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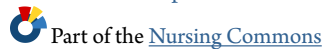
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Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa

Jill Smith

*The University of Notre Dame Australia*

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**Development, implementation, evaluation and validation of a  
haemophilia nurses' education program in South Africa.**

**Jill Smith**

**ID 20103001**

**A thesis submitted to fulfil the requirements for the Degree of  
Doctor of Philosophy**

**School of Nursing and Midwifery  
The University of Notre Dame Australia  
2017**

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## List of Acronyms & Explanations

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ANC</b>	African National Congress. Political party in South Africa.
<b>Bleed</b>	Term used to describe a bleeding episode in haemophilia.
<b>BSA</b>	Black South African
<b>CCT</b>	Culture Care Theory (Leininger).
<b>Cryo</b>	Cryoprecipitate, a haemophilia treatment option
<b>DDAVP</b>	Desmopressin acetate, bleeding inhibitor in specific bleeding disorders.
<b>EAHAD</b>	European Association for Haemophilia and Allied Disorders
<b>Factor</b>	Factor eight (VIII) or nine (IX), used to treat haemophilia bleeding.
<b>FEIBA</b>	Factor Eight Inhibitor Bypassing Activity
<b>FFP</b>	Fresh frozen plasma
<b>GDP</b>	Gross Domestic Product
<b>GNI</b>	Gross National Income
<b>Haemophilia/hemophilia</b>	Interchangeable, reflects the origin of the text UK or US
<b>HCV</b>	Hepatitis C virus
<b>HDI</b>	Human Development Index
<b>HFSA</b>	Haemophilia Foundation of South Africa
<b>HIV</b>	Human Immunodeficiency Virus
<b>HNEP</b>	Haemophilia Nurses' Education Program
<b>HRF</b>	Haemophilia Resource File
<b>HTC</b>	Haemophilia Treatment Centre
<b>MDG</b>	Millennium Development Goals
<b>MMR</b>	Mixed Methods Research

<b>PHC</b>	Public Health Clinic
<b>PWH</b>	People with Haemophilia
<b>RN</b>	Registered Nurse
<b>ROI</b>	Return on Investment
<b>SA</b>	South Africa
<b>SANDoH</b>	South African National Department of Health
<b>SANC</b>	South African Nurses Council
<b>SDG</b>	Sustainable Development Goals
<b>TCN</b>	Transcultural Nursing Theory (Leininger)
<b>UNDP</b>	United Nations Development Project
<b>VWD</b>	von Willebrand Disease or Disorder
<b>VWF</b>	von Willebrand Factor
<b>WFH</b>	World Federation of Hemophilia
<b>WHO</b>	World Health Organisation

## **Abstract**

Haemophilia is a rare, inherited bleeding disorder found in all races and ethnic groups. Intervention regimens are more complicated in developing countries, such as South Africa, where numerous challenges present impediments to effective health care. This study investigated the value of the Haemophilia Nurses' Education Program (HNEP) in the South African context where no comparable program of training for haemophilia nurses exists.

The HNEP has been in operation in South Africa for some fifteen years. The researcher, as one of the key instigators of the HNEP, was keen to determine whether the course was delivering the outcomes that had been hoped for. Accordingly, a three part research study was designed to determine the course's effectiveness. The epistemology utilised was constructionism and the theoretical framework was based on Leininger's Cultural Care Theory, Watson's Theory of Human Caring, Knowles' Theory of Adult Learning, and Kirkpatrick's four levels of evaluation. To Kirkpatrick's theory a fifth level was added which considered Return on Investment, identified as important by Phillips. The conceptual design of the research was one of action research which finds its basis on the work of McNiff, Lomax and Whitehead. The methodology chosen was action research and mixed method, and the tools for data collections were surveys, focus group and individual interviews, and document examination.

The study consisted of three parts. The first part revolved around obtaining opinions about the course from the three haemophilia coordinators who resourced all of the South African provinces. The second part gathered data from haemophilia nurses who had previously participated in the HNEP. The third part consisted of forwarding all HNEP materials to experts for comprehensive evaluation. Together, the three parts of the study

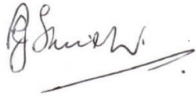
helped to provide an important overview of the effectiveness of the HNEP and provided valuable ideas and information for inclusion in the next iteration of the HNEP.

Results indicated that in the main, expert nurse educators considered the program to have merit in terms of its design, contextual relevance, and delivery strategies. It was also found that the program was efficacious for training nurses to address the needs of persons with haemophilia. Nurses reported a higher degree of job satisfaction as a result of having completed the program, with many reporting feelings of empowerment and respect, and greater confidence and competence after having completed the HNEP. It was further found that people with haemophilia received better care and education about haemophilia and exhibited improved self-care as a result of their carers having participated in the program.

Although not directly transferable, it was concluded that the program as a sub-specialty is likely to have application in other developing countries. Recommendations for the improvement of the HNEP are made.

## **Declaration of Authorship**

I declare that this thesis is my own account of my research and contains as its main content work which has not previously been submitted for a degree at a tertiary education institution.

A handwritten signature in black ink, appearing to read 'P. Smith', with a long horizontal stroke underneath.

Pamela Jill Smith

02 January 2018

## **Acknowledgements**

It is a challenge for an individual to complete a project such as this without the support of a group of people around them. I was very fortunate to have such a group of understanding and compassionate people to help me on my journey.

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Special thanks goes to my South African colleagues: Three haemophilia nurses who taught me a great deal and earned my admiration for the dignified manner they carried out their work in trying circumstances. The three "As" – Anne Gillham, Anne-Louise Cruickshank and Alice Banze – all of whom gave me permission to use their full names, are extraordinary nurses and South African haemophilia services are better for their dedication.

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