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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

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

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

Pamela Jill Smith

02 January 2018

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Chapter 1

Background to the Study

1.1 Introduction

This study evaluated a purpose-designed program to educate Registered Nurses (RN) in South Africa (SA) about the care and management of people with haemophilia. Since South Africa is a developing country, factors such as poverty, illiteracy, inequality and poor infrastructure were considered in designing a program for RNs concerned with haemophilia care. In a context where appropriate care is often difficult to find, this congenital bleeding disorder has the potential to be fatal and to have effects well beyond the immediate sufferer.

In this chapter the nature of the disease known as haemophilia was considered. The study aims were then presented and the theoretical underpinnings introduced. The significance of the study was also explored.

1.2 Haemophilia

Haemophilia is a rare, genetically linked lifelong bleeding disorder for which there is no cure. Globally, haemophilia occurs in 1 in 10,000 live births (World Federation of Hemophilia, 2012). Essentially, proficient management of the disorder is the only means to avoid severe morbidity and ultimately death. The disorder is characterised by prolonged bleeding due to a missing clotting protein which prevents the formation of a solid robust clot. Predominantly affecting males, haemophilia is an inherited genetic disorder carried on the X chromosome (World Federation of Hemophilia, 2012). In approximately 30 percent of haemophilia births, for reasons which are unclear, a spontaneous mutation occurs and a child is born with haemophilia (World Federation of Hemophilia, 2012). Haemophilia can

be classified as severe, moderate or mild. In the most severe form, bleeding can occur unexpectedly without reason or trauma. An untreated bleed, which can progress for days or weeks, can have catastrophic results with significant morbidity and mortality and inflicting severe pain (World Federation of Hemophilia, 2012).

The most common sites for bleeding are into joints and less commonly in muscles and organs such as the brain or kidneys. Uncontrolled and repeated bleeding into joints causes acute pain and results in severe osteoarthritis and crippling. Untreated bleeding into muscles can result in nerve damage and permanent loss of function and bleeding into organs such as the brain can be fatal. Without treatment most individuals with severe haemophilia will not survive past adolescence (World Federation of Hemophilia, 2012).

Haemophilia and its consequences have been known to physicians for hundreds of years. The first documented episodes of excessive bleeding were described by the Jewish community in the second century when deaths occurred from severe bleeds following male circumcision (Ingram, 1976). An Egyptian physician, Albucasis, in the tenth century also observed that this bleeding tendency was linked to familial tendencies. Furthermore, an Arabic physician in the twelfth century suggested that cautery was the best method to treat excessive bleeding, thus providing the first record of effective treatment (Ingram, 1976). At the end of the eighteenth century, a New York physician Dr John Otto published his observations of haemophilia, hence provided a sounder understanding of the phenomenon. Otto wrote of a woman with no symptoms of bleeding who had birthed several sons all of whom had excessive bleeding tendencies. From this observation he concluded that the disorder was sex-linked and related to premature death (Lee, 2010). These discoveries paved the way to improved management and care.

1.2.1 Treatment of haemophilia.

Haemophilia is a deficiency or absence of clotting proteins called factors. The clotting mechanism relies upon there being sufficient properly functioning factors to form a clot. Principally, the treatment for haemophilia is to replace the missing clotting factor (World Federation of Hemophilia, 2012). Factor is separated from donated blood plasma in a complex manufacturing process and is therefore expensive to purchase (Muller, 2004). Many developing countries cannot afford to purchase factor replacement so people with haemophilia (PWH) in these nations are denied optimum management and treatment. In contrast, PWH who are citizens of developed economies have access to recombinant factor replacement; a synthetic product (World Federation of Hemophilia, 2012). This differentiation is important as in previous years the plasma-derived product was manufactured using plasma that was infected with blood-borne viruses such as the Human Immunodeficiency Virus (HIV) and hepatitis. These viruses contaminated the blood supply and therefore infected the factor replacement. In South Africa (SA), there is sufficient factor replacement available for all PWH, however the factor is plasma-derived, and it therefore poses the risk of transmitting blood-borne viruses.

Since haemophilia is a rare disorder, there is scant information in relation to care and management available in medical or nursing textbooks. As a consequence, nurses' and doctors' knowledge of haemophilia is limited. Additionally, there is a paucity of information in relation to the existence of haemophilia nursing education programs in the public domain. There is, however, a small, albeit slowly-growing, body of literature about various aspects of haemophilia nursing care written by nurses, for example the WFH Nurses' Committee produced a Power Point program outlining the basics of haemophilia

nursing (WFH Training module for nurses, 2007). Nevertheless, the paucity of literature makes the task of seeking information about haemophilia and its management difficult.

Education of nurses serves multiple purposes. Education is essential to equip nurses to provide appropriate and competent care to the patient and family. Regardless of geographical location, every human being has the right to safe and quality health care. Supporting better understanding and knowledge of this concept is the notion of patient reported outcome measures (PROMS). The Australian Commission on Safety and Quality in Healthcare takes the PROMs patient opinions seriously. Williams, Sansoni, Morris, Grootemaat and Thompson (2016) were commissioned to provide a literature review to learn how PROMs are utilised in health systems similar to Australia's. This aspect of learning from the experiences of others will help to ensure that the best care is available to Australian patients.

Education by nurses is expected and presents in different scenarios: Mentoring and clinical instruction of student nurses by experienced nurses in the practice setting is important to help bridge the theory-practice gap. The nurse also plays a large part in the education of the patient and family to help them understand their disease condition and the steps needed to provide self-care. Additionally, nurses play a significant role in health education by promotion and education about health interventions and disease prevention (Wills, 2014).

It is vital that nurses comprehend the significance of patient education. However, according to Aghakhani, Nia, Ranjbar, Rahbar, Beheshti, et al., (2012), ineffective education provided by the health care system is the most common complaint made by patients. Education is essential to assist patients to accept and adapt to the physical and psychological changes related to health. Despite having received information in relation to their condition,

patients demonstrate low levels of knowledge and therefore understanding about their health issues and relevant self-care behaviour (Aghakhani et al., 2012). Miller (2016) undertook a meta-analysis of studies that explored the correlation between patient health literacy and adherence to medication and non-medication interventions. Findings from this study showed that a health literacy intervention, that is education, is more effective in improving patient's health knowledge (literacy) and adherence to treatment. Thus, an educated patient is more able to problem solve, improve their health status, and practice preventative measures (Beta, 2014).

This aspect is a factor when considering chronic diseases, such as haemophilia, as the transition from paediatric healthcare to adult care is an important step for adolescents and young adults. Empowerment of this group to enable a successful transition to self-care is central to augment chronic healthcare management. According to Coyne, Prizeman, Sheehan, Malone and While (2016), successful transition seems to assist with observance of appointments, patient satisfaction, parent satisfaction, autonomy, and balanced disease control. These are precisely the factors likely to contribute to PROMs.

In view of the lack of nurse education about haemophilia, the role of the haemophilia nurse plays a vital part in the management of these patients. In countries where haemophilia treatment is not well-funded, such as developing countries, conservative measures can be employed to assist reduce the severe consequences of bleeding episodes. Simple interventions such as rest, application of ice packs, compression bandages and elevation of the bleeding limb will assist to slow the bleeding and promote clot formation at the site of the bleed. These measures can be implemented in the hospital setting but can also be taught to the PWH and his family so they can be applied at home immediately when bleeding occurs.

1.2.2 Education of the nurse to manage the care of the PWH and family.

In developed countries such as Australia, education of the PWH and family is a major priority. In Australia, care of the PWH is implemented using a team approach and referred to as comprehensive care. This approach involves a multidisciplinary team of health professionals and is considered the optimum choice of care for PWH (World Federation of Hemophilia, 2012). The team is located at a Haemophilia Treatment Centre (HTC) which is usually based at a major teaching hospital. The core team members consist of a haematologist with expertise in bleeding disorders, a haemophilia nurse, a physiotherapist and a laboratory scientist with expertise in diagnosing bleeding disorders in the laboratory. By concentrating services within one area, any staff members who are new to managing PWH have immediate access to appropriate expertise in the diagnosis and management. Staff members employed in haemophilia care are encouraged to attend conferences and scientific meetings to stay abreast of new research. Experienced staff at other HTCs such as nurses and physiotherapists, provide mentoring and backup.

As outlined above, education of the PWH and their family plays a vital role in the health of the PWH. Therefore, the role of the haemophilia nurse is central. In the absence of factor replacement, conservative measures are taught to the PWH and his family. Furthermore, education can include preventative measures to avert a bleeding episode, such as avoidance of common medications such as salicylates. Advice is given in relation to physical activities which facilitate physical fitness without the danger of inflicting serious injury. Advice about when to contact the haemophilia centre if the bleeding progresses or an emergency occurs, for example after trauma, is provided. Invasive medical procedures such as surgery should never be attempted without adequate factor replacement and the PWH and his family need detailed education about self-advocacy to prevent cataclysmic

bleeding in these circumstances (Australian Haemophilia Centres' Directors' Organisation, 2016). The transition to adult care and therefore self-management, is an important step, guided by the haemophilia nurse. Although haemophilia is a significant health issue, if properly managed, with factor replacement, the individual can lead a predominantly normal life. Prior to factor replacement being available, most people with severe haemophilia were unlikely to live beyond adolescence.

1.2.3 Management of PWH in SA: The education imperative.

In SA there are situations which prevent all PWH accessing appropriate treatment. Although SA has sufficient factor replacement to treat the haemophilia population, approximately one-third of affected individuals have not been diagnosed, so remain untreated (verbal communication with Professor Karabus, the administrator of SA's haemophilia database). Despite being diagnosed and being provided with a treatment plan, however, good outcomes are not always guaranteed for PWH. The treatment plan may be either ignored by staff when the PWH presents at hospitals and clinics, or PWH are not treated appropriately. Substandard management of episodes of bleeding can have catastrophic outcomes such as amputation of limbs, brain damage and death.

The SA haemophilia coordinators, considered expert nurses commonly refer patients to the HTC's for diagnosis, genetic counselling and education (of PWH, caregivers and health professionals); and lobby for treatment facilities and programs. In addition, these nurse coordinators are part of an outreach program which was developed to provide support to RNs who participated in the HNEP. It was these coordinators who suggested that by educating nurses in haemophilia management, outcomes for PWH could possibly improve. It was further indicated that education would be of particular benefit to nurses who work in

health facilities in regional and rural areas geographically distant from HTCs. Education is therefore fundamental to furthering competent and confident nursing care of the PWH.

Unfortunately, there are many issues that conspire against adequate provision of healthcare in developing countries. Munyewende, Rispel and Chirwa (2014) conducted a study to investigate barriers to health provision in SA. They found purchasing of material resources such as pharmaceuticals, medical equipment, refrigerators to correctly store the drugs and maintenance of buildings was inadequate. Frequently there were insufficient financial resources to ensure adequate staffing levels of doctors and nurses in wards and clinics, clerical and maintenance personnel.

Additional significant socio-economic issues also exist in the population, such as poverty, unemployment, and illiteracy. The social determinates of health such as adequate housing, sanitation, clean water supplies and malnutrition impact on the health of the socially disadvantaged of SA. The ability to achieve adequate medical support is also hampered by the long travel distances, inefficient public transport, poorly maintained roads, unreliable or absent power supplies and inadequate telecommunications. These problems pose barriers to the provision of health services, especially in remote and regional locations and provinces.

Finally, many developing countries have a history of various degrees of colonisation and government which were not designed for the well-being of the indigenous population. In SA, colonialism followed by apartheid discriminated against groups and communities on racial grounds, thus preventing marginalised groups from acquiring education in relation to decision-making and governance issues. Once the old regimes were dismantled, many of the government employees who came from these disadvantaged groups were expected to assume management roles. Consequently, these employees were inadequately prepared

which resulted in policies and projects either not implemented or poorly managed. Indeed the knowledge of how to govern and implement health policy was not available, which lead to inadequate service across many areas of health provision.

1.2.4 Resources to treat haemophilia.

Clearly the gap between developed countries and developing economies in their ability to provide haemophilia care is wide, and varies from nation to nation. Some governments do not attempt to address chronic disorders such as haemophilia because they perceive it to be too costly and too difficult. In more recent times, Tagny, Moudourou, Ndoumba, Mbanya (2014) published an article about haemophilia diagnosis and care in Cameroon describing the infancy of haemophilia management and the limitations due to lack of resources. However, this does not mean that the PWH in these countries need to feel abandoned. The importance of educating the individual with haemophilia, their family and health care providers about how to manage haemophilia with limited resources, that is, factor replacement, is espoused by clinicians in many developing countries. Chandy (2005); Chuansumit (2003) and Shamsi and Chughtai (2001), clinicians working with PWH in developing countries, agree that education of clinical staff is the key to delivering better haemophilia care and thus reducing morbidity.

1.2.5 Development of the Haemophilia Nurse Education Program in SA.

In 2000, the SA National Department of Health (SANDoH), conducted a survey which revealed that it would be advantageous to establish a haemophilia care program in SA. One of the terms of this proposed program was that the key to provide a high standard of care for PWH could be achieved by training nurses to manage PWH and their families.

After some delays, in 2002 planning for the Haemophilia Nurse Education Program (HNEP) began in earnest. As no ready-made curriculum was available, the four haemophilia coordinators, three based in SA and the author of the present work from Australia, set about writing the curriculum, utilising their extensive clinical knowledge. The first HNEP was implemented in the same year. Since its initial creation and development, it was realised that the program needed to undergo a formal evaluation. Evaluation is an essential component of any teaching program (Worral, 2008) since it is imperative that the nurse educator determines whether learning has occurred and to what level. A robust evaluation process to determine whether the HNEP has been effective in improving the knowledge of haemophilia management needed to be undertaken.

1.3 Aims and significance of the study

Since its inception in 2002 and to the point of this research, the HNEP had been offered for 15 years. Within that time no comprehensive evaluation process had been completed. Formative evaluations had been conducted at the completion of each program however, the appraisal was simplistic and did not gather the sort of data required to facilitate a deeper analysis of content and delivery. It was recognised that a robust evaluation would be beneficial to the programme in terms of its on-going credibility and funding requirements.

The aim of the study is to firstly, determine if the introduction of the HNEP in SA has improved the care of a PWH and their family. Secondly, to determine whether the education program changed the participants behaviour and attitude toward the PWH and finally, whether attendance at the HNEP had increased the confidence of the nurses to manage a PWH and advocate for the PWH and family. The aim of this present study therefore is to explore whether a transfer of knowledge, skills and attitudes occurred and

whether it has increased the confidence and competence of Registered Nurses (RNs) in SA to manage the care of a PWH.

The study is significant in both its theoretical and applied endeavours. The significant theoretical aspects include firstly, the use of Leininger's (1998) Cultural Care Model to help the creators and organisers of the HNEP to take into account the multiple cultures in SA. Secondly, the utilisation of the Kirkpatrick (2006) Four Levels of Evaluation, which guided evaluation of the responses from the RN interviews to be presented as meaningful data. The significant applied aspect takes account of the fact that cultural differences amongst PWH in SA are varied. Teaching nurses about generalised haemophilia care, while taking account of cultural aspects of the individual, would likely ensure that there was improved compliance by the PWH and his family. The RNs were instructed that to be mindful of the particular cultural mores among the patients they manage and the context of the situation facilitated the ability of the PWH to be compliant.

A further significant aspect of the program was to educate nurses about basic haemophilia care. This was important, especially in regional and remote areas, as it assisted to overcome the lack of medical personnel in these areas. The haemophilia-trained nurse can assess the risk to the PWH and has the capacity to refer on to, or seek advice from, a Haemophilia Treatment Centre (HTC) at the same time ensuring that appropriate treatment is initiated promptly.

1.4 Study research questions

Based on the foregoing discussion, the following questions will be answered by the researcher as a result of having completed the study:

- a) What factors need to be considered when developing a purpose-driven haemophilia curriculum for nurses in South Africa?
- b) What factors need to be considered when implementing a purpose-driven haemophilia curriculum for nurses in SA?
- c) What transfer of knowledge, skills and perceptions is likely to occur as a result of training received via a purpose-driven haemophilia curriculum?
- d) How robust is a purpose-driven haemophilia curriculum when subjected to expert evaluation?
- e) On the basis of feedback received for research question four, what are the implications for a future iteration of the HNEP?

1.5 Chapter summary

In summary, this introductory chapter presented a brief overview of haemophilia. It acknowledged that education of nurses is an important aspect of efficient and effective management of haemophilia but contested that such is received by many nurses. In developing countries such as SA, PWH are not proficiently managed due to lack of recognition and understanding of the disorder by healthcare professionals. To address this problem, a decision was made by health authorities to approve a nurses' education program. This program, the Haemophilia Nurses' Education Program (HNEP), was developed and implemented by four haemophilia nurse coordinators in 2002. Although the HNEP had been in operation for fifteen years, a formal evaluation had not been undertaken. The aim of the study was to address this omission.

In Chapter two, the term haemophilia is defined. Also considered is the literature in relation to the history of haemophilia, its inheritance patterns, clotting mechanisms, diagnosis, potential complications, treatment regimens, and the nurses' role in caring for the PWH in the SA context. In Chapter three the creation, development and implementation of the HNEP is explained within the context of culturally sensitive care approaches. Aspects of epistemology, theory, conceptual design and method are elaborated in chapter four.

Chapter five describes the method of the research in detail. Chapters six and seven contain the results of the interviews from the haemophilia coordinators and the RN participants respectively. Chapter eight presents three critical incidents in support of the RN's perspectives. Chapter nine relates the data from the expert nurse educators who examined the haemophilia resource package and Chapter ten refers back to the theoretical framework in discussing the work of the four theorists to whose work reference has been made. The final chapter, Chapter eleven, presents the study conclusions and recommendations for further research.

Chapter 2

Literature Review: Haemophilia

2.1 Introduction

This chapter describes the rare congenital disorder of haemophilia, the devastating effect on the affected person and the preferred management. As an inherited disorder of blood clotting function, if untreated, haemophilia has the ability to inflict significant morbidity and mortality on the individual. Those PWH who have severe haemophilia but no access to treatment usually do not survive beyond adolescence. Although haemophilia has no cure, there is treatment available to effectively manage the disorder. This treatment is dependent upon the PWH being correctly diagnosed, availability of sufficient supplies of treatment being available and access to a haemophilia treatment centre (HTC) or health-care staff knowledgeable about haemophilia management.

A history of haemophilia diagnosis, the mechanism of blood clotting and how haemophilia is defined is now discussed. Also diagnosis procedures, inheritance patterns, treatment options and management, possible complications, and the role of the nurse in haemophilia care are considered. The state of haemophilia care in developing nations and specifically in the South African context will be highlighted.

2.2 Haemophilia defined

Haemophilia is the result of the clotting mechanism not functioning correctly. It is caused by a deficiency of factor VIII in haemophilia A and factor IX in haemophilia B. Haemophilia A is a more common disorder than haemophilia B, occurring in 80-85% of people with haemophilia (World Federation of Hemophilia, 2012). Worldwide, the number

of people affected with haemophilia is estimated at approximately 400,000 (World Federation of Hemophilia, 2012). Haemophilia occurs largely in males, therefore throughout this thesis the PWH is identified as “he”. Furthermore, to eliminate confusion, both haemophilia A and B will be discussed jointly and referred to as haemophilia.

Haemophilia is a rare genetic disorder carried on the X chromosome which occurs in 1:10,000 live births (Mahlangu & Gillham, 2008; World Federation of Hemophilia, 2012). It occurs in all races and ethnic groups. Haemophilia is characterised by prolonged and uncontrollable bleeding unless adequately treated. According to Sohail and Heijnen (2001), diagnosis of haemophilia is a profound encumbrance for the PWH and his family. If the PWH is living in a developing country, haemophilia is “a heavy social and economic burden on society” (p. 14).

Significant morbidity is common. Crippling can occur from bleeding into joints resulting in severe arthritis. Bleeding into muscles can result in muscle atrophy. Serious physical disability is the outcome of these bleeding episodes. The individual is unable undertake normal daily functions and attend school which severely reduces his education level and consequent ability to obtain work (Sohail & Heijnen, 2001). The level of mortality has a direct correlation with untreated bleeding into vital organs and structures such as the brain or neck, resulting in respiratory obstruction. Since such bleeds can have severe consequences, haemophilia is considered a life-threatening genetic disorder.

A complex physiological process is initiated in response to a bleed. Due to a deficiency in the clotting process, the bleeding will not be spontaneously arrested, resulting in blood leaking into joints and tissues causing further injury, severe pain and possible damage. Administration of the missing factor is the ultimate effective treatment for a PWH. However, complications can occur as a result of treatment. The most common

complications are antibodies in the blood, known as inhibitors, and blood-borne viruses, such as hepatitis C and HIV (Haemophilia Foundation of Australia, 2010). The pivotal issue here is that haemophilia can initiate serious and sometimes fatal health consequences. It is for this reason that a PWH must be provided with the appropriate treatment to avert serious health consequences and premature death.

2.3 History of haemophilia

Throughout history, information about haemophilia was gathered by those who witnessed it. The first written descriptions are attributed to the Jewish community in 2C when links were made with circumcision and death from bleeding. Rabbi Judah the Patriarch ruled that a woman who had lost two sons from bleeding after circumcision should not have subsequent male children circumcised (Ingram, 1976). Similarly, another Rabbi forbade the son of a woman to be circumcised because the sons of her older sisters had bled to death following circumcision. Further references to fatal bleeding after minor trauma in sons or cousins who are related through the maternal line are documented in Jewish manuscripts (Ingram, 1976). Moses Maimonides, a Jewish physician, decreed that sons of women whose first and second born sons died of exsanguination after circumcision should not have subsequent sons circumcised, even if the father of the subsequent sons is a second husband. This edict indicates that this ancient people concluded that boys inherit the bleeding tendency from their mother, thus recognising the hereditary nature of haemophilia. Albucasis, an Arabic physician, describes cautery as the best treatment for males with a tendency to excess bleeding, thus providing the first written reference to the treatment of bleeding due to haemophilia.

It was not until the end of the eighteenth century that clinicians began to identify haemophilia as a clinical syndrome or collection of symptoms. Dr John Otto, of the New

York Hospital (USA), published his observations of haemophilia from 1796 to 1817, and it was these observations which added significantly to the understanding of this complex disorder. At this time Otto described a woman who was a haemophilia carrier, noting that while she displayed no symptoms, her sons were afflicted with excessive bleeding. He concluded that the inheritance pattern was sex-linked and that haemophilia was associated with premature death of the person with the disorder (Lee, 2010). These patients were termed “bleeders”, and in 1828 Hopff introduced the word haemophilia, from the Greek *haima* = of the blood, *philia* = affection (Ingram, 1976).

By the early nineteenth century, haemophilia had attracted accounts from numerous sources tracing family trees back several generations or describing the damage to joints caused by prolonged bleeding. The rare presentation of haemophilia in the female emerged. A lengthy monograph by Bulloch and Fildes documented 1000 case reports and 200 pedigrees of families with haemophilia (Ingram, 1976; Lee, 2010). This information added to the increasing pool of knowledge about the disorder and in essence developed an accurate account of the devastation that haemophilia can impose on the individual and his family.

2.3.1 History of the management and treatment of haemophilia.

A documented account exists of a boy in 1840 with haemophilia who was administered a blood transfusion which stopped the bleeding. Samuel Lane, a surgeon, was credited with the realisation that a blood transfusion was the only effective treatment for a haemophilia bleed (Schramm, 2014). In 1840 there was no knowledge of blood typing, so the boy was fortunate to survive. While a transfusion of plasma was effective for the treatment of minor bleeds, the volume of whole plasma required to arrest a major bleed risked overloading the circulatory system.

In 1976, Ingram from the Department of Haematology at St Thomas' Hospital in London published a paper which traced the history of treatment for haemophilia (Ojeda-Thies & Rodriguez-Merchan, 2003). It is remarkable that some of these measures described in the publication are still currently used. The first documented effective treatment was in 1934 when Macfarlane experimented with the topical application of Russell's viper venom (Ingram, 1976). He found that the venom was effective in rapidly clotting the blood of a PWH. When the venom was added in the laboratory to the blood of a PWH at the dilution of 1:1000 000, the blood sample clotted as quickly. Thus, Viper venom was used regularly for local application.

It was not until 1965 that the particular deficiency was able to be treated with a specific product. Professor Judith Pool reported that by slowly thawing frozen plasma, much of the residue of fibrinogen which was slow to dissolve, was rich in factor VIII (Ingram, 1976). This product became known as cryoprecipitate or "cryo". Cryo was especially useful for controlling life-threatening bleeds and to provide haemostatic cover for emergency surgery. It was however, only effective to treat people with haemophilia A who were deficient in factor VIII. In 1961, MacMillan in the USA, first used factor VIII and around the same time Edith Bidwell, based in Oxford, England, pioneered much of the work in the use of factor IX (Lee, 2010).

In the early 1970s, pharmaceutical companies began to produce factor concentrates derived from donated pooled plasma in large volumes and in lyophilised (freeze-dried) form which could be reconstituted in small volumes of sterile water. This innovative process meant that the factor could be immediately administered at home by the PWH or family member (Bolton-Maggs, 2006; Lee 2010; Mannucci, 2008). Additionally, during the 1970s Swedish physicians began to treat PWH using primary prophylaxis by administering factor

on a regular basis to prevent bleeds occurring in a response to a bleeding episode (secondary prophylaxis). The use of primary prophylaxis helped to eliminate the worst of the musculo-skeletal damage that resulted from poorly treated bleeds into muscles and joints. The availability of factor meant that life changed dramatically for PWH (Lee, 2010), in developed countries at least.

2.4 Inheritance patterns of haemophilia

As almost all PWH are male, the disorder is passed to all daughters of men with haemophilia as these daughters inherit the defective X chromosome from their fathers (Vidler, 2003). The father of any child has only one X chromosome to transfer to his female off-spring and if defective, the daughter will inherit that faulty X chromosome. Consequently, these daughters have one normal functioning X chromosome and one faulty X chromosome. They will therefore be carriers, with a 50% chance in each pregnancy of passing the affected X chromosome to their children. The carrier mothers may have daughters with the faulty X chromosome who in turn inherit haemophilia carrier status or sons who may have haemophilia. Of note is that the severity of the disorder remains constant from one generation to the next, for example, a man with severe haemophilia will pass on that level of severity to the his carrier daughter who in turn will pass it on to any children who inherit the disorder. Regardless of the transfer of the X chromosome, one third of people born with haemophilia can demonstrate no family history of haemophilia; as did British Queen, Victoria (1819-1901) (DiMichele & Neufeld 1998; World Federation of Hemophilia, 2012). This form of inheritance is known as a spontaneous mutation. The following section has been included in order to show how this congenital condition affected subsequent progeny.

2.4.1 The effect of haemophilia on a particular family.

Although no history of haemophilia had been detected in Victoria's family, she was nevertheless, a haemophilia carrier. Following her marriage to Prince Albert, they had nine children, three of whom were affected by haemophilia (Figure 2.2). Leopold died as a young man and Beatrice and Alice were both carriers. Beatrice had a daughter Ena, who married into the Spanish royal family. Ena had two sons who were both affected with haemophilia. There was a daughter, a carrier, who went on to have two sons both with haemophilia. Alice's daughter, Alexandra was a carrier and married into the Russian royal family. Alexandra was the mother of Alexis, the Tsarevitch of Russia, and heir to the throne, who inherited a severe form of haemophilia. Alexis was prone to prolonged and severe haemophilic bleeds which caused his parents great distress. In a desperate bid to cure her son of this disorder, Alexandra became inappropriately influenced by Rasputin, known as the mad monk. It is this association that some historians suggest can be attributed to the downfall and subsequent assassinations of the royal family in Russia in the early 20th century culminating in the end of the Romanov Empire (Ingham, 1976; Lee, 2010).

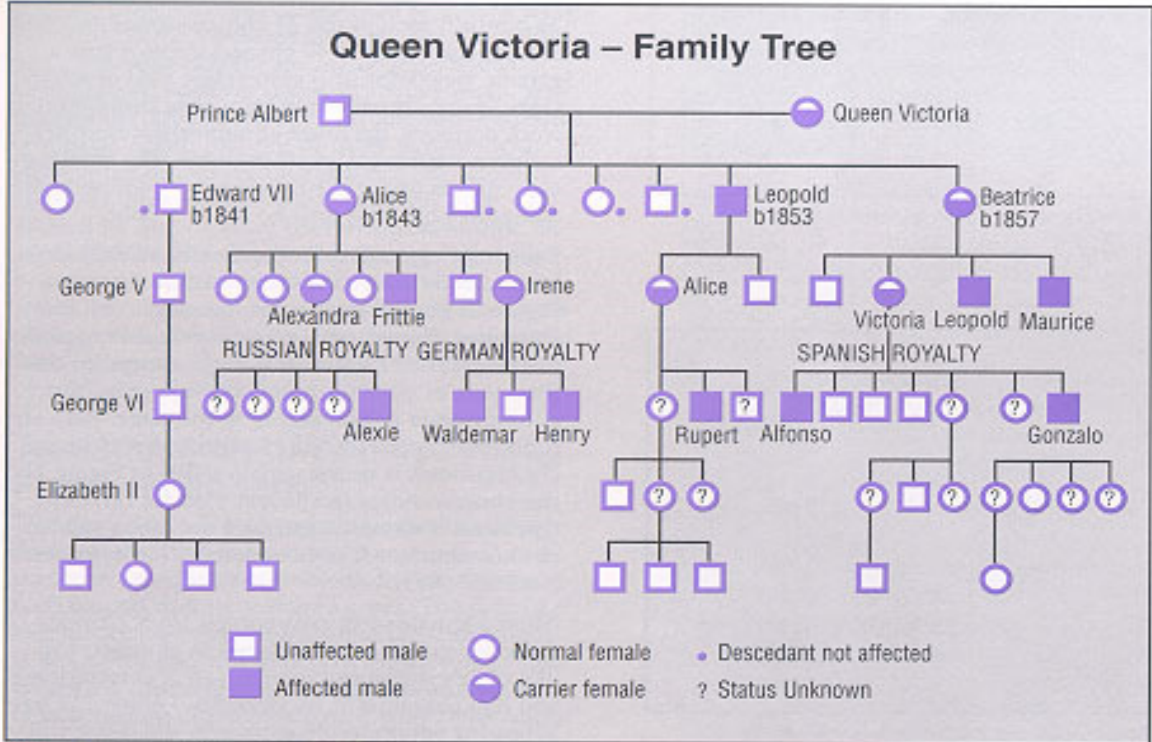


Figure 2.1 Queen Victoria's family tree. Source: National Hemophilia Foundation (U.S.).

2.5 Mechanism of blood clotting

In order to comprehend the impact of haemophilia on a person, it is necessary to understand the mechanism of blood clotting and the process of haemostasis. Haemostasis means “the stoppage of bleeding or haemorrhage” (American Heritage Medical Dictionary, 2007). This is a complex process which results in the formation of a blood clot to plug the site of injury in a blood vessel wall. This blood clot prevents unnecessary blood loss, while simultaneously maintaining a clot-free environment in unaffected blood vessels. The clotting response is vitally dependent on normal functioning and sufficient numbers of circulating platelets; and coagulation factors that are functioning normally and in sufficient amounts (Higgins, 2012).

The physiology of coagulation is a delicate and complex mechanism that the body utilises to ensure that blood clots at the site of the blood vessel injury. Immediately after injury, vasoconstriction occurs at the injured blood vessel site and adjacent small arteries with the effect of slowing the flow of blood to the area. This system process allows adhesion of platelets to the injured blood vessel wall, a process partly facilitated by von Willebrand factor (VWF) which is stored in the endothelial cells of the blood vessel walls. Platelets are produced in the bone marrow from stem cells and circulate in the blood. The main function of platelets is to plug holes in injured blood vessel walls. The platelets circulating in the blood stream secrete many substances, some of which allow the platelets to change shape and bond together, a process termed aggregation. The adhesion and aggregation of platelets form a platelet plug. The secretion of substances from the surface of the platelets further activates clotting proteins resulting in the formation of fibrin strands which weave around and between the platelets to stabilise the platelet plug (Ziedins & Mann, 2010).

The proteins required for clotting act sequentially which is known as the clotting cascade or the coagulation pathway (Figure 2.2). This is a collection of proteins, termed factors, which circulate in the blood and are activated when bleeding occurs. As each factor is activated, the next factor in the clotting cascade is stimulated to become activated, with the end product being fibrin. There are thirteen known factors, identified by Roman numerals, although, factor VI is no longer thought to exist. For fibrin to be formed, adequate amounts of clotting factors which function normally are required (Hoffman & Monroe, 2007; Smith, 2009).

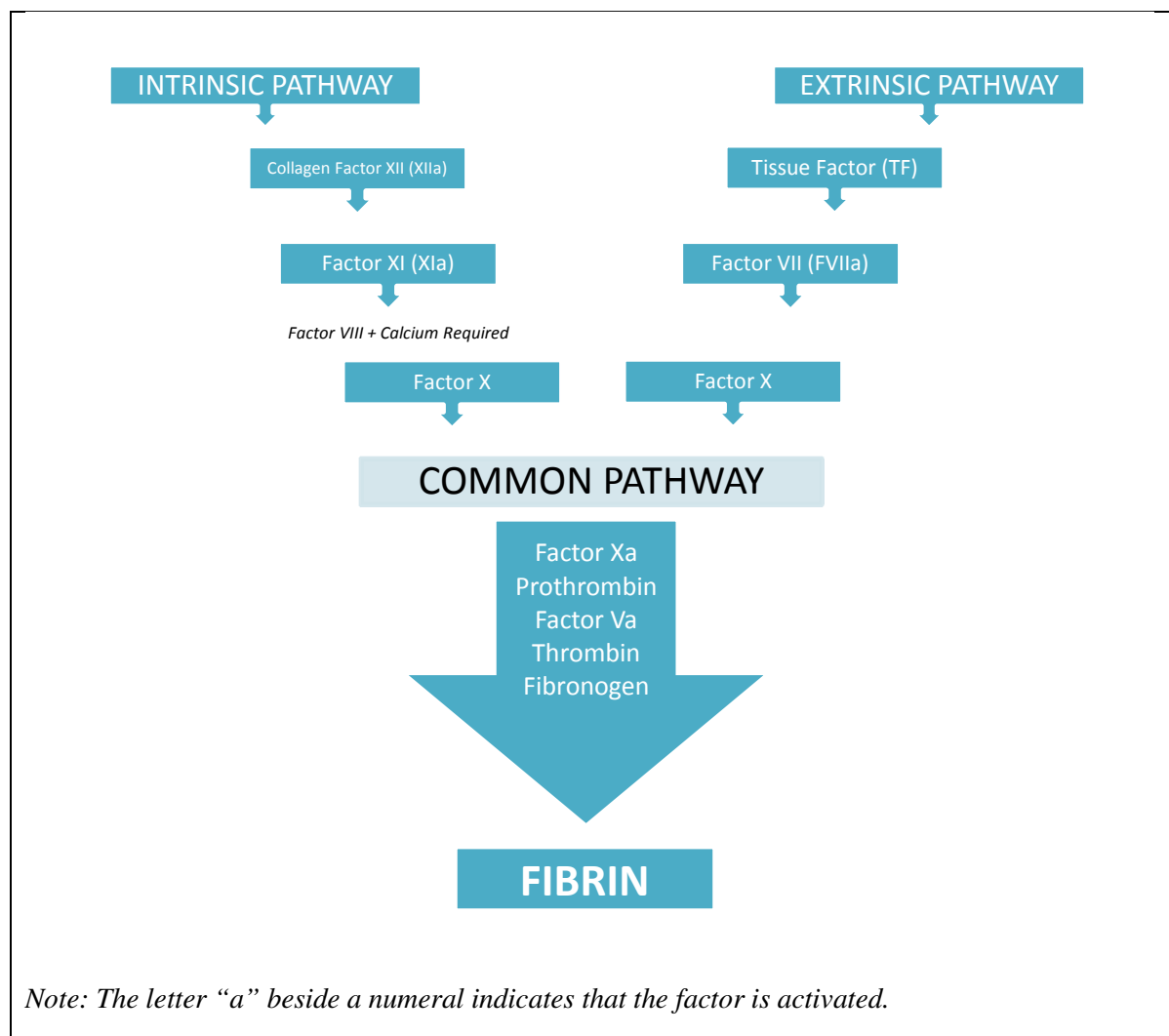


Figure 2.2 Coagulation pathway/cascade.

The clotting pathway/cascade is not a complete explanation for the activation of clotting factors. The clotting cascade model can be used to explain laboratory tests that indicate coagulation abnormalities and also demonstrates the relationship between clotting factors. However, the clotting cascade does not fully explain the process of haemostasis in vivo (in the body), where the ultimate outcome is the formation of a robust fibrin clot to stop the bleeding (Hoffman, 2003; Smith, 2009).

The cell-based model of fibrin formation explained by Hoffman (2003) and Smith (2009) may help to explain more fully the coagulation mechanism in a dynamic environment that is, circulating in the blood. In particular, this model may provide possible reasons why some factor deficiencies such as factor VIII and factor IX, the deficiencies that cause haemophilia, are related to significant bleeding while others, such as factor XII deficiency, are not associated with bleeding (Hoffman & Monroe, 2007). The cell-based model highlights the relationship between clotting factors and the surface of specific cells. Studies of the cell-based model indicate that coagulation in vivo takes place in three distinct, overlapping stages and that two different cell types are required: cells containing tissue factor (TF) and platelets (Smith, 2009).

The cell-based model consists of three phases, firstly, the Initiation Phase where TF is activated when exposed to flowing blood following an injury to the blood vessel. A small amount of Factor IXa and thrombin diffuse away from the TF-bearing cell surface to the platelets. The second stage is called the Amplification Phase when the thrombin activates platelets, releases vWF and activates Factor V, Factor VIII and Factor XI. The third and final phase is known as the Propagation Phase where various enzymes gather on the surface of the platelets to form intrinsic tenase and activate Factor X. Prothrombinase forms from this action and a burst of thrombin is generated on the surface of the platelets, resulting in

sufficient fibrin to form an insoluble fibrin matrix (Smith, 2009). In haemophilia this process does not occur since an essential substance (Factor VIII or IX) is absent.

2.5.1 Coagulation inhibition.

If the blood clotting process is allowed to go unchecked, clotting in healthy blood vessels (thrombosis) would occur. It is therefore vital that the effect of the clotting mechanism occurs only at the site of injury. Substances circulating in the blood called inhibitors regulate the process of coagulation inhibition by inactivating the activated clotting factors. Examples of these substances are protein C which inactivates factors V and VIII, and antithrombin which inactivates factors Xa and thrombin. The clot at the site of injury will be broken down once the blood vessel wall is healed. This process is known as fibrinolysis, and occurs when fibrin is degraded by a substance called plasmin. Fibrinolytic activity can be detected in the laboratory by the presence of fibrin degradation products (FDPs). Anti-fibrinolytic medications, such as tranexamic acid, slow down the fibrinolysis process, maintaining the clot in situ longer, giving the injured site more time to heal (Smith, 2004).

Clot formation and fibrinolysis are usually well balanced but sometimes the tissue damage is so severe that large amounts of thromboplastin are released into the circulating plasma, causing widespread clotting throughout the body. This is known as disseminated intravascular coagulation (DIC), which occludes blood vessels and causes ischaemic damage to tissues, which release more thromboplastin. Finally, the circulating platelets dwindle and the clotting factors become exhausted, so that clotting can no longer take place and bleeding occurs. Any organ in the body can be affected and without prompt treatment, death can result (Robertson, Wu & Greer, 2004).

2.6 Diagnosing haemophilia

Accurate diagnosis of haemophilia is essential to enable the correct treatment to be prescribed and administered. In developed countries such as Australia, if a person is suspected of having haemophilia, the initial diagnosis is made through rigorous assessment including clinical presentation, family history and laboratory testing (World Federation of Hemophilia, 2012). This is done to exclude other inherited bleeding disorders which can be similar, such as von Willebrand Disorder (VWD). It is important to observe that the family history and clinical signs of haemophilia A and haemophilia B are identical (World Federation of Hemophilia, 2012) and the differentiation cannot be established until the laboratory assays are performed.

Since haemophilia impairs the coagulation process, it is imperative that early diagnosis is made to reduce the risk of morbidity and mortality. If a PWH has access to quality management and treatment, as is the case in developed countries, the person's lifespan will reflect that of the non-haemophilia population (World Federation of Hemophilia, 2012).

2.6.1 Clinical presentation.

Symptoms of haemophilia include bleeding which can occur in any part of the body but most commonly into joints, muscles, gums, nose and mouth, and urinary tract. In severe haemophilia, bleeding can be spontaneous with no apparent cause. Trauma or even minor surgery, such as dental extraction, can cause a devastating haemorrhage. A bleed that occurs in the central nervous system, gastrointestinal tract, neck, after surgery and following severe trauma is considered life-threatening and requires prompt and appropriate intervention to arrest the bleeding (World Federation of Hemophilia, 2012).

Uncontrolled bleeding in joints and soft tissues can result in severe pain. Repeated bleeding into the same joint, known as a target joint, can lead to progressive arthritis and eventual crippling due to joint and muscle damage (Sohail & Heijnen, 2001).

It is possible to diagnose a child with haemophilia soon after birth as symptoms of birth trauma such as intracranial haemorrhage, cephalic haematoma and/or bleeding from the umbilical cord are often present (Giangrande, 2003). When toddlers begin to walk it is predictable that they will have falls. However, if the child shows signs such as excessive bruising, or prolonged bleeding from the mouth due to the usual spills experienced at this age, haemophilia should be considered (WFH, 2005). Unfortunately, parents are often suspected of child abuse because of the extensive bruising before a diagnosis is made (Swedish guidelines for the care and treatment of haemophiliacs, 2003), especially when there is no family history of haemophilia.

2.6.2 Family history.

In order to make a definite diagnosis, data are collected in relation to the medical histories of the individual and both male and female family members who might describe similar bleeding episodes. For example, females may report post-partum haemorrhage or menorrhagia (Gringeri, 2005) and other family members may describe lifelong frequent and prolonged epistaxis or easy bruising. Women who are haemophilia carriers may present with bleeding into joints, muscles and mucosa (Lambing, 2007), while others may not have experienced any bleeding symptoms. In developing countries, due to lack of education or health awareness, including haemophilia, relatives often do not know the cause of death in a family member, so it is sometimes difficult to elicit an accurate family history. To further complicate the situation, many clinicians are unaware of the symptoms and clinical presentation of haemophilia, so the disorder can remain unrecognised and undiagnosed.

2.6.3 Laboratory tests to aid diagnosis.

Laboratory tests result in the definitive diagnosis of haemophilia. However, specimens must reach the laboratory within four hours of collection from the patient (World Federation of Hemophilia, 2012) to maintain integrity of the specimen. Initially platelet count, bleeding time, prothrombin time and activated prothrombin time will be performed. If these tests are within normal limits, further tests such as coagulation assays (tests) which measure levels of factor VIII, factor IX and von Willebrand Factor may be required which will provide a more definitive diagnosis (World Federation of Hemophilia, 2012). From these tests a diagnosis of haemophilia A or B will be determined.

Factor assays are required to monitor treatment when a PWH requires management for an acute episode such as surgery or trauma. The laboratory scientists will perform regular factor assays to assess the factor levels. These levels will guide the haematologist about factor dosage, to facilitate haemostasis and minimise the threat of a further bleed (World Federation of Hemophilia, 2012). When a known haemophilia carrier, a mother or a woman with a family history of haemophilia goes into labour, it is recommended that umbilical cord blood be collected at the time of delivery to test for haemophilia. Collecting an umbilical cord blood sample has two advantages. Firstly, the sample can be delivered to the laboratory as soon as the cord is cut; and secondly, attempts to obtain blood samples from a peripheral vein in a newborn is difficult and may result in severe bruising or bleeding, thus requiring factor (Giangrande, 2003).

Expensive laboratory equipment and reagents to perform blood tests are required to establish the level of deficiency of factor as it is this result which determines the severity of haemophilia. Those individuals with less than one percent of factor are considered severe, one to five percent of factor is deemed moderate, and five to 25 percent of factor is

considered mild. Many people with mild haemophilia are not diagnosed until they sustain trauma or undergo surgery when such an experience can trigger excessive bleeding (World Federation of Hemophilia, 2012).

2.7 Complications of haemophilia

There are several complications that may arise with regard to haemophilia such as inhibitors and blood borne viruses. These are discussed in what follows.

2.7.1 Inhibitors.

A complication of haemophilia which can have serious consequences for PWH is the development of antibodies, known as inhibitors, to the factor replacement. When a PWH is given treatment with factor VIII or IX to raise the level of the missing factor, the body perceives the factor as an invading foreign protein and the inhibitor attaches to the factor, impeding its action and rendering it ineffective. The development of an inhibitor makes management of haemophilic bleeding more complex and difficult (Kasper, 2004).

Inhibitors occur more frequently in those people with severe or moderately severe haemophilia A, and are much less common in people with haemophilia B. Inhibitors have been reported to develop most commonly in PWH less than 12 years of age and after they have been exposed to an average of nine to 12 treatments. There is a tendency for the development of inhibitors to occur in families, and ethnic groups; for example, Africans are twice as likely to develop inhibitors as Caucasians (DiMichelle, 2008; Kasper, 2004). This statistic is of significance to this study since the management of haemophilia is being evaluated in SA, where the majority of PWH are of African heritage.

If an inhibitor is present it is usually discovered by either a routine blood test taken at the time of a regular visit to the haemophilia treatment centre (HTC) or when the normal

doses of factor are not arresting bleeding effectively. The presence of inhibitors is confirmed by the Bethesda inhibitor assay, a blood test carried out in the coagulation laboratory. This test indicates the level of inhibitors present, with the level being measured in Bethesda units (BU) or Bethesda titre. The higher the Bethesda titre, the greater the amount of inhibitor present in the blood (Mitchell & Phillott, 2008). A PWH with a Bethesda titre more than five is known as a high responder and those with a Bethesda titre less than five are termed low responders. This level is an important distinction because the treatment differs according to the level of the Bethesda titre. Fortunately, most HTCs in SA have laboratories with the capacity to perform these assays.

Treatment using factor VIII or IX for low-responding inhibitors is frequently effective, although the dosage may need to be higher, given more frequently or as a large bolus dose to overwhelm the inhibitor (DiMichelle, 2008; Kasper, 2004). For most PWH with high responder status, a bypassing agent such as recombinant factor VIIa or Factor Eight Inhibitor Bypassing Activity (FEIBA), prothrombin complex concentrates and activated prothrombin complex concentrates which contain other factors, are used to “bypass” the requirement for factor VIII or IX and therefore do not activate the inhibitor. In developed countries, PWH are fortunate to have access to immune tolerance which can be accomplished by giving frequent doses of factor over a long period of time. The aim is to overwhelm the inhibitor so that it no longer has the ability to produce antibodies to the factor (DiMichelle, 2008; Kasper, 2004). Immune tolerisation and the use of bypassing agents is expensive therapy and therefore rarely available to PWH living in developing countries.

2.7.2 Blood-borne viruses.

Cryoprecipitate and factor VIII and IX are plasma-derived products produced from donated blood. It was not until the 1980s that transfusion scientists and haematologists identified that some donated blood was contaminated by viruses; most notably, HIV. However, this discovery was too late for countless PWH, many of whom developed Acquired Immune Deficiency Syndrome (AIDS). This event was disastrous as many PWH died (Lee, 2010) before effective treatment became available to arrest the debilitating progress of HIV and AIDs. Other viruses, which contaminated the blood supply and its products were the hepatitis viruses. Scientists were able to identify the hepatitis B virus, however the hepatitis C virus (HCV) was not visible under microscope and was referred to as non-A, non-B hepatitis. In the early 1990s, more sophisticated diagnostic techniques became available (Lee, 2010) and the non-A non-B virus was identified and is now referred to as hepatitis C (HCV). Although these are now identified and effective treatment is available, there are still some genotypes of HCV that are resistant to treatment (Hepatitis Australia, 2017).

In developed countries, recombinant factor VIII and IX, which are manufactured in a laboratory and do not contain any human tissue, are now available for the treatment of PWH. These products have a very low risk of contamination by viruses. In contrast, PWH in developing countries continue to be treated with plasma-derived products such as factor VIII, factor IX and cryoprecipitate, as the recombinant products are unavailable.

Countries in the developing world that produce their own plasma-derived product have put in place safeguards to protect the consumers from contamination. These safeguards reflect those that well-resourced nations had developed to protect PWH recipients prior to the introduction of recombinant products (Farrugia, 2017). The

safeguards include strict pre-screening of the donors prior to donation; firstly, to exclude high-risk behaviour, for example, unprotected sexual encounters; and, secondly, serologic screening assays to identify viruses that are transmissible by blood and plasma products; and thirdly, treatment such as pasteurisation and nano-filtration of the plasma to ensure the products are safe (Muller, 2004). Cryoprecipitate is manufactured in some developing countries but the viral reduction techniques used for factor are not easy to apply to cryoprecipitate because the product's low purity prevents it being decontaminated by heat processes such as pasteurisation (Farrugia, 2008).

2.8 Treatment and management of haemophilia

Joint bleeding, termed haemarthrosis, is the most common presentation in haemophilia. The PWH will present with pain, swelling, restricted range of movement, stiffness and tingling in the affected joint. If the bleeding continues and the joint fills with blood, it becomes hot, more swollen and painful with a significant decrease in articulation. If provided with appropriate treatment, soon after the symptoms appear, the bleeding stops quickly and the symptoms often resolve promptly. Muscle bleeds are also common and managed in the same way as joint bleeds to prevent contractures and nerve compression (Chandy 2005; Shamsi & Chughtai, 2001).

Essentially, the aim of treatment is to arrest the bleed, minimise damage to the joint, muscle or other tissues, stop the pain and restore the affected part to the level of function prior to the bleed. Prompt treatment, using the appropriate product for the deficiency even if only with minimal doses of factor, fresh frozen plasma (FFP) or cryoprecipitate ("cryo") can provide haemostasis better than delayed application. If the haemophilia diagnosis is known, this treatment should be administered immediately before any further investigations (Mahlangu, 2008). In some cases, particularly in the developing world, there can be delays

of several days before administering treatment after a bleed due to poor transportation, or the PWH needing to travel long distances to access treatment. Conservative measures such as immobilisation, application of ice and gentle compression can be implemented by the PWH or a family member to reduce the pain and swelling until factor can be administered and should be continued until the bleeding stops (World Federation of Hemophilia, 2012). The PWH can be given a personal supply of factor to instigate treatment if a bleed commences. Pain can be managed by using paracetamol or mild opioid preparations. Aspirin and salicylates such as non-steroidal anti-inflammatory drugs are contraindicated since they influence the agglutination of platelets, affecting the body's ability to achieve haemostasis. Once the bleeding ceases, rehabilitative exercises are commenced to restore strength to the muscles surrounding the affected joint or limb (World Federation of Hemophilia, 2012). The objective is to strengthen the muscles so they can support the joint, restore range of motion and reduce crippling. These exercises can be taught to the PWH so he can continue them at home, helping to reduce frequency of bleeds and damage caused by bleeding into joints (Shamsi & Chughtai, 2001).

Bleeding in the region of the head, neck, chest, abdomen and gastro-intestinal tract are life-threatening bleeds, considered as emergencies and should be treated with factor replacement without delay (Chandy, 2004). Mucous membrane bleeds such as nose bleeds and bleeds from the oral cavity are treated with tranexamic acid, fibrin glue or a single dose of factor. The application of a suture if necessary after dental extraction or skin laceration can be safely carried out and the first aid measures of ice packs and elevation can also be implemented. Bleeding after circumcision can be fatal if not adequately managed. In neonates, a blood transfusion followed by the appropriate factor once the bleeding disorder has been identified should be administered to arrest the bleeding. Fibrin glue has been shown to be effective post-circumcision (Shamsi & Chughtai, 2001). Surgical procedures,

including orthopaedic surgery, require careful management and are ideally performed in establishments that have access to both experienced surgeons and a haemophilia comprehensive care team who can work in tandem to ensure that the PWH receives optimal and appropriate care.

The WFH's Guidelines for the Management of Hemophilia (2012) recommend that optimal haemophilia care be delivered using the comprehensive care model involving a multidisciplinary health care team approach. This approach, directed by a haematologist, includes a nurse, physiotherapist and social worker as core team members. The team members can access further resources including a coagulation laboratory, appropriate clotting factor concentrates and specialist consultants such as an orthopaedic surgeon, dentist, rheumatologist and geneticist. The Haemophilia Treatment Centre (HTC), which is usually located in the capital city of a province or country, is the specialised care centre for the PWH and has a multi-functional approach. It provides outpatient facilities for those patients not requiring hospital admission as well as education to healthcare staff, education of PWH and their families, instruction and support for home therapy (infusions of factor at home) and psychosocial support (Hoots, 2003). In Australia, there is sufficient factor available for all PWH provided free of charge. Also within Australia and other developed countries, a PWH who receives this level of care will maintain health outcomes enabling a more positive future. In contrast, a PWH living in developing countries, particularly if they live in regional areas may never be diagnosed, and those who are, may not receive this level of care.

2.9 Current treatment protocols

As currently understood, several haemophilia treatment options are available. These are described below.

2.9.1 Plasma-derived treatments.

Optimal treatment of haemophilia requires intravenous replacement of the clotting factor. In haemophilia A the clotting factor is factor VIII and in haemophilia B the clotting factor is IX. The dosage of factor is calculated by the body weight of the PWH, the severity of the individual's haemophilia and the severity of the bleeding episode (World Federation of Hemophilia, 2012). In developed countries such as Australia, management of children with severe haemophilia is replacement of factor two or three times weekly, known as primary prophylaxis. This process raises the factor levels sufficiently to achieve haemostasis and prevent bleeding (Khair, Lawrence, Butler, O'Shea & Christie, 2008). In contrast, a child with haemophilia in a developing country in the best-case scenario will be treated "on demand" that is, in response to a bleed, known as secondary prophylaxis. If factor is unavailable, the risk of death significantly increases. According to Mahlangu (2009), there were ten deaths per annum from haemophilia causes in the years 2004 to 2007 in SA. In Australia it is rare for a PWH to die of the disease. Sufferers are more likely to die of complications such as hepatic malignancy as a result of hepatitis C infection.

Factor is either plasma-derived from blood donations or recombinant, a synthetic version made in a laboratory, containing no human plasma (DiMichele & Neufeld, 1998), which would be the treatment of choice given the AIDS risk in SA. In plasma-derived product, the clotting factor is separated from the blood plasma and freeze-dried (lyophilised) to a powder to be reconstituted with sterile water when ready to be administered. This procedure however, requires a sophisticated manufacturing process to eliminate blood-borne viruses, such as hepatitis C (DiMichele & Neufeld, 1998). This complicated procedure means that the replacement factor is very expensive (Mahlangu & Gillham, 2008). As the cost is around US\$1 per unit, with an average dose for an 80kg male being in the region of

2500 to 3000 units of factor to stop a bleed, the cost per dose would be US\$3000, being approximately the same in Australia.

The discovery and introduction of factor replacement therapy significantly changed the way haemophilia was managed (Lee, 2010) Prior to the discovery of this treatment, the life expectancy of a PWH was short and children died of the disorder at a very young age, for example, in Sweden life expectancy was eight to 11 years. From the 1970s to the present time, however, survival rates have extended to around 65 years (Bolton-Maggs, 2006), a significant improvement. Immediate treatment of spontaneous bleeds with factor eliminated the long periods of recovery and rehabilitation following a bleed. Previously, children had to endure prolonged hospital admissions, which resulted in erratic school attendances and educational opportunities. Consequently, employment opportunities were reduced.

2.9.1.2 Cryoprecipitate (Cryo).

Cryo (from the Greek word, kruos, meaning cold) was used widely in the 1960s in the management of haemophilia A and was the forerunner of factor replacement concentrates (Bolton-Maggs, 2006, Hoffbrand & Pettit, 1993). After thawing at one to six degrees Celsius, cryo is separated from fresh frozen plasma (FFP) and is found in the remaining precipitate, which is then refrozen. Factor VIII, Fibrinogen, factor XIII and fibronectin are contained in cryo (PathWest, 2011). Cryo is produced in blood centres in developing countries, such as Thailand and Cuba, providing the main source of treatment product for haemophilia A and can be used without further processing. Approximately 600 units of factor VIII can be supplied from one litre of plasma with the final result a freeze-dried product which can be stored at home by PWH and reconstituted and self-injected when required (Farrugia, 2008).

The use of safe cryo without supplies of factor concentrates is an affordable and viable alternative for treatment of PWH in developing countries. However, Farrugia (2008) explains that techniques used to eliminate viruses from factor concentrates are not suitable for use in cryo. In the blood centre setting, heat treatment cannot exceed 60° C, which is not sufficient to nullify viral contamination. Until technology is available to perform viral inactivation for cryo, other methods need to be implemented to ensure that the product is safe from blood-borne viruses. Consequentially, appropriate selection of low-risk blood and plasma donors is the most important preventative measure available to policy-makers and producers of cryo in developing countries (Farrugia, 2008).

2.9.1.3 Fresh frozen plasma.

Fresh frozen plasma (FFP) contains factor VIII and factor IX, 250 units in 250 millilitres. Given by infusion, care needs to be taken during administration that fluid overload does not occur, particularly with children. Fresh frozen plasma carries similar problems with viral screening as cryo (Shamsi & Chughtai, 2001).

2.9.1.4 Fibrin glue.

Fibrin glue, also known as fibrin sealant, is made using a mixture of fibrinogen and thrombin. It acts as a sealant, and promotes haemostasis and healing. It is used for dental extraction, circumcision and to arrest mucous membrane bleeding. It is available as a commercial product, which is very expensive, but can be made inexpensively in transfusion laboratories using cryoprecipitate (Chandy, 2005), so is a useful adjunct therapy in developing countries.

Desmopressin Acetate (DDAVP) is a pharmaceutical treatment option which raises the activity of the von Willebrand Factor (VWF). It increases the levels of VWF and factor

VIII in the bloodstream by stimulating the release of VWF from the endothelial cells in blood vessels. It is a synthetic analogue of vasopressin, an anti-diuretic hormone.

Advantages of using DDAVP are that it is inexpensive in comparison to factor replacement and being a pharmaceutical, carries no blood-borne viruses. Its use is indicated in some forms of von Willebrand Disease, mild haemophilia and to carry out DDAVP trials which are implemented to test the effect of DDAVP. Contra-indications for the use of DDAVP include severe haemophilia A, haemophilia B, severe von Willebrand Disease, type 2B von Willebrand Disease, pregnancy and older patients or those with a history of cardiovascular disease and/or hypertension.

The drug DDAVP can be given intravenously, intra-nasally and subcutaneously. It is given as an intravenous infusion diluted in 50 - 100mls of normal saline over 20-30 minutes. Intra-nasal DDAVP is a spray containing 150 micrograms per dose to each nostril. Subcutaneously DDAVP has been found to be effective and is particularly useful if intravenous access is difficult. As DDAVP is an anti-diuretic hormone, it causes fluid retention therefore it is necessary to observe for hyponatremia and over-hydration which can lead to cardiac failure and death. Children and the elderly are particularly susceptible to these problems (Smith, 2004).

Tranexamic acid is an anti-fibrinolytic which acts by delaying the process of fibrinolysis and is especially useful in controlling bleeding of mucous membranes. It can be used as a mouthwash after dental or oral surgery, epistaxis and menorrhagia (Chandy, 2005). However, it is important to note that tranexamic acid is contra-indicated for urinary tract bleeds. The oral dosage is 25 milligrams per kilogram of body weight taken three to four times per day for 10 days to allow wound healing.

2.9.2 Further considerations in developing countries.

In developing countries, the financial burden of factor replacement often results in reluctance of governments to purchase the product (Chuansumrit, 2003; Evatt & Robilliard, 2000) resulting in the PWH being untreated, thus increasing the risk of morbidity and mortality. However, these outcomes can be reduced if the patient, his family and the physician are knowledgeable about the management and treatment of haemophilia, even if factor replacement availability is limited (Chuansumrit, 2003). Chandy, in his WFH Monograph "*Treatment Options in the Management of Hemophilia in Developing Countries*" (2005), supports this position. The importance of education of the PWH, their families, health care providers and the general public is stressed by Shamsi and Chughtai (2001), Pakistani physicians, who believe that education is the basis of haemophilia care where financial resources are inadequate and factor is unattainable. These physicians state that simple first aid measures such as immobilisation and applying ice to the site of the bleed can help to minimise morbidity. Chandy (2001) maintains that education is not expensive to implement in the developing world and that much of the morbidity associated with haemophilia could be reduced if the PWH, and those involved in his care, have sufficient knowledge about the disorder.

2.10 Recent developments

In 2000 the United Nations Millennium Development Goals (MDGs) were signed by 191 countries. Each signatory member state agreed to strive to accomplish these goals by the year 2015. The goals were aimed at eradicating extreme poverty and hunger; providing equality, empowerment and improved maternal health for women; reducing child mortality; combating diseases; and developing global partnerships for development and environmental sustainability. The eight Millennium Goals came to the end of their tenure and have been

superseded by a new plan. In 2015, the World Health Organisation, (WHO) introduced seventeen Sustainable Development Goals (SDGs) to take the place of the MDGs, building on the successes of the MDGs and broadening the scope to encompass climate change, economic inequality, sustainable consumption and peace and justice.

Although haemophilia is not identified directly in the United Nations MDG and SDG goals, improved care of people with haemophilia would help address goal four by reducing child morbidity and mortality. However, the treatment of haemophilia is expensive, even in developed countries, and the cost burden is considerable. In developed countries, five to ten percent of Gross Domestic Product (GDP) is expended on health, whereas under-developed countries are only able to channel less than two percent of the GDP on health (WHO/WFH] International Society of Thrombosis and Haemostasis, ISTH, 2002). In countries where as little as US\$1 per head is spent annually on health care, the cost of haemophilia treatment is unattainable (WHO/WFH/ISTH, 2002). South Africa has haemophilia treatment available for all PWH who require it which reflects expenditure of 8.8 % of the GDP on health (WHO, 2015b).

The United Nations has a variety of programs that assist governments to develop specific plans that will benefit their citizens. One of these programs is the United Nations Development Program (UNDP) which uses the Human Development Index (HDI) and encompasses the following three dimensions: health, education and living standards, to estimate a nation's living standard. The indicators for the health dimension include life expectancy at birth (in years), public health expenditure expressed in percentage of the GDP and under-five years of age mortality rate per 1,000 live births. For education, the indicators are public expenditure on education as a percentage of the GDP, expected years of schooling of children under 7 years of age, adult literacy rate which includes the percentage

of both sexes over 15 years of age, mean years of schooling of adults over 25 years and the combined gross enrolment in education of both sexes expressed in a percentage. The indicators for living standards are GDP per capita in Purchasing Power Parity which describes whether the cost of goods purchased in two different countries is the same when expressed in US dollars. Also utilised is the Gross National Income (GNI) which is an indicator designed by the World Bank which expresses the average income of a country by dividing the dollar value of the country's annual income by the population (UNDP Human Development Report, 2011). Using this method, the UNDP is able to differentiate between developed countries and developing countries. On the HDI, SA is rated 123, in contrast to Australia which is rated two. This figure demonstrates that Australia has a much higher standard of living than SA and shows that SA has little expenditure focussed on essential health and education.

However, the UNDP has found that a country's overall HDI can disguise the fact that different groups within the country can have different levels of development: examples are groups characterised by income, geographical regions, urban or rural habitation, gender or ethnicity. By using disaggregated HDIs, (applying the HDI components to the sub-group of concern and treating them like a separate country), inequalities can be identified which can be used to guide policies and implementation of recommended actions to address gaps. The use of the HDI and disaggregation can help to illustrate more strongly disparities that are already known of in a community. There is evidence to support that the HDI provides assistance to social and regional groups to strengthen their case for more resources. Therefore, if more resources are available in health, there is a greater probability that more resources for haemophilia care are available.

2.11 The nurse's role in haemophilia care

As Chandy (2005) observed, education is the keystone to improvement in healthcare. Haemophilia nurses play a vital role within the haemophilia comprehensive health care team. These nurses create a link between the PWH and other health providers and serve two functions, firstly, to treat acute bleeding episodes; and secondly, to take on the role of educator. The haemophilia nurse educates patients and their families about haemophilia, the inheritance patterns, treatment options available and when and how to treat a bleed, and at the same time supporting the families so that they can better deal with the challenges of living with haemophilia (Oyesiku & Butler, 2007). Following initial diagnosis, the haemophilia nurse or doctor will administer the factor to the child with haemophilia. Gradually the parents of the child are encouraged to learn how to undertake venepuncture and inject the factor. Through such education, treatment can eventually be provided at home, known as home therapy, thereby eliminating repeated hospital visits and reducing the strain on a fragile haemophilia care system which currently exists in SA. Essentially, teaching patients to administer factor as soon as the bleed occurs means that immediate treatment can reduce the pain and possible damage to joints or organs (Di Michelle & Neufeld, 1998; Evatt, 2006; Vidler, 2000).

Studies have demonstrated that prophylaxis is the most important measure to prevent joint damage in children with haemophilia (Lofqvist, Nilsson, Berntorp & Pettersson, 1997; Panicker, Warriar, Thomas & Lusher, 2003). Prophylaxis is therefore much easier and more convenient if the venepuncture and administration can be delivered at home. Parents are also instructed how to perform immediate care such as applying ice and conservative measures such as resting the affecting area. Educating the family provides the necessary skill to assess and respond immediately to bleeding episodes. Often only one injection of

factor plus the application of conservative measures are required to stem the bleed. It is evident that such treatment and intervention is cost-effective in both human and financial terms (WFH, 2005).

Education of the patient and family is a central component within the role of the haemophilia nurse and pivotal to the efficient management and treatment of haemophilia. Once a treatment plan is formulated, the nurse will ensure that the PWH and his family understand the plan and that it must be evaluated regularly to address any difficulties with implementation. Progress of the PWH is monitored continually, ongoing support is provided and accurate records are observed to document progress and identify any problems. The nurse works with the PWH and family to ensure that the plan is successful and acts as the liaison with other haemophilia comprehensive care team members (WFH, 2007).

The nurse endeavours to educate all people involved with the PWH, such as the wider community, school staff and employers. It is also essential to advocate for the PWH in relation to schools and workplaces. For example, contact sports, which some schools would expect boys to participate in, are not recommended for children with haemophilia (WFH, 2007).

Studies by Khair, Lawrence, Butler, O'Shea, and Christie, (2008) and Miller, Guelcher and Taylor (2009) support and indeed reinforce the importance of education in the care of PWH and the haemophilia nurse is crucial in this endeavour. As the PWH reaches adulthood he must assume responsibility for his health. An independent pilot study conducted by Miller et al., (2009), involving haemophilia nurses in the USA, found that 187 PWH or their caregivers rated health care providers (nursing and medical) as the most important source of information about haemophilia and treatment. This study is supported

by a survey conducted by haemophilia nurses in the US, UK, Sweden and Canada, which found that education similar to that described above, was the most suitable method to conquer difficulties with prophylaxis and home therapy in more than 10,100 patients with severe haemophilia A (Khair et al., 2008).

2.12 Haemophilia care in developing countries

The care and support in developing countries significantly contrasts with a wealthy country such as Australia. Prophylaxis, as practiced in developed countries, requires an annual supply of hundreds to thousands of units of factor for each PWH each year. Factor replacement is a very expensive commodity for the individual to purchase, thus the PWH is reliant on the government to provide this treatment. In developing countries, a government with a low GDP and limited health budget has little chance of purchasing factor for prophylactic purposes, therefore other measures need to be initiated to manage haemophilia (Chuansumit, 2003). Prevention of a bleed is the primary aim and maintenance of good health will assist fulfilment of these aims. It is essential for the PWH to avoid situations which may provoke bleeds, for example, poor dental health. Regular exercise to improve fitness; regular check-ups at the haemophilia clinic, especially of examination of joints and muscles; avoiding contact sports; and obtaining vaccinations against hepatitis will help the PWH to remain well (Chandy, 2005).

Conservative management of a bleeding episode consists of first aid and analgesia. First aid measures recommend rest, for example a sling for a wrist bleed, intermittent application of ice packs for the first 48 hours and gentle compression using an elastic bandage. Analgesia such as paracetamol or codeine are suitable, although aspirin and other salicylates should be avoided. Rehabilitative physiotherapy exercises can commence once the pain and swelling have abated. If a physiotherapist is available, they will carry out the

exercises initially (Battistella, 2001). Once the PWH begins to recover, he is then taught how to perform these exercises. Exercise will help restore muscle and maintain the range of motion in joints, both of which can decrease the frequency and severity of bleeds and avoid permanent damage (Chandy, 2005). In developing countries often a physiotherapist is unavailable, therefore it becomes the responsibility of the haemophilia nurse to initiate the rehabilitation program.

2.13 The South African context

The focus of care in haemophilia in SA generally reflects treatment in Australia and other developed nations but managed with fewer resources. Currently, in SA there are 17 government-funded haemophilia centres (Mahlangu, 2009) and availability of factor is rarely a concern, which demonstrates the commitment to addressing the problem. However, it is the lack of resources and infrastructure in some areas of SA which prevent access to health care and as a consequence increase the risk morbidity and mortality of PWH (Mahlangu, 2009). Furthermore, there is also the issue of access to specific drugs such as FEIBA. Unfortunately, it is the poor black South African who is already disadvantaged and is at an increased risk due to the limited access to healthcare.

As stated earlier, individuals living in rural and remote areas have to overcome substandard infrastructure, such as poor roads, inadequate telecommunication and unreliable power supplies; all of which make it difficult to access health care (Cruickshank, 2009). The photographs (Figures 2.3, 2.4 & 2.5) below show the poor state of roads and inadequate modes of transport in some rural areas.



Figure 2.3 Road in rural area. Source: Researcher's personal photographs.



Figure 2.4 Primitive means of transport. Source: Researcher's personal photographs.



Figure 2.5 A "Settlement". Source: Researcher's personal photographs.

In 2001, to help surmount problems related to remoteness and poor infrastructure, consultation with SA Haemophilia Foundation Medical Advisory Committee members such

as haematologists and provincial government health department coordinators was convened to decide how to transfer haemophilia treatment to the provinces. As a result of discussions, the following guidelines were recommended:

- All PWH would attend the haemophilia treatment centres for assessment and treatment plan;
- PWH would then be referred back to their local health care facility after collaboration with the provincial health care person in charge;
- This action would allow the PWH to be treated close to where they lived, in essence, reducing the risk of non-treatment.

As a consequence of this recommendation, the SA National Department of Health (SANDoH) approved a training program which would involve the education of Registered Nurses (RNs) to recognise, diagnose, manage, and care for people with haemophilia (Cruickshank, 2009). The implementation of this training program was a progressive initiative to address the inequality of care for PWH in rural and regional areas. By educating nurses in a post graduate program, the SANDoH believed that these nurses had the ability and enthusiasm to engage in education and apply this new knowledge to clinical practice. This became the catalyst to develop a dedicated teaching program – the Haemophilia Nurses’ Education Program (HNEP).

Anecdotally, doctors and nurses in HTC’s in SA report that since the implementation of the HNEP, outcomes for PWH have improved. Fewer catastrophic bleeding events have occurred, including fatalities, and those which had resulted in serious disability as a result of a bleed, such as brain injury, have been averted. Thus, it is necessary to formally establish whether the HNEP has contributed to this improvement.

2.14 Conclusion

This chapter explained the inherited, incurable bleeding disorder known as haemophilia. The symptoms, diagnosis, inheritance patterns and treatment options have been explored. It has attempted to show the important facts about haemophilia, the history of the diagnosis and treatment of haemophilia, and the management of a PWH in a country with adequate resources to provide best available treatment. The difference between haemophilia treatment in developed countries and developing countries and the consequences of inadequate and delayed treatment have been outlined. The country in which the PWH resides is the determinant of how heavily haemophilia impacts on the wellness, fitness and life expectancy of the individual PWH.

SA has been categorised as a middle-income developing country by the UN and has treatment for all PWH but has difficulty delivering that treatment. These impediments are due to inadequate infrastructure such as transport, telecommunications, poor quality roads and unhealthy water supplies in some areas. Social problems such as unemployment, illiteracy, poverty and high crime rates impact on PWH especially in rural and regional areas, preventing them from receiving the treatment they require. These factors are compounded by healthcare staff in these areas not understanding haemophilia management and therefore the PWH suffering greater morbidity, or in several cases death. After lobbying by stakeholders in haemophilia, the government approved the implementation of an education program for RNs in an attempt to overcome the problem of poor management of PWH.

The next chapter discusses the review of the literature regarding cultural care, adult learning, curriculum development and evaluation in order to describe the development and implementation of the HNEP.

Chapter 3

The HNEP for Registered Nurses in South Africa

3.1 Introduction

Presented in this chapter are the reasons why the HNEP was created, and the people involved in the development and teaching of the program in SA. The chapter also discusses nurse education in SA and the state of health services in SA. The discussion provides insight into the context in which nurses practice. A significant role of the nurse is to provide evidence based care and education to patients and their families. This education can take place in the clinical setting or the community. Additionally, current developments in healthcare are such that patients are expected to assume a higher level of self-care, with the onus of teaching this type of care falling predominantly to nurses. As nurses are the front line healthcare providers and have most contact with patients, they are most easily accessed for information and most trusted by patients (New South Wales Nursing and Midwives Association, 2005). In many countries, nurse education is governed by Nurses' Boards and strict guidelines are in place to ensure all nurses maintain a high standard of care. The South African Council of Nurses' (SANC) performs a similar role.

In 1994, democratic elections were held in SA. The African National Congress (ANC) formed a government and the apartheid system of government was dismantled. One of the reforms the new government implemented was a focus on health, which required all healthcare professionals, including nurses, to concentrate on community health.

3.2 Health resource challenges in South Africa

No discussion about haemophilia care would be complete without information on the overall state of the health system in SA and the challenges which impact on the service. Coovadia, Jewkes, Barron, and McIntyre (2009) described the challenges to the SA health system as being related to historical events and policies, particularly racial and gender discrimination. When apartheid came into being in 1948, policies were based on racial divisions of all South Africans into whites, coloureds and blacks. This classification governed where an individual could live, work and attend school, whom they could marry, whether they could vote and what resources were assigned to their education, health and pensions (Coovadia et al., 2009). Discrimination impacted most heavily upon black South Africans and underpinned the present-day problems of subservience of women, poverty, unemployment, criminal activity, violence and inequality of essential services such as health and education.

The 1994 change in government in SA not only saw the end of apartheid but ushered in a health care system which concentrated on community health. It was anticipated that this change meant that those who lived in poverty, particularly in regional and rural areas, would have access to health care (Ehlers, 2002). Below is a synopsis of Coovadia's et al. (2009) presentation of the current SA health system structure:

- The National Department of Health is responsible for national health policy.
- Nine provincial departments of health are responsible for developing provincial policy within the framework of the national policy and public health service delivery.
- Three tiers of hospital exist: Tertiary, regional and district.
- The primary health care system – mainly a nurse-driven service in clinics – includes the district hospital and community health centres.
- The local government is responsible for preventative services and promoting health.
- The private health system consists of general practitioners and private hospitals, with care in private hospitals mostly funded through medical (insurance) schemes. In 2008, 7% of private hospitals were located in three of the country's nine

provinces, with 38% located in the Gauteng (Johannesburg and Pretoria) province alone.

South Africa is currently regarded by the United Nations Development Program (UNDP) to be a developing country with a middle income economy. In the 2012-2013 survey, the UNDP rated SA at 118 in the world for their estimated standard of living which is assessed on health, education and living standards (Human Development Report, 2014). It is therefore reasonably well-placed economically to provide health services to its population. However, some twenty years since the abolition of apartheid, a democratically elected government still struggles to meet the requirements of the poor in SA society. Racial differences continue to be reflected in living and health conditions. For example, prevalence of HIV is 13.3% in blacks and 1.9% in Indians but only 0.6% in whites. Infant mortality is six times higher in blacks than whites and white women live 50% longer than black women (McIntyre, Thiede, Nkosi, Mutyambizi, Castillo-riquelme, Gilson & Goudge, 2007).

The publication of a series of papers on the state of health in SA in the *Lancet* by Coovardia et al. (2009) was followed by a paper written by Mayosi, Lawn, van Niekerk, Bradshaw, Abdool Karim and Coovardia (2012), also in the *Lancet*. In 2014, Mayosi and Benatar published a paper describing the state of health and healthcare in SA twenty years after the “peaceful transition from apartheid to a constitutional democracy” (p. 1344) under the leadership of Nelson Mandela. The above researchers concluded that although there has been considerable progress made to improve health care services in SA, many difficulties still needed to be overcome. A synopsis of the findings of three sources cited above, with regard to the challenges still faced, has been compiled by the researcher:

Major/Overarching challenges

1. So-called “colliding epidemics” - HIV/AIDS, TB, non-communicable diseases (NCDs) and mental health, violence and injuries, maternal and child health. Disease burden includes premature deaths from violence, excess alcohol abuse.
2. Large disparity between the races
3. Wealth inequality = health inequality.
4. 45% of population exist at the upper limit of poverty
5. Poverty diseases – HIV/AIDS and TB
6. Private health system versus public system. Private expenditure per capita 10 times greater than public expenditure. Public system services 84% of population served by 30% of medical staff.
7. Public health system in crisis

Human resource challenges

1. Ratio of doctors 1:1000 of population,
2. Emigration to developed countries of locally trained health care personnel
3. Shortage of doctors in rural areas, health systems run by nurses
4. The burden of HIV/AIDS requires three times the health care staffing levels available at present.

Improving access to healthcare challenges

1. Introduction of national health insurance will give universal health coverage: it is hoped this will help overcome the long waiting times and interruption to treatment due to unavailability of medicines.
2. Greater support is needed for primary health services based in regional and rural areas.
3. Better surveillance required to monitor health outcomes.

Economic and political challenges

Impact of unemployment, corruption and the global economic crisis of 2008.

3.3 The Role of education in nursing

At this juncture, it is useful to provide an account of education within the nursing profession. The word education is derived from the Latin word *educare*: to bring up, rear, educate (retrieved from <http://www.etymonline.com>). John Dewey (1916) in his seminal work “*Democracy and Education*”, described education as aims and habits that live on in a

group from one generation to the next and as a means of a society to pass on knowledge, skills, customs and values to the next generation. A broader concept of “education” can be thought of as instructing students by imparting a skill or knowledge; a program of instruction; and the theory of teaching and learning. Historically, education has been the responsibility of nurses not only to teach fellow nurses but also the patient, family and community (Bastable, 2008). Nurse education has witnessed significant change over the past few decades, moving from a hospital-based medical model of care to a tertiary based patient and family-centred care. Evidenced-based practice is the current emphasis; that is, care based on research and science.

The education process is a systematic, logical “planned course of action consisting of two major interdependent operations, teaching and learning” (Bastable, 2008, p. 11). The process engages two mutually dependent players – the teacher and the learner. According to Reilly and Oermann (1992), “learning is a process by which behaviour is changed as a result of the experience” (p. 27). Barry and King (1998) describe learning as a change in behaviour (knowledge, skills or attitudes or a combination of these) in response to external motivation, such as teaching.

Bastable (2008), a nurse educator, contributes further to the explanation by stating that learning is important in the nursing context because it enables individuals to deal with changing circumstances in their lives. These changes may be in the form of a patient who needs to learn new skills to deal with an illness, a student nurse learning the education required to become a nurse, or nurses who need to identify and review more effective treatment for patients. Furthermore, the teaching process has some close parallels with the nursing process, with each step of the nursing process corresponding with the teaching process, albeit with different goals and objectives (Reilly & Oermann, 1992).

An important function of haemophilia nurses is to teach their community and hospital based peers, doctors and allied health professionals about genetics, diagnosis, treatment and complications. Peer teaching is a recognised method of educating colleagues about a subject that requires specialist training. Priharjo and Hoy (2011), nurse educators at the Anglia Ruskin University in England, discussed the importance of patient education to student nurses by involving the use of peer teaching. After choosing a topic to teach to their peers, each student nurse developed and delivered a lecture which aligned to a topic that is commonly taught to patients, for example hand washing. Such a strategy allowed the students to engage in the experience from an active learning perspective. Formative evaluations from the HNEP demonstrated the importance of peer teaching in nurse education in allowing the students to experience the role of peer teaching in preparation for their role as educators of patients and colleagues upon graduation.

3.3.1 Nurse education and practice in South Africa.

Historically, nursing education and healthcare systems in SA were based on the British health system. Education was hospital-centred with the emphasis on the curative model of care (Ehlers, 2002). The Republic of South Africa (RSA) gained independence from Britain in 1960, but this change heralded the implementation of apartheid. The apartheid system of government required by law, separated services, including health care delivery, for the four main racial groups – Whites, Blacks, Indians and Coloureds. Nurses were educated in hospitals which catered for their specific racial groups: therefore four education systems for nurses existed. However, no matter which hospital they trained in, all nurses sat the same SA Nursing Council (SANC) examinations and all nurses were registered by the SANC (Ehlers, 2002). In 1985, nursing education in SA became affiliated with universities.

Prior to moving to tertiary-based courses, nursing education in SA had operated under the auspice of the health system. Currently, students obtain SANC registration based on receiving university results in the categories of general nursing, midwifery, community health nursing and psychiatric nursing at the completion of four years instruction. Students who obtain their nursing education at universities are awarded a degree upon completion and students who attend nursing colleges, obtain a diploma. All students who successfully complete a degree or diploma are registered to practice with the SANC as RNs (Ehlers, 2002). In SA any program completed after becoming an RN is classed as a post-basic program and enables a nurse to specialise in a specific field of practice. Management of PWH is not addressed by institutions providing nursing education in South Africa. It is for this reason that the HNEP is not part of a nursing curriculum but a stand-alone course.

Diseases and disorders that are recognized and treated in developed countries are often overlooked in under-resourced nations (Chandy, 2005), such as those that exist within the African continent. The major health issues which capture media focus are HIV/AIDS, tuberculosis, malaria, and malnutrition exacerbated by the level of poverty endemic to the area (Mahlangu, 2009). It is in this environment that nursing education is undertaken in SA. Consequently, nurses are not adequately prepared to practice in sub-specialities such as haemophilia. There are many published articles about the working conditions and educational opportunities for nurses in SA providing insight into the nursing environment. Findings from several of these studies are noted in what follows.

Uys, Gwele, McInerney, van Rhyn, and Tanga, (2004) conducted a study on whether process-based curricula are appropriate in nursing programs in SA. In describing the context of the study, the researchers commented that a high percentage of SA nurses are admitted to graduate programs from disadvantaged educational backgrounds. Furthermore,

upon graduation, these nurses received minimal support and supervision and are expected to perform in roles far beyond those required of newly graduated nurses in well-resourced countries such as the USA or Australia. Armstrong and Rispel (2015) supported these findings with regard to the selection of suitable individuals to train as nurses indicating that there was a need for further improvement in nurse education and mentoring and that some schools of nursing required updates.

Magobe, Beukes and Muller (2010) undertook a study on nursing students' clinical competency levels in primary healthcare. They sampled student nurses (n = 34) and clinical instructors (n = 6) on why the students' clinical competencies were perceived as poor. In this study, student nurses were assigned to experienced nurses working in the primary health care clinics (PHCs) who acted as preceptors (mentors) for the students. The evidence from the study showed that there were challenges to the delivery of quality nursing care and therefore poor clinical experiences for the nursing students. The reasons for this were found to be lack of human and clinical resources which was related to overwork and decreased opportunities for continuing education. Low morale and staff burnout were also shown to be the result of a lack of human, material and clinical resources.

As indicated, HIV/AIDS in SA attracts attention from authorities in health both globally through the World Health Organisation (WHO) and nationally (SANDoH). A report relating to the United Nations Acquired Immunodeficiency Syndrome (UNAIDS, 2016) indicated that estimated around 19% of the South African population was infected with HIV/AIDS, the highest number of infected people in the world. This high prevalence adds a further burden on the health system resources of SA.

A study reported by Smit (2004), a sociologist at the Rand Afrikaans University in Johannesburg, SA, discussed the perceptions and experiences of nurses caring for people

with HIV/AIDS (n =35) while working in a public hospital in SA. While the HNEP offered to nurses in SA is not directly impacted by the high HIV/AIDS infection rate in SA, Smit's study provides some insight into the attitudes and working conditions of nurses employed in the health system in SA. In 2003 it was estimated that three out of four patients admitted to hospital were HIV positive and the nurses were aware that they could be treating a person with HIV/AIDS, whether the patient's HIV status was or was not known. Most of the nurses surveyed articulated a sense of powerlessness when caring for people with HIV/AIDS because there was no cure and the patients were considered to be terminally ill. All nurses felt physical and mental fatigue, as caring for patients dying of HIV/AIDS was emotionally taxing in the extreme.

Smit (2004) reported that fear of being infected with the disease was not expressed by the nurses as they had been given specific education about AIDS and all knew about universal precautions to protect themselves from transmission by accidental exposure to infected body fluids. However, the nurses did have concerns about poor quality or unavailability of gloves, aprons and masks which they felt increased their risk of being accidentally exposed to infection. This was probably justified as, according to the report, half of the nurses had received needle-stick injuries or been exposed to eye splashes from infected body fluids. Although the nurses did not feel fear about their own well-being, most reported that their loved ones frequently expressed fear of their exposure to HIV/AIDS due to the occupational setting. Many nurses expressed anger and frustration about patients who treated them disrespectfully, the government whom they felt was not doing enough to prevent and treat HIV/AIDS and some members of society who treated them with derision (Smit, 2004). Nurses also expressed concern about the deteriorating health care infrastructure, understaffing and lack of equipment. An increased number of patients, which resulted in overcrowding of wards, and expectations that they would perform non-nursing

duties such as cleaning in the absence of auxiliary staff, added to the perceptions of the nurses that the HIV/AIDS patient had increased their workload. In addition, most nurses felt unsupported by nurse managers and hospital administrators (Smit, 2004).

In such an HIV/AIDS demanding environment, it is understandable that other needs, such as those of PWH, can easily fall between the cracks. It therefore behoves nurses working in the area of haemophilia care to find means other than the traditional pathways for furthering their education and expertise in this important area. The HNEP was created to meet this need.

3.3.2 Development of the HNEP.

The four haemophilia nurses who first met at the WFH conference were determined to create and develop an education program for nurses to facilitate care of the PWH. This initiative was in part responsible for the WFH recording in 2004 its desire to have education for healthcare staff, patients and their families available as a means of providing basic care and treatment. Chandy (2005) later concurred, stating that education is the “cornerstone of haemophilia care when resources are scarce” (p. 1).

In 2002, the first HNEP in SA was offered, one that was approved by the South African National Department of Health (SANDoH) and endorsed by the WFH. As haemophilia is rare, scant information was available in relation to the recognition, diagnosis and management of haemophilia in medical and nursing texts. Since that meeting in 2002 and subsequent development of the program, numerous papers have been published in nursing and medical journals about haemophilia nurse management, including those by Khair (2010; 2013), Greig (2014), and Peyvandi, Garagiola, and Young (2016).

The four-and-one-half-day HNEP is held at a designated venue offering conference facilities and accommodation for all attending participants and lecturers. The program is designed to prepare these RNs to be better informed about haemophilia management in both theory and practice. Over the fifteen years the program has operated, to the end of 2016, a total 861 participants has attended the course (communication Cruickshank, January 2017).

The working environment for RNs in the public sector in SA is not optimal. Uys, Gwele, McInerney, van Rhyn and Tanga (2004), all senior nursing lecturers, wrote that a high percentage of SA nurses are admitted to graduate programs with minimal education. Upon graduation, these nurses are expected to perform in roles far beyond those required of newly graduated nurses in well-resourced countries such as the USA or Australia. South African graduates receive minimal support and supervision and as such are less prepared for critical situations. Given this context, it is crucial that these nurses are allowed study leave to attend courses. However, release from the workplace is difficult because of the cost of replacement. Further expense such as the cost of travel, accommodation and the financial burden to the individual nurse are incurred. It is important that the employers encourage the nurses to attend education programs which are funded by hospital staff development finances so that the financial resources are utilised to their greatest extent.

3.3.3 Creation of the HNEP.

The Haemophilia Nurses' Education Program (HNEP) was created specifically to teach the management and care of a PWH in the SA context. Although incurable, with effective care and education, the burden of haemophilia can be reduced and the PWH is able lead a healthy life. It is therefore vital that nurses are educated about the recognition and management of haemophilia. It is emphasised that the role of the nurse in haemophilia care is essential to provide efficient and effective management to the patient and education to the

patient, his family and other healthcare members. However, a comprehensive review of the literature revealed scant information about programs developed to educate nurses on haemophilia management, especially in developing countries. This lack of information in 2002 was the catalyst for creating such a program.

3.4 Cultural factors impacting HNEP education

Culture can be described as the context in which we live and the way we are socialised. Cultural values are shared abstract ideals about how society should behave. Values provide guiding principles of life and encompass beliefs, practices, specific norms and personal values (Sagiv & Schwartz, 2007). Thus, culture is an important consideration when planning a teaching program, especially in regard to the HNEP, which is taught to SA nurses.

According to Brancato (2006), the culture of education in Africa has been influenced by colonialism, characterised by linear learning, hierarchical structures and authoritarianism. Such an approach does not always bode well for the African population with its specific cultural-based approaches to learning, such as family expectations that community duties take precedence over studies and lack of support due to no understanding of the commitment required for tertiary studies (Lephalala & Makoe, 2012). Significant factors include ethnicity, birthplace, gender, age, educational background and language. Literacy and comprehension can also be impacted by factors such as English as a second or third language, limited education achievement and poor resources such as lack of access to libraries, electronic learning devices and electricity (Lephalala & Makoe, 2012). The participants of the HNEP were predominately Black African women, some of whom were of an age to have experienced the apartheid era. During this time, Black people were persecuted, segregated and discriminated against on racial grounds (Mabokela & Mawila,

2004). Access to education, healthcare, housing and economic prospects were based on race and gender, with the Black population bearing the brunt of this discrimination. Poverty, unemployment, poor education standards and under-resourced health services were the result. An example of this discrimination is that in the apartheid era, the languages of instruction were English and Afrikaans (Meier & Hartell, 2009). Since 1994 and the introduction of democracy, schools were desegregated and language rights guaranteed, allowing Black languages to be implemented into schools by the Republic of South Africa Constitution (Act 108 of 1996). However, as there was a dearth of educators fluent in these languages to be able to teach them, the multilingual ideal was not well established and most schools continued to use the language they had historically used. This resulted in linguistically disparate learners, who spoke diverse home languages and therefore had different levels of competence in the language used at school (Meier & Hartell, 2009).

Language competencies of the HNEP participants were apparent during lectures. The HNEP was presented in English and there were occasions when it became evident that some learners had not understood a concept being presented. This was particularly noticeable when lectures about abstract concepts such as genetics were given. To overcome this obstacle, the lecturers provided one-one-one tutoring after the day's teaching had been completed to assist those nurses who were struggling to understand. Whilst this was a time-consuming activity, it was successful as it allowed the nurses to gain a working knowledge of the topic.

Culture and class status are related. Simon and Mosavel (2008), who worked in community-based health promotion in SA, found that differences among people and their communities are more strongly related to socioeconomic factors which they called "class competence" in contrast to "cultural competence". Whilst Simon and Mosavel (2008) made

comparisons about the youth in “settlements” [highly impoverished areas] who perceived that having material goods enhanced prestige and therefore was the driving force behind improving their socioeconomic status, the ability to obtain access to healthcare was a more urgent need driving adults living in these settlements.

Cultural considerations also influence the broader society. Pre-and-post apartheid, women in SA especially Black women were and are subjected to a dominant patriarchal society. They were considered to be second-rate and incompetent, with men using this entitlement mentality to fill management positions over women (Mabokela & Mawila, 2004). Despite the implementation of legislation by the post-apartheid government regarding gender rights, women in SA continue to be victims of domestic and sexual violence (Dunaiski, 2013, Jewkes & Morrell, 2010). Dunaiski (2013) suggested that violence is an expression of power otherwise denied in the context of material deprivation. Such a description seems to fit the SA context with regard to the status of women more generally.

Jewkes and Morrell (2010) found similar characteristics when researching women who were at an increased risk of HIV. They suggested that culturally, characteristics such as toughness, strength and sexual prowess in a Black African man is attractive to some Black African females. The cultural ideal of femininity in these women is in turn embodied by the woman’s compliance, acceptance of violent behaviour and infidelity. Consequently, women who are submissive to these cultural ideals are at increased risk of HIV and even possible homicide. Such findings are supported by De Matos Ala (2012), a lecturer in gender theory at a SA university, who affirms the existence of a patriarchal society in SA embedded in cultural and religious pressures with entrenched female and male roles.

While it is difficult to judge a situation from contact with learners while conducting a short-term training program such as the HNEP, the researcher can report that she was not aware of any participants who had experienced domestic violence or been the victim of sexual attack. However, there is no doubt that because of the high rate of occurrences of these crimes in SA, some of the participants in the HNEP had experienced these attacks. Certainly some of the mothers of PWH had related to participants during the case history interviews, episodes of violent assaults because they were mothers of children with a disability.

3.5 An overview of the content of the first HNEP

The first HNEP commenced in late July 2002 at the Randburg Towers Hotel, Johannesburg. The program consisted of six and one half days of teaching. Didactic teaching methods supported by Power Point presentations were conducted over the first three days. These sessions gave the participants a solid theoretical grounding in haemophilia and other bleeding disorders such as von Willebrand's Disease (VWD). Haemophilia and similar inherited bleeding disorders are not commonly taught in schools of nursing so most nurses would not recognise symptoms. Therefore, it was considered important that the clinical presentation, inheritance patterns and treatment were presented to the HNEP participants prior to the introduction of more complex issues. To accommodate participants with different learning styles, lectures were interspersed with videos, case histories and small group work.

The content of the HNEP included information in relation to clinical aspects of haemophilia such as physiology of haemophilia, history taking, physical examination, assessment of a bleed, treatment protocols, genetics, genetic counselling, constructing a genogram, laboratory testing, product safety, management of specific events such as

surgery, complications such as inhibitors and blood-borne viruses, women and bleeding disorders, and other bleeding disorders such as VWD. Information is also provided about the available societies which support PWH such as the Haemophilia Foundation of South Africa (HFSA) and the World Federation of Hemophilia. Instruction is given on how to run a haemophilia clinic and how to lobby for haemophilia care. Guest speakers were invited to facilitate sessions including a haemophilia physiotherapist who demonstrated rehabilitation of joints following a haemophilic bleed, and an occupational therapist who demonstrated how to make a backslab of plaster-of-paris to immobilise the limb of a PWH who was experiencing an active bleeding episode. The curriculum as presented and the Power Point slides used in the lectures can be found on a thumb drive (Appendix A).

Both theory and practical instruction is provided in a lecture format. All lectures are contained within a file known as the Haemophilia Resource File, which is given to the participants at the beginning of the program. The RNs are expected to take the file with them to their workplace as a resource for their colleagues.

To assess competency of management of PWH during the program, the participants are expected to interview and assess a PWH, promoting problem solving and analysis. The assessment data is then presented in a case study format to the group and at the same time the lecturers are assessing how well the participant is applying the new learning. According to Sprang (2010), a case study approach consolidates learning, is similar to clinical practice and has been shown to facilitate critical thinking and decision-making. Sandstrom (2006) concurs, describing the use of case studies when educating student nurses about diabetes mellitus. Critical thinking is developed by collaboration with the patient and focussing on their needs. This collaboration fosters an understanding of the disease, the effect of the disease on the patient and how the patient reacts to the disease. The case study approach to

learning is an active learning process engaging the student in the topic so they can determine the relevance of theory to practice. Thus critical thinking skills such as analysing and reasoning are developed, thereby increasing motivation to continue learning (Sandstrom, 2006). On conclusion of the HNEP, a summative examination assesses theoretical knowledge.

On return to the workplace, assessment of skills competency and ongoing support is provided by the haemophilia nurse coordinators, who are expert haemophilia nurses. The role of the specialist haemophilia nurses in SA is described by Mahlangu (2009) as having the “greatest impact on haemophilia health care delivery compared to all other professionals combined” (p. 139). The RNs are encouraged and mentored by the expert haemophilia nurses to firstly, apply their new knowledge to the care and education of the PWH and his family; and, secondly, to provide in-service training at work sites, which includes demonstrations of factor administration to staff at their workplace. The level of support provided reflects the findings of a study by Gibb, Anderson and Forsyth (2004), which explored the practice of nurses in geographically remote areas in New South Wales, Australia. These authors investigated a program which provided advanced clinical learning in the remote area workplace, followed by support and mentoring. The findings revealed that the level of competency attained by mentees had improved and that they had a greater interest in acquiring learning in the workplace. The high level of mentoring was considered by the researchers to be closely related to the increased level of competency and interest demonstrated by the nurses. Similarly, findings from a study by Stein, Lewin, Fairall, Mayers, English, Bheekie, Bateman and Zwarenstein (2008) showed that SA nurses who had undertaken a course in the care of people with lung disease, benefitted from regular contact with their educators. They provided psychological support to the trainees, especially when caring for patients with AIDS-related problems, acknowledged as a stressful work

environment. This is pertinent to SA since the AIDS epidemic has increased significantly (Mayosi, & Benatar, 2014). PWH are at risk of contracting the disease because plasma-derived product is used in SA for the treatment of haemophilia.

On completion of the didactic component of the course and the presentation of findings resulting from the patient interviews, the participants were asked to complete a short closed-book examination (Appendix B). The aim of this examination was to determine the understanding of new knowledge. The first twelve questions which addressed the inheritance of the disease were multiple-choice. Participants were expected to draw a genogram (diagram of a family pedigree) using a fictitious family and include a diagram of inheritance patterns of haemophilia, diagnosis, symptoms and treatment of haemophilia. The next ten questions related to complications of haemophilia, manifestations of bleeding disorders in women, VWD, management of surgical interventions and other bleeding sites such as gastro-intestinal bleeds, and laboratory testing. The examination papers were marked by the lecturers and a percentage allocated: the pass mark required was 80 percent.

On the final day of the program, the participants were transported to the HTC at a local hospital to meet PWH where the nurses were divided into small groups and introduced to PWH who had agreed to be interviewed. On completion of the interviews, the participants presented their findings. Once the group presentations were concluded, the participants returned to the conference venue to complete an evaluation of the HNEP (Appendix C). Finally, the participants were awarded a WFH certificate to honour their achievement.

3.6 The researcher's involvement in the development of the HNEP.

The researcher, a haemophilia nurse in Australia, was invited by the SA haemophilia nurses in 2002 to join the initial planning committee of the HNEP after meeting the SA nurses at a WFH conference. At that time, there were three nurses, Coordinator A, Coordinator L, and Coordinator M (who was the predecessor to Coordinator B, who is identified later as a participant in the research). The SA coordinators recognised that the researcher had sufficient expertise of haemophilia care and understood the challenges of living in a developing country, to be involved in planning and facilitating the project.

Since the inception of the HNEP, the existence of several haemophilia nurse education programs have been reported. The European Association for Haemophilia and Allied Disorders (Harrington, Bedford, Andritschke, Barrie, Elfvinge, Ronhaug & Schrijvers, 2016) nurses' working group established the knowledge and skills needed for a nurse to work with PWH by accessing six existing haemophilia training programs for nurses. Although there is no reference to five of these programs, it is to be assumed that these six training programs were from other European countries with only one being named, that being, the "Essentials of Haemophilia", which is offered in the UK at a cost of well beyond the means of nurses in developing countries. This program is similar in content to the HNEP, but was not available to HNEP cohorts for the period covered by the present research. The previously mentioned "Essentials of haemophilia care" offered by the Canterbury Christchurch University is one of two face-to-face programs offered in the UK, in addition to "Advanced haemophilia nursing" which is conducted by the Sheffield Hallamshire University. In the US a course entitled "The role of the nurse in haemophilia care" is offered as an on-line course by the American Nurses Association. As previously pointed out, these programs are out of reach of nurses from resource-poor nations due to

lack of funds, and limited access to computers. Furthermore, there is no evidence in the literature about the effectiveness of these programs. There is literature in education and more specifically nurse education about the need for evaluation of teaching programs

Therefore, the researcher could not assess whether a face-to-face education program for nurses would transfer sufficient information to nurses to care for PWH effectively.

3.7 Subsequent HNEP rollouts

As a consequence of the success of the initial program, the HNEP has been offered every year since the first in 2002 and during this time improvements have been made. These changes were made based on evaluation responses from the participants. A significant change was to reduce the course to four-and-one-half days in duration. Other changes were related to lectures, in particular how to interpret blood results to improve understanding and clarity. The format suited subsequent participants and their employers.

Upon returning home to Australia, the researcher set about sourcing information that would provide understanding of coagulation studies, how they were carried out and how the results were interpreted. Specialised laboratory studies, such as tests for coagulation, is not a topic usually taught to nurses in great depth. Advice was sought from the chief coagulation scientist at her workplace who agreed to teach the researcher the relevant information. This enabled the researcher to ensure that new laboratory lectures were written at a level suitable for the participants in SA and were used in subsequent HNEPs.

Another topic that the participants found difficult was genetics and constructing a genogram, a diagrammatic form of a family tree. Although the participants understood the family relationships and the inheritance patterns of haemophilia, the difficulty was in grasping the concept of illustrating the family pedigree. It was essential that the participants

understood how and why it is important to construct a genogram as it is crucial to have a complete record of a PWH to formulate management.

Despite having expert geneticists teaching the topic, it was realised that it would be more effective if nurses presented this lecture. Peer teaching was elected as the best option since it is an approach that ensured the information was pitched at the right level. Once established, this step overcame the difficulties the participants had in understanding how genetics and family pedigrees were applied in the haemophilia context. However, mastering the drawing of the genograms, considered vital by the lecturers, remained elusive and often did not reach an acceptable standard. However, by making the task more personal by asking the participants to complete their own family tree using a genogram, the participants began to understand how a genogram described their pedigree. To reinforce the concept, the participants were given a fictitious family to describe by drawing a genogram for homework which was then assessed the next day by the lecturers. Finally, progress was made and by the last day of the HNEP, the participants were assessed as proficient at drawing a genogram.

3.8 Teaching and learning exigencies

Key factors exist which lead to success in teaching and learning. What follows is a brief discussion of these and how they relate to the development of the HNEP. As different strategies are required when adult education is being undertaken, the issue of andragogy is also considered.

3.8.1 Theories of and strategies in learning.

In devising a curriculum to teach adult learners about a new topic, several aspects must be taken into account to ensure that the learning opportunity is exploited to its fullest

extent. To maximise the benefit of the HNEP, the lecturers needed to familiarise themselves with theories of learning and know something about the learning styles of students.

Braungart and Braungart (2008) described learning as “a dynamic process by which individuals acquire new skills and/or knowledge, which alters their thoughts, feelings, attitudes and actions” (p. 52). Braungart and Braungart summarise five major psychological learning theories that nurses can utilise in education and clinical practice. These theories include Behaviourist Learning Theory, based on what is observable so learning takes place in response to stimuli. This is used in the HNEP by exposing the participants to PWH (observation) and providing the opportunity to respond to their lived experience (stimuli). Cognitive learning theory involves the student making sense of the new information, internalising and processing it to provide new understanding. An example of this process might be the utilisation of strategies to provide a better understanding of the pain associated with the process of bleeding into a joint. Social learning theory takes into account the personal characteristics of the learner, their patterns of behaviour and the context of the learning. An example of this theory in action is the change in behaviour and perceptions that occurs in the RNs when they realise the importance of social motivation and context in treating a PWH.

Psychodynamic learning theory emphasises the conscious and unconscious thoughts which impact behaviour, personality and the long-term effects of childhood experiences. This theory can be utilised in bringing to the surface any latent fears or anxieties the nurses might have when addressing the needs of the PWH. Humanistic learning theory can come into play in addressing any uncaring attitudes and behaviours by nurses towards PWH. Discussing the importance of sensitivity when attending to the specific needs of the PWH can create a valuable learning experience.

Learning strategies have been well explicated by Edgar Dale who presented them in the form of a cone (1954), ranging from textual/verbal symbols (being at the top of the cone and least effective for the purpose of retention), through to direct purposeful experiences (being at the bottom of the cone and the most effective for retention). These were later embellished by researchers such as Lalley and Miller (2007) and applied specifically to a pedagogical context.

Each theory introduced here focuses on one important attribute of learning. Developing an understanding of each theory via the HNEP can enable the teacher to meet the needs of learners in a more effective fashion. Each student learns differently and utilising strategies which emanate from the range of available theories has a better chance of successfully addressing individual learning styles.

3.8.2 Teaching strategies.

The teacher as a facilitator of information and attitudes is indispensable to effective learning. Contextualised teaching is what provides relevance to the learner. As Barry and King (1998) pointed out, “Good teaching is a problem-solving activity that is linked to context – students, school, and community” (p. 15). Teaching is likely to be most successful when it is evidence-based; when it moves from the known to the unknown (Vygotsky, 1930-1934/1978); and when it encompasses the cognitive, psychomotor and affective domains of learning (Borich, 1996; Krathwohl, 2002). Teaching within the cognitive domain refers to activating perceptual and intellectual process such as problem-solving and logical reasoning. Psychomotor learning pertains to physicality and incorporates gross and fine motor skills such as those required in giving a PWH an injection. Teaching in the affective domain focuses on aspects such as caring, attending and empathising. All of these were highlighted as important components in the HNEP.

An essential aspect of course design is selecting teaching strategies suitable for group learning. In this regard, an understanding of the VARK (Visual, Auditory, Read/write, Kinaesthetic) processes is important (Fleming & Mills, 1992; Fleming & Baume, 2006). Some learners may prefer the visual mode, such as pictures, images and interactive technology (Brancato, 2006). Others may be auditory and so acquire information by listening. Still others may prefer accessing materials via reading and writing resources. Finally, there are those who may be better attuned to kinaesthetic pedagogy, so in order to achieve at their potential, need to be engaging in learning by doing which may include interviews and field trips. As well as these four modes of learning, there are learners who operate in any combination of these modes. Accordingly, as far as practicable, teachers would be wise to cater for all VARK modalities. Lectures use direct strategies such as face-to-face communication while indirect strategies such as the use of audio-visual equipment and Power Point slides, will promote learning using multiple sensory faculties (Bastable, 2008). Iwasin, Goldenberg and Andrusyszyn (2005) list a variety of components needing consideration when planning teaching strategies. These complement the VARK modalities and include factors such as group size, cost, available infrastructure, preparation time for instructors, intent (abilities expected from the students) and the environment of the learning context. A VARK approach is essentially an approach that remains cognisant of styles of learning. Learning styles are the unique way an individual processes and responds to new tasks and new learning.

At the beginning of the HNEP, to ensure a basic understanding of haemophilia and management, traditional didactic strategies were employed to ensure the participants had a sound platform on which to base the new learning. As the HNEP progressed, contemporary teaching strategies were introduced to promote more active learning. The RNs participated in cooperative and collaborative projects with peers such as small group work and

interviews of PWH and presentation of case studies, thus providing an active learning opportunity. Clinical teaching strategies are commonly used in nursing. In the case of the HNEP, the RNs observed the examination of a haemophilic joint, preparation and implementation of factor replacement, and rehabilitation of a joint after the bleeding had stopped. It has been reported (Iwasin, Goldenberg & Andrusyszyn, 2005) that although distance educational strategies are a useful pedagogical option, such resources are not available to nurses in SA to learn about haemophilia. Accordingly, this strategy was not utilised for the HNEP.

3.8.3 Adult education and commensurate learning and teaching strategies.

There are two broad paradigms in education: the education of children, known as pedagogy and andragogy, the education of adults. The evaluation of sub-specialty nurses' education programs requires a more in-depth examination of andragogy and the learning and teaching theories used specifically in adult education. Andragogy was first described by Alexander Kapp and identified by Dewey (1938) as experiential in nature. Malcolm Knowles (1975, 1980) further developed the concept and wrote prolifically on the subject. In his book, *The Adult Learner, a neglected species* (1990), Knowles cited humanistic psychologist Carl Rogers (1969) who described adult learning thus:

It makes a difference in the behaviour, attitudes, perhaps even the personality of the learner..... He knows whether it is meeting his need, whether it leads toward what he wants to know, whether it illuminates the dark area of ignorance he is experiencing (p. 5).

According to Braungart and Braungart (2008), no single theory can explain how adults learn but it is well established that they learn through formal and informal education and life experiences. Knowles (1990) suggested that adult learners prefer to be self-

directed, by identifying their learning needs, setting their own goals, choosing how to learn, searching out resources and appraising their progress. Knowles also identified several assumptions upon which the andragogic model of learning is based. These are paraphrased below:

- a) the learner is independent and self-directed;
- b) the learner is strongly influenced by their life experiences, a valuable resource for future learning;
- c) the learner needs to know why they must undertake the learning which includes the benefits and consequences of not undertaking it;
- d) the learner is ready to learn;
- e) the learner's orientation is towards learning and is strongest when the individual believes that the learning will help them to achieve tasks or deal with problems, and;
- f) the learner's motivators are related to intrinsic demands such as job satisfaction, self-esteem and quality of life.

Knowles' theory has been widely used as a guide and framework for teaching nurses, patients and other health professionals (Bastable, 2008). The assumptions articulated above apply to the participants in the HNEP since all the participants are RNs involved in the course are mature learners and bring with them a breadth of clinical practice and experience. Adult learners play an active role in their learning, with prior experience, beliefs and attitudes influencing future learning experiences.

With regard to appropriate strategies for adults, Filene (2005) and Knapper (1995) suggested that in selecting apposite material, the instructor must meet the learner's needs at the same time as meeting the learning outcomes of the instruction program. This can be achieved by deciding on learning objectives in addition to learning outcomes. Primarily, the question must be asked, "is the intention of the program to increase knowledge, learn new skills or change attitudes?" The expectations of the students also need to be taken into account by having clear objectives about what is learned in the classroom and how it is to be

applied in practice. By identifying these objectives, the instructor can decide on activities to encourage the desired learning and then obtain formative feedback from the students to ensure learning is taking place once the instruction is underway. For example, moving from passive to active teaching by encouraging interaction can enhance motivation. Research reveals that the life experience of adult learners can be useful in the classroom setting and harnessed in the service of teaching others (Baskas, 2011).

Motivation as a significant factor in adult learning cannot be overestimated. The teacher needs to consider that motivation is based on motives, that is, a response to personal needs. As Maslow (1943) asserted many years ago, a basic human need is to strive for self-esteem. It has been stated that self-esteem has four components: striving for success; striving for affiliation; striving for influence (power) over others; and striving for recognition (Barry & King, 1998). In an effort to accomplish these undertakings the individual will apply energy, commitment and alter behaviours in order to achieve their objectives. Furthermore, if a student perceives that with effort, they will succeed at a task, completion of that task is valued. Barry and King (1998) explained that research by Eccles and Wigfield (1985) found there are three types of value students place on tasks:

- Attainment value, which encompasses the success and power value for self-esteem and includes the positive effects of mastering a skill or understanding a new concept;
- Intrinsic value which is the pleasure students gain from completing a task;
- Utility value which is the estimation by the learner of usefulness of the learning which can be applied to life.

Motivation can be classified as either intrinsic or extrinsic. Intrinsic motivation can be explained as the satisfaction of the learner's natural inquisitiveness about a task or topic and the learning is for its own sake. Extrinsic motivation is explained as learning in order to receive a reward, such as a prize or award at the end of the completion of the learning task.

It is therefore incumbent upon teachers to structure their teaching so that the students are successful if they apply effort and ensure that the tasks that they are expected to achieve have value (Barry & King, 1998). Brancato (2006) supports this proposition by suggesting that structuring the learning tasks so that early success is likely will encourage learner behaviour. The lecturer's enthusiasm for the topic can also influence the learner. Encouraging a curiosity about the subject and using case histories or similar reality scenarios about patients may also encourage a motivation to learn.

Teaching the HNEP to the participants was undertaken in a way that remained cognisant of adult learning principles; utilised appropriate strategies and attempted to move the learners in the direction of being intrinsically motivated.

3.9 Evaluating educational processes and the HNEP

A crucial aspect of teaching and learning is the evaluation process. Popham (1988) perceived evaluation as “an appraisal of quality” (p. 7) and Fitzpatrick, Sanders and Worthen (2004) suggested that the role of evaluation is to determine the worth of something. The following extract from a UNESCO document sees evaluation as:

the systematic and objective assessment of an activity, project, program, strategy, policy, topic, theme, sector, operational area or institution. An essential part of the policy development process, evaluation provides timely assessments of the relevance, efficiency, effectiveness, impact and sustainability of interventions (Handbook of Evaluation, 2007, p. 5).

Popham (1998) explained that evaluation in education can encompass a number of aspects such as outcomes of instruction, the program/s that produced these outcomes, educational products or the objectives that are incorporated into the educational efforts. In education,

teachers use the word “evaluation” to describe testing student knowledge, although the term evaluation has a much wider application than simply testing knowledge in an educational context.

In terms of the development of the evaluation processes, Tyler (1949) described evaluation as the act of “determining whether educational objectives have been realised” (p. 69). These objectives are aimed at changing behaviour patterns in students and evaluation determines whether and to what extent these changes have taken place. Emphasis is placed on outcomes, not organisational and teaching inputs. Tyler advocated that certain steps in the evaluation process needed to take place: a) determine the objectives; b) define the objectives in behavioural terms; c) find situations where attainment of objectives could be demonstrated; d) select or develop assessment techniques; and e) measure whether the objectives have been met. Tylerian principles were utilised in the evaluation of students participating in the HNEP. The objectives were established; behavioural outcomes were stipulated; opportunities for demonstrating competency were provided; appropriate assessment techniques were generated; and performance against established criteria were assessed.

The objectives were established by identifying the anticipated learning outcomes which appeared in the beginning of the haemophilia resource file. Embedded in these learning outcomes were the behaviour outcomes expected and there were demonstrations and opportunities for practicing these during the course. Assessment techniques such as an examination and assessment of case study presentations were implemented and the performance of these tests were compared to recognised standards in haemophilia care

It is worth mentioning that ideally, the educator would offer the students a means of assessing their learning style prior to the commencement of the course to maximise the

learning experience for the individual, although in most cases, time constraints can prohibit the use of learning style assessments. As the HNEP was limited to four days of instruction, assessing learning styles was not undertaken, however, utilisation of a variety of styles in teaching the material did occur.

Evaluation in nursing takes many forms. Chan, Chien and Tso (2009), nurse educators in Hong Kong evaluated nurses' knowledge, attitude and competency after delivering an education programme on suicide prevention. There were similarities in the work environment in Hong Kong to those in public hospitals in SA regarding haemophilia such as low staffing levels, lack of support from senior colleagues, poor communication with specialists and no protocols for management of suicide prevention. The findings showed a positive impact on the competence and attitude of the nurses and the motivation to re-examine previous practices due to the new knowledge of patient care in suicide prevention.

With regard to evaluating the success of the HNEP, the insights of Michael Scriven were adopted. In 1967, Scriven described two complementary forms of educational evaluation, namely, formative and summative. If the main purpose of the evaluation is to elicit information about program improvement, then formative evaluation is considered the suitable concept. Summative evaluation is concerned with judgements about a program's merit or value (Taras, 2005). HNEP evaluation was undertaken in a summative fashion and conducted immediately upon the completion of each program. It was valuable to ascertain whether the program had equipped the participants with new knowledge about haemophilia management but did not elicit information about whether this new knowledge enabled RNs to affect outcomes for PWH in a positive way. This is something that could only be evaluated once the nurses had returned to the field to apply their newly acquired knowledge and skills: Hence the need to evaluate the HNEP more formally and comprehensively.

3.10 Chapter summary

This chapter outlined the pertinent elements considered when developing the HNEP. Firstly, health resource challenges were considered prior to an explanation of the creation of the HNEP being provided. Next, the important of on-going education in haemophilia nursing was discussed and cultural factors considered. This was followed by an articulation of important teaching and learning principles such as theory, strategy and evaluation protocols. These were considered within the context of adult learning. The next chapter introduces the epistemological, theoretical, conceptual and methodological considerations pertinent to the present study.

Chapter 4

Epistemological, Theoretical, Conceptual and Methodological Considerations

4.1 Introduction

This chapter discusses the epistemological position in which the research is located. Next, theoretical and conceptual frameworks pertinent to the research are considered. Whereas, theoretical frameworks are supported by known theories germane to specific research, conceptual frameworks connect the concepts that could be related but have not been tested (Borbasi, Jackson, & Langford, 2008). The literature reveals that some researchers discuss theoretical and conceptual frameworks as interchangeable, while others treat them differentially (Polit & Beck, 2010). In the present research, the two are considered independently but with the understanding that they are nevertheless connected by the aims of the study.

4.2 Epistemological position

Epistemology is “the study of knowledge and justified belief” related to “creation and dissemination of knowledge in particular areas of inquiry” (Stanford Encyclopaedia of Philosophy, 2005). Crotty (1998) defined epistemology succinctly as “a way of understanding and explaining how we know what we know” (p. 8). The epistemological position adopted in the present study is one of constructionism. In the constructionist view, meaning is not so much discovered as created. As Crotty (1998) pointed out, “meanings are constructed by human beings as they engage with the world they are interpreting” (p. 43). The world is constructed by humans as they interact with it and develop an individual

understanding of what they perceive. Such a perspective finds its genesis in the work of Jean Piaget (1936; 1957) who coined the term “accommodation” for this process of devising personal “schemas” of reality. Constructionism is subjective in nature and is thus congruent with the qualitative approach to research. Accordingly, the researcher endeavours to be closely aligned with the participants so that the data collected is based on individual understandings. It is essential therefore that the study is conducted close to where the participants live and work so that the context of the data can be closely scrutinised.

4.2.1 Phenomenological perspectives.

Phenomenology was originally considered a philosophy until the German philosopher Husserl introduced modern-day phenomenology, which studied the lived experience of people. Such a perspective was seen as an alternative approach to positivism and the world of science. Whitehead (2007) described Husserl’s phenomenology in the following way that humans “were subjects in the world of objects and that phenomenology was the study of the consciousness of those objects” (p. 109). Whitehead (2007) further described Husserl’s contributions: He introduced the methodical analysis of consciousness and objects by advocating the detachment of moods, thoughts, memories and emotions from the the conscious awareness of objects, known as “bracketing”. Husserl aimed to reach an understanding about intuition and judgement to arrive at the truth or the “essence” of things that define the consciousness of humans (Whitehead, 2007). This approach is known as descriptive phenomenology, essentially asking the question “what do we know...?” (Polit & Beck, 2010, p. 268). In the present research, and as Bednall (2006) advised following the interpretive phenomenological analysis imperative, the researcher was aware that she needed to “bracket” or “suspend” her own experience so as not to compromise data objectivity.

Heidegger disagreed with Husserl about the association between objects and consciousness and thus helped to found the alternative branch of phenomenology. Known as interpretive phenomenology, it is based on an ontological approach which seeks the nature and meaning of “what is being....in the world” (Polit & Beck, 2010, p. 268). Heidegger believed it was important to study the human experience in the context in which people exist and the conditions necessary for them being in their worlds, stressing understanding and interpretation of the data rather than merely describing it. Heidegger held the view that people are aware of their own existence and questioned what it means to be them in their world. This is related to the individual’s concept of self and correlates to a wider context of their community and world, namely, people can reflect on their different worlds and make comparisons to those around them (Whitehead, 2007). The Heideggerian approach is a close parallel to the philosophical requirements of the evaluation of the HNEP where the phenomenon to be studied (haemophilia) could be seen as “subspecialty education” for nurses in situ in developing countries. The researcher is interested in the experiences of nurses who participated in the HNEP and who are using the knowledge learned to manage PWH (“what is being”) in their workplace (“in their world”). Heideggerian phenomenology affords a means of research which centres on the individual and the context in which they are placed.

Mackey (2004), a nurse educator, indicates that phenomenology is not only a methodological framework that is frequently used in nursing research but as previously discussed, a philosophy with epistemological and ontological branches. As Cresswell (2013) pointed out, there is a requirement for researchers to discuss the concepts and methodological processes underpinned by the philosophy. Mackey’s discourse addresses this topic in the context of nursing research using Heidegger’s interpretive phenomenology,

which consists of four concepts: Being-in-the-world; Fore-structures; Time; and Space. These are considered in what follows.

Being in-the-world was a term Heidegger used to highlight that the object and subject were indivisible and that humans cannot exist unless they are situated within an embracing world. Heidegger (1996/1962) believed that the most important way of being-in-the-world was an awareness of oneself, by exploring one's own existence which he called "dasein" (p. 143). Mackey (2004) suggested that phenomenological nurse researchers using Heideggerian's approach need to involve both descriptive and interpretive writing.

Descriptive writing is employed to relate the description of the participant's experience of the phenomenon and interpretive writing is used to describe the researcher's interpretation of these experiences, including identifying themes within the data. The researcher in the present research was aware that while gathering data from the HNEP participants, there was a risk of simply describing the data, and that an interpretation of these descriptions needed to be undertaken to identify common experiences and feelings from the RNs.

Fore-structures refers to the interpretation already in existence of the phenomenon and recognises that interpretation requires articulation. Mackey (2004) cites van Manen (1990) who suggested a methodological technique of applying hermeneutical phenomenological writing. By utilising a circular activity of writing and re-writing the researcher can clarify and reflect upon the writing, thus arriving at a more profound understanding of the phenomenon. In this regard, the researcher was aware that there was a tendency to assume that the findings would reflect what was already known about nurse education. However, the context of the HNEP that is, situated in a developing country, and the absence of literature about requirements for a haemophilia nurse education program to use as a benchmark, ensured that there were few preconceptions about the topic.

Time is a basic configuration of human existence and according to Mackey (2004), Heidegger's phenomenology of understanding, through interpretation, cannot be arrived at without taking into account the importance of time. Heidegger referred to the awareness of time by experiencing being in time, which he called temporality. Temporality allows the convergence of past, present and future which become one entity, thus the experience of the past, aligns with the experience of the present and will be experienced in the future. This understanding is important to the nurse researcher as the participant's descriptions of their experience of the phenomenon places them in the world situation including in the context of time. Accordingly, the researcher needed to take into account how the experience of the phenomenon has impacted on the participant in the past, present and in the future. In this study, the researcher explored the past experiences of the participants' experience with PWH, inquired about the present experiences and asked about how they see the future.

Space is the fourth component of Heidegger's hermeneutic phenomenology. By being-in-the-world, the participant is not only established in time but in space, or a setting, because everything has its place in the world (Heidegger, 1962; Mackey, 2004). To Heidegger, the spatial component meant the concerns and cares of an individual in their world, thus illuminating their state of being in the world. By interpreting, analysing and reflecting on the participant's care and concern about the phenomenon, the researcher connects the phenomenological method and philosophy of phenomenology.

Phenomenology facilitates acceptance of human experience as a legitimate source of knowledge and is suitable to nursing research due to its alignment with nursing ideals. In the case of the HNEP, the RNs were experienced nurses who were able to apply their skills of compassion for the patient to understanding and empathy for the PWH once they understood the problems haemophilia caused. Heidegger's phenomenology helps to reveal the multifaceted aspects of the human experience in context. By conducting the research for

Part One in SA, the researcher explored the experiences of the participants in the setting of their own country.

More recently, and in line with previous understandings, Crotty (1998) advanced the following definition of phenomenology.

Phenomenology suggests that if we lay aside , as best can, the prevailing understandings ofphenomena and revisit our immediate experience of them, possibilities for new meaning emerge for us or we witness at least an authentication and enhancement of former meaning (p.78).

As Crotty emphasises above, insights gained from study of the topic are used to interpret the experience and inform future action. In the present study, the researcher is interested in the values and beliefs that the nurses who participated in the HNEP have about the health of PWH, and whether they believe that they contribute to positive health outcomes.

Phenomenology is one of the most common research approaches used by nurses and recognizes the influence of the phenomenon rather than making assumptions about the phenomena as in quantitative research. Phenomenology is congruent with nursing research because it allows questions that are important to nurses and reflects values and beliefs that are compatible with the nursing profession (Whitehead, 2007). It facilitates an understanding of an individual's experience in a holistic manner and helps to understand phenomena that do not align well with quantifying, controlling or comparison (Whitehead, 2007). Phenomenology, has been chosen as best hermeneutical approach suited to Part One of the study as it most accurately reflects the views of the RNs and their opinions about the effectiveness of the HNEP in their workplace.

4.2.2 Interpretivism and pragmatism.

The interpretive model has its basis in the human sciences such as history, philosophy and anthropology. Holloway and Wheeler (2013) describe interpretivism as being linked to Weber's "Verstehen" concept which means understanding something in its context, that is, embracing reflective construction and interpretation of the behaviours of those under study. Crotty (1998) stated that interpretivism was developed in contrast to positivism (quantitative research) to help understand "human and social reality" (p. 66). Interpretivism looks for "culturally-derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 66).

The philosophical position of pragmatism was adopted for research into Part Two of the present study. Creswell and Plano Clark (2011) considered that pragmatism stresses the importance of the research questions, the value of experiences and outcomes, and the appreciation of phenomena. Pragmatism seeks inspiration from many sources, appreciating both objective and subjective viewpoints and adopting "what works" (Creswell & Plano Clark, 2011, p. 43). This approach can be implemented by using mixed methods research. Creswell and Plano Clark agree with Teddlie and Tashakkori (2011) that a pragmatic approach aligns well with a mixed methods research. The present research effects a pragmatic emphasis within a mixed method approach. Contextually, the researcher was familiar to the nurses interviewed because she had acted as an instructor when the RNs participated in the HNEP and as a nurse herself, held similar values to the participants.

Qualitative research in nursing is premised on the values of compassion; respect for the dignity of the individual and humankind; truth and integrity; a preference for dealing with words rather than numbers; a belief in effective communication; a strong belief that nursing is a honourable profession; a robust conviction that caring for the carer takes the

profession of nursing to a higher dimension; and a belief that education is a respectful and effective way to help others as well as oneself. Such convictions align well with those of the researcher who also has an interest in the culture of other races and ethnic groups and identifying how similarities and differences are expressed and influenced by context. The researcher lived in Papua New Guinea for almost a decade and has visited countries in South-East Asia, Sub-Saharan Africa, Western Europe and North America, thus experiencing a variety of cultures and ways of living. Fifteen visits to SA over as many years to contribute to, and participate in the HNEP, gave the researcher insights into the country of SA, particularly its challenges, cultures and diversity.

4.3 Theoretical framework

Four theoretical viewpoints were selected to guide the study. Two theories are nursing theories based on the concept of “caring”: Leininger’s Culture Care Theory and Watson’s Theory of Caring. Knowles’ Adult Education Theory is the third theory adopted and the fourth theory is an evaluation theory borrowed from business and commerce known as Kirkpatrick’s Four Levels of Evaluation. These four theories were harnessed to assist with the intricacy of describing and explaining nursing education in a society of eleven languages and of various cultures. These are now discussed in detail.

4.3.1 Leininger’s Cultural Care Theory.

As far as the researcher could ascertain, Leininger’s Theory of Culture Care is the only nursing theory based in culture. Leininger recognised that recurring behavioural patterns in children were based in culture and saw a lack of cultural knowledge as the missing link which prevented holistic care to patients to enable compliance, healing and well-being. Leininger (1997) asserted that culture means “the lifeways of an individual or

group with references to values, beliefs, norms, patterns and practices” (p. 95) and further maintained that culture is learnt by group members and transmitted to other group members or transferred from generation to generation. She held the view that traditional characterisations of culture usually include shared values, beliefs, ethno-history, language and behaviours which in turn govern values and actions of its members in a considered manner. Law and John (2012) agreed, but argued that transcultural nursing theory can be applied to cultures beyond the narrow view of ethnicity.

Leininger, a RN who also held a PhD in cultural and social anthropology, identified several areas of commonality between nursing and anthropology. From this identification, Leininger developed concepts, a theory and practices suitable in transcultural nursing (1994). A follow-up book (1995) paved the way for transcultural nursing in practice. Figure 4.1 presents Leininger’s Cultural Care (Sunrise) model, which evolved from her research.

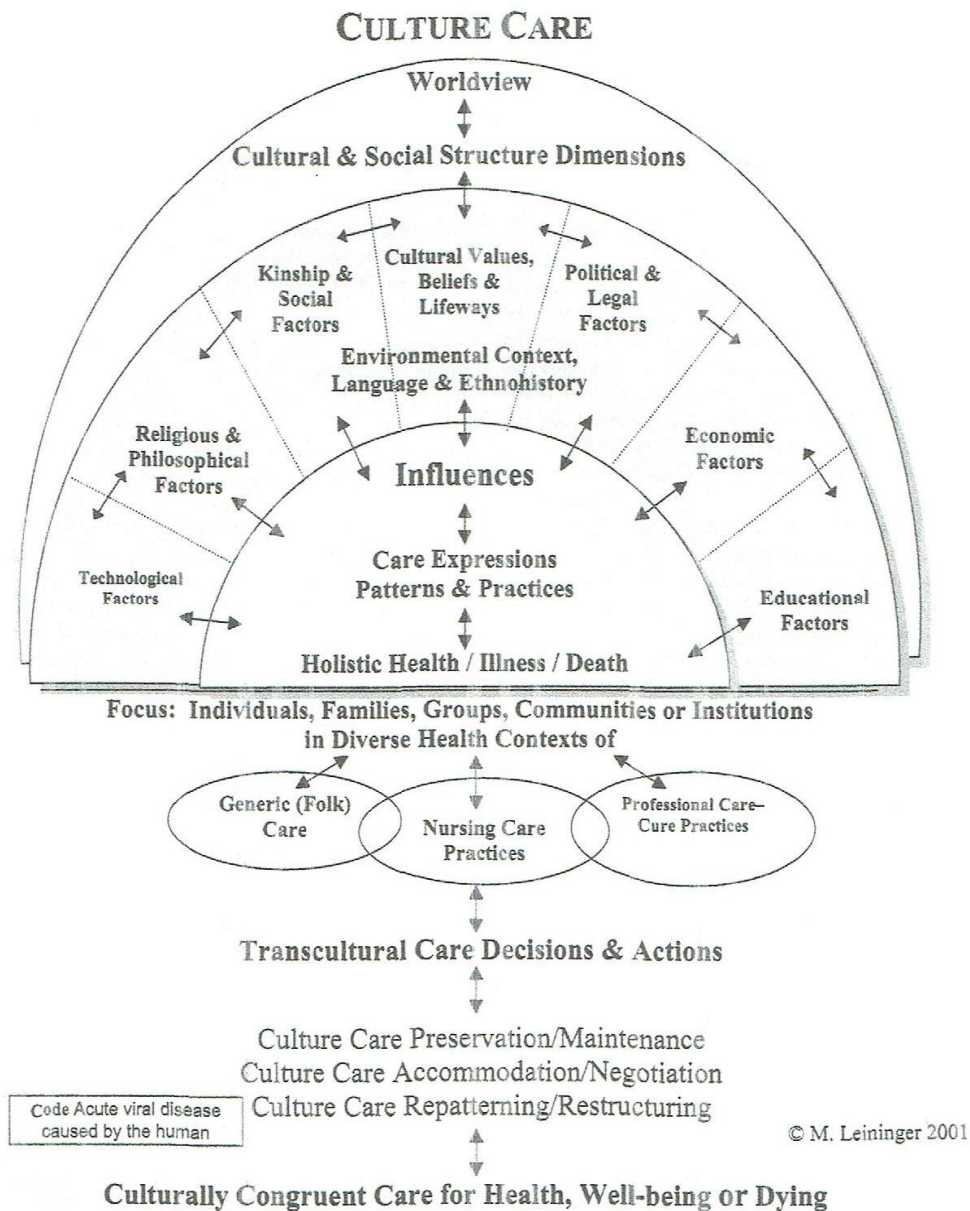


Figure 4.6 Leininger's Cultural Care (Sunrise) model (2002, p.191).

It can be seen from the Culture Care model, which Leininger labelled an “enabler” (2002, p. 92), that the diagrammatic form resembles a sunrise. The social and cultural dimensions contain seven elements that influence the delivery of holistic health, illness and dying. The focus is on individuals, families, groups, communities and institutions. There are complex issues associated with the variety of cultures in SA, for example, the vast differences between Zulu and Africans. By recognising this diversity, the developers of

the HNEP acknowledged that haemophilia nursing interventions are likely to be more effective if the complexities of cultural values are taken into account. The Theory of Cultural Care guided the structure and development of the HNEP curriculum, which was aimed at maximising learning. The researcher was specifically interested in the three circles located at the base of the diagram describing how transcultural decisions and actions in health are made: generic care, nursing care practices and professional care-cure practices (Leininger, 2002). The researcher recognised that for the HNEP to be successful, receptivity on the part of the PWH, appropriate nursing care, and cooperation from medical staff were essential.

Leininger's understandings became the basis for the phenomenon of transcultural nursing and the development of the Theory of Cultural Care: Diversity and Universality (Sitzman, Wright & Eichelburger, 2011). Leininger (1995) defined transcultural nursing as:

a substantive area of study and practice focused on comparative cultural care (caring) values, beliefs, and practices of individuals or groups of similar or different cultures with the goal of providing culture-specific and universal nursing practices in promoting health or well-being or to help people face unfavourable human conditions, illness or death in culturally meaningful ways (p. 58).

The theory resides within the qualitative paradigm and is based on the following assumptions:

1. Nursing is based within the concept of "caring";
2. Caring is an essential component of nursing, therefore there can be no "curing" without caring;
3. Nursing is a transcultural and scientific discipline whose purpose is to serve all of humankind;
4. Every culture has generic care knowledge and practices;

5. Culturally harmonious nursing care can only be applied when the nurse is sensitive to cultural values as these apply to the individual patient;
6. Patients who encounter nursing care that ignores their cultural beliefs may become stressed and noncompliant. (Welch, Alexander, Beagle, et. al., 2011).

The assumptions underpinning the Culture Care theory are relevant to the present study because of the wide variety of cultures existant in SA, all with specific behaviours pertaining to healthcare, illness and dying. Therefore, when developing the HNEP, the teachers were required to take into account several barriers which impact on the delivery of haemophilia care. Firstly, the isolation of some PWH, both geographical and with regard to telecommunication. Secondly, the two-tier health system operating in SA where the majority of individuals are from poor socio-economic groups who are not well-serviced; and thirdly, illiteracy in some populations in SA requiring alternate means of communication other than the written word.

4.3.2 Watson's Theory of Human Caring.

First published in 1979, Watson's Theory of Human Caring continues to evolve to remain relevant to the changes in society and healthcare. Watson believes caring is the essence of nursing practice and is related to moral behaviour rather than a task-oriented act; with the goal of safeguarding human dignity and compassion in healthcare. Watson supports nursing education that draws upon the humanities and sciences to present a human caring process between nurse and patient which surpasses time and space and encompasses spiritual elements (Cara, 2003). Watson's Theory of Human Caring shares commonality with Leininger's Culture Care Theory, so providing the researcher with increased awareness of the learner in the particular context of the research.

Watson's theory of the caring process between nurse and patient accentuates the encounter for both parties in recognising the mind-body-spirit connection (Cara, 2003). A

significant feature of Watson's model is the emphasis on the competencies of *caritas* (*Lt.* Christian love of humankind). Her insights have been succinctly summarised by Wagner (2010) and are presented in Table 4.1. The Table shows how humanistic-altruistic values interface with the instillation of hope to result in a nurse-patient encounter which operates at an essential level of understanding regarding what it means to be human. The Table then provides examples of behaviours, or what Watson terms "caritas literacy competencies", for facilitating the relationship between the nurse and the patient.

Table 4.1 Evolution of Jean Watson’s Carative Factors/Caritas Processes Over Time.

(Assembled by A. L. Wagner, 2010, Watson Caring Science Institute)

	Carative Factors (1979, 1985)	Caritas Processes (2002-2008) (Some agencies/individuals refer to the Caritas Processes as “Caring Practices.”)	Caritas Literacy (Competencies) <small>(from draft of working document subgroup of International Caritas Consortium, © June 2007, Jean Watson, et al.; modified by Jean Watson, Jan. 30, 2008) from Watson, J. (2008). <i>Nursing: The Philosophy and Science of Caring</i> (rev. ed.), Boulder: University Press of Colorado (pp.281-288).</small> Caritas Consciousness
1	Formation of humanistic-altruistic system of values	Practicing loving-kindness and equanimity within context of caring consciousness. Wording of other systems using Watson’s theory: Embrace altruistic values and practice loving kindness with self and others. Practice acts of kindness. (Hebrew Rehabilitation Center[HRC])	My respect for this patient (others) allows me to be available to him/her: <ul style="list-style-type: none"> ❖ Opens to connectedness w/ self, others, environment, universe; ❖ Models self-care and caring for others. ❖ Validates uniqueness of self and others. ❖ Acknowledges acts of kindness. ❖ Honors own and others’ gifts and talents. ❖ Recognizes vulnerabilities in self and others. ❖ Treats self and others with loving kindness. ❖ Listens respectfully with genuine concern to others. ❖ Accepts self and others as they are. ❖ Demonstrates respect for self and others. ❖ Listens to others. ❖ Treats others with kindness. ❖ Pays attention to others. ❖ Respects others. ❖ Honors human dignity of self and others.
2	Instillation of faith-hope	Being authentically present and enabling and sustaining the deep belief system of self and one being cared for. Wording of other systems using Watson’s theory: Instill faith and hope and honor others Instill trust and hope by being available to meet the needs of others. (HRC)	By listening, I was able to honor this patient’s (other’s) belief system and enable him/her to feel his/her own sense of faith/hope. <ul style="list-style-type: none"> ❖ Creates opportunity for silence/reflection/pause. ❖ Promotes intentional human connection with others. ❖ Views life as a mystery to be explored rather than a problem to be solved. ❖ Able to release control to a higher power. ❖ Interacts with caring arts and sciences to promote healing and wholeness. ❖ Incorporates other’s values, beliefs, and what is meaningful and important to them into care plan. ❖ Utilizes appropriate eye contact and touch. ❖ Calls others by their preferred name. ❖ Helps others to believe in themselves. ❖ Learns about and supports others’ beliefs. ❖ Supports others’ sense of hope. ❖ Encourages others in their ability to go on with life. ❖ Views person as human being and not object.

Wade and Kasper (2004) wrote that when student nurses’ educational experience is set in a caring environment they learn a professional way of being which parallels the nurse-patient relationship. Following a meta-analysis of 130 studies of caring in nursing students, Swanson (1999) determined that their caring demonstrated heightened clinical discernment,

an increase in skills and knowledge, an increase in empathy and a love of nursing. By infusing “caring” into the management of PWH through education, the HNEP teachers demonstrated the carative concept of caring to the participating nurses.

4.3.3 Knowles’ Adult Education theory.

Knowles’ Adult Education theory (1975, 1980) argues that adults learn differently to children and suggests that adult learners prefer to be self-directed in their learning.

Knowles’ theory is compatible with health education and has been used as a framework for teaching nurses, patients and other health professionals (Bastable, 2008). The participants involved in this present study were adult learners and came from a variety of work settings, bringing with them a diversity of nursing experience and skills. Adult learning theory is a good fit for this study as the RNs are all adults and participating voluntarily in a sub-specialty nursing program that enables their thinking to be challenged with regard to how PWH is managed. Accordingly, Knowles’ adult learning theory was used to guide the methodology and teaching strategies utilised to develop the HNEP.

Knowles was mindful of the fact that there are two major divisions in education studies, namely, the education of children (pedagogy) and the education of adults (andragogy). As the present study is concerned with educating adults, andragogy is of greatest significance. Andragogy has already been considered (Section 3.8.3) and repetition here is not warranted. Suffice it to reiterate that Knowles’ (1990) theory finds its basis in the following assumptions:

1. learner independence and self-direction;
2. the influence of life experiences;
3. benefits of and consequences of not undertaking the learning;
4. learner readiness to participate;

5. content relevance; and
6. personal motivation.

Knowles based his assumptions on the belief that adult learners are independent, self-motivated, have experience and are most interested in solving problems. He therefore appreciated that adult learners were capable of setting goals, choosing how to learn, searching out resources and appraising their own progress. Being mindful of this premise, it was deemed appropriate to include a wide variety of teaching strategies and resources in the creation and implementation of the HNEP.

4.3.4 Kirkpatrick's Four Levels of Evaluation.

Kirkpatrick's Four Levels of Evaluation was first presented in the late 1950s and has continued to evolve and provide educators and trainers in many disciplines with a means of evaluating the effectiveness of programs (Kirkpatrick, 1975; McCallum, Curran-Smith, Wojnar, & Williamson, 2002; Menix, 2007; Yardley & Dornan, 2012). Kirkpatrick's Four Levels of Evaluation was selected to evaluate the effect of the HNEP on the participants as the theory has been successfully used to evaluate related healthcare education programs (McCallum, Curran-Smith, Wojnar & Williamson, 2002; Sandhusen, Rusynko & Wethington, 2004; Yardley & Dornan, 2012). The four levels of the Kirkpatrick model include:

1. Satisfaction: which assesses the students' opinions of the course immediately upon completion;
2. Learning: encompassing an increase in knowledge and skills and change of perceptions;
3. Behaviour: which identifies how the education/training has changed the performance of the student in the workplace;
4. Results: which express how the education/training has impacted on the organisation or department.

Return on Investment (ROI) is a fifth level proposed by Phillips (2003), which assesses the cost/benefit of training undertaken and supported by the company or organisation. In recent years Kirkpatrick (2009) adopted a similar fifth level which he named ROE (Return on Expectations).

Level 1, Satisfaction, pertains to past evaluation responses from participants who attended previous HNEPs. These comments were used by the lecturers to help decide which components of the program should be retained and which should be modified or discarded. Level 2, Learning was assessed by the results of tests which are held at the end of each HNEP to assess whether learning has taken place. Level 3, Behaviour, was assessed in this study by analysing the data collected in the focus groups and interviews which asked the nurses how their behaviour has changed when caring for PWH. Level 4, Results, which measures the effect on the organisation, has been included to provide a more complete picture of the model. Although the impact of the HNEP on an organisation was not assessed in this study, it may be of prospective benefit to others wishing to build on the present research. Level 5, ROI, assesses the financial metric of the programme against the benefit of the programme. There were no financial figures to include in the study but non-financial benefits have been identified. These are known as “intangibles” or “soft benefits” and cannot be converted to financial figures (Phillips & Phillips, 2009). Some examples of ROI of the HNEP include impact on patient care and job satisfaction. The overall model, as described, is presented in Figure 4.2.

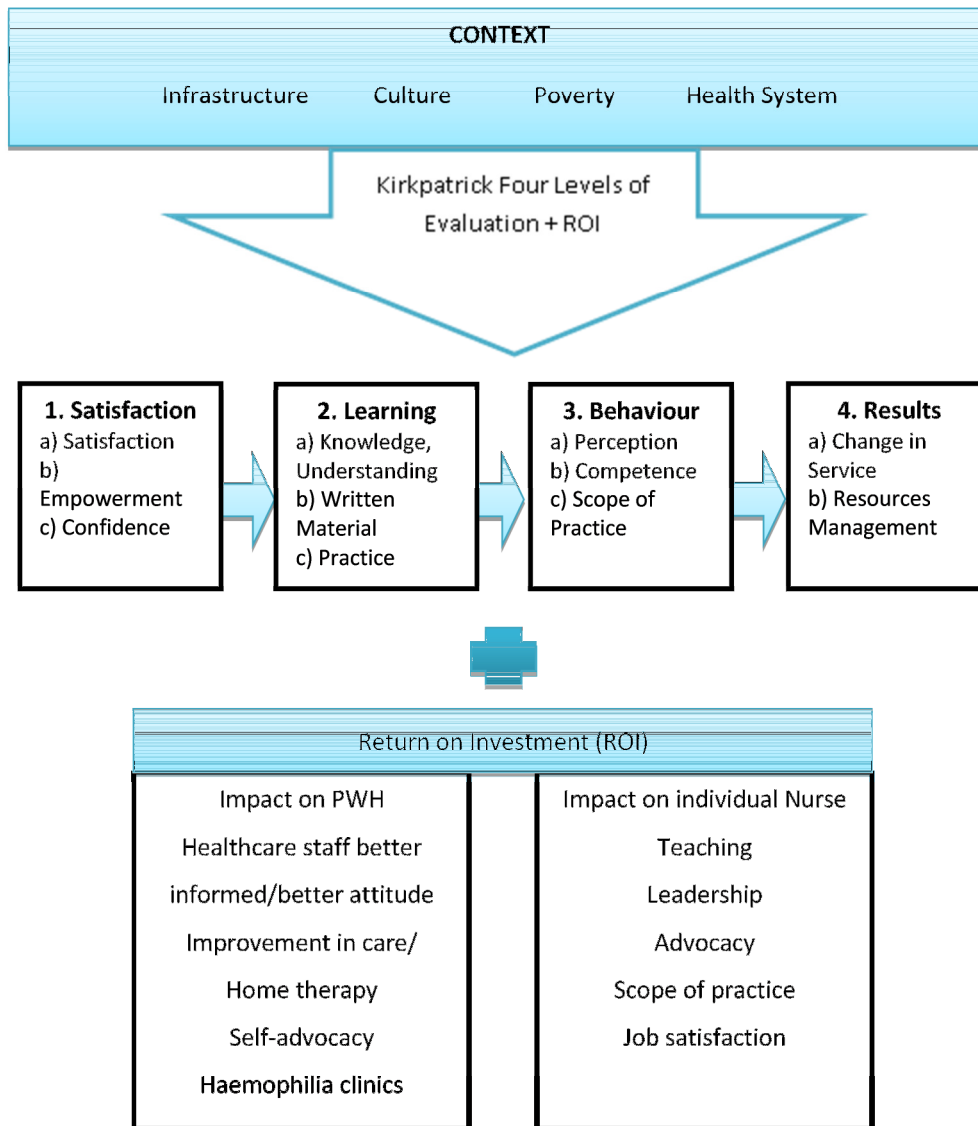


Figure 4.7 Kirkpatrick's Four Levels of Evaluation + Return on Investment.

4.3.5 Theoretical framework summarised.

Knowles' Adult Learning Theory, Leininger's Culture Care Theory, Watson's Caring Theory and Kirkpatrick's Four Levels of Evaluation + ROI guided the framework for this study. The four theories provided the researcher with pathways to encompass teaching strategies suitable for the South African cultural context, utilising caring strategies to demonstrate the act of caring in nursing, respecting the preferred learning of adults and

evaluating the programme in such a way that it would be useful for others to emulate. How the theoretical framework is envisaged, based on the four models identified, is presented in

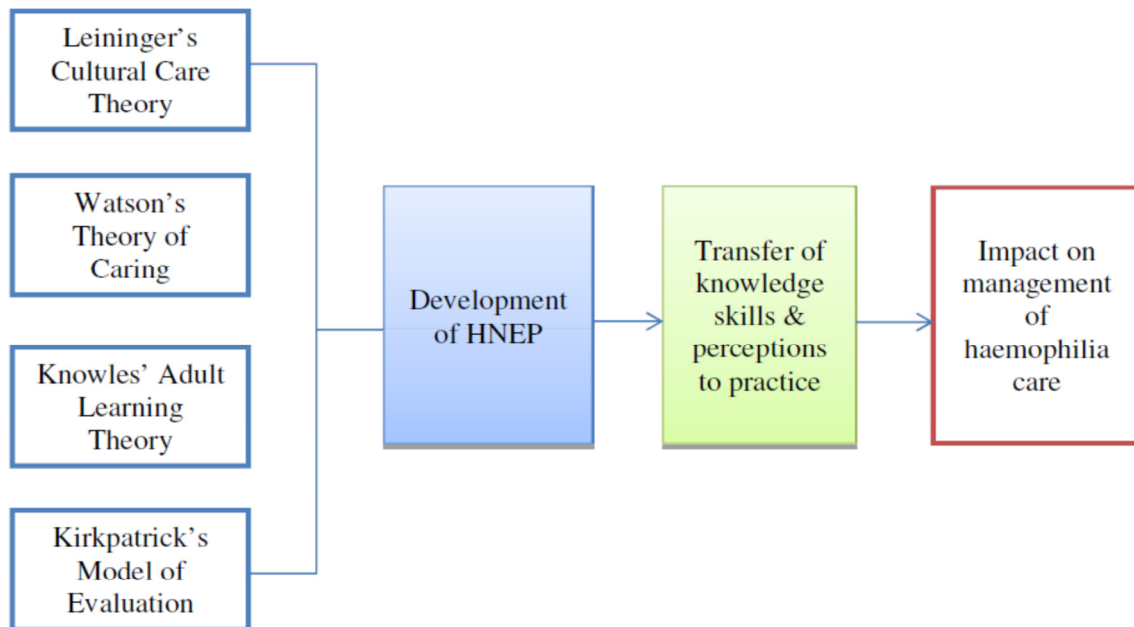


Figure 4.8 Theoretical framework for the HNEP.

4.4 Conceptual framework and the HNEP

Concepts and correlations that have been substantiated by research can be the basis for the development of theory, which in turn must be tested by additional research. As such, concepts and theory inform any research. Concepts frame the research, theory guides it, and research in turn evaluates the theory and provides grounds for the development of new theories, thus broadening the scope of the research (Borbasi, Jackson, Langford, 2008, Polit and Beck, 2010).

Nurse educators and researchers such as LoBiondo-Wood and Haber (2006) classify a conceptual framework as a set of concepts which are the important elements of a theory and express the abstract ideas within the theory. The conceptual framework is unique to each study and plays a fundamental role in establishing the relationship between the various

components under investigation (Punch, 2005) and specifies the design and organisation of the study. A conceptual framework, usually displayed as a diagram known as a conceptual model, is a depiction of the main concepts of the study. Such a model, considered suitable within the context of action research method utilised in the present research, has been developed by McNiff, Lomax and Whitehead (2002) and is presented as Figure 4.3.

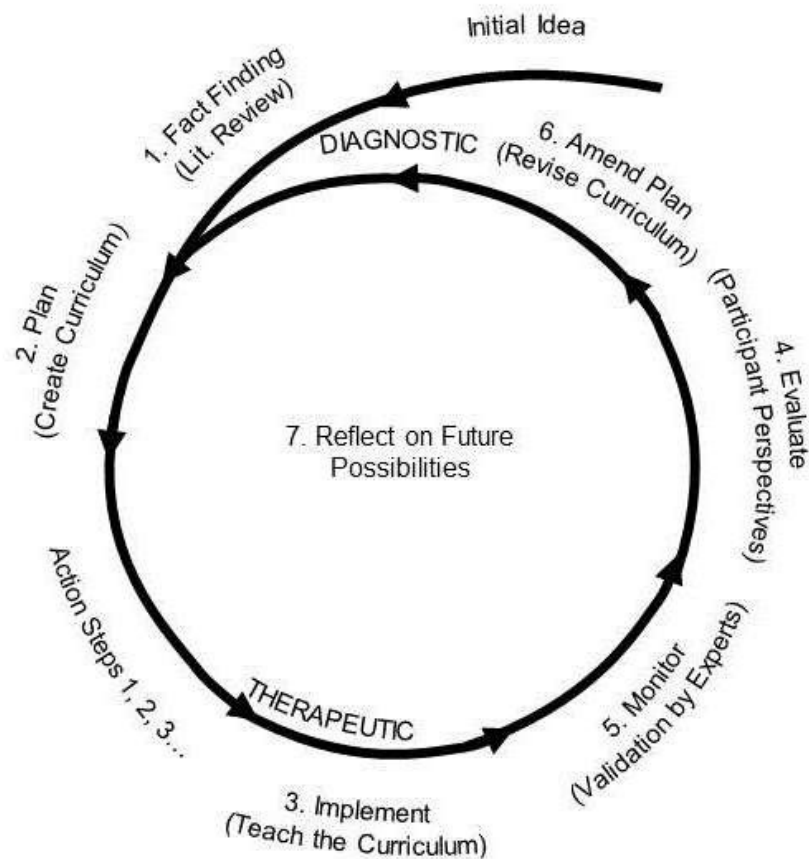


Figure 4.9 HNEP conceptual framework. After McNiff, Lomax and Whitehead (2002).

The conceptual framework complements mixed methods research well. The initial task conceptually is to be aware that there is a problem. McNiff (2002) asks these questions which could be posed as “what am I concerned about?”, “can I improve the area of concern?” and “what can I do about it?”. These were questions that the three South African

haemophilia coordinators asked themselves when regularly confronted with preventable deaths and poor outcomes after bleeding events in PWH. Their knowledge of haemophilia management made them aware that simple, timely interventions during a haemophilia bleeding event could save a limb or even a life. The realisation dawned that by educating nurses about haemophilia management, the incidence and severity of bleeding events could be reduced. This was the stage at which the researcher was invited to participate in the creation of the teaching program, now known as the HNEP.

The next stage of the cycle was to fact-find. Although there existed a database of PWH in SA, it was unreliable and the nurse coordinators were forced to rely on anecdotal evidence to support their ambitious teaching program. The researcher undertook an extensive literature review seeking information about nursing education programs which explained the recognition (diagnosis) and management of PWH. Unfortunately, as there was a paucity of information that advised nurses specifically about haemophilia, it quickly became obvious that the four experienced nurses initiating the research would need to design and write the curriculum for the HNEP. Other aspects to be organised such as advertising, recruitment, selection of venue and catering were undertaken by the SA nurses while the researcher returned to Australia to write the HNEP lectures.

Upon completion of the curriculum, the HNEP was rolled out to the first group of RNs. At the end of the first course, participants' perspectives were sought regarding the usefulness and potential efficacy of the curriculum. From this point the course was regularly, albeit informally, monitored and evaluated, with adjustments being made on the basis of feedback received. These survey evaluations and one-to-one interviews, where practicable, were retained. It was at this point and in line with points 4-7 of the conceptual framework, that it was decided to engage in a more formal evaluation to test the robustness

of the HNEP and to provide it with greater overall credence. To add further weight to the process, seven expert nurse educators who had experience in teaching nurses in developing countries, were asked to evaluate the existing HNEP curriculum.

4.5 Methodology

The methodology chosen for the study is that of action research supported by mixed methods. In action research, the emphasis is on the circular nature of the action (termed “action steps” in Fig 4.3) that could be repeatedly applied until a satisfactory solution is obtained (Holloway, 2008). Developed mainly by academics in education, action research has also been utilised in management and organisational studies and social and healthcare research (McNiff, 2002). Webb, Turton and Pontin (1998) suggested that action research should be viewed as an approach to research that can incorporate a variety of methodologies. This is the case in the present study where focus groups, one-on-one interviews, and questionnaires were employed to gather data. Grundy and Kemmis (1981) saw action research in education as a sequence of activities that can be applied to curriculum development, improvement of school programs and systems planning. Burns (1990) suggested that there are four basic features of action research, these are:

- Situational: the problem is recognised and attempts to solve it are within the specific setting;
- Collaborative: the researchers and the practitioners work together to solve the problem;
- Participatory: as team, members participate in the implementation of the research;
- Self-evaluative: modifications are evaluated continuously.

In nursing, the immediate aim of action research is to change practice, if necessary, by assessing the data and acting on the findings of research to modify processes. The ultimate aim of action research in nursing is to assist patients to improve their circumstances

and to augment practice in context (Holloway, 2008). Accordingly, action research was an appropriate methodology for the evaluation of the HNEP, as it aligns very well with the conceptual thrust of the present study.

The traditional approach of action research methodology is most strongly applicable in the initial action steps, being the creation and implementation of the HNEP prior to the decision to undertake the study. Nonetheless, action research methodology remained relevant as an approach during the action steps of evaluation, monitoring by experts, revision to curriculum and reflection on future possibilities (Figure 4.4).

4.6 Chapter summary

The epistemological, theoretical, conceptual and methodological aspects of the study have been considered in this chapter. The introduction describes the differences between the theoretical and constructual frameworks and how they are applied. The epistemological position is constructionism which aligns with qualitative research. Part One and Part Two are supported by phenomenology and interpretivism and Part Three by pragmatism. Pragmatism is linked to mixed methods research which values both qualitative and quantitative methods to undertake research. The theoretical framework combines the following theories: Leininger's Cultural Care Theory; Jean Watson's Theory of Caring; Knowles' Adult Education Theory; and Kirkpatrick's Four Levels of Evaluation to guide the study. To establish the relationship between the components being studied and to guide the organisation of the study, the conceptual framework utilises the methodologies of action research for Part One and Part Two and mixed methods for Part Three. The next chapter describes the study design and how that design was applied to research into the HNEP. The research questions to be addressed are presented and the method used to collect and analyse the data explained.

Chapter 5

Method

This chapter presents a description of the study design, the research questions to be addressed and the method used to collect and analyse the data. Also included is a description of the sample group. Ethical factors as these relate to the study are also considered. Initially, this current research was to be a Masters thesis. Following the data collection an application was made to the University of Notre Dame Research Committee to undertake the study at a Doctoral level. The application was granted.

5.1 Aims of Study

The general aim of the present study was to conduct an evaluation of the HNEP to determine if the participants expressed an increase in knowledge, confidence and competence to care for a PWH. This present study investigated whether attendance at the HNEP better prepared RNs to care for PWH in South Africa, and determined whether the HNEP has contributed to an improvement in haemophilia care. For ease of reference, the questions being researched and identified in Chapter 1 are re-presented below.

5.2 Research Questions

1. What factors need to be considered when developing a purpose-driven haemophilia curriculum for nurses in South Africa?
2. What factors need to be considered when implementing a purpose-driven haemophilia curriculum for nurses in South Africa?
3. What transfer of knowledge, skills and perceptions is likely to occur as a result of training received via a purpose-driven haemophilia curriculum?
4. How robust is a purpose-driven haemophilia curriculum when subjected to expert evaluation?

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

5.3 Study Design

The study design involved a mixed method approach which was elucidated in the previous chapter and consisted of three parts.

Combining both qualitative and quantitative approaches provided a wider perspective on the research questions by yielding complementary data sets, therefore enabling data triangulation (Carr, 1994). Triangulation allows for evidence corroboration to occur thus resulting in a more robust study.

Part One of the study elicited data from three RN haemophilia coordinators who supported haemophilia interventions in SA and who were responsible for creating and delivering the HNEP. Qualitative data was sourced for this part of the study. Part Two accessed the insights of RNs who had previously attended the HNEP. This data was also sourced using qualitative methodology. To gain greater insight regarding the complexities experienced by haemophilia nurses, Part Two data was supported by three critical incidents which highlighting their experiences. Part Three of the study sought the views of expert nurse educators who evaluated the curriculum contained within the Haemophilia Resource File (HRF) supplied to the attendees of the HNEP. A quantitative survey was used to obtain data for this part of the study and was supported by written statements from the experts. Data from the three parts were then integrated in order to answer the research questions. Each of the three parts of the study is explained in detail in what follows. A diagrammatic representation of the relationship between the research questions, participants and methods used for collecting data is presented in Figure 5.1.

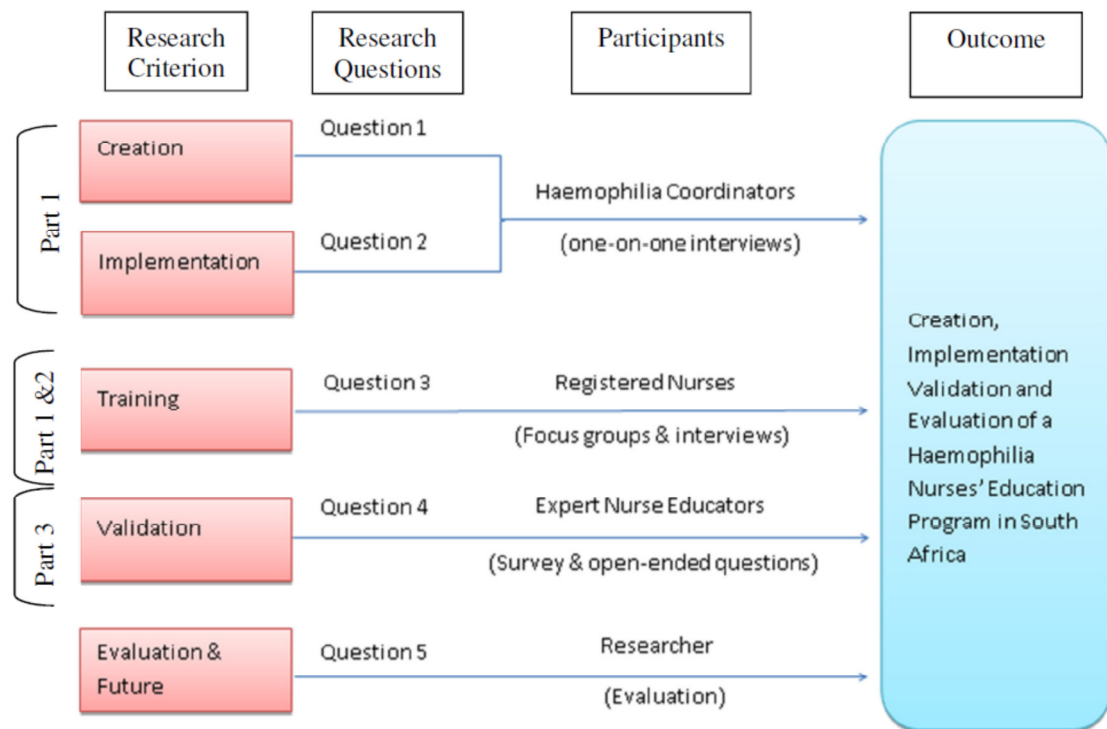


Figure 5.10 The relationship between the research questions, participants and data collection methods.

5.3.1 Part One: The haemophilia coordinators.

5.3.1.1 The sample group.

Part One involved one-on-one interviews with the three South African haemophilia coordinators who provided the background to the context of the development of the HNEP. The researcher was involved in the initial development of the curriculum and teaching in the HNEP and had knowledge of how decisions were made; however, she was more interested in the context of the how the HNEP should be conceived and delivered SA. Accordingly, the questions to the haemophilia coordinators were designed to elicit information about the history and context of haemophilia in SA (Appendix D).

The three nurses involved in the care of PWH differed in relation to their education and abilities. At the time of writing, there are only three haemophilia nurse coordinators to provide care for an estimated population of 5000 PWH. Prior to 2001, Coordinator A was

assisted by Coordinator M who joined the service in 1998. Coordinator L was employed in 2001 to provide a service to Cape Town and surrounding areas.

Two of the haemophilia coordinators are white South Africans (WSA) and the third is a Black South African (BSA). All three are female practitioners with an age range of 33 to 53 years. Of the three nurses, two work full-time and the third works 30 hours per week. One full-time coordinator is hospital-based and has the responsibility for the Eastern Cape, Western Cape and Northern Cape provinces. The other two coordinators are employed in the community specifically to care for PWH. One coordinator, who is full-time, provides outreach services, including to regional areas, providing support and expertise to hospitals which have recently established haemophilia clinics. The most senior coordinator, who works 30 hours per week, practices mostly in a teaching role educating health professionals, community groups and PWH and their families which also includes writing pamphlets and updating manuals in relation to haemophilia management.

In relation to nurse qualifications, all the coordinators are Registered Nurses (RNs). The two WSA nurses hold hospital-based diplomas while the BSA nurse holds a university-based tertiary nursing diploma. The level of education reflects the era of nursing in which the nurses trained. The two WSA coordinators are hospital-based trained which was the only system available at the time. The BSA coordinator is the youngest of the three, and is tertiary educated indicating that nursing education in SA had progressed to a higher level of education in recent years. Given that SA has diverse cultures with eleven official languages, two of these nurses speak various languages, with the BSA nurse speaking seven languages. The demographic data for the three haemophilia coordinators is presented in Table 5.1.

Table 5.1 Demographic Data of the Three Haemophilia Nurse Coordinators

<i>Haemophilia Coordinators</i>	<i>BSA</i>	<i>WSA</i>	<i>WSA</i>
<i>Qualifications</i>	<i>Tertiary Nursing Diploma Registered Nurse</i>	<i>Hospital Diploma Registered Nurse</i>	<i>Hospital Diploma Registered Nurse</i>
<i>Place of work</i>	<i>Haemophilia Foundation Head Office, Johannesburg</i>	<i>National Bioproducts Institute, Johannesburg</i>	<i>Groote Schuur Hospital, University of Cape Town</i>
<i>Languages spoken</i>	<i>English, SePedi, SeSotho, Setswana, Africaans, Zulu, Tsonga</i>	<i>English</i>	<i>English, Africaans</i>
<i>Experience specific to haemophilia</i>	<i>5 years</i>	<i>28 years</i>	<i>23 years</i>
<i>Area where experience gained</i>	<i>Haemophilia Foundation, of South Africa, Oxford Haemophilia Centre UK., Outreach visits to Regional hospitals in South Africa</i>	<i>Haemophilia Centre Mt Sinai Hospital, New York, USA and Haemophilia Centre at Johannesburg General Hospital.</i>	<i>Haemophilia Centre at Johannesburg General Hospital, Red Cross Children's Hospital and Groote Schuur Hospital, Cape Town.</i>

5.3.1.2 Data collection procedure.

Data were collected by engaging in one-on-one interviews with each of the three haemophilia coordinators. Such a technique provides the opportunity to probe particular responses, and is a means of eliciting a person's complex feelings or perceptions about an event (Polit, Beck & Hungler, 2001). In-depth interviews also provide an opportunity to

explore and observe phenomena in an individual context (Jackson & Borbasi, 2008; Whitehead & Annells, 2007). This approach allows the researcher to engage with the world of the participant, or an event, in detail. Such interviews generate rich, comprehensive and pertinent information (Whitehead & Annells, 2007). The researcher was an experienced interviewer, thus allowing for data of high quality to be collected (Jackson & Borbasi, 2008).

Whitehead and Annells (2007) and Lambert and Loiselle (2008) describe interviews as the most common method of collecting data in nursing research using oral narrative. According to Patton (1990) interviews are a means “to find out what is in and on another person’s mind” (p. 278). Tellis (1997) agrees, stating that interviews can elicit details from the viewpoint of the participant thus adding to the evaluation process of the HNEP.

Interviews are a mechanism for evoking what cannot be seen, eliciting thoughts and feelings that are not observable and provoking situations or behaviours that may have occurred at some time previously (Patton, 1990). The questions asked by the researcher were open-ended to encourage the participant to fully express their “story”, with the researcher assuming an active listening attitude and probing with questions to clarify a point as required.

5.3.2 Part Two: The haemophilia RN participants.

5.3.2.1 The sample group.

Part Two of the study included a purposive sample of 20 participants who had previously attended a HNEP and were caring for PWH. The sample was selected by the senior haemophilia nurse coordinators in SA. Participants came from four clinics in Nelspruit, Johannesburg, Cape Town and George. According to Schneider and Elliott (2007), the researchers’ “knowledge of the population and its elements are used to handpick

cases typical of the population to be included in the sample” (p. 181). Purposive sampling is a common method used in nursing, and has several sub-categories such as snowball sampling and convenience sampling. In this instance, the participants were selected using criteria sampling where those selected were required to meet the criteria that had been established on the advice of the haemophilia coordinators (Table 5.2). Although the sample size was small (n = 20), the researcher was confident that the participants selected would be able to provide sufficient information as they were immersed in the context of the phenomenon the researcher sought to explore (Bloomberg & Volpe, 2008), and that the sample size had a great capacity to provide rich data (Polit & Beck, 2010).

Table 5.2 Selection Criteria of Prospective Participants (RNs) in Study Part One.

1. completed the HNEP in the last ten years;
 2. live and work in South Africa;
 3. currently caring for PWH; and
 4. managed a crisis situation in haemophilia.
-

5.3.2.2 Data collection procedure.

Focus groups were utilised in the service of collecting relevant data. Polit and Beck (2010) considered that focus groups are an efficient means of gathering opinions and experiences about a specific investigation. According to Tellis (1997), group interviews can elicit details from the viewpoint of the participant thus adding to the evaluation process. The advantage of a focus group is that it allows collection of rich data about an homogenous cohort (Curtis & Redmond, 2007; Rothwell, 2010) within the context of their work setting

(Freeman, 2006). By utilising focus group methodology, the researcher was able access information in relation to how the HNEP influenced haemophilia management in the workplaces of the former attendees.

Despite some potential shortcomings such as generating a Hawthorne Effect, focus groups are a cost-effective method of gathering data since a group of participants can produce individual ideas, which in turn stimulates further discussion (Goodwin & Happell, 2009; Happell, 2007). Also, data are collected immediately which is in contrast to a written survey where there exists risk of a low postal response rate (Punch, 2005). A postal survey was considered for this present study however, because of the unreliability of the postal service in SA it was decided not to utilise this option.

Focus group questions (Appendix E) were generated using the Kirkpatrick Four Levels of Evaluation (2006) model and the South African Standards of Care for Haemophilia. Four focus groups were conducted with two to six nurses in each group, as participant availability permitted. The focus groups were moderated by the researcher with a SA senior haemophilia nurse acting as an observer. It is common practice that these senior haemophilia nurses act as mentors and advisors for the nurses who have previously completed the HNEP. The inclusion of this senior nurse was to ensure that cultural issues not fully understood by the Australian researcher/interviewer were duly considered. The participants were comfortable with the presence of a senior haemophilia nurse observing the sessions since they viewed her as a mentor-colleague. They were accustomed to consulting her when they needed advice about haemophilia patients and reported regularly to her. The participants did not appear to be inhibited by her presence, speaking frankly about their experiences as nurses who cared for PWH. To corroborate evidence and to gain more fine-

gained exposure to major issues, four of the nurses agreed to take part in on-on-one interviews lasting about 30 minutes each.

A small meeting room was hired for focus group interviews at each of the venues where participation occurred. Comfortable chairs and refreshments were provided to help promote a relaxed setting so that the participants would feel at ease. Before commencement of the focus groups, each participant was given an outline of the study in plain English (Appendix F). Once they had acknowledged that they understood the purpose of the study, they were given a consent form (Appendix G) which was signed and collected immediately prior to participation. The participants were seated in a circle to facilitate group discussion. They were asked to introduce themselves, provide an overview of the area of health in which they worked and when they had completed the HNEP. To prevent one or two individuals from dominating the session, the researcher, at the beginning of each session, explained that all participants would be given an equal chance of responding to questions. The focus group interviews were audio-taped and transcribed verbatim.

5.3.2.3 The critical incidents.

Three critical incidents arising from interviews have been included to provide the reader with a greater sense of the sort of issues that haemophilia RNs face on a regular basis. A critical incident of a person or event involves the observation of a single incident that provides insights into that specific incident (Frankfort-Nachmias, & Nachmias, 1996). A further reason for their inclusion is to contribute to the evaluation process of the HNEP by adding to accumulating evidence (Yin, 2003), in this case as acquired via the RNs at one-on-one interviews.

Four RN focus group participants volunteered to describe an incident with a PWH which may have had a poor outcome if the nurse had not intervened. Questions asked were:

- Since completing the HNEP, can you recall and perhaps describe for me, a life-threatening situation where your intervention decreased the likelihood of a poor outcome for a PWH? and
- Can you describe how that intervention and subsequent outcome made you feel?

Three of the four responses proved to be so illuminating (with one person providing two responses) that they were deemed significant for the purpose of including in the present work. Paton (1990) explained that critical incidents can add rigour and in-depth information to other available data. The critical incidents provide an insight into the actions of two individual nurses to resolve high-risk situations with competence and confidence, post their HNEP training. These critical incidents are presented in Chapter 8.

5.3.3 Part Three: The expert assessors.

5.3.3.1 Rationale for the inclusion of Part Three.

Part Three of the study addresses the evaluation of the robustness of the curriculum which was undertaken by expert nurse educators. As important as it is to obtain insights from course participants, such participants have a certain level of ignorance regarding course efficacy that would not apply to expert educators. Whereas participants can evaluate the course per se, experts are in a far better position to consider the course in comparison to whatever is available in the market place. As educators, they are also better placed to comment on the adequacy of the pedagogical strategies utilised. There appears to be pragmatic disagreement among researchers regarding the precise number of experts required to obtain an accurate evaluation. Dumas, Sorce, and Virzi (1995) suggested five; Burns and Grove (2005) suggested that to reach consensus, between five and ten experts are recommended; and Podvezko (2008) recommended that the number be between six and nine. As validation of the HNEP was sought in Part Three of the study, seven experts were considered sufficient, as a larger number would be unlikely to reveal any further insights.

5.3.3.2 Defining expertise.

Seeking expert opinion has been identified as a bona fide method of determining content validity (Bruce, Langley & Tjale, 2008). According to Webster (1976), expertise is gained through “professional training and practical experience” (p. 800). In the case of expert nurse educators, such expertise has been gained through clinical proficiency and tertiary education. To fully appreciate what is meant by an expert, one needs to establish how expertise is characterised. The two most common ways to assess the nature of expertise is to firstly, compare the traits or characteristics of experts and novices (Chi 2006; Tsui 2003); and secondly, to study exceptional performers to gain an understanding of how they function in their domain (Chi, 2006). The first of these methods was chosen as it was thought that comparative identification had greater relevance for the present study.

There exists a plethora of literature describing the characteristics of experts and comparisons with the traits of novices (Benner, 1984; Chi, 2006; Dreyfus & Dreyfus, 1981; Moore, O’Neill & Barrett, 2008; Tsui, 2003). Table 5.3 presents a compilation of these traits as found in the citations above. The Table shows the traits of experts as opposed to novices, which the researcher utilised in selecting the appropriate experts for evaluating the HNEP curriculum and the HRF. The traits were determined by scrutinising the curriculum vitae of each potential expert.

Table 5.3 Comparison of Traits of Expert and Novice Practitioners.

<i>Domain</i>	<i>Expert</i>	<i>Novice</i>
<i>KNOWLEDGE</i>	<i>Domain-specific</i>	<i>Little situational understanding</i>
	<i>Automaticity</i>	<i>Adherence to rules or plan</i>
	<i>Self-assured, confident in their knowledge</i>	
	<i>Knowledge & skills aligned to context of work</i>	<i>No connection of knowledge to practice</i>
<i>PERFORMANCE</i>	<i>Opportunistic, makes best use of resources</i>	
	<i>Analytic in novel situations or when problems</i>	<i>Minimal understanding of complexity</i>
	<i>Creates own interpretations</i>	
	<i>Can make rapid decisions</i>	
	<i>Displays efficiency, fluidity and effortlessness</i>	
	<i>Performance is superior</i>	<i>Needs close supervision, instruction</i>
<i>EDUCATION</i>	<i>Holistic understanding of the problem</i>	<i>Inclined to see actions in isolation</i>
	<i>Has specific qualifications, education & training</i>	<i>Knowledge minimal, textbook knowledge</i>
	<i>Self-improvement is important to individual</i>	

On the basis of the information gleaned from Table 5.3, it became possible to establish a list of essential selection criteria, with justification, for an expert nurse educator (Table 5.4). Each participant's eligibility was then tested against these established criteria.

Table 5.4 Essential Criteria for Selection of Expert Nurse Educators.

Criteria	Justification
<p>Holds a postgraduate qualification in nursing.</p> <p>Possesses some experience in curriculum evaluation.</p> <p>Has had some exposure to educating nurses in developing countries.</p> <p>Currently teaches in a tertiary institution; or has a supervisory role within the clinical setting; or has credible experience in the area of haemophilia.</p>	<p>Exhibits evidence of higher learning.</p> <p>Absolute necessity for the present task.</p> <p>Sensitivity to challenges existing in developing countries.</p> <p>Recency established. Position of leadership or responsibility indicates a higher skill level and reasoning capability.</p>

5.3.3.3 The sample group.

Seven expert nurse educators were selected as evaluators. None had participated in the development or teaching of the HNEP. Three nurse educators were from Australia: the first was employed in the nursing school of a tertiary institution, the second in a tertiary teaching hospital in Perth, Western Australia, and the third in a private hospital outreach service to developing countries. Two experts were from universities in the UK and two from Africa who were employed at universities in SA and Malawi respectively. Each expert was assigned a code for identification purposes. The code appears under the heading “Expert” in Table 5.5.

Table 5.5 Expert Demographics.

<i>Expert</i>	<i>Country</i>	<i>Qualifications</i>	<i>Place of work</i>
<i>MH</i>	<i>United Kingdom</i>	<i>RN, lecturer</i>	<i>Large tertiary education facility</i>
<i>MB</i>	<i>United Kingdom</i>	<i>RN Senior lecturer</i>	<i>Large tertiary education facility</i>
<i>LK</i>	<i>Malawi</i>	<i>RN Senior lecturer</i>	<i>Large tertiary education facility</i>
<i>SA</i>	<i>South Africa</i>	<i>RN Senior lecturer</i>	<i>Large tertiary education facility</i>
<i>JT-R</i>	<i>Australia</i>	<i>RN, Lecturer</i>	<i>Private hospital outreach service</i>
<i>BS</i>	<i>Australia</i>	<i>RN Clinical Nurse Consultant</i>	<i>Large tertiary hospital</i>
<i>AB</i>	<i>Australia</i>	<i>RN, Senior lecturer</i>	<i>Large tertiary education facility</i>

5.3.3.4 Data collection procedure.

The expert nurse educators were contacted by email inviting them to participate in the evaluation of the HNEP and the haemophilia resource file (HRF). When an expert agreed to participate, the relevant material was delivered to them by courier. Courier expenses were paid for by the researcher. Included in the package was:

1. A covering letter informing the expert nurses about the research and explaining their participation (Appendix H);
2. Researcher contact details;
3. A consent form (Appendix I) to be signed and returned to the researcher by email;
4. An overview of the HNEP and the resource file contents (Appendix J);
5. A document containing the context of the program (Appendix K);
6. A Likert-type survey by Discenza (1993) (Appendix L); and

7. A thumb drive containing the Power Points sessions from the HNEP program (Appendix A: thumb drive). Access to the Power Point presentations allowed for a more thorough evaluation.

The expert nurse educators were each paid AU\$200.00 upon receipt of the requested items. According to Fry, Ritter, Baldwin, Bowen, Gardiner, Holt, and Johnson, (2005) this type of remuneration is an acceptable practice to ensure that a busy professional will complete and return the evaluation to the researcher, as well as receive some recompense for time and effort provided.

Quantitative data were collected from a survey adapted with permission from Discenza (1993), which according to Bastable (2008), is considered “a valid instrument for selecting and evaluating instructional materials” (p. 506) developed to assist with selecting and evaluating instructional materials. The survey (Appendix L) consisted of five categories covering content, instructional design, technical production, quality of the DVD presentations; and the packaging of instructional materials of the HNEP. The experts were asked to respond to each of the category items via a Likert-type scale ranging from strongly agree, agree, disagree to strongly disagree.

Qualitative data were collected from the responses to eight open-ended questions in relation to assessment of the HRF. Questions were specifically structured to elicit information about the experts’ overall impression of the HNEP, and their impressions of HRF content and associated pedagogy. Responses to the questions were analysed to identify themes and patterns occurring within the data. The findings from the survey and the open-ended questions were merged and the data results compared to help inform the research questions. The relationship between the three parts of the study and data collection is represented in Figure 5.2.

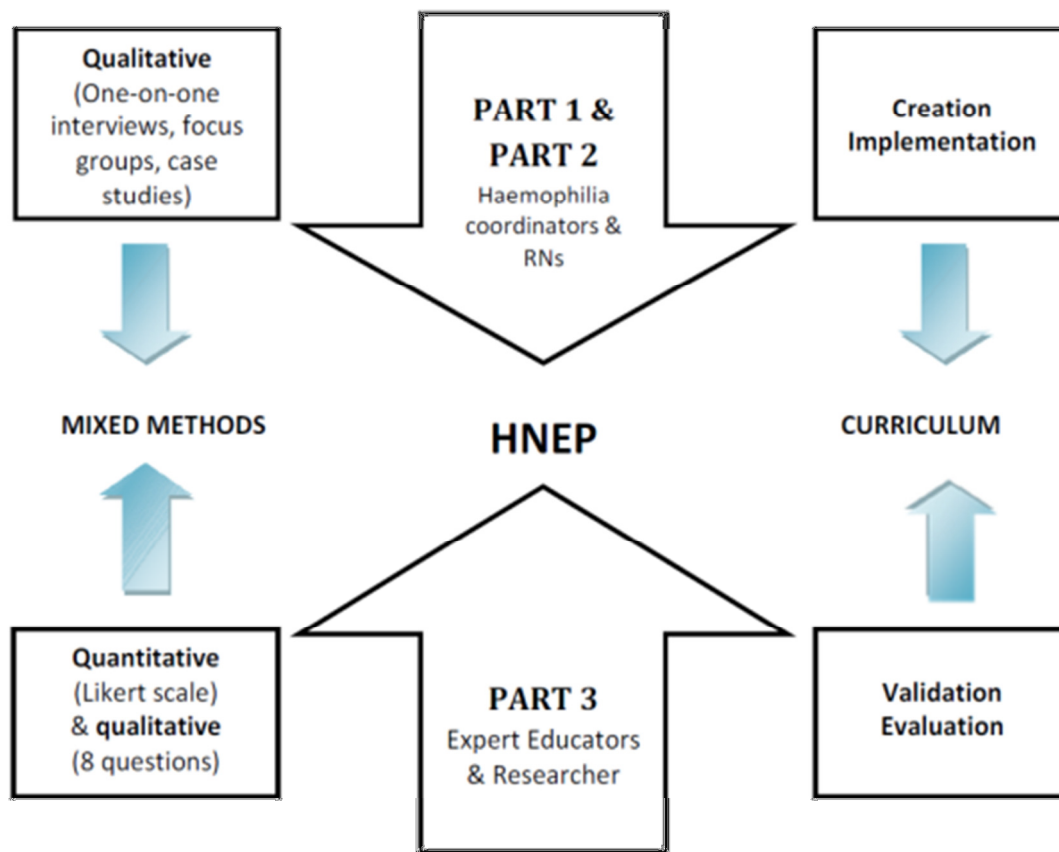


Figure 5.2 The relationship between the three parts of the study and data collection

5.4 Validation procedures: Quantitative, qualitative and mixed method research

5.4.1 Quantitative research.

Quantitative enquiry, finding its origins in positivism, advocates a methodology based in objective measurements using statistical or numerical data (Polit & Beck, 2010). Methods typically include data sourced from polls, surveys and questionnaires, which are analysed in an endeavour to discover relationships between variables (Whitehead, 2007). Cross-sectional data is used to gain information at one point in time, whereas longitudinal data may be gathered where information is being sought over time. Large sample populations are normally involved and generalisations may be made on the basis of what has been discovered from a representative sample of the population (Cresswell & Plano Clark,

2011). In the present study, as part of a broader mixed method approach, quantitative data in the form of cross-sectional responses to questionnaires was collected and analysed.

Likert-type scales are commonly used to rate the degree to which respondents agree or disagree with a statement in a survey (Sullivan & Artino, 2013). Although there is some disagreement about whether the Likert-type scale is an ordinal scale or an interval scale, the researcher has chosen to select ordinal data for the survey used in this study. In ordinal scales the responses can be ranked but the distance between each response cannot be measured, whereas in interval scales the distance between each response can be measured and the responses can be calculated. As the survey in this study was used to determine the attitude of the expert nurses towards the content of the teaching package, by using the agree/disagree scale, there is no need to measure the distance between each response as this would not add anything useful to the data. Data from the survey was calculated in percentages and frequencies and illustrated using a diverging bar chart. Selective data from the RNs was also evaluated quantitatively as the Tables presented in Chapter 7 show.

5.4.2 Qualitative research.

Qualitative research can be described as enquiry situated in a naturalistic setting in which the researcher is exploring phenomena sympathetic to the people under investigation. This is done to ascertain the meaning they ascribe to such phenomena (Cresswell & Plano Clark, 2011). The researcher is a key instrument in the study by using observation and interviewing techniques to capture the data. Multiple methods of collecting data such as examining documents, interviews and focus groups are utilised, and researchers typically position themselves in the study as a participant-observer. Qualitative research, stemming from a constructionist orientation, investigates what individuals are encountering in their lives as a result of direct personal experience (Streubert & Rinaldi Carpenter, 2011). The

present research encompassed a qualitative aspect and was conducted in SA so is directly relevant to the needs of those nurses working with the PWH. Those involved in the research were participant observers; data was collected in a variety of ways; and participants' lived experiences were used as a starting point from which the HNEP was delivered.

In qualitative inquiry, the term validity is generally replaced by trustworthiness (Onwuegbuzie & Johnson, 2006). Leung (2015), a professor of family medicine stated that the essence of qualitative research such as subjectivity and contextual implications have served to provide contentious views about quality and trustworthiness in studies in health. As a result, there are no common qualitative criteria or terminologies for qualitative research. However, Lincoln and Guba's framework (1985) is viewed by some qualitative researchers as the benchmark for frameworks for quality criteria (Polit & Beck, 2010). Lincoln and Guba (1985) discussed the parallel perspective, comparing standards of reliability and validity in quantitative research to standards of "trustworthiness" in naturalistic inquiry. Their criteria for trustworthiness in qualitative inquiry were credibility, dependability, confirmability and transferability. In later publications they added another criterion, authenticity (Guba & Lincoln, 1994). The researcher has chosen to authenticate the trustworthiness of the study by using Lincoln and Guba's framework as it has been verified by researchers over many years (Polit & Beck, 2010).

Credibility is the confidence the researcher has in the truth of the data and its interpretation. The researcher must "strive to establish confidence in the truth of the findings for the particular participants and contexts in the research" (Polit & Beck, 2010, p. 492). The present research is credible in that the purposeful sample of participants were keen to describe the truth of what they were experiencing. They realised that the research

had a practical purpose and that it was to assist them in their ongoing activity supporting PWH.

Dependability relates to the stability of the data over time and conditions. The researcher needs to ask whether the findings from the data would be similar or the same if the study were repeated using the same or similar participants in the same or similar contexts. Dependability in Part One was determined by interviewing RNs who had attended different HNEP courses over several years. Their experiences once they returned to the workplace were very similar, thus providing evidence of the stability of the data over time.

Confirmability conveys the sense of objectivity in the findings. In the present study, the data reflects the information given by the participants, which is evidenced in the extensive utilisation of participant quotations. As indicated previously and in line with Bednall (2006), the researcher was aware that she needed to suspend her own judgements in order to maintain credibility. Further, member checking was utilised to validate the researcher's interpretation of the qualitative data presented.

Transferability refers to the extent that the findings can be transferred to other groups or contexts and parallels generalisability in the quantitative paradigm. Transferability was established by the researcher providing clear descriptions about the creation and implementation of the HNEP, which was further enhanced by the positive opinions of the RNs who had completed the course and applied their learning to practice. Other developing countries are not dissimilar to SA in the broad health care challenges they encounter, and specifically with regard to haemophilia care. As such, the likelihood of transferability is high.

Authenticity represents the extent to which the researcher conveys the realities of the participants or describes the lived experience of the participants. An articulate and accurate

portrayal allows the reader to live vicariously through the participants' experience of an incident or existence. Case study investigations were utilised to ensure that the criterion of authenticity was met.

5.4.3 Mixed methods research.

Mixed methods research (MMR) is an alternative paradigm to quantitative or qualitative techniques. Teddlie and Tashakkori (2011) maintain that MMR is grounded in pragmatism, where the methodological viewpoints are congruent and can be used in combination. In MMR, data are collected from more than one source and the results compared for like findings in order to confirm accuracy. Essentially, MMR is the combination of qualitative and quantitative approaches in a single study. The approaches can be utilised at any stage of the research – philosophical position, inference techniques, methodology, data collection and interpretation of results (Creswell & Plano Clark, 2011). Both qualitative and quantitative research methods have unique strengths and weaknesses. In a mixed method approach, the limitations of one approach can be compensated for by the strength of the alternative approach, thus providing a more comprehensive appreciation of the research problem than if one approach alone was used (Punch, 2005).

Mixed methods is appropriate for researching nursing topics because nursing is a complex discipline that embraces humanistic and holistic tenets on one hand but is set in the context of biology and science on the other. Using mixed methods suggests that nursing research reflects this diversity and is suitable to research question four because it allows for analysis using descriptive statistics as well as analysis of written protocols (Whitehead & Elliott, 2007).

Validity in mixed method research takes account of the factors considered under both the quantitative and qualitative paradigms (Creswell & Plano Clark, 2011). More specifically, it remains cognisant of the need for checking the quality of the data and the results and interpretation of the results. As mixed methods research combines the two paradigms of qualitative research and quantitative research, data analysis is undertaken separately for each paradigm (Creswell & Plano Clark, 2011) and then integrated in the interest of presenting more robust findings. Such integration enriches the research task in ways that would be impossible using quantitative or qualitative methodology separately.

5.4.4 Mixed methods and action research.

A further consideration is that MMR is compatible with action research. Action research is the act of identifying a specific problem, envisaging a possible solution, implementing it, and evaluating the changes (McNiff, 2002). The aim of action research to address the needs of real life in-situ problems, with an orientation toward changing future practice. Webb, Turton and Pontin (1998) make the comment that knowledge acquired through action research is valuable in that it is based on actual practice.

When combined, action research and MMR can provide the opportunity to collect qualitative and quantitative data in the same study (Creswell, 2012). Mills (2011) points out that although qualitative methods appear to be more compatible with action research, the use of qualitative and quantitative methods, such as when numeric data is required to strengthen qualitative narratives, may be justified.

Common features of mixed methods and action research include conceptual features which aim at providing comprehensive information. Examples are progressing from exploratory to explanatory and to confirmatory in a dialectical manner; using reflective

practice; and implementing a collective attitude to research. Philosophical features include holding a pragmatic philosophical basis; adopting advocacy in the pursuit of social justice; and embracing outsider-insider viewpoints. Procedural features include implementing principles of systematic research inquiry and employing quantitative and qualitative methods (Ivankova, 2015).

Ivankova (2015) suggests that stakeholders are more likely to acquire a greater understanding of decisions made on the basis of data, recognise the role of evidence-based plans for improvement and encourage the process of transformation of evidence into practice after participating in action research.

The traditional approach of action research methodology noted above is most strongly seen in the initial action steps, being the creation and implementation of the HNEP prior to the decision to undertake the study. Nonetheless, action research methodology remained relevant as an approach during the action steps of evaluation, monitoring by experts, revision to curriculum and reflection on future possibilities (Figure 4.4). This is because it continued the aim of addressing real life problems with the object of changing future practice.

5.5 Data analysis

Data collected from the interviews with the three expert haemophilia nurses were manually analysed to identify themes and patterns in relation to the history and the development of the HNEP. Data from the interviews and focus groups involving the haemophilia coordinators and the RN participants were managed using NVivo10 (Richards, 2009) and were coded using the Kirkpatrick Four Levels of Evaluation (2006) model. Also added was the fifth level introduced by Phillips (2003) and utilised by Sandhusan, Rusynko

and Wethington (2004) to assess Return on Investment (ROI). The complete categories utilised are shown in Table 5.6. An example of coding of data from the interviews and focus groups using the Kirkpatrick Four Levels of Evaluation (Level 1) is presented in Figure 5.3.

Table 5.6 Kirkpatrick Four Levels of Evaluation + Return on Investment (ROI).

Level	Coding
1. Reaction	Satisfaction with the learning process
2. Learning	Increase in knowledge and skills
3. Behaviour	Change of performance in the workplace
4. Results	Impact on the department or organisation
5. ROI	Cost/benefit, includes intangibles

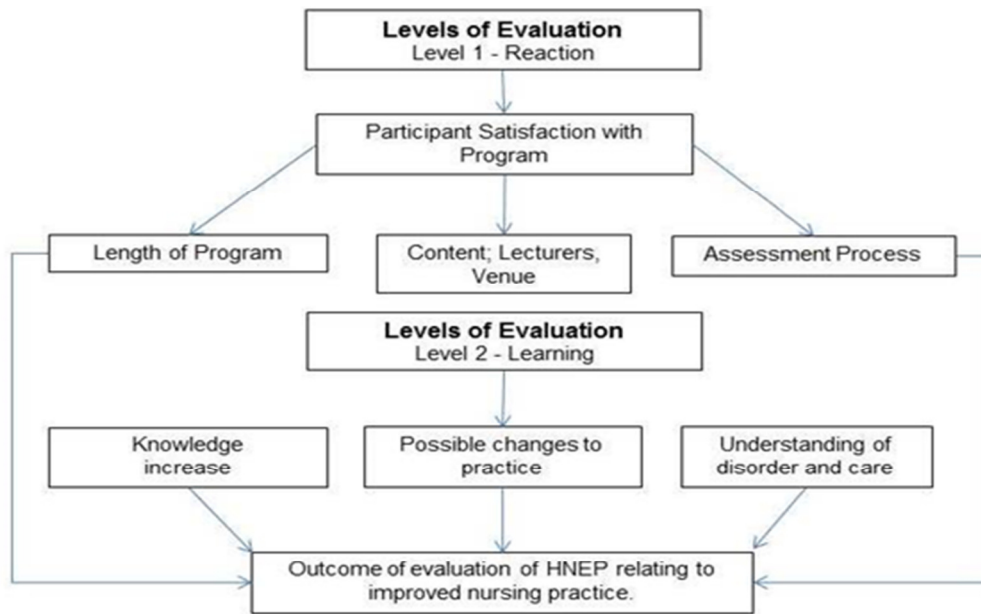


Figure 5.7 Example of coding of data from the interviews and focus groups using the Kirkpatrick Four Levels of Evaluation.

Data collected from the focus groups and interviews support the research questions and align with the Kirkpatrick Evaluation Model. As this is the first time the HNEP has been formally evaluated, there was no baseline from which to judge whether or not any aspect of the program had improved. What was sought in this analysis is the nurses' assessment of the program. Trustworthiness of the coding was achieved by the researcher reviewing and cross checking to ensure that duplication and miscoding did not occur. Further, an individual not involved with the development of the coding system was given four randomly selected interviews in order to verify the coding procedure.

Data from the seven expert reviewers and sourced via a Likert-type scale (Appendix L) were analysed using descriptive statistics (means and frequencies). Analysis was undertaken using the Windows Excel program. Free responses supplied by the experts were categorised by similarity and thus reported. Verbatim comments (quotations) were presented in support of any interpretations made.

5.6 Ethical considerations

Approval to undertake this study was granted from the University of Notre Dame Australia Ethics Committee (Appendix M) and the Ethics Committee from the University of Cape Town (Appendices N & O). Obtaining approval from Cape Town University was a lengthy process as written permission was required from the Directors of Nursing of all participants in the focus groups and interviews before they granted Ethical Approval.

All participants in the study were provided with a plain English statement information sheet explaining the study (Appendices H and J) and were requested to read and sign a consent form (Appendices G and I). The participants were informed that participation in the study was on a voluntary basis and any one could withdraw at any time without censure. The researcher affirmed that all the data gathered from this focus group and interviews would be kept confidential. Participants were informed that no one would be mentioned by name in any report related to this study. To ensure anonymity each participant was allocated a code.

All data generated from the study was stored in a locked filing cabinet drawer in the researcher's home office. Data were entered onto a password-protected computer. Only the researcher and supervisors have had access to the data and transcripts. Tapes and transcripts will be destroyed five years after the completion of the study.

5.7 Chapter summary

This chapter described the method used to collect data for Part One, Part Two and Part Three of the study. The aims of the study were reiterated and the study design and its application to the HNEP explicated. The research questions and the methods used to gather and analyse the data were considered in detail. Validity/trustworthiness was established and

ethical considerations discussed. In the next chapter, results from the interviews with the haemophilia coordinators (Part One of the study) are presented.

Chapter 6

Results and Interpretation (Research Questions 1 & 2): Part One

6.1 Introduction

In this chapter, the results from Part One of the study are presented. The findings from the interviews with the three haemophilia coordinators regarding care for PWH in SA are discussed. The interviews with the three haemophilia coordinators correlate with Research Questions One and Two, the creation and implementation of the HNEP respectively (see Figure 5.1, study design).

6.2 Research question one: Creation of the HNEP

What factors need to be considered when creating a purpose-driven haemophilia curriculum for nurses in South Africa?

Verbatim comments from the coordinators are presented followed by more interpretive comments based upon further dialogue with each coordinator. Coordinator A described the early ambitions of the haemophilia stakeholders (doctors, nurses and PWH and their families) to provide quality haemophilia care which included education of nurses:

The planning for the HNEP goes back a long way, it goes back beyond the immediate time doing it. The seeds were sown as to how can we have a program for haemophilia care in South Africa? However, because I was working at the Johannesburg hospital at the time, there was no possibility for me to move out of my clinic and go and do any outreach work; there was no such thing. I was actually the only haemophilia trained nurse in the country. So I just concentrated on building up that clinic in the way that the WFH [World Federation of

Hemophilia] program worked and because of being allowed to be dedicated to do that, obviously that did grow up into being proper dedicated [haemophilia] clinic. With these things more people [PWH] are getting treated (Coordinator A).

In some respects it is understandable that the SANDoH were slow to recognise and address the needs of PWH in SA since they had to deal with the horrendous aftermath of HIV (Rispel, 2015). The health system in SA was (and still is) fragile, lacking in both financial and human resources. This situation is reflected in the services provided to PWH which continues to need more recognition. Specialist haematology doctors who care for PWH are included in the scarcity of human resources. However, these specialists cannot provide services to remote areas since they are employed by one hospital. Therefore an RN who is educated about haemophilia management provides a valuable service to PWH. Coordinator L explains the inadequate level of care provided to the PWH:

The doctors that are working with haemophilia, looking after patients, first of all they might not be there forever and second of all, they are usually working in very busy haematology/oncology clinics or paediatric units and only 1% of their work is PWH. When they come and see them [PWH] they just see them, they are not giving them advice, they're not giving them home living tips, they're not giving them any advice on how to make their quality of life better or understand the disease so they [PWH] know what to do. They [the doctors] are not able to do any of that [due to time constraints] (Coordinator L).

Many doctors who do not have expertise in bleeding disorders and other haematology diseases are poorly-informed about the management of a PWH, thus consistent mismanagement of cases is a significant issue. In addition, as Rispel (2015) noted, doctors were spending a disproportionate amount of time having to

attend to those with other conditions such as HIV/AIDS, tuberculosis, non-infectious diseases, violence and mental health issues.

When asked about what they considered the most important elements to be included in the curriculum, each haemophilia coordinator had a different opinion. Coordinator A. believed that an understanding of the genetics, family pedigrees and the construction of genograms (diagrammatic form of a family tree) was most important so the nurse participants could “identify people [PWH] and give them a chance of having care”.

Coordinator L, who serviced the Cape Provinces, believed that an overview of haemophilia, the importance of early treatment, and the psychosocial aspect of haemophilia care were the most important. Coordinator B believed that the practical aspect of the HNEP was essential because it would give the participants an opportunity to apply their new learning. All four lecturers (the three coordinators plus the researcher) agreed that it was essential that a curriculum that supported practical training was essential to learning about haemophilia. Coordinator A was determined that the participants would experience haemophilia in a holistic way, “we wanted to add into the curriculum the more practical training like actually meeting PWH and hearing, feeling and knowing what it was from the horse’s mouth” (Coordinator A).

Regarding HNEP curriculum development, this moved along rapidly and it was only a matter of months before the first program was offered. Once the content of the curriculum was decided, and a list of subjects was agreed upon, specific topics were allocated to three of the four lecturers. Coordinator A explains:

We played around a lot with what should be on the curriculum. In the beginning, you will remember, we had lots of things on the curriculum. In fact our course was [nearly] two weeks’ long and it was far too long. We had to cut it back but

we didn't want to miss anything, we wanted to try and think of everything they might need to know about haemophilia.

To avoid a totally didactic approach and to accommodate different learning styles, a variety of teaching strategies were included, such as group work and videos. Preparation of the lectures was undertaken by three coordinators, one of whom was the researcher. The following insight shows how the discussion regarding the need for a variety of presentation modalities remained uppermost in the mind of the coordinators:

We wanted to add not just talking and Power Point presentations but other means of communication so that if you weren't a good listener maybe if you watched a video or did group work, you would get it (Coordinator A).

A great deal of attention was given to deciding which subjects to include in the curriculum. Coordinator A explained "we looked at all kinds of things; we looked at training in hospitals because we are getting candidates from all over the country". The lectures were based on whatever scant literature was available which addressed the nursing care of a PWH. The four lecturers were especially on the lookout for any education program for haemophilia nurses that might be available, but as explained previously, primarily had to rely on their own experience. However, they were cognisant that care should be research-based as the following statement demonstrates, "actually J. [the researcher] taught us how we have to have it evidence-based.....you have to say, does it work for everyone, what's the evidence for that?" (Coordinator A).

Another consideration was that English was not the first language of many of the participants, so care was taken to ensure that the lectures used appropriate terminology.

Coordinator A observed,

“.... for most of our students, English was not going to be their first language. Even though they had English in school, it still doesn't mean to say they could cognitise (sic) those phrases....”

The level at which to pitch the teaching for the RNs was also discussed. Coordinator A proposed that because all the lecturers were nurses, they could teach at a level that would be comprehended by the RNs using a theoretical base which the participants could apply to clinical practice. As Coordinator A stated:

Most of the nurses we were going to be training had been in the field for as long as us. Most of them had come through the system as diplomas and not university students so very practical with a good theoretical base (Coordinator A).

Coordinator L offered the following statement,

“I think that the most important part was trying to make it simple, trying to make it applicable so that you will have someone who is able to use the information and use it wisely”.

6.3 Research question two: Implementation of the HNEP.

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

Coordinator A took responsibility for the overall organising of the program since she possessed a large and diverse network of contacts and was familiar with the SA infrastructure. Frequent emails and telephone conference calls between the researcher and the three SA coordinators ensued. The time difference between SA and Australia meant that the researcher often discussed the HNEP program in the evening to correspond with the time difference between Australia and SA. In later years Skype became the communication medium.

It was decided that the initial HNEP would be held in Johannesburg. However, recruitment of participants would be from further afield, therefore suitable accommodation for the participants and coordinators was required. It was necessary to find a hotel which had a conference room equipped for teaching, could cater for a large group and with accommodation at a price that was reasonable. Land transport was required to collect the participants from the airport, train and bus stations. Additional transport was needed to ferry the participants from the conference centre to the Haemophilia Treatment Centre (HTC) situated at the Johannesburg General Hospital so that the participants could meet with PWH. Coordinator A explained some of the organisational challenges she faced:

But then we had problems with logistics of where do they [the participants] stay, and then how do we get them from A to B and we had to find money for the food. So there was lots of investigation that went on and a lot of time and effort....
(Coordinator A).

The cost of these arrangements as previously discussed, was met by the WFH grant awarded to Coordinator A. Therefore, although participants were recruited from a variety of provinces, attendance was cost-free to employers. These employers would ultimately

benefit from employees who attended the program and be knowledgeable about haemophilia management.

When recruiting RNs, the coordinators targeted hospitals that treated PWH, but where management of haemophilia care tended to be substandard. As Coordinator A stated; “we wanted the candidates to come from hospitals where there were PWH being treated, so they would have key people there who would know how to manage them”.

Despite the support of the SANDoH, local governments also influenced the implementation of the HNEP. The following quotes from Coordinators A and B explain the situation:

You do need the support of the provincial health department to say that they agree that this is a training that must be done. Then it has to filter down from the leadership to say [approve sending a nurse to training] and then the most important thing is to find a key person who’s going to show leadership in the hospital (Coordinator A).

And

If the local doctor of the hospital is not supporting the program then it won’t be implemented. If you can get the interest then the local doctor is the most important person because the local doctor can open up a clinic, can prescribe then it’s easy to get the local hospital and provincial government to support them (Coordinator B).

Recruitment proved to be difficult. Firstly, the Directors of Nursing of targeted hospitals were contacted by letter, providing details about where and when the HNEP would occur and asking them to send a nurse who would benefit from the course and then be able

to bring the knowledge back to the hospital. If there was no response, follow-up telephone calls were instigated. Sometimes a direct approach was required. A coordinator would visit the hospital and ask the Director of Nursing to allocate a RN to attend the program.

Coordinator L.'s perceptions of the recruitment process are representative of the experiences of the other two coordinators:

I think we've always battled. I don't think it's been easy to get the nurses, actually to attend. I would go to every unit, every single manager, it can be sent out from the directorate, from the Department of Health and you still get no response. When bad things happen in the area, I say, 'you have the training why don't you come?' and they don't respond (Coordinator L.).

The hospitals had difficulty releasing a nurse to attend the HNEP because of the lack of human resources to free a nurse from clinical responsibilities. Since the hospitals could not confirm that the nurses could be released, it made the planning and pre-payment of accommodation and catering costs difficult and made relations with the hotel more complicated. Difficulty with recruitment continued for subsequent HNEP intakes, as Coordinator L observed, "the biggest challenge every single time was to get the nurses to the program".

Funding to support subsequent HNEPs was sourced from government health departments in the various provinces. Coordinator A related the difficulties about these departments and allocation of funds.

We demanded that the Health Department pay for their trainees to come themselves because then they [the nurses] would be accountable, they would know that they'd sent them for training and they expected them to work. They

[the various Health Departments] do have money for training – it's to get them to part with it and agree on the costing of it.

Pertinent cultural aspects of care needed to be accommodated and were included in the curriculum. Considered were the use of English as the language of instruction, the variety of ethnic groups represented and the customs of some of these groups. As all the participants spoke English and had received basic nursing training in English, the lecturers expected that the participants would be fluent in English and therefore understand the content of the lectures. However, the use of English for instruction in the classroom was not explored with the RNs in the evaluation process after they had completed the HNEP. Therefore it was not fully appreciated until the researcher conducted the interview with Coordinator B, the BSA, who explained how the use of English affected learning in black South Africans:

....[something] that might be [a] barrier is people not understanding based on the language.... you know English is different and you find for us being black people if you are going to speak English.... you would like someone to speak slowly so you can read their lips...it's not something we grow up talking at home.....

Another issue that emerged from the interview with Coordinator B was that for the BSA, the culture of learning is dissimilar to a western perspective, as she explained:

.... even if it is written, you have to be told again and again and again. I'm not saying that people are not understanding because they take things easy, but you have to tell people again and again.

Some of the traditions within ethnic communities needed to be considered. One of these traditions was witchcraft. Haemophilia Coordinator B related a story of a young boy

with haemophilia whose parents no longer lived together. The mother would bring the boy to the haemophilia clinic but his attendance was sporadic. The coordinator arranged to visit the mother at her home to determine why the boy did not attend the haemophilia clinic. The mother explained that when the boy went to stay with his father, he did not attend the clinic. It transpired that the father and his family were sangomas (traditional healers) and the mother believed that the paternal family had bewitched the boy. The mother related that when the boy stays with her family he is much better and because the father's family did not want the boy to be with his mother, they put a spell on the child. Consequently, the mother was afraid to have another child because she believed that her ex-husband's family had put a spell on her too. The haemophilia coordinator gave her some education about haemophilia but the mother was unconvinced about the origins of her son's condition until she eventually brought him to a haemophilia clinic. At the clinic she found other parents with children, some of whom were white, and as the quote reveals, she began to question the role of witchcraft on her son's disorder. "[She said to me] if this is witchcraft, who has bewitched white people because I saw white people [at the clinic] as well?" (Coordinator B).

When teaching the management of a PWH, the custom of ritual circumcision practices required attention. In the Eastern Cape Province, for example, young men are expected to undertake "manhood ceremonies". This involves a ceremony carried out over several days at a secret location in the bush, conducted by the men from their ethnic group. During that time these young men learn about the traditions and mores of their society, thus honouring their ancestors. One important part of this tradition is the ritual of circumcision. For a PWH, circumcision is a high-risk procedure; and ideally should be performed in a hospital setting. However, many young men believe that by not following the traditional form of initiation in the bush, they are diminished as men, so they choose tradition over safety. This risk factor was recognised by the traditional circumcision coordinators who are

male nurses. The traditional coordinators approached the haemophilia coordinators about education in relation to the management of the PWH who elects to have a traditional circumcision. A modified version of the HNEP was offered to the circumcision coordinators, omitting topics about women with bleeding disorders as they were deemed irrelevant by the haemophilia nurses. However, the circumcision coordinators objected, because they believed a holistic approach to haemophilia care could benefit all members of their ethnic group, not just the males. The following quote from Coordinator L emphasises this belief, “The men in the Eastern Cape said ‘no Sister, this is important, you really must include this as well’ and it’s true, they are going to come across women” [who have bleeding disorders].

Violence in the society was also a topic of discussion during implementation the HNEP. One nurse described how she advocated for a child with haemophilia at his school. This nurse gave information to the teachers about haemophilia and indicated that the child should not be beaten as it could be catastrophic for the child. She stated:

The mothers will even report to me that the child is being beaten at school by the teachers. Then I visited one school to tell the principal that this child is haemophilia (sic) and that the beating is just not allowed. (F/G1, N1)

[Note: F/G = the focus group identifier; N = nurse identifier]

Inadequate infrastructure, particularly in rural and regional areas in SA, undeniably impacts on haemophilia care. This inadequacy emphasised how important it is to educate health care providers. Coordinator B explained the importance of education in this regard:

The [haemophilia] treatment cannot reach certain areas especially if they are far from the hospital setting. I think most important is education. If the nurses and

doctors are not well-educated with haemophilia it really hinders the implementation of treatment in rural areas (Coordinator B).

In SA, especially in regional and remote areas, poor infrastructure impacts on health services and many patients living in these areas travel long distances to access health services. Roads are an important part of infrastructure and it was difficult bringing PWH to the training centre as guest speakers and to ensure their safety and wellbeing. The poor quality of some roads directly impacts on the ability of the PWH to access assistance, as Coordinator B explained: “for haemophilia patients you find that the ambulance system is not reaching those areas and it takes time for them to get assistance with the ambulance.” (Coordinator B). And further:

....when the PWH gets treatment [for a bleed], they go home then they play like a normal person would play. Where they live and play, [for example in the street] the ground is uneven and they twist and they get bleeds often (Coordinator B).

The condition of the roads also affects the ability of participants to reach the HNEP venue. For this reason, the participants needed to arrive the day before, incurring extra financial costs, as Coordinator A identified:

....people might live too far or the roads are bumpy and they have to get up at three o'clock in the morning to get there in time to start the course..... they are just too exhausted to actually listen, too anxious, everything's new and the first day is very important (Coordinator A).

Long distances, poor road systems and poor infrastructure were major issues to consider in implementing the HNEP. The three haemophilia coordinators spoke about how long distances made it difficult to treat the patients who resided in outlying areas. These

distances can be extreme, for example from Johannesburg to Nelspruit it is 326 kilometres by road. This particular part of the country is serviced by a good highway but there are many regional areas with road systems in poor condition. Two coordinators mentioned distance as an issue preventing adequate quality of care to PWH. The frustration of attempting to reach a remote area was expressed by Coordinator B:

Sometimes....when I am going to do outreach I will look at the map before I go and see where I am going. But when you arrive you don't know whether it's this village because there are no signs and you try to phone them, no network. The roads are so bad (Coordinator B).

Poor infrastructure, which includes interrupted electrical supply resulting in power failures are commonplace in SA and can impact on the provision of the HNEP. As mentioned earlier, the lectures are accompanied by Power Point presentations and interruptions in the power supply can disrupt teaching sessions. The following quote shows that the lecturers were aware that there may be interruptions to power supplies and that versatility was essential to overcome this. "Now we've had so much experience a power failure is much easier to deal with. In the beginning we would have been fraught but now I think it probably wouldn't play such a role." (Coordinator L.)

While not impacting directly on the implementation of the HNEP, other insufficiencies can affect the delivery of adequate care for the PWH. For example, participants had been informed about the importance of sanitation but encountered practices that were contrary to what they had learned. The following quote emphasises the despair expressed by Coordinator B, "I went to one village and I asked myself, is this happening in SA? People were drinking water with cows and donkeys."

6.4 Compensations

It would be remiss to leave the reader with the impression that planning for and implementing the HNEP was no more than a matter of grind in overcoming obstacles. Despite the difficulties, all three coordinators related positive experiences in their roles and their involvement with the HNEP. They were fully engaged with their work with Coordinator B describing how she “enjoyed her work enormously”. The haemophilia coordinators related stories which illustrated that education is vital. As previously mentioned, education of PWH and their families is an integral part of managing a PWH. When family members are illiterate and cannot read pamphlets and other educational material, oral teaching is fundamental to health. The following reports the experience of Coordinator B when she visited a remote province:

We had this mother, she is illiterate. She didn't seem to understand anything. In my mind I thought let me teach all the mothers and then we talked to the mothers, every time we talked about haemophilia. When you get to your local hospital tell them that your child is bleeding, when you touch its hot tell the doctor he's bleeding, you have to give his treatment and transfer him to the hospital, you know all those things. The other day we had a World Hemophilia Awareness Day in their hospital and we met her at the gate and she came with us. She said what are you doing here and she hadn't been for some time. She had a baby, a new baby [she said] “I have a baby and I want to take the baby to the clinic but I'm not going to take the baby today I am coming to join you”. That's how she came, she was not prepared. In the hall where we had the Awareness we had the heads of the hospital, we had the matron, we had the student nurses, everybody was there to hear about haemophilia and they didn't have a patient. But S. [the

manager] said as we have this mother of a patient here, we would like this mother to tell you about her child. I got goose-bumps because she spoke exactly how we spoke about haemophilia to her. When she gets to Emergency she says “no, no, no, this is not how you mix it you don’t shake it” [the factor]. You know I nearly cried because you cannot measure what you are doing but with that you can see that something is happening (Coordinator B.).

From its original conception, the HNEP underwent refinements over the years. The importance of having an understanding of teaching strategies is exemplified for Coordinator L. in the following:

The good thing about the course and the way it’s done now.... is the repetition. Repetition from different angles so that at the end all fits together like a jigsaw puzzle. All the pieces fall into place because that one links to that one, links to that one....because you repeat stuff (Coordinator L).

When Coordinator B was asked to provide an opinion in the context of being involved in teaching in the HNEP after it had been well-established, she remarked, “for now I think the program is absolutely perfect.” This response conveys that coordinator B who had been a previous participant in the HNEP, believed the program had provided the necessary information to deliver effective haemophilia care and management.

The three coordinators were asked about their personal gains from their involvement with the HNEP. Responses were:

Firstly, knowledge: I didn’t know haemophilia. Most of all what I got was from the fulfilment after treating them [PWH].... it’s something you can’t explain. Patients come back [and you find] they understand themselves (Coordinator B).

And

It's an extremely rewarding job, I enjoy my job tremendously. Obviously there are hiccups and battles but as you get more experienced you manage them [PWH] better so the job gets better. I think being passionate about it makes it so much better for the patient (Coordinator L).

Also

I've had an enormous amount of self-education through being involved with it [HNEP]. I've learned such a lot because I've had to learn more through my research getting ready for all my talks. I've had an enormous amount of satisfaction in empowering people with knowledge, not only knowledge about haemophilia care, with knowledge about life, knowledge about caring for someone else, knowledge about being ethical, being moral and to be given that platform, I have been absolutely blessed (Coordinator A).

6.5 Chapter summary

This chapter presented haemophilia coordinator insights that illuminated answering Research Questions One and Two. Some of the positive effects of having participated in the HNEP were also relayed. The following chapter addresses the experiences of the RN HNEP participants.

Chapter 7

Results and Discussion (Research Question 3): Part Two

7.1 Introduction

In this chapter, the results from Part Two of the study are presented. The findings from the interviews with the RN participants regarding care for PWH in SA are discussed. The interviews with the RNs correlate with Research Question Three, the extent of HNEP transfer of knowledge, skills and perceptions has occurred (see Figure 5.1, study design).

7.2 Research question three: HNEP transfer of learning

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

Responses to research question three were provided through focus groups and one-on-one interviews with four RNs. Questions asked how effective the HNEP was in allowing them to transfer knowledge, skills and perceptions about haemophilia into the field experiences.

Analysis was conducted using the Kirkpatrick (1975) Four Levels of Evaluation, namely, Satisfaction, Learning, Behaviour and Results. A fifth level Return on Investment (ROI), added by Phillips (2003), focused on intangible characteristics such as competencies, organisational commitment, innovation, and creativity. Being more covert in nature, such characteristics are difficult to evaluate using traditional metric-based procedures. Results in terms of the Kirkpatrick levels + ROI are discussed in what follows.

7.2.1 Kirkpatrick model level 1: Satisfaction.

Of the total number of participants (n=20), nine used the word ‘satisfaction’ to describe the potential of the HNEP to meet their prospective needs. Six mentioned feeling empowered, five stated an increase in confidence and five stated an increase in knowledge about haemophilia. Further information is presented in Table 7.1.

Table 7.2 Kirkpatrick Level 1: Satisfaction with HNEP to Meet Prospective Needs.

<i>Level 1</i>			
<i>Satisfaction</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Satisfaction with teaching content</i>	9	45	<i>When I did the course I have to say it was excellent. (F/G3, N1)</i> <i>[I 2] enjoyed the training, I think it was excellent. They covered everything. (F/G3, N2)</i>
<i>Empowerment</i>	6	30	<i>I felt empowered. (F/G4, N2)</i> <i>Yes, in other ways it also empowers because I think the course itself can help you to have a positive attitude. (F/G4, N5)</i>
<i>Increase in knowledge</i>	5	25	<i>The course developed our understanding and our skills. (F/G2, N2)</i> <i>Since I attended the course, it was an eye opener. (F/G2, N1)</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

7.2.2 Kirkpatrick model level 2: Learning.

Eight of the participants confirmed that they felt more knowledgeable about haemophilia following completion of the program. Four nurses commented that prior to completing the HNEP they had no understanding of haemophilia or the urgency of care required by a PWH. Four stated that they had used the HRF and pamphlets provided at the

course in a clinical setting. Six nurses stated that they were more aware (meaning having a better perception) of the intricacies of haemophilia and had a better understanding of the impact of haemophilia on the PWH. Of the n = 20 participants who were interviewed in either the focus groups or one-on-one interview situation, all agreed that the transfer of new knowledge to clinical practice was potentially invaluable. These statistics, together with examples of statements, are presented in Table 7.2.

Table 7.3 Kirkpatrick Level 2: Learning as a Result of Having Attended the HNEP.

<i>Level 2</i>			
<i>Learning</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Joy in Learning</i>	8	40	<i>It's actually such an easy condition to learning (sic) so yeah no I enjoyed it, I think it was excellent. (F/G3, N2)</i> <i>So lots of information was given, I think it was almost like a doctors course but squashed into one week. (F/G4, N2)</i>
<i>Knowledge pre course</i>	4	20	<i>I went to the course with nothing, no knowledge at all (F/G3, N3).</i> <i>I didn't have any contact with patients with haemophilia prior to the course. (F/G3, N5)</i>
<i>Transfer of knowledge to practice</i>	20	100	<i>It feel very nice to come back in a set up where you can work with a patient and that you can practice what you have first learnt in the course. (F/G4, N2)</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

The following verbatim responses further show that the nurses valued and used the HRF for themselves and others, including doctors, when they returned to the clinical area:

I keep my haemophilia folder with me.... if there's something the doctor will come to me then we'll look up something, it helps a lot (F/G3, N3).

And

All the leaflets & brochures are useful....I constantly refer to that (F/G4, N5). I still use the haemophilia training [book] which were [sic] given to us at the HNEP because sometimes you will do something, you just want to read (F/G4, N4).

Six nurses (30%) articulated that they had a greater awareness of the needs of the PWH after they had completed the HNEP. Examples of this awareness are shown in the following statements:

....made me more aware of the patient's physical and social needs (F/G4, N5).

I gained such a lot especially when I was there and that made me when I came back I could identify the patients with haemophilia, even in our community (F/G3, N3).

I'd heard about haemophilia before, before I did the course but afterwards because I didn't know there were people [PWH] in our area having the condition 'cause I'd never heard about the people (F/G3, N5).

When asked whether the new knowledge they had received from attending the HNEP had helped when they returned to clinical practice to care for PWH, two participants contributed the following experiences, demonstrating how informed they had become:

Working at the gynae [gynaecology] clinic just really opened my eyes - when a woman comes in and say she's got menorrhagia, [heavy bleeding at menstruation] I become very concerned [because this is common symptom of a bleeding disorder] [I 4].

...the most horrific incident that could make you realise what could happen to a haemophilia patient (F/G3, N1).

Participants were also asked if, and how, this new knowledge had made a difference to their practice and how they were perceived by their work colleagues. Two participants volunteered:

[before the training] we didn't have the background [but now] the doctors even listen to you, they don't call the haematologist on call, they ask you (F/G3, N2).

I'd never [given factor] with prophylactic because our doctors didn't know much about haemophilia [so it was not prescribed] (F/G4, N2).

7.2.3 Kirkpatrick model level 3: Behaviour.

Level three relates to if and how the information gained from the HNEP had made a difference to the nurses' competence when managing a PWH. Of the total number of participants (n = 20), there were 39 responses commenting on the increase in competence the nurses felt caring for a PWH. Eighteen participants related how better awareness of the needs of a PWH created changes in perception for the PWH, with many moving from being a demanding and querulous patient to one who was grateful for the prompt and effective treatment received. Moreover, four nurses related how they had, through an exchange of knowledge, influenced a change in the perception of their colleagues towards these patients. Seven of nurses indicated that there had been an improvement in their scope of practice. A summary of these changes in behaviour is presented in Table 7.3 and discussed in what follows.

Table 7.4 Kirkpatrick Level 3: Evidence of a Change in Behaviour as a Result of Attending the HNEP.

<i>Level 3</i>			
<i>Behaviour</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Changed perception of the PWH</i>	18	90	<i>Because we're working such a long time in the clinic they like family to us (F/G4, N2). After the training you just have that little bit of soft spot with them (F/G4, N5).</i>
<i>Scope of practice</i>	7	35	<i>So now after I have done this course I'm able to explain to them [PWH] what is going on then I refer them and they go to hospital (F/G3, N2).</i>

n = 20 interviewed in focus groups.

Identifiers: F/G[x] = Focus Group [x = number]; N = nurse participant.

The nurses also related how their competence in relation to clinical practice had increased following the HNEP. Nineteen stated that they were better able to manage critical incidents in the care of a PWH. The account from one nurse (considered in greater detail in the next chapter) of how she successfully advised doctors about the management of the PWH who was bleeding into his neck, is an example of the competence in the management of a critical incident.

When asked whether they felt competent to manage a PWH, ten nurses replied that the HNEP had encouraged them to advocate for better treatment of the PWH. The following quotations express this level of confidence in practice:

I called the pharmacy and I said to them, this is Christmas Eve you cannot tell me that you don't have factor in the province please get factor [I 3].

So we actually need to format a document to say you know if this treatment doesn't work try that, try that, try that (F/G2, N3). [The patient was] a haemophilia carrier and [had] a HIV issue and we really thought that she must attend our high risk clinic and I even encourage it because this was her tenth pregnancy [I 3].

Eighteen nurses discussed how their attitude towards the PWH had changed once they had completed the HNEP. Two nurses related the profound change in the following way

I really care about haemophilia since I attended the course (F/G2, N1).

.... after the training I just realised you know you must give them also the special care that you give the haematology patient (F/G3, N5).

The participants also discussed how some nurses have a negative attitude to PWH. As the following statements show, this negativity emanated from the nurses not understanding the ramifications of haemophilia:

The course itself can help you to have a positive attitude because there was a very negative approach there [in my workplace] and I felt it did make a difference because I just felt the need to be positive about the whole treatment (F/G4, N4).

Even my Sister [senior nurse] was afraid everybody was like when the patient [with haemophilia] comes, everybody will just have to get a room to go in because we know that if you prick this patient he can bleed and die. So we are afraid of this haemophilia [I 2].

They [the ward nurses] were so mad, why is this woman coming here with the child so often? I said it's not her fault, it's not their fault. Now [I am] explaining

what happened to the child, [with spontaneous] bleeds, about everyday life with the child. Anything can happen and it's not like any normal child (F/G4, N3).

Nevertheless, it was clear that positive changes were occurring, as the experience of one nurse exemplifies:

There are so many patients who are coming in, at least now they're getting help because everybody knows that I'm there and if the patient doesn't get what they're supposed to get then I'll come and then it will not be nice, so everybody is trying their best to do the right thing with haemophilia patient (I 2).

Scope of practice in nursing relates to the extent of the individual nurse's practice and is determined by their education, training and competence to meet the needs of their client group. Seven nurses related how the knowledge obtained from the HNEP had widened their scope of practice. In this instance, the scope of practice of the participants had broadened because by participating in the HNEP, they had received education, training and the opportunity to put the learning into practice. When they returned to the workplace, they became the specialist haemophilia nurse, which in turn increased their competence in the haemophilia client group. They indicated how this increased scope of practice impacted on the care of PWH:

When I came back I could identify the patients with haemophilia even in our community (F/G3, N5).

What personally changed me was my position as a nurse and my impact in the specific clinic where I work (F/G2, N4).

It feels very nice to come back in a set-up where you can work with a patient and that you can practice what you have first learnt in the course (F/G4, N5).

7.2.4 Kirkpatrick model level 4: Results.

Level four of the Kirkpatrick model relates to Results; in this case, how did the completion of the HNEP impact on the institutions, the employees and the available health resources? From n = 20 participants, 21 comments were made about the effect that the HNEP training had had on the service provided to PWH and the subsequent use of resources. Thirty-four comments made by the participants related to the delivery of a more efficient service and nine participants commented on how their delivery of service was influenced by management decisions. Results are reported in Table 7.4.

Table 7.5 Kirkpatrick Level 4: Results Pertaining to Change in Institutions, Employees and Resources.

<i>Level 4</i>			
<i>Results</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Change in service</i>	21	105	<i>Now you find that when you, there is a haemophilia you actually like to include their whole family (F/G2, N2).</i>
<i>Efficient use of resources</i>	34	170	<i>When they call me then I liaise with the haemophilia doctor on call and I liaise also with the doctor which is in ward 20 so that the proper treatment can be given (F/G2, N4).</i>
<i>Management</i>	9	45	<i>I've got a problem with our management side (F/G2, N3). Now in the hospital we must train more nurses because T. is by herself now. [Nurse Manager] (F/G1, N1).</i>

n = 20 interviewed in focus groups.

Identifiers: F/G[x] = Focus Group [x = number]; N = nurse participant.

A change in service such as the establishment of a haemophilia clinic or heeding the advice of a nurse who has attended the HNEP, was mentioned twenty-one times by the participants. The following three examples illustrate the impact of the change in service.

Firstly, there were fewer presentations for bleeding episodes because the PWH was better educated in self-care and take precautions to prevent bleeding, as this quote illustrates:

There is a difference because the patients who used to come on a monthly basis, our doctor [converted them] to three monthly [clinic visits] except for those who really are regular bleeders. Most of them don't come often to the clinic [outside of their regular appointments] (F/G2, N4).

Secondly, prompt treatment of PWH as an outpatient reduced the extent of the bleeding and avoided hospital admission:

Gives a challenge to me so that is why I have to work hard in order to like gear up more with the doctor's help so that we can help the patient to attend to their needs quickly (F/G 2, N1).

Thirdly, appropriate management when a PWH was admitted as an inpatient resulted in reduced lengths of stay. Appropriate management was implemented when a PWH was admitted as an inpatient. By supporting the ward staff and reassuring them that the PWH was receiving adequate treatment, the HNEP-trained nurse contributed towards a positive outcome for the PWH:

He spent two weeks there [in another hospital] without the factor. I think it was five days in my hospital [because he had received appropriate treatment] [I 2].

They [the staff in the clinic or hospital] don't really understand haemophilia but they say they [PWH] have to wait their turn and then I just explain to them.

That was in the beginning, now I don't have that problem anymore (F/G3, N2).

All these initiatives are an effective means of reducing the financial cost of treating the PWH thus freeing up in-patient facilities such as the availability of beds. Participants

were mindful that there had been a positive change in the management of PWH in the hospital where they worked and that they played a significant role in this improvement, as is indicated by the following quotes:

There is a huge improvement on the [haemophilia] work in XXX Hospital (F/G4, N3).

I think we are doing a very good job with the patient now and in the hospital also (F/G2, N4).

We also have input in the care of the patient by guiding the doctor, “what about this, what about that” (F/G2, N3).

The quality of treatment as a whole is much better than it was before (F/G3, N5).

In total, participants identified 34 changes which had occurred in haemophilia management resulting in more efficient use of the health resources available. The following statements identify the more significant – with key words being *italicised* – of these changes:

Even the nurses in OPD (Outpatients Department) know that in that cupboard there is factor for this *patient* when he comes. When he says I’m coming for my factor they say ok here’s your factor (F/G1, N2).

[I said to the pharmacist] “the PWH did not receive any *factor* because you [the pharmacist] don’t have factor in stock” and then this woman [the pharmacist] will phone around and she will call me back and tell me “no, phone your patient and tell your patient to come and fetch the factor” [I 3].

I asked Prof before the clinic to go and give some information on women with bleeding disorders to the gynae [gynaecology] *doctors* and ever since then the *management* of women who are bleeding in the hospital has really changed [for the better] [I 1].

I can remember in the past we had haemophiliacs in hospital in the school holidays, the whole *school holidays*. Now we don't see that anymore (F/G4,N5).

Nine of the 20 participants had identified that there has been some resistance from hospital management to provide leave for the HNEP trained nurses to attend meetings to educate or provide outreach care. Outreach is defined as the provision of information or services to a group or individual in society who otherwise may not be able to access the information or services. These participants expressed frustration at management for not considering the importance of outreach care:

When I request a certain date to attend a community meeting or whatever and sometimes like when we need to take another person for the training it's like he [the nurse manager] doesn't understand why (F/G2, N3).

We have asked for an extra one [nurse to work in haemophilia clinic] for almost two years at the hospital but they don't have the money to provide it (F/G2, N1).

7.2.5 Return on investment: [Level 5].

The fifth level, Return on investment (ROI), was added to the Kirkpatrick model by the researcher. This level considers the value of intangible measures when engaging in a cost/benefit analysis of the outcomes of an education program. Examples of intangible components of a program are leadership, advocacy, informal sharing of new information

(Phillips, 2003). In the case of the HNEP, the following intangibles were identified within two specific areas: benefits to the PWH and gains to the individual nurse.

7.2.5.1 ROI benefits to the PWH.

Table 7.5 identifies the eight main intangibles that emerged from focus group dialogue and one-on-one interviews. These are discussed individually with verbatim comments indicating the significant role that intangibles play in having well trained haemophilia nurses in situ. The data identify important factors such as the realisation by the PWH that a nurse with haemophilia education will understand their needs and they can develop a relationship, resulting in a better level of care. The nurse can advocate for the PWH, educate him and his family about self-care and instruct him to become proficient in accessing veins and sterile technique to enable home therapy. For some PWH, with this knowledge, a critical bleeding episode can be averted.

Table 7.6 Return on Investment: Benefits to the PWH.

<i>Level 5: ROI</i>			
<i>Benefits to PWH</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Recognises the nurse can help</i>	13	65	<i>He was excited to know that now there's a nurse who knows his condition (F/G1, N2).</i>
<i>Improvement in care</i>	3	15	<i>The quality of treatment as a whole is much better than it was before (F/G3, N2).</i>
<i>Develop a relationship</i>	6	30	<i>I think they're also used to us (F/G 4, N1).</i>
<i>Advocate for self</i>	3	15	<i>This boy was really instructing the Sister [I 4].</i>
<i>Home therapy</i>	8	40	<i>If the mums observe the child [having the port needed] they can be confident [that they can needle the port] (F/G 4, N1).</i>
<i>PWH who have died</i>	3	15	<i>Many women that we normally lose after delivery through certain bleeding problems [I 3].</i>
<i>Effect of treatment</i>	6	30	<i>The improvement is much, much better and the education also because the bleed is less (F/G3, N4).</i>
<i>Nurse advocacy for PWH</i>	19	95	<i>I did insist that the patient get the factor first; first treat them then get them to get the scan because the bleed could continue in that time (F/G4, N5).</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

Thirteen nurses spoke about how the PWH understood that once the nurse had completed the HNEP, they had the skills and ability to help them. The following quotes by the participants indicate how they and the PWH have benefitted from the nurse attending the HNEP:

I get phone calls from (sic) other problems they've got and at least I can refer them to someone else if I can't help them (F/G3, N5).

The patient when they come [to the hospital] they know that there's Sister F.
[who will be able to help] [I 2].

We also had a case where the patient was sent away from the hospital and I
was phoned half past ten in the evening, so I phoned the hospital [to explain
that the PWH needs treatment and to not turn him away] (F/G3, N2).

She had the Caesarean section eventually she came back to me to say the
baby is negative [for HIV] and also the baby does not, is not a (sic)
haemophilia [I 4].

Three nurses recognised that the haemophilia training had made a beneficial impact
on the care of the PWH. One of the significant benefits was professional support, as these
comments indicate:

The fact that after I did the course and [now] they've got someone at least. [For
example] I will phone the ambulance on their behalf and explain.... it's easier for
the patients to get help now than it was before (F/G3, N2).

It's always nice to have someone specific you can contact. Because today
that one's on duty, tomorrow it's another one on duty and if you've phoned the
hospital if you've got someone specifically to phone then I definitely think it's,
the quality of treatment as a whole is much better than it was before (F/G3, N5).

It's definitely better if you have someone specifically that you know I can phone
this person and she will be able to know what to do. Be able to phone someone
else or ask (F/G3, N1).

Six nurses described how they developed a relationship with the PWH and their family and how this relationship resulted in the PWH having more confidence and trust in the health system. These participants related how this relationship improved care:

I built a relationship with the family because of the fact that our paediatrician has explained to them the product that we're using here in South Africa [is similar to the one they are used to using in the UK] (F/G3, N2).

Now she's one of the mothers who is always coming to me when she goes to the clinic because the baby is, the boy is now 3 years old and he is on prophylaxis and it's really nice to work with such a mother [I 3].

Education from the haemophilia nurse has informed the PWH and his family of the importance of self-care when a bleeding episode occurs. If the haemophilia nurse is not present at the time of admission to hospital, the PWH has been taught to self-advocate, which gives them the confidence to insist that they receive the correct treatment. Six nurses related how the patients (PWH) demonstrated this self-advocacy when placed in a situation when they were not satisfied with the treatment given. Examples of comments include:

This one lady said to me, "I want to know what is haemophilia because when we got to the accident scene we wanted to put on a drip but this boy said to us 'please don't touch me just take me to XXX Hospital' " [PWH to ambulance officer] [I 3].

This boy was really instructing the Sister and telling her how to draw the factor telling her "I don't want bubbles in my body so you must be very careful" [I 3].

Eight nurses described the advantages of home therapy for the PWH and their family. Home therapy allows the PWH, or their parent/guardian, to manage a bleeding

episode when in the home environment. Treatment can be given promptly at home, thus reducing the incidence of a critical or prolonged and damaging bleed. Such a strategy also serves to minimise disruption to the family and the individual and to ensure safety, as the following quotes show:

Our people really love it, [the preparation for home therapy] the washing of the hands ... (F/G4, N4).

This mum.... she came in she demonstrated to a group of [haemophilia] people how to prime the port and give the factor through the port (F/G3, N3).

Unfortunately, due to mismanagement of the PWH experiencing a bleed, death could be the outcome for the PWH. Nurses with haemophilia training find such a situation extremely difficult because they know that a death was probably avoidable. These three nurses (15 percent) express their sadness when patients die unnecessarily.

When we are releasing the balloons [to celebrate Haemophilia Awareness Day] we'll be thinking of the patients that we've lost through some haemophilia event [I 4].

The many women that we normally lose after delivery through bleeding. [I 4].

[There are] patients that are undiagnosed because we've got many bleeding disorders [I 3].

Competent management improves quality of life for the PWH. Six nurses discussed how good treatment has made a difference to some PWH. The PWH is better informed about how to recognise a bleeding episode and can seek treatment early, thus preventing complications. Home therapy allows the PWH more autonomy and reduces the need to attend the hospital or health centre for treatment, causing less interruption to school or work.

Haemophilia education can allow the nurse to advocate on behalf of the PWH when an intervention is necessary, thus ensuring that bleeding episodes are treated adequately and appropriately:

If it's someone say with haemophilia, that is as I say rather easy to treat, and that the treatment can make such a huge difference in the patient's life and in the quality of life that they have if you treat immediately (F/G3, N5).

Of the 20 nurses who participated in focus groups, 19 described how learning about haemophilia had invested them with the confidence to advocate for the PWH in a crisis situation. All 20 participants recognised that a PWH requires assistance 24 hours a day, seven days a week. To accommodate this, all the nurses interviewed carried their own personal mobile telephone. This allowed the PWH or hospital staff members to contact them when the PWH needed urgent treatment. The nurses admitted that they paid their own phone bills and were not recompensed for the use of their phones, thus indicating their commitment to the welfare of the PWH.

As stated, some doctors did not know about the treatment or management of PWH. If this is the case, the nurse must advocate on behalf of PWH to ensure they receive the correct management. To confront a doctor requires considerable courage and tenacity, as nurses do not usually instruct doctors about patients' treatment regimens. An account of this advocacy has been related by a nurse and is presented as a case history in Chapter 8.

7.2.5.2 ROI benefits to the individual nurse.

Six nurses expressed how they had developed skills such as outreach work (where the nurse leaves the hospital and takes healthcare to people in the community) and teaching about haemophilia. They also described how being able to help the PWH provided them

with satisfaction in the work they were doing. From the data, Table 7.6 outlines the variety of ways that the nurses believed they had gained from completing the HNEP, which are then described in detail. These gains are differentiated from Kirkpatrick's Level 1, Satisfaction, which describes the participant's satisfaction with the HNEP program.

Table 7.7 Return on Investment: Benefits to the Individual Nurse.

<i>Level 5: ROI</i>			
<i>Gains to the nurse</i>	<i>No of responses</i>	<i>%</i>	<i>Examples of statements</i>
<i>Teaching other professionals</i>	32	160	<i>we share information....during the ward round. (F/G3, N 2).</i> <i>I'm able to educate the nurses in my hospital about haemophilia. [I 2].</i> <i>what to tell the doctor... (F/G3, N2).</i>
<i>Know PWH better</i>	4	20	<i>They can relate to you (F/G3, N3).</i>
<i>Improvement in the health of PWH</i>	17	85	<i>Even the family will come to you and thank you because they can see there's a difference now [I 2].</i>
<i>Skills: outreach</i>	6	30	<i>This was my first outreach, so far from my hospital [I 4].</i>
<i>Job satisfaction</i>	8	40	<i>I was also happy because if I didn't intervene that patient would have stayed in that hospital without the factor and then we don't know what would happen to that patient [I 2].</i>
<i>Influence of nurse</i>	7	35	<i>You know your presence there in that room at that moment made the difference in the child's life (F/G3, N2).</i>

n = 20 interviewed in focus groups and one-on-one interviews.

Identifiers: [I] = Interview data; F/G[x] = Focus Group [x = number]; N = nurse participant.

The nurses interviewed indicated how important the role of teaching was for those with knowledge about haemophilia. Four of the 20 nurses spoke about educating doctors.

Although doctors are considered better educated than other health care workers such as nurses, when a nurse who has received education about haemophilia management from the HNEP attempts to inform doctors, this action possibly will not be well-received by some doctors. Nevertheless, the nurses understand that they must attempt to educate other healthcare professionals about haemophilia management as illustrated by these examples.

We managed to teach the medical staff [I 1].

At the emergency unit we were helping the newer doctors, so we do a lot of training (F/G4, N2).

Since PWH came into contact with nurses and a range of other allied health professionals such as pharmacists, dentists and physiotherapists, who were involved in the management and care of PWH, it was important that the health professionals understood the significance of symptoms and the management of haemophilia. Six of the nurses realised that they were responsible for educating these staff members who would be part of the team caring for the PWH, as these statements indicate:

After I finished the course I did some training in XXX Hospital with most of the staff (F/G3, N1).

After I finished the course I did some training at the hospital (F/G3, N5).

Regarding home therapy instruction, it is essential to teach the PWH or parent about sterile techniques in order to reduce the risk of infection. Haemophilia nurses are usually the front line personnel who provide instruction in appropriate technique. The nurses also ensure that the PWH or parent understands the need for correct dose of factor replacement, how to prepare the solution, when to administer factor and what to do in the event of a bleeding episode that is not improving. To learn venous access is not an easy task and the

PWH or parents require on-going support and encouragement from the haemophilia nurse both during the learning process and when the technique has been mastered. The same applies to other nurses who may not be familiar with the correct technique. Three nurses described their involvement in this process:

Patients...have also been teached (sic)...how to do home therapy (F/G3, N5).

My colleagues that work with me obviously I inform them and give a little bit of training with them (sic) (F/G3, N5).

[If] the nursing staff they don't know how to mix the factor they will always phone [me] and ask over the phone (F/G4, N1).

An important role for the nurse with haemophilia training is to be able to educate the PWH and their family about the disorder. If the child is very young when diagnosed, the parents are supported in their learning to understand haemophilia. Ten nurses described the experience involving teaching the parents of the PWH about how to manage the disease. The following insights are illuminating:

Teach (sic) the mother about haemophilia care and the disease and she was compliant [I 1].

My two patients are trained, they know what they will tell the doctor, even if they need an ambulance they will tell the ambulance that 'I must go to XXX [hospital], don't take me there' [to another hospital] (F/G3, N4).

[I explain to the PWH] the Sisters won't know if you don't tell them that you are from a family where there's boys with haemophilia [I 1].

After they had completed the HNEP, the participants had a better understanding of how the experience of haemophilia impacted on the lives of PWH. They were able to empathise which helped them to gain the trust and confidence of the PWH. In addition, the nurses could manage the situation during a bleeding episode or a crisis, engendering in the PWH confidence that the nurse would know how to help them. Four nurses related how their interactions with PWH improved as a result of them having participated in the course:

I came to know my patients better (F/G1, N1).

There's a better relationship between me and the patients (F/G3, N2).

They [PWH] can relate to you (F/G3, N4).

Seventeen of the nurses believed that their expertise had improved the health and well-being of the PWH. The following quotes are indicative of this belief.

The patients will come straight to you and say, "Sister I want you to treat me" (F/G3, N1).

Acknowledgement that you can accept as a haemophilia nurse to know that you had thought right (sic) in a specific patient treatment to make him feel better (F/G3, N2).

So I was also so happy because there are so many patients who are coming in, at least now they're getting help because everybody knows I'm there [I 2].

Outreach is considered an acceptable means of reaching the wider community who may not otherwise have access to health information. World Hemophilia Day raises awareness in the community about the disease of haemophilia. This awareness is especially important when factor supplies are plasma-derived as the supply is dependent upon blood

donations from the community. Celebrating World Hemophilia Day, one nurse was able to educate pupils at the school of a PWH and then raise awareness by organising a street parade highlighting haemophilia. As she indicated:

In 2009 for our World Hemophilia Day celebrations we went out on an outreach to Kimberley [I 3].

[Kimberley is a city located in a remote region of Northern Cape in SA]

This is one example of a nurse using outreach to broaden the services of haemophilia. Six other nurses also spoke about increasing their outreach skills.

It was evident that some nurses working with PWH found utilising their new skills very satisfying. Eight nurses expressed job satisfaction, with the following quote regarding professional fulfilment being fairly representative of the group:

The fact that you know that someone can call you.... I can just tell whoever is on the other side “just send them in immediately to XXX [hospital] or XXX” [hospital] (F/G3, N4).

Of the 20 nurses interviewed or in focus groups, one nurse held a senior management position, with seven of the other nurses believing that nursing management had an influence in haemophilia care. One nurse indicated how she worked directly with management to help with the organisation of a significant haemophilia event:

When we’re preparing for World Hemophilia Day I request[ed] that she [another nurse] has support (F/G1, N1).

7.3 Chapter summary

Research question three asked about whether there was a change in knowledge, skills and perceptions of RNs since undertaking the HNEP. Focus groups and one-on-one interviews were utilised to gather data from the RNs who had completed the HNEP and were working with PWH. Responses were organised around Kirkpatrick's Four Levels of Evaluation (1975) + Phillips (2003) Return on Investment (ROI) concept.

The next chapter presents three critical incidents which elaborate on how a nurse who had completed the HNEP was able to intervene at critical times for a PWH. The critical incidents are also included to provide the reader with a more comprehensive understanding of the conditions under which the haemophilia nurses work and the challenges that they encounter.

Chapter 8

Three Critical Incidents in Support of Study Part Two

8.1 Introduction

Three critical incidents were selected from the participants interviewed in the previous chapter. The critical incidents demonstrate different situations when an RN, who had completed the HNEP, was engaged in culturally complicated interventions. Although the cases are different, together they demonstrate the advocacy role of the nurse. In each instance, decisions were taken that could be considered courageous and would probably (on the basis of the information presented in the previous chapter) not have been made without the benefit of the knowledge gained from the HNEP. The three critical incidents emphasise the danger to the PWH if not treated promptly and appropriately.

8.2 Critical incident 1: The need for cultural sensitivity

This critical incident concerns the circumcision of an adult male with haemophilia. The procedure of circumcision is undertaken for cultural reasons and demonstrates the possible associated problems for a PWH. Historically, African societies have been socially organised for millennium into groups who share cultural standards and beliefs about socio-economic, technology, cultural values and governance issues (Konare, 2004). According to Halloran (2004), culture is a system of shared knowledge and practices which are significant to groups within a society and to the individual as a member of that society. Shared knowledge includes beliefs, norms and values while practices encompass language, law and kinship mores. One of these cultural rites is circumcision, a private ritual, performed by certain members of the tribe.

To safeguard confidentiality, the nurse in this critical incident will be called Steven. He completed the HNEP within the past five years and regularly provides a service to haemophilia patients in the hospital where he works, in the Eastern Cape Province of South Africa.

Steven was asked to relate the most memorable event related to a PWH and the part he played in the management of this individual. He told the story of a young Xhosa man who wished to undertake the traditional manhood initiation ceremony common to his tribal customs. The young initiates, all males, are taken into the bush for several days or weeks and instructed in the initiation rituals, including circumcision. This practice is widespread in the Xhosa population and is supervised by traditional practitioners who are bound by the provincial Eastern Cape government legislation known as the Application of Health Standards in Traditional Circumcision Act 2001. The Act promotes the use of hygienic standards and good conduct when the manhood ceremony is undertaken by the traditional practitioners during traditional initiation rituals (Meissner & Buso, 2007). In accordance with this law, traditional practitioners are required to be recognised and registered with the Eastern Cape Department of Health (Peltzer, Nqeketo, Petros & Kanta, 2008). Halloran (2004) writes that culture creates an opportunity for the individual to acquire a sense of personal value by adhering to the cultural values of the social roles, personal values and conduct that the culture stipulates to stave off fears of social isolation.

For a PWH, the risk of bleeding after surgical intervention, even a minor procedure, is high unless factor replacement is administered prior to the intervention and at regular intervals afterwards, until healing of the wound has taken place. Steven was well aware of this risk when he began to plan how best to manage this situation. Risks are increased because the rituals are carried out in secret and attended by the traditional coordinator, the

traditional doctor and the traditional nurse, none of whom had any knowledge or training about haemophilia. To complicate matters, these rituals were carried out in a remote location in the bush on a mountain far from medical help.

It was clear that this traditional ceremony had great significance to the young man, Thabo, and his family. Although he had severe haemophilia B, Thabo was "...adamant he wanted to go to be circumcision in the mountains like his forefathers, his uncles and the rest of his family" (Steven).

Steven was unfamiliar with this young man because he attended the haemophilia clinic in another hospital in the same province. A nurse from this clinic telephoned Steven to inform him that Thabo wished to undergo the initiation process in accordance with the custom of his father's family. Thabo had been reared by his mother and had spent most of his life in Cape Town. However, for traditional reasons he returned to his place of birth so that his foreskin could be buried there.

Steven advised Thabo and his mother to meet him so that a full assessment could be conducted. Baseline blood tests and a general check-up were performed on Thabo to ascertain his health status. The blood tests would determine whether Thabo had inhibitors or sexually transmitted diseases. Steven hoped to use this opportunity to convince Thabo to have the circumcision at the hospital in a clean theatre. However, Thabo was adamant that he would undergo the traditional ceremonies in the bush: he was steadfast that he wanted to follow his culture. He stated, "I want to go and circumcise in the mountains". This emphasises that circumcision is an important ritual and regardless of Thabo having haemophilia, he was determined to adhere to his culture. Steven understood that if they consent to a clinical circumcision performed in a hospital, the young men are "not regarded as real men and are stigmatised and subjected to all sorts of ugly things".

Steven acknowledged that the culture and traditions were important to this young man, however, it was imperative that Thabo realised that there was an element of danger associated with circumcision in the bush, requiring untested procedures with no precedent to use as guidelines. Steven decided to call in a local circumcision coordinator to help explain the position to Thabo and his mother. Steven commented, “my own background coming from a predominantly coloured population and my patient coming from a predominantly Xhosa culture, I had to respect his [Thabo’s] wishes.”

A precise plan needed to be devised to accommodate Thabo’s requests. After much discussion with Thabo and his mother, managers of the hospital and the CEO, it was agreed to offer assistance to enable Thabo to undertake a cultural circumcision. Permission was granted for Steven to travel to the bush near the town of Cofamvaba to administer factor IX to Thabo at the time of the circumcision. The traditional circumcision coordinator, the registered traditional doctor and the registered traditional nurse would be present for the circumcision but since Steven is coloured (of mixed race heritage) and would be bringing western medicine into a traditional setting, permission from the tribal elders was required. Steven was aware that he would be a guest at the ceremony; saying “me not being African coming from [XXX] my forefathers, I am welcome there as a [XXX] and they are happy that western medicine can be brought into the circumcision camp”. Steven's recognition of the importance of maintaining tradition is clearly evident from this comment.

A further setback to the ceremony plans was due to a delay in the return of blood results which caused more anxiety. Thabo’s mother was anxious about whether her son had HIV or other infections. The tests results were negative and she was relieved. Apart from anxiety about her son's health, Thabo’s mother had made a substantial financial investment in this traditional ceremony for her son. She had bought new clothes for Thabo and for the

ceremony. Liquor and food must be provided so she purchased a sheep and a cow, to be slaughtered to honour the forefathers. Steven's expertise and knowledge of haemophilia care helped to allay her fears and validate her spending.

Steven made every endeavour to ensure that Thabo could be initiated in the cultural tradition, despite misgivings about the safety of undertaking such a procedure on a PWH. He successfully negotiated with the health authorities to release him from his hospital duties so he could accompany Thabo. He worked diligently to support Thabo's mother and her anxiety about her son's health and that the money she had spent on the traditional manhood ceremony was not wasted. He effectively negotiated with the Xhosa traditional circumcision personnel to allow him to attend to Thabo during the ceremony even though he understood the taboos surrounding the presence of non-Xhosa individuals at these ceremonies.

Finally, with the preparations in place, the traditional coordinator and Steven drove to the hospital close to where the initiation rituals were to take place. At the hospital, Steven was introduced to Thabo's father and to the local traditional coordinator, the traditional doctor and the traditional nurse who would be conducting the ceremony. Steven gave Thabo the prescribed first dose of factor replacement intravenously. Following this, the initiates and their mentors departed on foot for the mountains. Left behind, Steven became very apprehensive about the well-being of his patient. The following words exemplified that Steven was taking a huge risk which he worried may not pay off, "this was my first outreach so far from my own hospital". Then, the enormity of the situation was realised:

....something went through my head and I started to cry. I thought, what is going to happen to this young man. It's such an urgent mission, it's not just an

outreach, this is a first circumcision that we are treating with no clinical trials we know and this young man led away into the mountain and he's standing on the other side of the river.

He continued to worry. His haemophilia education and experience caring for PWH, alerted him to the potential for excessive bleeding after circumcision and there was no immediate support should anything go wrong. The circumcision is performed in the traditional way with a spear and Steven knew that this crude instrument could increase the likelihood of excessive bleeding. His anxiety was justified. Peltzer, Nqeketo, Petros, and Kanta, (2008) described how circumcision in non-clinical settings carry a risk of complications such as haemorrhage, infection, mutilation and death, thus supporting Steven's concern about the welfare of Thabo.

As Thabo and the other young men were led up the mountain, Steven described how "cold shivers" went down his spine. He phoned his wife and then his mother, asking them to pray because he was so apprehensive that something would go wrong. As they drove back to town from the river, Steven asked the coordinator, his guide, several times about the amount of blood loss with traditional circumcision. The circumcision coordinator assured him that the blood loss was normal; "no my friend, don't worry, the blood loss was like any other one, nothing, there was no excessive blood loss."

That afternoon, Steven and the coordinator drove back to the village close to where Thabo was staying to administer the second dose of factor to Thabo to significantly reduce the risk of excessive bleeding. As they drove, it began to rain. Closer to the village they found that the rain had been heavy in that area. Creeks were in flood, bridges were under water and roads damaged. Eventually they had to leave the vehicle and walk. Upon reaching the rendezvous site, they found that:

...the little stream was turned into a river. The village was situated in a valley and all the water was running down the mountain and the little stream which we crossed very easily in the morningwe couldn't even cross it.

At this point Steven's anxiety increased. He called the haemophilia coordinator in Cape Town for help and advice as he could not contact the haemophilia doctor by telephone. The doctor returned Steven's call after receiving the haemophilia coordinator's call: "Dr M said 'no, it's not worth it, risking your life going across that river'." Steven and the coordinator decided to return to the town but when they reached the vehicle, Steven's fears for Thabo intensified. Thabo needed to have the second dose of factor to ensure that he did not bleed post-circumcision: "I started to cry and this is the first time I mention it now to anybody".

Despite the advice he received from Cape Town to abandon the project, Steven was convinced that it was necessary for Thabo to receive his second dose of factor. He informed his companion of his decision to return to the river and try to cross it. His companion cautioned Steven to be very careful and tried to discourage him. However, Steven was convinced that he needed to find a way to Thabo. He carefully packed the factor and implements to administer the injection in a carry bag and strapped it around his waist. He and the coordinator then headed back to the river bank to find a way across. The next paragraph describes the difficulties Steven faced to cross the river:

I said to Mr [XXX] you go to your left I go to my right. About one kilometre upstream I saw these big rocks, boulders. I didn't see it in the morning when we was [sic] there because I was just looking, it was not necessary to look up and then I saw them myself. I can see that rock but how deep it is down there and there's the same, never tested the water with both feet but as I was putting my left

foot I could feel another boulder and Mr [XXX] was screaming to me “Steven please don’t slip, if you slip there you are gone”. I managed to cross the dam.

The two men found the crossing treacherous and were exhausted from the effort. Eventually, they proceeded up the mountain to find Thabo. It was still raining, there was thick cloud on the mountain and sometimes they lost sight of each other. They were relieved to smell smoke and then finally found the hut where Thabo was staying. Steven questioned the traditional nurse about Thabo’s welfare. The nurse was perplexed about why they had returned: He had applied the traditional dressing made of leaves and said there had been no bleeding. Steven explained why another dose of factor was important and subsequently the second dose was administered. Steven and his companion decided to wait until the rain had stopped and the river water had receded before attempting to return to their vehicle. There was no mobile phone reception at this place and Steven began thinking about what could have happened:

What went through my mind is that if the PWH get a huge bleed because of not receiving this dose. Number one how would the ambulances reach the place now and number two we’ve got a shortage of almost everything in [this province]. It was a do or die situation.

Steven stayed in the area for several days until Thabo had completed his initiation with no complications and was invited to the initiates’ home-coming ceremony, a privilege which is afforded to very few outsiders. Unfortunately he had to decline because he knew he needed to return to his workplace.

Steven described an incident that occurred a little later as the most embarrassing part of the story. He was approached by a local magazine who wanted to write his story. He was not in favour of this because he was concerned about violating Thabo and his family’s

confidentiality. However, the newspaper were more interested in why Steven found the courage to cross the swollen river to ensure the welfare of a young man in the mountains in such conditions. He replied that it was because there was a young man who had his future in front of him and that he (Steven) was very fortunate to be privy to this ceremony. He stated:

God was looking after me and people praying for me to reach that man.if I never had the insight or the interest in haemophilia I could have stopped this thing in my clinic already and say listen, I am doing haemophilia in the clinic.....not outside the hospital. But in respecting the culture of another person and going beyond the call of duty, going to the authorities and saying you must put pen to paper and say yes or no you cannot go, and assist this young man.

The following quote emphasises the humility of this nurse. When asked about his feelings in relation to the incident, Steven said, “the incident itself I don’t really talk about, it means nothing to me as long as this young man’s life has been saved”. And, “this could have been done by anyone who had the courage and to really consider haemophilia as an important part of nursing throughout the world.”

Also,

As a haemophilia nurse you must always put your patient before yourself and really the training I received from [HNEP coordinator] and [HNEP coordinator] and the other [HNEP coordinator]... I think is one of the best and I’d do it again.

Steven wrote a report to the authorities which he considers helped to raise awareness of haemophilia among management at his hospital and the importance of having nurses

educated in haemophilia care. He believes they are now working together as a team for the betterment of PWH. An example of this is the case of twin brothers, one of whom had traditional circumcision last year and his brother, who is factor VIII deficient and will undertake the initiation program later this year. This young man is better prepared than Thabo. His parents are well-educated and he attends the haemophilia clinic regularly, understanding his condition well. When he becomes an initiate, the ceremony will take place locally and if the hospital management agree and sign the indemnity, Steven is willing to attend and assist if required.

8.3 Critical incident 2: Advocacy in the face of a haemophilia emergency

This critical incident demonstrates how a RN who had completed the HNEP was able to challenge the management of a PWH in a crisis situation. In essence, the case demonstrates the confidence of the RN to advocate for the patient. To maintain confidentiality the nurse is given the pseudonym Amanda.

Advocacy is defined by Macquarie Dictionary (2013) as “pleading for, supporting or recommending” (p. 15). Within the nursing profession, advocacy for a patient is an accepted part of the role of the nurse and is incorporated into the International Council of Nurses (ICN) Code of Ethics which states: “The nurse shares with society the responsibility for initiating and supporting action to meet the health and social needs of the public, in particular those of vulnerable populations” (2012, p.2).

Amanda lives and works in SA, and currently facilitates clinics for PWH. Amanda completed the HNEP in 2009, and is currently employed as a haemophilia coordinator based in Johannesburg, supervising and mentoring nurses in haemophilia care in several provinces. Amanda stated that since completing the HNEP, her capacity to advocate for the patient has improved greatly, stating, “being haemophilia trained nurse has helped me a lot

with advocacy”. To demonstrate how the HNEP has influenced her practice, she related two situations where, without her advocacy, the PWH almost certainly would have died.

The first case concerns Tom (a pseudonym), a four year old boy who has severe haemophilia A. Tom was the first child in his family to be diagnosed with this disorder. Once the diagnosis was established, the nursing staff educated Tom’s mother about haemophilia care. She was informed about how to recognise a bleed, how the disorder is inherited, how to administer first aid when a bleed occurs at home, when to contact the haemophilia treatment centre staff and what situations will almost certainly provoke a bleed. The mother was very compliant and brought her son to the HTC when necessary. Unfortunately, Tom had veins that were difficult to cannulate and only one doctor at the HTC was able to regularly accomplish venous access. After some months, Tom’s mother married and moved to another province with her husband. There was a small hospital but no staff, doctors or nurses, skilled in haemophilia care. This situation for Tom became more critical because of the difficulty in venous access, which caused some concern for the staff.

A short while after the relocation Tom’s mother contacted Amanda to inform her that her son had an elbow bleed and she had taken him to the local hospital. The doctors admitted Tom as an inpatient but were not prepared to accept the parents’ word that Tom had haemophilia, so due to Tom’s inaccessible veins, the doctor decided to take blood from his neck. The site where the needle was inserted continued to bleed and the child’s neck was increasing in size. The parents tried to inform the doctors and nurses that the bleeding was due to haemophilia and emphasised that the bleeding would not stop without the correct treatment, that is, factor replacement. The medical staff refused to listen. In desperation, the mother called Amanda and asked her to speak to the doctors at the hospital. Amanda tried to do this but a member of the nursing staff assured her that Tom was improving and

there was no need for Amanda to speak to the doctors. The next day Tom's father visited the boy and was so concerned that he also phoned Amanda. The father said; "his neck (Tom's) is as big as his head" and Amanda realised there was a very large haematoma on his neck.

Recognising that Tom was in imminent danger of an obstructed airway due to a haematoma, and as the nursing staff continued to prevent her from speaking to the doctors, in desperation, Amanda phoned the doctor at the nearest HTC. The response to Amanda's concern was immediate. Arrangements were made for a helicopter to transfer Tom to the HTC facility as soon as possible. Here the boy was appropriately treated and recovered within days. As Amanda stated, "I don't think if I was not haemophilia trained I could have managed to follow up and make sure that the boy gets the right treatment."

Following this terrifying incident the parents and the medical staff at the local hospital began cooperating and working together to ensure that Tom received the correct treatment should he have another bleed. For Amanda this collaboration was a positive outcome. She stated:

.... being able to help the boy survive, it makes me feel very good, and it was not only the process of helping the boy survive but we managed to teach the medical staff, the parents and everybody who was involved so that makes me feel good that at least I've helped someone.

According to Beyea (2005) nursing advocacy is critical to maintaining patient safety while they are in the care of the health system. Mallik (1997), a British nurse who conducted a review of the literature of nurse advocacy agrees, suggesting that if a nurse should be in a similar situation and believed their professional knowledge was central to the decision-making process, then patient advocacy was appropriate. However, Mallik (1997)

cautions that the nurse would be required to have “knowledge of ethical decision-making” (p. 135) in order to apply the advocacy role.

8.4 Critical incident 3: Advocacy in the face of doctor’s resistance

Amanda related another incident that had a similar level of seriousness in terms of patient morbidity. The event occurred during the Easter break when there were reduced staffing levels. In this situation, Amanda had to deal with a challenging doctor. Amanda was well aware of the difficulties that may arise, stating, “since this boy [pseudonym, Jim] has been diagnosed we have dealt with this doctor who he [PWH] has been taken to and he’s not an easy person”.

Jim suffers from severe haemophilia and inhibitors. His mother contacted Amanda to say that he had injured his neck and that it was swelling. The family understood the urgency of the situation and rushed him to the nearest hospital. However, the treatment for inhibitors was not available. Amanda spoke to the doctor and asked him to send Jim to a hospital where treatment for this condition was available. She was aware that the doctor was obstinate, and that a difficult situation could occur. According to Mallik (1997), the need for advocacy arises when there is an unequal balance in power relationships between the vulnerable patient and the professional in control in the particular context. This situation reflected such an unequal balance but Amanda was cognisant that she must be an advocate for Jim and his family.

After some uneasy dialogue between the nurse and the doctor, the doctor agreed to send the boy to the hospital which had a supply of factor for inhibitors but would not acknowledge there was any urgency and admitted Jim to the ward at his hospital overnight. Throughout the night Jim’s neck continued to increase in size. Clearly, this was a crisis situation and as the hours passed, the bleeding continued. Amanda felt that there was a

problem with the doctor acknowledging that Amanda, as a nurse, knew the risks involved in delaying appropriate treatment better than he did, so chose not to treat the case with any sense of urgency.

When Jim was finally transferred to a hospital with available factor, the doctors were horrified at the severity of the boy's condition because according to Amanda, "he was already drooling saliva and the neck was big and they wanted to take him to ICU." The doctors telephoned Amanda to check that it was safe to transfer the boy to ICU. Amanda indicated that it was, on the proviso that they continued to give Jim the factor. Two hours later, they again contacted Amanda to inform her that they wanted to transfer the boy to a large metropolitan hospital, where there was a dedicated HTC, as they were concerned that the treatment was not working quickly enough. Amanda strongly advised the doctors to keep the boy at their hospital and to continue to give him factor. If the transfer took place this would cause an interruption in the treatment which could increase the risk of further bleeding and a real danger of airway obstruction. Convinced by Amanda's assessment of the situation, the doctors kept the boy at their hospital and continued to administer factor. This action is in stark contrast to the first doctor who saw Jim and continued to keep him under his care even though he did not have the necessary treatment that the child so desperately needed. Amanda knew that she may well be faced with opposition from the doctors or that they may simply ignore her advice but that she had to be insistent in order to do all that she could to save Jim's life. Her experience in the second hospital renewed her faith in the fact that there are doctors who do respect the expertise of haemophilia nurses.

The next day, when Amanda phoned and enquired after the boy's well-being, she was informed there was no change in his condition. By the time Amanda phoned again in the evening, Jim had made a slight improvement. The next morning, Amanda was informed

that he was out of bed and playing. She was relieved that his condition had greatly improved and there was a plan to discharge him the next day. On hearing this news Amanda stated:

That made me realise that my training is very important, being a haemophilia trained nurse is very important because I wouldn't be able to ask them about the symptoms of this boy. When they told me that he's drooling saliva I knew that it was serious.

Kohnke (1980) advised that the nurse needs a mix of "personal qualities and specific education for the role" of patient advocate and that they need to be "innovators and risk-takers" (p. 135). Mahlin (2010) supported this view by stating that nurses face challenges when advocating for patients, as the institutionalised system that prevents patients from accessing appropriate health care, also impacts nurses, as was the case in this incident. In the following statement, Amanda concurs with the above viewpoint, stating, "I feel very happy to realise that at least I can help the patient and also by just giving advice, the patients are able to be saved."

8.5 Chapter summary

The incidents related in this chapter serve to demonstrate the actions two nurses, who had completed the HNEP, took to mitigate a crisis situation in three separate incidences involving PWH. The physical bravery of one nurse to provide treatment in a dangerous geographical location, and the strong sense of advocacy in the other nurse, almost certainly saved their lives.

The next chapter details the data collected from the expert nurse educators in the service of evaluating the HNEP. Data were collected in Australia as this is where the researcher resides and locating herself in SA for this phase of the study was not necessary.

Chapter 9

Results and Discussion (Research Question 4): Part Three

9.1 Introduction

This chapter presents the data of evaluations collected from the seven expert nurse educators. Research question four sought to determine whether the HNEP teaching program was suitable to teach nurses in developing countries about haemophilia diagnosis and management. The experts were asked to evaluate the contents of the HRF and complete a survey (Appendix L). They were also asked to complete a free response section where any more general strengths and weaknesses could be identified.

9.1.1 Research question four: Evaluation of the HNEP by expert nurse educators.

How robust is the purpose-driven haemophilia curriculum when subjected to expert evaluation?

To answer this question, the expert educators were each provided with a copy of the HRF. The HRF contains the HNEP curriculum. The contents of the HRF have been detailed elsewhere (Section 3.5).

9.2 Survey Responses

Expert nurse educator responses to the survey items are presented as frequencies and percentages and values generated using an Excel program (Table 9.1). The Table shows a column for “neither agree/disagree”. Although there was no capacity on the actual survey for such a response, one of the respondents nevertheless chose a neutral option, placing a

mark between “agree and disagree”. As this action was not compliant with the instructions, the researcher chose to discard those three replies in any analysis.

It appears clear from Table 9.1 that the vast majority of experts indicated a positive response to the categories being evaluated. These data are presented in a different form by way of a stacked bar chart (Figure 9.1). This visual representation indicates a very positive response from the evaluators with regard to the categories assessed.

Table 9.8 Frequencies and Percentages from Survey Data.

<i>n = 7 Experts</i>	<i>Strongly Agree</i>		<i>Agree</i>		<i>Neither Agree/ Disagree</i>		<i>Disagree</i>		<i>Strongly Disagree</i>		Σ (f)	<i>n=7</i> (%)
	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>	<i>f</i>	<i>%</i>		
<i>Objectives appropriate¹</i>	1	20	4	80							5	71.4
<i>Contents relevant</i>	5	71	2	29							7	100
<i>Evidence based</i>	1	17	4	66			1	17			6	85.7
<i>Purpose stated</i>	5	71	2	29							7	100
<i>Outcomes realistic, measurable, achievable</i>	1	17	3	50			2	33			6	85.7
<i>Logical presentation</i>	4	57	3	43							7	100
<i>Appropriate to RNs in SA</i>	1	25	1	25			2	50			4	57.1
<i>Teaching strategies actively engage the learner</i>	1	14	2	29	1	14	3	43			7	100
<i>Summative evaluation</i>	2	29	4	57	1	14					7	100
<i>Power Points clear, uncluttered, readable from 10m</i>	1	14	5	72			1	14			7	100
<i>Package user-friendly</i>	3	43	3	43	1	14					7	100
<i>Handouts are a valuable resource</i>	4	57	3	43							7	100
<i>File learning/teaching resource</i>	5	71	2	29							7	100

Not all experts chose to answer every question so the sum of the frequencies for some questions does not always add up to seven. This is reflected in the last two columns of the Table.

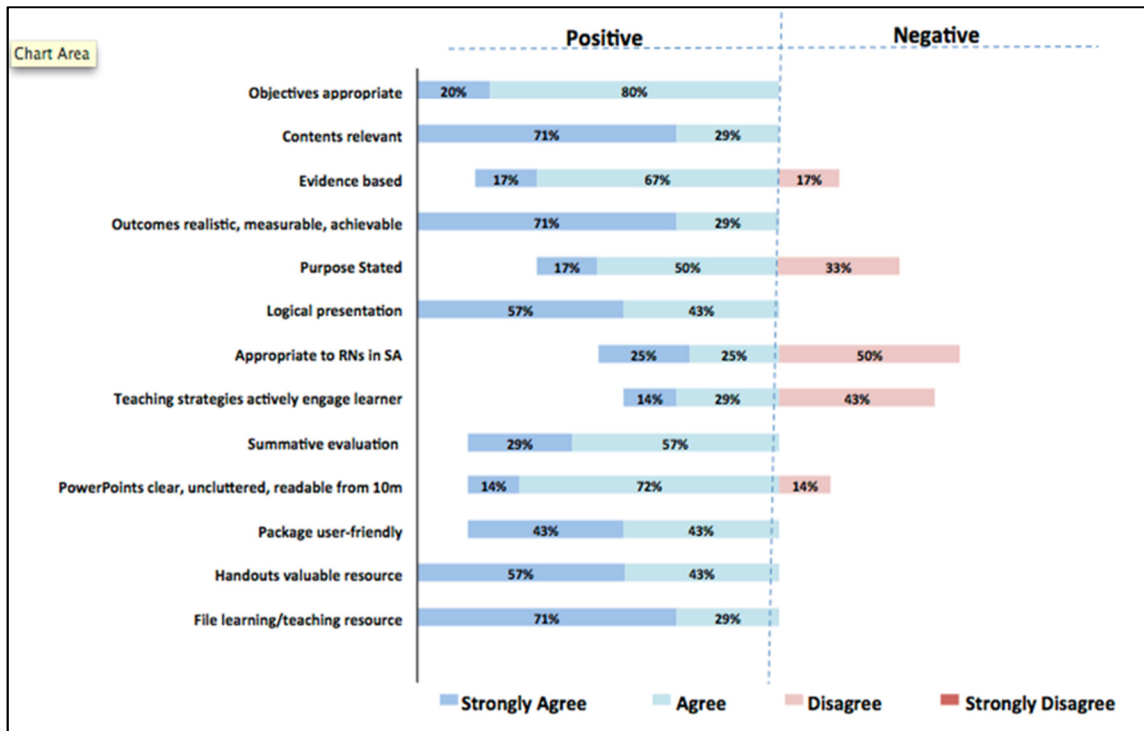


Figure 9.11 Expert evaluators' assessment of the HNEP criteria under investigation.

The greatest spread of disagreement centred on “Teaching strategies actively engage the learner”. Such an outcome may have occurred as a result of the experts not being familiar with the strategies suitable for learning in the present context, or there may have been variability in interpretation regarding the category. Nevertheless, with three of seven experts disagreeing with the statement, this aspect of the HNEP will have to receive further attention prior to the next course being offered.

A further observation is that “Outcomes realistic, measurable and achievable” and “Appropriate to RNs in SA” do not rate as highly as the other categories. Again, this may have resulted from unfamiliarity with the SA context and the capabilities of the participants. Regardless, these categories will also have to be subjected to further scrutiny prior to the course being offered again. It is significant to note that “handouts are a valuable resource” scored highly. This is pleasing, as during focus group sessions, several of the nurses indicated that they subsequently copied handouts to distribute to PWH.

Further interpretation of these results is possible. The open-ended questions throw greater light on the results found in Table 9.1.

9.3 Open Ended Question Responses (n = 8)

In addition to the survey the expert nurse educators were asked to respond to eight open-ended questions (Appendix L). The first three questions asked experts to provide an overview of the HRF. The next four questions were related to the content of the HRF; and the final question asked about the appropriateness of the pedagogy for the present cohort. The questions are now addressed separately. Coding used for expert identification has been presented previously in Table 5.5.

9.3.1 HRF overview questions (1-3).

- a) *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?*

All respondents agreed that the breadth of information required had been achieved and the information followed a logical sequence building from basic to more complex material. JT-R stated that adult learning principles had been observed and MH noted that there was sufficient information to permit the RNs to provide “safe and effective care”. MB acknowledged that teaching the subject (haemophilia) was approached from a variety of perspectives focussing on information relevant to nurses. One of the African experts, LK, remarked that the HRF was well-summarised within the overview followed by the pathophysiological, diagnosis management and complications of haemophilia, which were provided in a clear way. SA expressed the opinion that the HRF was very comprehensive package and AB described it as “robust and comprehensive”.

AB noted that the Table of Contents relates a strong biological approach which could be adjusted to include inquiry-based learning using scenarios and case studies to encourage student centred learning. A further comment about the Table of Contents identified that the language used does not align with the content of the lectures which “may confuse the learner”. AB further identified that the role of the nurse in haemophilia care should be placed at the commencement of the course thus reflecting the importance of the nurse in the care of PWH.

While one expert MH approved the inclusion of information about HIV, he questioned why hepatitis B was not included. Three experts, MH, MB and LK commented that they would liked to have seen more information about psycho-social support for PWH, and MH suggested that end-of-life issues could be addressed. One expert educator, SA, was critical of the amount of content the participants were required to learn over the four and one half days program, commenting that the participants were inundated with a great amount of material in the first three days. She conceded though that the final two days concentrated more on applied information rather than introducing more new information.

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

Four experts, BS, LK, MH and MB acknowledged that the curriculum was based on international standards, guidelines, protocols and current practice. However, JT-R noted that it was difficult to know about current evidence because the referencing was inconsistent and some of the existing references were more than five years old. Three experts, MB, SA and AB commented that the references were not always cited and MB pointed out that the Power Point presentations did not display references. One expert, AB, commented that there appeared to be no evidence-based approach to the content of the HRF, noting that

protocols relating to best practice were not apparent. Furthermore, AB noted that web-based links, protocols and best practice references should be provided, regardless of availability of technology to access these references and that instruction of research methods and evidence-based methodology be included in the curriculum.

Another expert, SA, while concurring with the above comments, suggested that if references were not available, that the lecturers could be satisfied with “eminence-based contributions”. MH made three suggestions that may improve the HRF as a learning tool and resource by proposing that: Firstly, a list of references could be included; secondly, a list of indicative reading may be helpful but also acknowledged that this may be difficult to access in the setting and; thirdly, that key material could be made available as a resource pack.

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

BS, LK and SA agreed that the stated outcomes were achieved and JT-R noted that the outcomes were clear and easy to understand. JT-R further commented that the individual lesson outcomes may be more difficult to achieve, as she felt 30 to 60 minutes was too short to allow in-depth discussions and explanations for complex topics. MH strongly agreed that outcome one, which addressed the physiology of haemophilia and the consequences if not treated; outcome four, the range of treatment modalities; and outcome six, the role of nurse as educator for PWH and their families, were strongly reflected in the program. However, this expert felt that the psychological, economic, ethical and social implications of bleeding disorders, represented in outcome two, and the range of therapeutic skills and nursing interventions for holistic care of PWH, family and friends, as embodied in outcome three, were not achieved. The suggestion was made that greater emphasis on the

theoretical aspect of living with haemophilia, including end-of-life care, could have met these outcomes. MH also suggested that outcome five, which addressed the research supporting best practice in haemophilia care, was not fully reflected, nor was there space made for analysis by students.

MB commented that the theoretical outcomes were achieved but therapeutical skills less so. This expert proposed that the summative examination could have been more “hands-on” using, for example, a Modified Objective Structured Clinical Examination (OSCE). SA agreed that the outcomes and content were in accord but added the following comment:

Outcomes should have included higher level outcomes encouraging nurses to use the info they have gained in terms of application, problem-solving & evaluation rather than pushing in more lower-level knowledge (SA).

9.3.2 HRF content-based questions (4-7).

d) Please comment on whether the content is pitched at an appropriate level for the educational status of RNs in developing countries.

BS, MB and LK believed that the HRF was pitched at a suitable level for RNs in developing countries. In contrast, MB was concerned that the more complicated topics such as coagulation may need simpler models and more visual aids to help explain the complexities of the subject. Moreover, MH proposed there was a great deal of didactic content in the HNEP and suggested that a wider variety of teaching methods based on activities would promote deeper learning. Further comment from this expert was that as the content required a high level of theoretical and scientific knowledge of anatomy, physiology, pathology and pharmacology, that it may be pitched at a level above the

capabilities of RNs in developing countries. This opinion was supported by expert SA, who stated:

I have concerns based on personal experience in SA, that the RN's lack sufficient background in science to understand some of the more complex physiology (SA).

Although not familiar with the educational status of RNs in SA, JT-R cautioned about generalising across developing countries and cultures. She believed that educators needed to be aware that there are differences within the nursing profession not only from country to country but also within a country, therefore it was important to avoid making assumptions about knowledge levels when working cross-culturally. She further suggested that although the language used in the HNEP is probably acceptable for RNs in SA, this may not be so in a different context.

AB pointed out that the national principles and qualification structure and the SA competency standards for a RN should govern the learning level for the HNEP, thus determining the education requirement of RNs entering the course and the suitability of the course content. Therefore, it was suggested, screening to ensure that the RNs have adequate educational levels should be carried out prior to the candidate undertaking the HNEP. AB asked further questions:

- For how long does the qualification remain valid?
- What responsibilities does the course provider have to the professional body?
- What is the length of time a course runs for before a formal review is undertaken?
- Is there an annual review processes and reporting requirement? If so, to whom?

e) *The HNEP has introduced new terminology. Do you perceive that this would be an issue for these nurses and if so, in what way?*

Five experts, BS, MB, LK, SA and AB agreed that the introduction of new terminology was appropriate so long as it was explained and discussed during the delivery of the HNEP. BS suggested that as the haemophilia terminology was used over the five days of instruction that it was presented in a supportive environment which would allow the participants to become familiar with its use. Another expert, AB concurred, saying that if the terminology was widely used in haemophilia that the RNs should be exposed to it in a supportive environment and when there was an opportunity, such as during the HNEP. Two experts, SA and LK remarked that new terminology was not an issue "...because at the level of an RN they have to comprehend these new terminologies" (LK).

SA and JT-R pointed out that the new terminology may only be a problem when the RN returned to work and none of her colleagues were using it. One expert, MH did not identify any new terminology. AB suggested that new terminology and other pertinent material such as acronyms be provided in a glossary, thus guaranteeing consistency in haemophilia nursing practice.

f) *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?*

All of the experts agreed that the HNEP had begun with foundational learning building to more complex topics. One expert, SA, believed that more time should be allowed for the participants to assimilate the new knowledge before proceeding to the next topic. This expert was concerned about the lack of physiology in the program and suggested a pre-course could address this shortcoming if there was insufficient time to include it in the

four and one half days of instruction. The following quote from one expert (MH) offers an interesting suggestion:

Could there have been more formative opportunities for checking the participant's learning before moving into the more complex material? There may have been space for quizzes and other strategies to enable consolidation of learning and an opportunity to assess the student's learning needs, with room for flexibility within the program so as to adapt the teaching strategy and content accordingly (MH).

AB agreed that foundational learning was followed by more complex topics but pointed out that the lecture on the role of the nurse in haemophilia care could have been introduced much earlier in the course.

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

Two experts, MH and SA, commented that the HRF was comprehensive, aptly supported by notes, and easy to navigate. Expert BS found that the information was presented in a logical fashion, allowing learning goals to be met. MH suggested that the file was a good resource and MB commented that the teaching plans standardised the key elements of the HNEP which could then be added to each Power Point. SA stated that as the HRF was predominantly word-based, some participants may have a problem with the written content, particularly in the context of below-standard literacy levels and English being the second language for the majority of the learners. LK and AB would have preferred to have more practice-based activities added.

However, JT-R found that the format of the HRF did not “spark interest” with the layout difficult to read. She further commented that the HRF appears to be a series of

lectures put together with no consistency or framework, which needs to be addressed if the HRF is to be promoted as a learning tool. JT-R suggested that all Power Point presentations should be accompanied by written notes. AB added that it was essential to include web addresses, electronic and hard-copy references to clinical guidelines and protocols to provide a wide-ranging package of information resources. AB also commented that there was no evidence in the resource package that indicated that there was a holistic approach to patient and family care.

Two experts, MB and JT-R suggested that a pre-test would indicate the participants' level of understanding about haemophilia prior to the commencement of the program. MB suggested that the participants could also be asked about their expectations of the program

9.3.3 HRF pedagogy-based question (8).

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

Three experts, JT-R, MH and SA, commented on the predominantly didactic approach of the HNEP pointing out that in their experience, this does not promote critical thinking, complex problem-solving or abstract thinking. Five experts, JT-R, MH, LK, AB and SA, suggested that more activity-based learning would be beneficial although MB remarked that while group activities would have been beneficial, “cultural factors may inhibit student-led approaches”. Two experts, JT-R and SA noted that there was a great deal of information presented which in the context of the time allocated for the HNEP could be overwhelming. SA commented that too much foundational information at the beginning of the program risked losing the participants' interest and LK wanted more strategies implemented to engage the student and maintain interest, although did not make any suggestions regarding how this could be achieved.

While two experts, JT-R and SA commented on the large number of Power Point presentations, they also noted that some of them were “busy” and overcrowded, thus providing limited value. In contrast, MB found the Power Points well-constructed and interesting. LK noted that the teaching strategies and tools used were appropriate and two experts, BS and MB, agreed that interest is maintained due to the variety teaching methods. MH disagreed, noting that a “greater variety of teaching strategies” could have been employed.

JT-R commented that the use of scenario-based learning promotes understanding. AB agreed that the use of scenarios and “shared story-telling” was important in learning settings and that “simulated erudition” could be considered. Another suggestion was the concept of peer mentors so the participants could support each other once they returned to the workplace.

AB suggested that “future courses should undergo self-assessment as part of the evaluation process”. This could be achieved it was suggested, by increased governance on the part of the organisers which could benefit the HNEP by introducing the following structures:

- application of current quality assurance processes as required by the peak haemophilia body;
- monitoring and review of processes and the implementation of quality improvement;
- placing a template at the beginning of the file showing program structure, course outcomes, method of instruction and hours of completion;
- itemising the tools used for course review, such as evaluation, teacher assessment, course needs analysis and how these influence the ongoing development of the course;
- involving course partners to ensure the course is current and to decide on national principles and anticipated results;

- supervising the qualification and education experience of staff delivering the course, thus contributing to information about course quality.

9.4 Chapter summary

The evaluation of the curriculum and content of the haemophilia learning package by expert nurses revealed that generally the teaching was satisfactory although some individuals had reservations about evidence-based information, including too few active learning opportunities and the level of scientific learning required by the RNs. The next chapter presents a discussion of the findings in relation to the previously established theoretical framework.

Chapter 10

Discussion in Relation to the Theoretical Framework

10.1 Introduction

This chapter presents a discussion of the findings from Chapters six to nine (Parts One, Two and Three respectively). The discussion is structured around the theoretical framework presented earlier in Chapter four (Figure 4.2), namely, taking into account the models proposed by Leininger, Watson, Knowles and Kirkpatrick.

10.2 Leininger's Culture Care Theory (CCT)

Leininger's (1997) contention that a culturally competent nurse respects the cultural beliefs of an individual in planning and implementing their chosen health outcomes underpinned the HNEP. MacFarland and Eipperle (2008) highlighted how culturally competent nursing care embraces a holistic approach and is not a separate entity in the care of an individual but an integrated element of the entire care package. Such an approach encompasses the physical, mental, emotional and spiritual care of PWH and their families.

Leininger chose the term "enabler" to depict the diagrammatic form of the CCT (Chapter 4, Figure 4.1). While the researcher acknowledges the holistic approach to the CCT, only those elements that were congruent with the data collected have been referred to in the present study. These elements focus on the influencers that were found to impact on the HNEP and the nurses implementing haemophilia care, of which environment, economics, education and technological factors were the major influences. Each of these is now considered.

10.2.1 Environment.

Leininger (2002) refers to the environmental context as the entirety of events, situations or experiences that influence people's understandings within a geographical, spiritual, socio-political and technological setting. Participants lamented the fact that they could be providing a far more effective service if extra resources were provided. They were however, realistic in recognising that such would take a long time to eventuate. The reality of existing in SA's townships exposes the vulnerable, such as black women (including nurses) and PWH (especially children, the elderly, the disabled), to gang violence, no running water or sanitation to their homes, unreliable power supplies and unpaved, potholed and uneven street surfaces. Furthermore, although health centres are available to many of these townships, the poorly-maintained clinic buildings, overcrowding due to large numbers of patients and broken equipment inhibit the ability of staff to deliver a satisfactory level of healthcare. Nevertheless, nurses do their best they can and HNEP training allows them to operate at an optimum level given the prevailing conditions.

The potency of Leininger's transcultural nursing theory was evidenced by some of the stories related by the PWH during the case study training part of the HNEP. Stories confirmed that PWH possess their own set of shared values such as beliefs, language, ethno-history and behaviours. An example of this culture in action included reference to an active bleeding episode being [termed a "bleed"], where a PWH knew how to manage his condition more effectively than healthcare workers (self-advocacy) because they had learned to look after themselves and attend to their own needs. An example of ethno-history being exhibited was at times when there was no factor replacement available and so PWH avoided culturally mediated behaviours such as refraining from games (that were likely to cause a trauma or damage to a joint) and delaying procedures such as circumcision. Aspects

of the HNEP course covered the need for nurses to be sensitive to cultural mores and to consider these as far as possible when delivering treatment.

10.2.2 Economics.

There was one finding from the study that articulated especially well with Leininger's culture care contentions. This related to "economic factors" in her "Sunrise" model (Figure 4.1, Chapter 4). The study found that socioeconomic factors, especially unemployment, consequent poverty and sub-standard housing, play a huge role in the health provision that is received. In a context of disadvantage, the poor appeared to create their own "culture" and one to which the haemophilia nurse carers had to earn the right to be invited. A culture of suspicion tended to prevail and this made the nurses' job more difficult than it might otherwise have been. Such economically induced inequity is difficult for a government to remedy given the economic fragility of the country itself.

The ability of government to generate sufficient funding to deliver infrastructure and other determinates of health appears to be hampered in developing countries. South Africa is no different in this regard. Added to this are unexpected outbreaks such as HIV and cholera which further deplete available economic resources. Funding restrictions that impacted directly on the HNEP were varied. One example was the difficulty in obtaining payment from the provincial health departments to fund the cost of accommodation and registration for the nurses to be sent to the HNEP. As one coordinator observed, "the course that I had the previous year was quite hard because I think for the provinces to pay was quite an issue" (Coordinator L). A further economic impediment was the inability of PWH to access clinics because they had insufficient funds to pay for public transport.

10.2.3 Education.

Through the HNEP education program, the RNs reported an increase in their skills and knowledge about haemophilia, which in due course changed their perceptions and opinions of PWH. This is perhaps the most pleasing aspect of the course – that information provided had transferability, longevity and the ability to create a change in consciousness. Participants not only became culturally aware of the living habits imposed upon PWH but actively sought to advocate on their behalf. One nurse participant applauded that fact that the HNEP had made a great deal of difference to how she approached her task of providing care for a PWH:

Mine [nursing colleagues] are very bad, some of the nurses, even myself before I did the course, there was this attitude of “who are these [PWH] coming in and ask them [nurses] why did they have to come for this time”, unaware they need immediate treatment when they come (GS1/N3).

Concern about nursing education was expressed by one expert educator who had personal experience of teaching RNs in SA. The concern related to the level of understanding by RNs of science topics. This was a justified consideration given that the HNEP included aspects such as the physiology of coagulation and genetics. Another expert expressed the opinion that the level of academic competency could be ascertained by perusing the regulation and accreditation standards in nursing education in SA. Unfortunately, although a strategic plan for nursing education in planning and practice in SA was mooted in 2013/4, with the aim of implementation in 2015, it has still not been instigated (Armstrong & Rispel, 2015), so up-to-date requirements for nursing standards are not available at the time of writing.

Armstrong and Rispel (2015) also found that there is a shortage of nurse educators, further adding to the burden of providing training. Additionally, they found that nurse educators lacked modern teaching skills and grappled with resource limitations similar to health facilities, such as access to technology. Further challenges reported by the researchers included weak leadership, poor teamwork, lack of emphasis on PHCs and competencies that did not align with patient needs. Such a perspective resonates with one coordinator's experience:

Without haemophilia education they will always tell you it's too expensive they were trying to save by giving him factor then he would be sent back home. The hospital manager was very angry saying No! No! No! This is too much for a knee bleed and this child's not even getting better (Coordinator B)

When surveyed about who they believed was responsible for nursing not being prioritised by health entities, nurses blamed the SANC who seemed disinclined to liaise with other government bodies, and the SANDoH for lack of planning, coordination and implementation. The provincial health departments who are responsible for "grassroots" health facilities such as PHC clinics were considered fragmented and low in morale (Armstrong & Rispel, 2015). It is in this environment of poor nursing governance and lack of health resources that the RNs practice what they learnt from the HNEP. Despite some of the participants not having a preferred level of education, Coordinator B indicated that the HNEP lecturers "try to make sure everyone understands. That person will leave with so much confidence and they will learn more when they get to their [clinical] area".

Already discussed are the education levels of the four haemophilia coordinators of which two had no university-based education. This deficit resulted in an incomplete understanding of the importance of evidence-based practice supported by research,

references, teaching and learning strategies and evaluation of teaching programs. However, the HNEP was created originally by four haemophilia nurses with extensive clinical skills in haemophilia care. It was encouraging to see theory and practice were beginning to synergise in the minds of the coordinators. This process also meant that as time progressed, the learning pattern that had now been established would likely be embellished into the future. This would eventually enable them to perhaps offer a train-the-trainer type of course to help address the lack of haemophilia nurse educators. It was heartening to hear Coordinator B, who had joined as a HNEP lecturer after completing the HNEP course, saying “I am telling you the people who are giving the education are really good”. In time, she may become just as good herself.

10.2.4 Technology.

In Leininger’s sunrise “enabler” model, technological factors encompass sophisticated machinery such as imaging technology, computers, mobile telephones and computers for databases. Sadly, the RNs in SA did not have access to much of the technology that is associated with health care in developed countries. Almost without exception though, they did have mobile phones and used them extensively in their work with PWH. After-hours phone calls from a PWH and communication of problems involving these patients from work colleagues came up regularly in focus group discussions. One RN articulated the need for her mobile phone, “so the doctors know I am the link, the link to other communications” (F/G 3, N2). The national haemophilia database is electronically managed and updated regularly with new information about PWH. But the use of computer technology is not always available to nurses caring for PWH, especially in the more remote areas without internet coverage. When computers were available, they required required servicing and help-desk assistance. Resolution may take weeks or longer in rural areas.

Consequently, the nurses often have to work around the technology in offering the required service to the PWH.

Governance is the term used to describe the culture and institutional environment in which the norms and values of public affairs are administered in a transparent, inclusive and responsive manner (UNESCO, 2016). Findings from this present study have added further detail to Leininger's sunrise "enabler". Leininger's model does not specify governance and management as influencers and her culture care theory and the sunrise enabler does not refer to the impact of poor governance on health. It could be argued that politics and legal factors encompassed in the sunrise enabler are more closely related to the making of policies rather than the oversight of operational aspects of policies. Sound governance is considered a necessary condition of an environment in which poverty reduction and sustainable human development can thrive. Good governance was deemed one of the United Nations Millennium Development Goals aimed at promoting participation, transparency, accountability, effectiveness, equity and lawfulness (United Nations Educational, Scientific and Cultural Organisation – UNESCO, 2016). Management is a component of governance, principally in place to operationalise the planning, implementation and monitoring of organisations within the guidelines set by the governance bodies. In developed countries this is usually undertaken with the assistance of sophisticated technological software with accountability structures being built into any governance protocol. In SA, creating a comparable mechanism of due diligence still has some way to go. Consequently, the trickle-down effect of potential benefits to grassroots level, such as haemophilia nurses, often does not occur.

It was evident from the present study that broader cultural context is an extremely important factor when preparing to support a PWH. As such, the decision to give it strong

emphasis in the HNEP was warranted. In fact, given the insights of several of the RNs and expert evaluators, it is clear that in further iterations of the HNEP, culture per se will need to be further differentiated. It is a mistake to define culture by country, especially in the SA context where a variety of cultural nuances exist.

10.3 Watson's theory of human caring.

Watson's theory encompasses components of nursing in its broadest sense and is applicable to all roles and specialties. Patient advocacy, a guide for ethical practice, recognition of the importance of patient safety and providing a framework for nurses to self-care so they can care for others such as patients, are all part of the application of this theory. Each of these factors was a topic of discussion for HNEP participants.

The application of the *caritas* processes in teaching and learning is evident in the HNEP. As the lecturers were cognisant of the constraints under which many of the participants worked, they understood the difficulties these nurses encountered in relation to the work environment, which often prevented them from engaging with patients and colleagues in a positive manner. In this regard, it is opportune for the researcher to acknowledge her lack of personal experience of working in the SA health environment, and to express her gratitude to the three coordinators who, in compensating for this deficit, added a tremendous amount to the creation and delivery of the HNEP. Although involved in numerous short-term visits to developing countries to lecture, and living in a developing country for some years, this was insufficient for the researcher to develop an in-depth understanding of the precise nature of "caring" as found within the SA cultural context. The lesson to be learned here is the need for engaging in collaborative projects if optimal success is to be achieved. There is little value in an overseas researcher simply coming into a

country and telling the Indigenous population what needs to be done and how to do it. Such an approach is not only culturally offensive but smacks of patriarchal arrogance.

The second and third of Watson's key concepts, namely, transpersonal caring-healing relationships and the caring moment, which describes the one-on-one nature of the nurse-patient occasion, were demonstrated to the participants by the Indigenous haemophilia coordinators who related scenarios about PWH; and by participants directly observing the relationship that had been built between the haemophilia coordinators and PWH.

10.4 Knowles' adult education theory

Knowles' (1975, 1980, 1990; Bastable, 2008) six assumptions (Chapter 4, Section 4.3.3) were integrated into the HNEP in a variety of ways. Based on the assumption that most of the learners were unfamiliar with haemophilia and its management, it was seen as essential that the initial days of the HNEP were conducted using a didactic approach supported by Power Point presentations and the lecturers' anecdotal vignettes. Thus, by allowing "interruptions" to help the learners clarify new knowledge, the lecturers encouraged the learning process. Each participant was encouraged to comprehensively introduce themselves at the beginning of the HNEP. This allowed the individual to become known to the rest of the group and have their experiences acknowledged, further enhanced by the implementation of group work in the later part of the program encouraging participation and collaboration. When the adult learner is exposed to new information, they are keen to see how this new information can be applied to their own situation, or what it would look like when viewed through the new lens. The HNEP provided the opportunity for the nurses to see how the new information about haemophilia can be applied through interviews with a PWH about the lived experience of haemophilia.

Further, when conducting the HNEP, the lecturers allocated case studies to each group, providing the participants with real-life scenarios which were linked to personal and client goals. Student groups were asked to “diagnose” a specific problem and to prepare a response. Each group then presented their opinion of the problem and their solution to the rest of the class. This setting accepted that mistakes may take place – considered by Knowles as part of the learning experience – which were corrected in a non-confrontational manner. Also, interaction with patients and their lived experience provided opportunities to apply theoretical knowledge to practice, helping to consolidate the new learning and gain confidence. Throughout, the lecturers showed respect by acknowledging the experience that the adult learner brought to the training and taking an interest in the individual student which reinforced student participation. Nurse feedback revealed an appreciation for the respect shown to them as experienced nurses and adult learners. The nurses stated they had learned a great deal about haemophilia and its management, with one nurse stating “now I’m sure what I’m talking about” (F/G4, N2). Such respect translated into empowerment when the nurses volunteered that post-HNEP, they felt secure in their knowledge about haemophilia treatment, were certain of treatment options they would now endorse, and were prepared to advocate more vigorously for the PWH. One nurse volunteered to the researcher that “after the training we become so effective...to say things you know to other people [coordinators]...and they appreciate them” (F/G3, N2).

10.5 Kirkpatrick’s four levels of evaluation + ROI

The five levels of the Kirkpatrick (1975; Yardley & Dornan, 2012) model of evaluation are now discussed in relation to the data obtained from the focus groups and interviews.

10.5.1 Level 1: Satisfaction.

The RNs were asked whether, immediately upon the conclusion of the HNEP, they were satisfied that the program had delivered sufficient information for them to believe that haemophilia had been well explained during the training. Without exception, all the participants agreed that the HNEP had provided the content of the curriculum and consequently had increased their knowledge about haemophilia and its management, with one participant's comments representing a conglomerate of views, "it made me more aware of the patient's physical and emotional needs" (F/G4, N4). Furthermore, one-third of the RNs stated they felt empowered by the knowledge they had gained. Such findings bode well not only for the continuation of the HNEP but for haemophilia practice and training in SA. It is once people feel competent and see that they are being supported that effective change becomes a real possibility.

On conclusion of the HNEP the RNs were asked to complete a feedback form which evaluated the program (Appendix C). This evaluation enabled the organisers to make changes so that subsequent programs were more efficient and would meet the needs of future participants. Being followed up several years after the RNs had completed the HNEP allowed them to examine their HNEP training with the benefit of hindsight. Not one of the RNs expressed any doubt about the value of the curriculum and its usefulness, with one stating "the haemophilia course was a very good thing because the doctors still come to me and the unit manager, [saying] we have a child bleeding". Such positive affirmation indicates that the HNEP curriculum is meeting the real needs of RNs, namely, enabling them to provide effective haemophilia management.

10.5.2 Level 2: Learning.

One-quarter of the nurses expressed that prior to the program, that they had no knowledge of or pre-training in haemophilia care. There were 26 comments about how the acquired knowledge had been transferred to clinical practice. The HRF was mentioned frequently by the participants as a useful reference tool, with one nurse stating “the course was well-structured and all the info I was given there, I use it daily with my patients” (F/G2, N1). This file was also a valuable resource for fellow colleagues, including doctors. Although an obvious comment, one might propose that the RNs would be unable, or lack in confidence, to implement haemophilia management and treatment to PWH had they had not learnt sufficiently well about haemophilia. Their comments and anecdotes about PWH demonstrate that they had a comprehensive understanding of the needs of PWH and their families: “Now you find that when there is a haemophilia you actually like to include their whole family because if the haemophilia patient wife is pregnant then you must know What if the child bleeds?” (F/G 4, N4). Post the course, nurses appeared to be asking all the right questions and showed an awareness of the intricacies of providing haemophilia care.

10.5.3 Level 3: Changed behaviour.

Advocating on behalf of PWH was acknowledged by 18 nurses, with 19 stating they felt competent to manage PWH. One third of the nurses recognised that their scope of practice had broadened after they had completed the HNEP. This is valuable information which substantiated that the RNs felt competent and confident in the management of PWH. Many participants exhibited a realisation that something cannot just be done for a PWH, but that they needed to ensure that it did in fact happen. One nurse indicated that when she had spoken with a patient recently she closed the session with the comment, “so I’ll do a follow-up, on Monday” (F/G2, N2). This is immensely encouraging, knowing that many nurses

realised that care extends well beyond merely the initial encounter. A further example of a nurses' change in behaviour was her realisation that in certain cases she needed to refer the patient. She indicated that rather than dealing only with the immediate symptom, she was able to explain to the PWH how the bleeding was impacting on their health and why they needed to attend the hospital: "so now, after I have done this course I can explain to them [PWH] what is going on and I refer them and they go to hospital" (F/G3, N4).

10.5.4 Level 4: Results.

The RNs stated that attending the HNEP had facilitated a better service for PWH in the clinical setting. Indicators such as decreased lengths of stay for inpatients, and new haemophilia clinics being established, were given as quantifiable examples of results. Proactive action was also being taken to obtain better results: "I phone the casualty department to inform them that a PWH is on their way, so then they usually get treated quickly" (F/G 4, N2). Unfortunately, some nurses expressed the view that management at their workplace was uncooperative; for example, not releasing the nurse to make an outreach visits to PWH. In an environment where nurses are attempting to provide the best possible care under already compromised conditions, such an attitude may preclude more positive results from being realised. It needs to be remembered though, that administrators and managers are also under pressure. As mentioned previously, their budgets simply may not allow them to offer the sort of nurse support that would be ideal and that might be their preference.

10.5.5 Level 5: ROI.

The fifth Level, ROI, is related to the cost of the training against the benefit to the workplace. Intangible benefits, which consisted of results which cannot easily be easily quantified, are part of the assessment of ROI. For example, the RNs feeling that they were

valued by PWH and their colleagues; bringing new knowledge and practice to their workplace; and having greater enthusiasm for their job, are extremely important and desirable employment characteristics. Eight nurses reported an increase in job satisfaction and that they felt they were an influential nurse in their workplace. There were thirty-two responses about their teaching role, with RNs educating nurses, doctors, PWH and their families and the community about haemophilia and as a result, witnessing an improvement in the care of the PWH.

The comments by the RNs pertaining to the HNEP were highly favourable, which was heartening, particularly in view of the context of nursing in public health establishments. Although there are no figures about a decrease in morbidity and mortality, one nurse, a midwife, explained that she was well aware that a pregnant woman who gave a history of heavy bleeding at menstruation may have a bleeding disorder. As such, she knew that when such a woman goes into labour, there is a chance she may be carrying a child with haemophilia and was also at risk of post-partum haemorrhage. This scenario shows how post-HNEP nurses have developed a greater awareness of haemophilia as a possible cause for symptoms with which they were being confronted. In short, haemophilia is on their radar in a way that it probably would not have been prior to participation in the HNEP. Unfortunately, potential prevention of disaster cannot be claimed as a quantifiable result, but it can as a ROI.

10.6 Chapter summary

This chapter has showed how the theoretical framework proposed at the outset of the work has been used to better understand and interpret the data. Data were considered using the models proposed by Leininger, Watson, Knowles and Kirkpatrick. The final chapter presents the conclusions and recommendations that stem from the research.

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).

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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.

(15)

4. Name two common sites that people with haemophilia bleed into.

Tick the correct answers:

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

(2)

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

(4)

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

(4)

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)

9. Tick four benefits of physiotherapy in haemophilia.

- 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

- f) Restores extension to limbs (4)

10. How can you immobilize a person with a joint bleed?

Tick the correct answers:

- a) Splints
- b) Crutches
- c) Sedation
- (2)

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
- (2)

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
- (4)

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

(5)

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

(5)

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
- (5)

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

(6)

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

(4)

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

(3)

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
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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 Haemophiliac 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 formed 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



Creation, 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 PARTICIPATE 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.

PARTICIPANT'S SIGNATURE:		DATE:	
RESEARCHER'S FULL NAME:	PAMELA JILL SMITH		
RESEARCHER'S SIGNATURE:		DATE:	

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



Creation, 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.

PARTICIPANT'S SIGNATURE:		DATE:	
WITNESS' SIGNATURE:		DATE:	
RESEARCHER'S FULL NAME:	PAMELA JILL SMITH		
RESEARCHER'S SIGNATURE:		DATE:	

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 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.

Category	Strongly agree	Agree	Disagree	Strongly disagree
Content				
the objectives are appropriate				
the content is relevant to caring for a person with haemophilia				
the content is evidence-based				
the purpose of the program is clearly stated				
instructional outcomes are realistic, measurable and achievable				
Instructional design				
the information is presented logically				
the format of the program is appropriate for the participants (RNs in South Africa)				
the teaching strategies would actively engage the learner				
summative evaluation material is provided				
Technical production				
Power point presentations				

a) focussed and clear				
b) uncluttered				
c) text is readable from a distance of 10m				
DVD presentations				
a) the sound is clear and intelligible				
b) there is no distracting background noise				
c) the pace of the narration is appropriate for the participants				
Teaching package				
the presentation of the package is user-friendly				
The “handouts” within the teaching package are/would be a valuable resource in the clinical setting				
the package is a valuable teaching and learning resource.				

Adapted from Discenza, D. (1993). A systematic approach to selecting and evaluating instructional materials. *Journal of Nursing Staff Development*, 9(4),196-198.

Appendix M

Ethics Approval from The University of Notre Dame Australia



19 Mouat Street (PO Box 1225)
Fremantle, Western Australia 6959
Telephone: +61 8 9433 0555
Facsimile: +61 8 9433 0544
Email: enquiries@nd.edu.au
Internet: www.nd.edu.au

ABN: 69 330 643 210
CRICOS PROVIDER CODE: 01032F

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,

A handwritten signature in black ink, appearing to read 'Natalie Giles'.

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

cc: Prof Selma Allieux, Dean, School of Nursing & Midwifery;
Prof Leanne Monterosso, SRC Chair, School of Nursing & Midwifery.

Appendix N

Ethics approval to interview haemophilia nurse coordinators



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Grootte Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

30 October 2014

HREC REF: 733/2014

Dr C Du Toit
Haematology
Ward E5
GSH

Dear Dr Du Toit

PROJECT TITLE: CREATION, IMPLEMENTATION, EVALUATION AND VALIDATION OF A HAEMOPHILIA NURSES EDUCATION PROGRAM IN SOUTH AFRICA (PhD candidate Miss J Smith)

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee dated 28 October 2014.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th October 2015.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the PhD student, Jill Smith will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

PROFESSOR M. BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

HREC 733/2014

Appendix O

Ethics Approval for interviews and focus groups for RNs



School of Nursing, Fremantle Campus.
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Ph: +61 8 9433 0223, fax: +61 8 9433 0227, email: nursing@nd.edu.au

13 January 2012

Dr Mark Blockman
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: Xfula@curie.uct.ac.za

Dear Professor Blockman,

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,

A handwritten signature in cursive script, appearing to read "J. Smith".

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.