
Theses

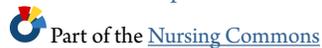
2017

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

Jill Smith

The University of Notre Dame Australia

Follow this and additional works at: <https://researchonline.nd.edu.au/theses>



COMMONWEALTH OF AUSTRALIA
Copyright Regulations 1969

WARNING

The material in this communication may be subject to copyright under the Act. Any further copying or communication of this material by you may be the subject of copyright protection under the Act.

Do not remove this notice.

Publication Details

Smith, J. (2017). Development, implementation, evaluation and validation of a haemophilia nurses' education program in South Africa (Doctor of Philosophy (College of Nursing)). University of Notre Dame Australia. <https://researchonline.nd.edu.au/theses/184>

This dissertation/thesis is brought to you by ResearchOnline@ND. It has been accepted for inclusion in Theses by an authorized administrator of ResearchOnline@ND. For more information, please contact researchonline@nd.edu.au.



Chapter 11

Conclusions and Recommendations

11.1 Introduction

The present study aimed to evaluate the HNEP offered to RNs living and working in SA. In this endeavour, the input of haemophilia coordinators, RN participants and expert evaluators was sought. The Australian researcher played the role of participant-observer once it was realised that her experience in haemophilia management would be of immense benefit in structuring and delivering the HNEP.

It was determined that the research would yield the best results if approached from a phenomenological orientation. Mixed methodology was identified as the most suitable methodology. The study was seeking to deliver a solution to an identified real-life problem, action research was considered appropriate for sourcing information from a community of practice.

In this chapter, conclusions are presented that are based on the findings and preceding discussion chapters. Recommendations are then offered in the hope that the findings of the present research will help strengthen the next iteration of HNEP delivery.

11.2 Conclusions

The research questions are reconsidered as an appropriate way of drawing the research to a conclusion. Conclusions are made on the basis of findings from the chapters as identified with each question. For ease of presentation and for future reference, dot points have been used to highlight the conclusions being made.

11.2.1 Research question 1 [Chapter 6].

1. *What factors need to be considered when developing a purpose-driven haemophilia curriculum for nurses in South Africa?*

- Historical antecedents create the environment in which haemophilia care is being delivered.
- The SA health infrastructure still has a way to go before it is able to care for all the haemophilia needs of its citizens.
- There is a scarcity of haemophilia coordinators – there are only three coordinators resourcing 3000 - 5000 PWH.
- Due to government budgetary constraints, insufficient funding is available to provide health care to public patients.
- Geographical isolation is an important factor in haemophilia treatment being delayed.
- Haemophilia RNs frequently have to travel long distances to meet with PWH and their families.
- Advanced haemophilia expertise resides in countries outside of SA and needs to be imported as required.
- The SA haemophilia community is represented by many languages with English not normally the first language.
- Cultural orientation must be taken into account when HNEP courses are offered.
- Doctors are, in the main, insufficiently trained in understanding the intricacies of haemophilia. Trained haemophilia nurses can help here.
- Most RNs have only initial training with little or no haemophilia-specific training. The HNEP helps to address this deficit.
- Practical experience is a very important aspect of any haemophilia course.

- Varied teaching styles need to be included to cater for culturally-mediated learning styles of participants.

11.2.2 Research question 2 [Chapter 6].

2. *What factors need to be considered when implementing a purpose-driven haemophilia curriculum for nurses in SA?*

- Information must continue to be imparted at a level that all participants can accommodate.
- Negotiating a suitable venue is not always easy as most participants have to travel long distances to any centre.
- To cater for the above point, a web-driven course may be considered, but internet connectivity is not always reliable.
- Poor infrastructure leads to problems with:
 - Longer travel time
 - Difficulties with mode and availability of transport
 - Road surfaces in places prevent vehicular access
 - There are regular electricity outages (among other things, this can make Power Point presentations difficult).
- Funding the course without a grant when participants are poor is a significant challenge.
- Recruitment difficulties exist in busy hospitals, so facilitating RN release to attend the HNEP can be challenging.
- Accommodating cultural care perspectives in a multicultural (and often tribal) society has its issues.
- Participants have a differing degree of familiarity with the language of instruction, English.

- There is at times a clash of Western and African world views during instruction which the lecturers must remain aware of.
- RNs must be taught how to accommodate superstitious traditions such as witchcraft.
- Ritual circumcision ceremonies affect the PWH and RNs must be taught how to sensitively deal with these.
- Inadequate sanitation practices exist in many PWH and these must be addressed early in any intervention protocol.

11.2.3 Research question 3 [Chapter 7 & 8].

3. What transfer of knowledge, skills and perceptions is likely to occur as a result of training received via a purpose-driven haemophilia curriculum?

This question was answered using Kirkpatrick's four levels of learning + ROI. The following conclusions can be drawn from analysis of data and subsequent discussion with study participants.

- Level 1: Satisfaction
 - Approval of content being covered with new information taken into clinical context.
 - Professional empowerment in being able to teach other nurses and doctors about better haemophilia management.
 - Personal fulfilment in terms of mentally converting a job into a significant occupation.
- Level 2: Learning
 - Increase in knowledge which was then shared with others including the PWH and their family.
 - Greater joy in learning in being prepared to be on call when a need arose.
 - Greater access to resources via the HRF which was then shared with others.
- Level 3: Behaviour

- Greater awareness of the acute needs of the PWH and a preparedness to advocate for them.
 - Better understanding that a particular symptom (e.g. heavy menarche) may be symptomatic of haemophilia.
 - Going to others who had participated in the HNEP for collegial advice which resulted in a community of practice developing around haemophilia care.
 - An extension in the scope of practice with regard to haemophilia care.
- Level 4: Results
 - Increase in overall competence in RNs and with it confidence regarding treatment options which resulted in better delivery of care.
 - More efficient use of available resources.
 - Ability to negotiate with management regarding requirements from a stronger knowledge base.
 - The creation of more haemophilia clinics as a result of nurse advocacy.
 - Reduced hospital visits and less time spent in hospital by PWH.
 - Return on Investment (ROI)
 - Increase in RNs taking leadership roles.
 - Informal sharing of new information with all stakeholders involved with haemophilia care.
 - Professional learning offered in a vicarious fashion to doctors.
 - Greater RN job satisfaction and patient satisfaction with care regimens.

11.2.4 Research question 4 [Chapter 9].

4. How robust is a purpose-driven haemophilia curriculum when subjected to expert evaluation?

For this section of the study, seven expert evaluators were invited to examine the HRF and the HNEP and present their findings via a survey and open-ended responses. The following conclusions can be drawn from the data.

- Prior to the HNEP being offered, there was very little training available to nurses engaged in haemophilia care in SA.
- The HNEP received strong endorsement as a course for the training of RNs in acquiring/updating haemophilia management skills in SA.
- The HRF was seen a valuable resource, although Power Point slides will need to be reconsidered, especially in terms of content presentation.
- The teaching approaches used were suitable for adult learners and remained respectful of the fact that participants possessed credentials and experience as RNs.
- Although the package as a whole contains context-specific information, generalising to the contexts of other nations may not be desirable until further investigation has been undertaken. Given this observation, experts noticed that there had already been a take-up in other countries (Appendix P).
- Further work needs to be undertaken to ensure that the content is specifically tailored to the SA context.
- The cultural environment needs to be taken into account when dealing with PWH from different people groups.
- Appropriateness of outcome levels may need to be reconsidered given the academic level and language capability of many of the participants.
- The notion of refresher course may need to be considered for past participants.

11.2.5 Research question 5 [Chapter 10 & 11] & Recommendations.

11 On the basis of feedback received for research question 4, what are the implications for a future iteration of the HNEP?

There are several factors that will need to be carefully considered in terms of the course durability and management prior to a future roll-out. In responding to this question, recommendations are made that will strengthen not only the HNEP but also address the needs of haemophilia care in SA.

- The HNEP has been presented in all provinces of SA, often on more than one occasion. The HNEP has been resilient, operating for over 15 years, when similar programs have not been sustained. Furthermore, the HNEP program is available on the WFH website making it accessible to nurses in over ten

developing countries (Appendix P). The momentum that has been generated must not be allowed to wane.

- Ensure the course is current using course partners such as the WFH research literature.
- Uphold the quality of the course by ensuring the qualifications and education experience of the staff delivering the course.
- Monitor and review these processes and quality improvement regularly.
- Develop a template which describes program structure, outcomes, method of instruction and hours completed.
- Itemise tools used for course review.
- Establish a credible evaluation process
- Emphasise the role of the nurse / carer in the education and health care of the patient and family.
- A training module such as “train the trainer” is a useful adjunct to help equip the teacher with basic skills in adult education and teaching strategies. Some nurses who teach sub-specialty programs are expert clinicians with little theoretical teaching background. The researcher, who personally completed such a module, found the training helpful for use in the HNEP and in supporting the SA haemophilia coordinators.
- Mentoring post-HNEP was found to be beneficial to the RNs. Many participants expressed a reliance on and appreciation of these roles undertaken by the haemophilia coordinators.

11.3 Recommendations for further research

It is anticipated that the work that has been begun in the training of RNs in haemophilia care via the HNEP will continue and be extended. In adding in this venture, twelve recommendations are made for future researchers wishing to further the cause of haemophilia training in SA, and perhaps beyond.

- Examine strategies for interfacing with the appropriate government agencies and professional haemophilia care agencies to develop comprehensive, robust, and well-funded policies to support PWH.

- Continue the implementation of partnerships with developed countries in the sharing of expertise, resources and technology with SA haemophilia care providers.
- Develop strategies for seeking alternative course funding sources through bodies such as the United Nations, pharmaceutical companies, and charitable organisations.
- Investigate the possibility of having the HNEP accredited through a tertiary education institution to give it greater credibility, allow for access to support, and the possibility of haemophilia care being offered as a stand-alone nursing sub-speciality qualification.
- Research the degree of interest of a publishing house in turning the HNEP into commercially available textbook and resource package.
- Evaluate the HNEP's use in other countries to determine the success of the course in other contexts.
- Develop a HNEP web-driven program for RNs who are unable to travel to a course centre for financial, geographical or employment related reasons.
- Explore the value of creating a "train the trainer"- type course for the purpose of training more haemophilia coordinators.
- Investigate the value of having a refresher course for past HNEP participants. Such a course may also prove to be a valuable way of creating a database of potential lecturers, coordinators and senior haemophilia nurse consultants.
- Engage in research with PWH who have benefited from the service provided by HNEP-trained nurses to comprehensively determine how such training has benefited the end-users.
- Engage in a needs analysis of PWH and their families to ensure that future HNEPs are hitting the mark from the patient's point of view.
- Examine the value of supplying haemophilia nurses with electronic devices connected to the haemophilia database, thus allowing them to access and add to currently available information more readily.

As can be seen from the above recommendations, there is still much that needs to be done to ensure that PWH and their families are receiving the best possible care. The present work represents a small beginning from which future researchers can springboard.

11.4 Final comments

For the researcher, the present journey has been as rewarding as it has been interesting. The HNEP achieved its aim of educating nurses in haemophilia recognition and management as evidenced by the overwhelmingly positive reaction of the nurses who worked with PWH post the course. The HRF made information about haemophilia management available to nurses and through them to their colleagues. The HNEP received further support from expert evaluators when recognised its significance as a resource.

The HNEP is also a useful template for nurses in other developing countries for creating a haemophilia education program. The program could also be a useful prototype for creating an education program for nurses who work in other areas of chronic health conditions such as severe headache, epilepsy and asthma. The “travelling” nature of the course might be particularly useful in remote or outlying areas where access to hospitals and haemophilia centres is more problematic.

The impact of the HNEP and its effect on PWH is reflected in the following quote by haemophilia coordinator B, when asked what she thought would happen if there was no HNEP:

Oh no! People would have been crippled, people would have been in the dark, people are still talking about witchcraft and there would have been many deaths of haemophilia that would not have answers (Coordinator B).