Approval from The University of Notre Dame Australia

10 October 2013

Dr Catherine Ward
School of Nursing & Midwifery
The University of Notre Dame Australia
Fremantle Campus

Dear Catherine,

Reference Number: 013128F
Project Title: “Development, implementation, evaluation and validation of a Haemophilia nurse education program in South Africa.”

Your response to the conditions imposed by a sub-committee of the university’s Human Research Ethics Committee, has been reviewed and based on the information provided has been assessed as meeting all the requirements as mentioned in National Statement on Ethical Conduct in Human Research (2007). Therefore, I am pleased to advise that ethical clearance has been granted for this proposed study.

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.

On behalf of the Human Research Ethics Committee, I wish you well with what promises to be a most interesting and valuable study.

Yours sincerely,

Dr Natalie Giles
Executive Officer, Human Research Ethics Committee
Research Office

cc: Prof Selma Afriex, Dean, School of Nursing & Midwifery;
Prof Leanne Martinsson, SRC Chair, School of Nursing & Midwifery.
Appendix N

Ethics approval to interview haemophilia nurse coordinators
Appendix O

Ethics Approval for interviews and focus groups for RNs

13 January 2012

Dr Mark Jillockman
Research Ethics Committee
E53 Room 44.1, Old main Building
Groote Schuur Hospital
Private Bag X4
Observatory 7935
Cape Town

Tel: + 27 21 406-6492
Fax: + 27 21 406-6411
Email: Mfusa@curie.sun.ac.za

Dear Professor Jillockman,

EVALUATION OF A NURSE EDUCATION PROGRAM TO ENHANCE
HAEMOPHILIA CARE IN SOUTH AFRICA

RE: HREC REF: 600/2010

I hereby submit this letter as a means of requesting an extension of Ethics Approval for the above-named study.

I, Ms Jill Smith, am the principal researcher with co-researchers, haemophilia coordinators Anne-Louise Cruickshank from Western Cape and Anne Gillham from Gauteng. Focus groups and interviews have been conducted with nurses in Nelspruit, Johannesburg and Cape Town who have completed the Haemophilia Nurses’ Education Program and are currently caring for people with haemophilia. The aim to evaluate this education program has not changed.

Permission was gained from Medical Superintendents from the centres listed below where the nurses are employed once Ethics Approval had been granted

Nelspruit Hospital
Steve Biko Hospital
Johannesburg General Hospital
Red Cross Children’s Hospital
Groote Schuur Hospital Sr A-L Cruickshank
George Hospital
Written consent was obtained from all the participants and confidentiality secured. User access will be on various levels and signed in all cases.

Information was successfully gathered from 20 nurses in May 2011 and the process of analysis is underway. As this study has revealed more valuable information than predicted, the University of Notre Dame allowed me to convert from Masters degree to a PhD in order to do justice to the education program and the information gathered. For this reason, the need for more time to complete the analysis and write up the findings is required. However, I do not at this stage plan to collect more data from participants in South Africa.

Please do not hesitate to contact me through the university if you require any additional information.

Yours sincerely,

Ms P. Jill Smith  R.N., B.Nurs
Appendix P

Nurse Training Programs undertaken using the WFH website

In 2013, the WFH adopted with permission from the HNEP organisers to use material from the program on the WFH website. This allowed access to information for nurses in developing countries about haemophilia. At present (2017), the following countries are known to have used the material.

   Kenya, plus other African countries

   Mauritius

   Ulaanbaatar, Mongolia

   Amman, Jordan

   Belgrade, Serbia (Balkan regional training)

   Zambia

   Tashkent, Uzbekistan (Central Asian regional training)

   Malawi

   Ethiopia

   Morocco (conducted in French)

Source: personal correspondence from Anne-Louise Cruickshank, June 2017.